



## Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

# Work Package 2: Report on Needs and Future Visions for Care of Children with Complex Conditions

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# **Report on Needs and Future Visions for Care of Children with Complex Conditions**

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## **Abbreviations**

<b>CA</b>	Country Agent
<b>CCN</b>	Complex Care Needs
<b>DIPEx</b>	Database of Individual Patients' Experiences
<b>EAB</b>	External Advisory Board
<b>ECTS</b>	European Credit Transfer and Accumulation System
<b>ED</b>	Emergency Department
<b>EEA</b>	European Economic Area
<b>EU</b>	European Union
<b>GP</b>	General Practitioner
<b>LTV</b>	Long-Term Ventilation
<b>NGO</b>	Non-Governmental Organisation
<b>PNAE</b>	Paediatric Nursing Associations of Europe
<b>TBI</b>	Traumatic Brain Injury
<b>UML</b>	Unified Modelling Language
<b>UN</b>	United Nations
<b>WHO</b>	World Health Organization
<b>WP</b>	Work Package

## **Executive Summary**

### **Background**

The United Nations (UN) Convention on the Rights of the Child (to which all European Union (EU) and European Economic Area (EEA) countries are signatories) defines the highest attainable standard of healthcare as a fundamental right of every child. Improvements in neonatal and paediatric care mean that more children with complex care needs (CCN) are surviving into adulthood. By their very nature, children with CCN, and their families, place great challenges on healthcare delivery in the community. Although the provision of care closer to home for such children is a policy objective internationally, integration of health services is insufficient with wide variation in systems of care for these children. The aim of our work in this section of the MOCHA project was to bring together the work from a large team, who have explored a variety of issues pertaining to the needs and care of children with complex health and social care needs across the EU/EEA. The dimensions presented are:

- The referral-discharge interface
- Management of a child with complex healthcare needs
- The social care interface
- Nursing preparedness for practice.

The report draws on the work of the DIPEx report on experiences of the child and family (Alma et al., 2017), with excerpts included to illuminate the findings across all areas of the report.

## **Main Findings**

### **The referral-discharge interface**

A total of 21 surveys were returned from a possible 30 MOCHA countries (70%).

- Fifty-seven per cent (n=12/21) of countries reported a General Practitioner (GP) led the primary care system, 24% (n=5/21) reported a combined system in which children could attend either a GP or a paediatrician for the management of minor illnesses, and 19% (n=4/21) reported a paediatrician-led system.
- In most countries (95.2%; n=20/21) the first contact professional for a minor illness in a child with a complex condition would be the same healthcare professional from whom a healthy sibling would seek support.
- Specialist support was routinely available for primary care providers providing care for a child with complex conditions, most commonly by telephone (90.5%; n=19/20).
- Over a third, 38.1% (n=8/21) of MOCHA countries identified pharmacy support in urgent community care.
- Policies surrounding transition to adult services were identified by only four countries (21.1%; n=4/19).
- No countries reported the availability of transition clinics, for children with asthma, to enhance the handover between adult and child services.
- All countries reported that standard processes in their countries would enable recognition of the urgency of the child's condition and immediate contact with specialist support either through a hospital-based paediatrician or the emergency services.
- After an emergency referral from primary to secondary care, most countries' health systems would include directly supervised transport of the child via an ambulance service or alternative emergency service (90%; n=18/20). After referral to secondary care, the primary care team would be involved in the child's on-going care in only seven countries (36.8%).

## **Management of a child with complex care needs**

- A higher proportion of countries have a system in place to identify all healthcare providers for children assisted with long-term ventilation (LTV), than for children with intractable epilepsy or following a traumatic brain injury (TBI).
- There is little standardisation of care coordination regardless of complex care need.
- Fewer countries have personalised care plans for adolescents with a TBI than for children assisted with LTV or with intractable epilepsy.
- Children assisted with LTV have less access to mental health assessments than adolescents following a TBI or children with intractable epilepsy.
- Families of children assisted with LTV or adolescents with a TBI have less engagement in community services and less opportunity to participate in policy development than parents of children with intractable epilepsy.
- Families of children with a TBI have less access to psychological support than other families.
- Quality assurance mechanisms are more established for the care of children with intractable epilepsy than for children assisted with LTV or with a TBI.
- Experience of care is not captured for 75-80% of all families, regardless of CCN.
- A slightly higher level of collaboration is present in the development of a care plan for a child assisted with LTV than a child with a TBI.
- In the majority of the countries, the development and implementation of the care plan are generally provided by single and/or individual professional, not working in a team, for both the child assisted with LTV and a child with a TBI. Generally, these professionals are hospital-based specialised medical practitioners.
- In a small number of countries a multi-disciplinary professional collaboration is in place for adolescents following a TBI.
- The involvement of primary care doctors is higher during the implementation of care plans than during its development.
- In a small number of countries social aspects of a child's care are implemented in a collaboration that includes social workers.
- The greatest progress on the integration of care in the last five years pertained to children with intractable epilepsy.
- There was a disimprovement in care coordination in the last five years for children assisted with LTV compared to an adolescent with a TBI or a child with intractable epilepsy.
- The absence of care coordination was identified as a barrier to integration of care.
- Training and retention of skilled healthcare staff was identified as a facilitator of integration of care for all CCNs.
- Media campaigns, parent lobby groups and conference debates are used across all CCNs to improve political awareness of the needs of children and adolescents.
- In addition to the standard provision of funding from Non-Governmental Organisations (NGOs) and the state, children with intractable epilepsy in some countries also benefit from funding from pharmaceutical and private enterprises, family and volunteer fundraising and the EU.
- Cross-country medical and academic partnerships are utilised to enhance the management and integration of care for children across all three CCNs examined.
- The fora for discussion, and the topics for debate, about the needs of children with CCNs varied across all three CCNs examined, highlighting different issues of public concern.

## The social care interface

- Contributions to the ‘mixed economy’ of personal social services are made from four sectors; the informal sector (families, friends etc.), the state, the voluntary non-profit sector, and the for-profit sector.
- Previous work has identified four ‘types’ of social care systems in Europe based on the different provider-mixes across different countries.
- Globalisation and de-institutionalisation can be expected to continue to impact on the future of social care in Europe.
- The most appropriate arrangements to enact a system where health and social care are integrated will likely differ between MOCHA countries according to system type.
- An aspect of integrated care which is especially important for children with CCN is coordination between social care and health care in safeguarding planning.
- Four themes were explored which emerged from the July report and which have the potential to have a considerable effect on how a child with CCN and their family will experience the care process:
- *Information provision:*
  - Information provision on a child’s complex need and on the supports that are available comes in a wide range of forms across the MOCHA countries - including websites and leaflets, and extending to professionally provided support.
  - DIPEX data shows that in some cases what is lacking is adequate signposting to family social care supports which can cause considerable frustration for parents of a child with CCN.
- *Enabling participation:*
  - Information provision and the encouraging of dialogue between families and health and social care professionals are important to consider in the context of empowering people to participate in the caregiving process.
  - The provision of support services for parents has been found to be a potential facilitator to their participation in the caregiving process.
- *Flexible support tailored depending on the needs of the child and family:*
  - Care coordination which can provide flexible personalised support is used in a number of MOCHA countries; this role differs markedly in practice across MOCHA countries.
- *Equity in access:*
  - Regional variation in service provision was apparent from the data; DIPEX data pointed to financial strain, and time management difficulties as potential results of the requirement to travel long distances to access services.
  - Potential facilitators to equity in access in rehabilitative care are compensation for travel and overnight accommodation costs where a child with CCN and their family need to travel in order to receive rehabilitative care, and field services in areas which are located far from a rehabilitation centre.
- Each theme must be understood in tandem as part of the wider picture of considerations when planning the care of children with CCN and their families.

## Nursing preparedness for practice

A total of 23 surveys were returned from a possible 30 MOCHA countries (76.6%).

- No specialised training is required to deliver community nursing care to children with CCN in 73.9% (n = 17) of the countries. For these countries, a general nursing qualification was the only requirement.
- General nursing training was of four years duration in eight countries (47.1%), three years in seven countries (41.2%), and three and a half years in two countries (11.8%).
- Although specific paediatric training is not required in these countries, the majority (70.6%, n = 12) offer undergraduate and/or specialised postgraduate programmes with a focus on children's nursing.
- Five countries (29.4%) stated that no paediatric options were available for further training.
- Almost three-quarters of the general nursing curricula analysed (70.6%, n = 12) offered one or more compulsory core modules focused on the care of the child.
- Most countries had child care mentioned within the context of other compulsory modules.
- Elective modules focused on the care of the child were mentioned in less than one-quarter of the curricula (23.5%, n = 4).
- In some countries, child care was mentioned in the context of other elective modules.
- The inductive content analysis conducted in the general nursing curricula, detected three main categories focused on the child: *Nursing Care of Children*, *Paediatrics* and *Psychosocial Aspects*. The category that focused on the *Psychosocial Aspects* had the least number of keywords.

## **Core Principles for the Successful Integration of Care for Children with CCNs in the EU/EEA**

### **Principle 1: Access to Care**

Access to health and social care for the child with CCNs refers to equitable access to consistently high quality, prompt and accessible services across the country to meet the needs and improve health of all groups within the population.

#### **Standards.**

- Each child with CCNs is afforded access to age-specific and developmentally appropriate care.
- There is a pathway in place to access non-urgent specialist care in the community 24/7 when a child has CCNs.
- Where possible children with CCNs and their family should be cared for by the same doctor and nurse on each consultation.
- Consideration should be given to the establishment of community complex care centres where the population and specialist expertise exists to support this.
- There is technical support in the community to assist parents caring for a child with CCNs in the home.
- Electronic health records are in operation to support shared care.

- Community pharmacists provide support to the child with CCNs and their parent(s)/guardian(s).
- A child with CCNs receives ongoing preventative care screening and developmental checks.
- The results of all screening are disseminated to all health services caring for the child.
- The results of all screening are communicated to the child's parent(s)/guardian(s).
- There is a transportation service that can accommodate the child and their assisted technology devices to access the child's daily activities and to attend health and social care visits.
- All information provided to families of children with CCNs is linguistically appropriate.
- All information provided to families of children with CCNs is culturally appropriate.
- When a child with CCNs has a medical crisis there is direct access to, and discharge from, a Paediatric ED and/or a Paediatric Intensive Care Unit.
- There is timely assessment for, and access to, rehabilitation services.
- Paediatric palliative care services are available to the child and family when required.
- There is timely access to respite care services.
- There is facilitated support in primary care for diagnostic tests that enable prevention and early detection of health concerns.

## Principle 2: Co-creation of Care

Co-creation in health and social care refers to equipping the child and family in partnership with the professional to design, create and deliver health and social services. In the drive to improve the efficiency and effectiveness of health and social care services, there has been a growing interest in co-creation as a way of redesigning services to achieve these objectives.

### Standards

- A discharge planning coordinator is available to the child and family when transitioning from the acute to the community setting.
- There is a standardised system to identify the clinical support needs for the child transitioning to home.
- Parents are supported to be clinically ready to care for their child in an incremental manner.

- There is a written personalised plan of care for the child, developed in consultation with the child's parent(s)/ guardian(s) and members of the healthcare team.
- A named care coordinator is appointed to the child with CCNs and their family to support multidisciplinary engagement and care in the community.
- Family advocacy groups are involved in making recommendations to home and community-based services.
- There is a standardised assessment of sibling support needs.
- Parent(s) / guardians(s) and siblings have access to psychological support from professionals with paediatric expertise.
- Children are included in national quality improvement initiatives for their care.
- Data is collected on the overall experience of care for children with CCNs.
- Data is collected on the experience of care from the perspectives of parents(s), guardians(s) and siblings.
- A plan of care is prepared with adult healthcare services before an adolescent is transferred from paediatric services.
- Data is collected on the experience of transitioning from paediatric to adult services from the perspective of the adolescent.
- Data is collected on the experience of transitioning from paediatric to adult services from the perspective of the parent(s) / guardians(s).

### Principle 3: Strengthening Governance

Effective governance is necessary to enhance accountability and to support the provision of safe, equitable, accessible and responsive cross-sectoral care to children with CCNs. Governance is strengthened by effective communication, access to suitably skilled healthcare professionals, transparent decision-making processes, and the inclusion of children and their families in the design and evaluation of services.

#### Standards

- Primary care providers have access to specialist support when caring for a child with CCNs.
- Consideration should be given to the development of specialist advanced nurse practice roles in the community for children with CCNs.

- There are standardised systems in place for the assessment of the child with CCNs in the community, including the deteriorating child.
- There is a standardised process for the clinical handover of the child with CCN to and from secondary care services.
- There is a system in place to identify all of the health and social care providers who care for a child with CCNs.
- There is a system in place to identify all of the voluntary agencies who care for children with CCNs.
- There is a system in place to govern all care delivery to the child with CCNs in the home.
- All primary care providers caring for children with CCNs have specialist training in the care of children with CCNs, relevant to the individual complex needs of the child they present to care for.
- Education for all social care staff caring for children with CCNs is standardised.
- There is a retention policy for skilled healthcare staff who care for children with CCNs.
- There is a national data base of children with CCNs.
- There are quality assurance mechanisms in place for service providers caring for children with CCNs.
- Cross-border initiatives are in place where no specialist centre exists nationally for children with CCNs.
- National integrated care programmes are in place to support care delivery at the acute community interface.
- There is a school health system in place to support the child with CCNs.
- There is specialised training for school teachers and education support staff when a child has CCNs.
- There is special reference to promoting the welfare of children with disabilities within wider child protection legislation.
- Safeguarding training for children with communication difficulties is provided to all health and social care staff caring for children with CCNs.

## Conclusion

The growing trajectory of children with CCNs places great challenges on health and social care delivery. However, prior to the instigation of the MOCHA project little was known about the management of the care of these children at a critical juncture in care delivery, the acute community interface. This report ties closely into the primary care function of coordination and continuity of care,

as described in WP1. This final report from WP2 has illuminated facilitators for an optimum acute community interface for children with complex health and social care needs, informing the overall model building for MOCHA in WP9. In doing so we have identified and presented the first core principles and standards for the care of children with CCNs in the EU drawing on all of the constituents of WP2.

## **Introduction**

This report builds on work presented in the *Final Report on the Current Approach to Managing the Care of Children with Complex Care Needs*, and the report on the *Social Care Interface*, from WP2, presented to the EU Commission in July 2017. Our remit overall in WP2 was to illuminate facilitators for an optimum acute community interface for children with complex health and social care needs, informing the overall model building for MOCHA in WP9. It is important to note that the concept of complex care is not yet an established entity in the majority of countries in the EU/EEA. Rather there is a trend in some countries to re-brand some branches of health and social care to begin to address the needs of this small but growing population. We were mindful throughout our work of the very interesting models of care delivery for children with complex health and social care needs internationally, while conscious that the work we are presenting is required to have meaning across a region of cultural, socio-political and legal diversity.

The issue of language was particularly important as the official language of the MOCHA project is English. To address the issue of terminology we developed a glossary of terms to afford clarity to participants (Appendix 1). As previously explained data was gathered in this WP through a Country Agent (CA) in each of the 30 countries. This is a key methodological feature of the MOCHA project, the remunerated retention in each study country of a part-time CA – a local expert in child health services – who acts as the informant for obtaining data requested by the principal scientists in the project, from local indigenous sources (for more information about the CAs please see the MOCHA website <http://www.childhealthservicemodels.eu/partnerlisting/country-agents>).

The first four chapters of this report present findings on the Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care across the EU and the EEA, with a focus on:

- referral/discharge pathways
- the interface of care for children with complex health care needs
- the interface of care for children with complex social care needs and
- nursing preparedness for practice.

Business process analysis is used within the report to reconstruct the child's care pathway through the identification of the actors and the activities performed to address a child's complex care needs. The methodology adopted to describe the care process using the Unified Modelling Language (UML) has been described in the deliverable D1.4, while the analysis outlining TBI and LTV was performed respectively in the deliverables D2.5 and D2.7. Throughout the report we also draw on the work of DIPEX International to illuminate our findings (Appendix 2). The specific objective of the work of DIPEX International within the MOCHA project is to provide insight into the experiences of children and parents in terms of primary health care for children and the primary/secondary care interface. Qualitative researchers from five different countries, that are part of the DIPEX International network, worked collaboratively to explore patients' experiences in their respective countries across Europe: Czech Republic, Germany, The Netherlands, Spain and United Kingdom.

The final chapter of the report presents the key findings that have emerged from the data gathered across the EU/EEA. It presents a set of core principles and standards of care for children with CCNs which may be incorporated into, and used to shape, the organisation of care for these children and their families.

# **Chapter 1 Referral-Discharge Interface**

**Ingrid Wolfe, Sapfo Lignou, Rose-Marie Satherley**

*...I am the messenger all the time between the doctors...I was very in favour of a central medical record, so to say. Please have a look into it, because it is only practical for our daughter...Have a look what the other doctor has said...That is absolutely important.* (Mother, The Netherlands)

## **1.1 Introduction to the Referral-Discharge Interface**

The United Nations Convention on the Rights of the Child defines the highest attainable standard of healthcare as a fundamental right of every child. Effective and efficient functioning across the interface between primary and secondary care is vital for ensuring good care for children. Primary healthcare addresses the majority of the population's health care needs, and is generally the first contact and entry point to the wider health system. Primary care is provided by a range of professionals with a broad range of generalist and specialist skills. Secondary care is the setting for more specialist healthcare. The boundary between these tiers of healthcare is crossed by children with acute serious illnesses, and with complex and long-term conditions. The child and family's experience of that journey, and the quality of care they encounter, is determined by the way that the systems and organisations interact, to provide varying degrees of coordination and engagement to support the child's care.

Different organisations and professions may comprise primary and secondary care services, often with differing cultures and funding models, therefore, the interface between primary and secondary care is a vulnerable point in the care journey for children and young people, posing challenges for effective coordination, communication, and continuity. Handovers between services are increasingly recognised as important opportunities for preventing harmful errors (World Health Organization, 2007), such as duplication or omission of treatments, medication errors, and inadequate transfer of information (Huynh et al., 2013, McHugh et al., 2013, Jones et al., 2015, Vermeir et al., 2015). Coordination of care implies effective communication and collaboration between primary care and secondary care, with the child and family at the centre, in order to ensure the child is receiving the right care, in the right place, and at the right time (Lee et al., 2013). Snow et al. (2009) describes this communication as '*a loop of continuous care*' (pg. 365), which is critical as the child navigates the primary-secondary interface, supported by referral and discharge structures and processes (Snow et al., 2009).

The structure and functions of the boundary between primary and secondary care vary according to the health system, shaping different behaviours and processes. Gatekeeping is one such important variable. Primary care providers in many countries have an important gatekeeping function, whereas, in others, families may directly access a specialist provider without a referral. Similarly, irrespective of gatekeeping processes, the system may be circumvented by directly accessing hospital emergency departments (ED). One function of gatekeeping is to regulate access to secondary care, restricting it to those individuals who cannot be managed at primary care level, and who require specialist diagnostics and/or intervention. However, there is conflicting evidence about the impact of gatekeeping, and the effect of different health systems is unclear. A systematic review by Garrido et al. (2011) found that gatekeeping mechanisms are associated with reduced use of secondary care services as demonstrated by shorter and fewer hospitalisations, and reduced ED utilisation. The impact on quality of outcomes is less clear (Garrido et al., 2011).

Irrespective of the health system, communication and coordination across care boundaries is a universally important and challenging aspect of care. The effective coordination of care between

providers requires clarity about who is responsible for the various aspects of the patient care journey, and when this responsibility shifts between providers. However, there is considerable ambiguity between primary care and hospital-based doctors about who is responsible for various elements of post-discharge care, highlighting the potential risks at the interface between primary and secondary care. Ruth et al. (2011) found that a greater proportion of hospital doctors than primary care providers felt that the responsibility for following-up outstanding laboratory results, management of adverse events and changes in children's status, rested at primary care level (Ruth et al., 2011). Similarly, Jones et al. (2015) identified a lack of consensus between primary care and hospital-based doctors about who was accountable for laboratory tests, with primary care doctors holding the view that a hospital based doctor was accountable unless otherwise communicated to primary care level (Jones et al., 2015). The lack of clear accountability for ensuring safe high-quality care across the primary-secondary care interface presents a risk.

The primary-secondary interface is a vulnerable and potentially high-risk point in a child's journey between healthcare providers and settings. This study explores the boundaries between primary and secondary health care in 30 European countries. We examine the structures and processes of the primary-secondary interface, asking specific questions that focus on common child acute and chronic health conditions and care needs particularly those for which there has previously been little or no research.

## **1.2 Methods**

This is a non-experimental qualitative descriptive study. The design has been reported in greater detail elsewhere in WP1 but will be described here in brief.

We constructed multiple universally applicable clinical scenarios which we used to design questionnaires as data collection tools with which to build a multi-dimensional picture of the interface between primary and secondary care (Yin, 2013). Clinical scenarios have been used before in European child health services research, with the purpose of eliciting reliable and meaningful information consistently between countries with differing health systems, different definitions, historic and cultural contexts, but the same child health problems (Wolfe et al., 2013). The questionnaires designed for this study were introduced with a clinical scenario, with accompanying questions that related to the scenario. Questions were designed to provide data that describe the structures and processes of care of the primary and secondary care interface for children with acute and chronic conditions and care needs. We included universal aspects of unscheduled and scheduled care, focusing particularly on common problems. We also explored the nature of the transition of care from children's to adults' services for adolescents with long-term conditions, asking what happens at the primary-secondary care interface during transition.

As is the case throughout MOCHA, WPs and tasks are interdependent and build on and provide foundations for other's work. This is also true for the clinical scenarios and case studies presented in this report which describe a partial picture of the primary-secondary care interface. The purpose here is to provide a basis for understanding previously neglected aspects of the interface between primary and secondary care for children. We hope to provide a foundation for further work investigating this important area of children's health services.

### **1.2.1 Data Collection**

Questionnaires were developed based on three potentially high-risk clinical scenarios: a child with a complex condition who develops a minor illness, an acutely ill child who is deteriorating clinically, and an adolescent with a chronic illness who is approaching the point of transitioning from children's to

adult healthcare services. The scenarios and accompanying questions are designed to interrogate the structures and processes of the primary-secondary care border. Questionnaire surveys were sent to all 30 MOCHA CAs, a key methodological feature of the MOCHA project. CAs are local experts in child health services, retained part time on a remunerated basis. CAs are informants and conduits for obtaining data from other local sources.

### **Scenario One: Child with an ongoing complex long-term condition who develops a concurrent minor illness**

*Lara is a 7-year-old girl with intractable epilepsy. She spends most of her time in a specially adapted wheelchair and is currently on a ketogenic diet administered through a gastrostomy tube. She is on several medicines to control her seizures. She has developmental delay and has significant physical and emotional care needs. She is under the care of a range of professionals including: a paediatric neurologist, epilepsy specialist nurses, community nurses, community general practitioner, pharmacist, speech and language therapist, physiotherapist, psychologist, occupational therapist and social worker. Lara has developed a mild fever and rash, and is clearly uncomfortable. As her illness develops, Lara develops diarrhoea and her parents are worried that she has not absorbed her anti-epileptic medicines.*

**Rationale:** This scenario explores the management of, and sources of support for, children with a common illness, possibly minor, but with a background of complex ongoing conditions. Children with complex conditions are often dependent on specialist services for much of their ongoing care. However, there is little evidence about the provision of care for minor and common illnesses among children with complex conditions. Children with complex and ongoing conditions are frequently on multiple medicines with some that may require monitoring for side effects, and many such medicines are unusual in primary care settings. Children often have long complicated medical histories, may have had numerous medical procedures, and have expert parents and carers. It may be challenging for non-specialists to manage minor illnesses in the context of complex medical problems, while specialists may be less experienced in minor illnesses irrespective of context. This area is under-explored in the research literature.

### **Scenario Two: Child with an evolving serious acute illness**

*A 2-year-old child develops a mild fever, and rash, and is clearly uncomfortable. It is Wednesday late afternoon (during usual business hours) and they are at home. The child was seen by a health professional, given some advice and sent home. She becomes more ill in the following 24 hours. She is listless and pale, not interested in anything. She has not drunk or eaten, and her parents find her difficult to rouse. Her parents want another consultation, and bring her back to be seen in primary care. The doctor examines her and finds a purpuric rash in the crease of her leg, suggesting meningococcal sepsis, a potentially life-threatening infection.*

**Rationale:** This scenario explores the balance between access to care and professional expertise available for a child whose illness evolves from minor to potentially life-threateningly serious. This scenario highlights the structures and processes at the primary - secondary care boundary for urgent and emergency care.

### **Scenario Three: Adolescent with a long-term condition who is approaching transition to adults' healthcare**

*Jacob is a teenager who developed asthma as a child, and his asthma has gradually worsened during adolescence. He takes regular medications (by inhaler). He has had several acute wheezy episodes or attacks, usually in response to a cold or flu, or when exposed to furry animals or grass pollen. He has several exacerbations which lead to admissions to hospital. His long-term condition management was shared between primary and secondary care in childhood. As he approaches late adolescence, his care must be handed over from primary and paediatric speciality to primary and adult speciality.*

**Rationale:** This scenario examines what happens at the interface between primary and secondary care, for an adolescent at the transition between children's and adults' healthcare. Both these points present potential risk in healthcare, for which there is insufficient evidence to date.

#### **1.2.2 Sample**

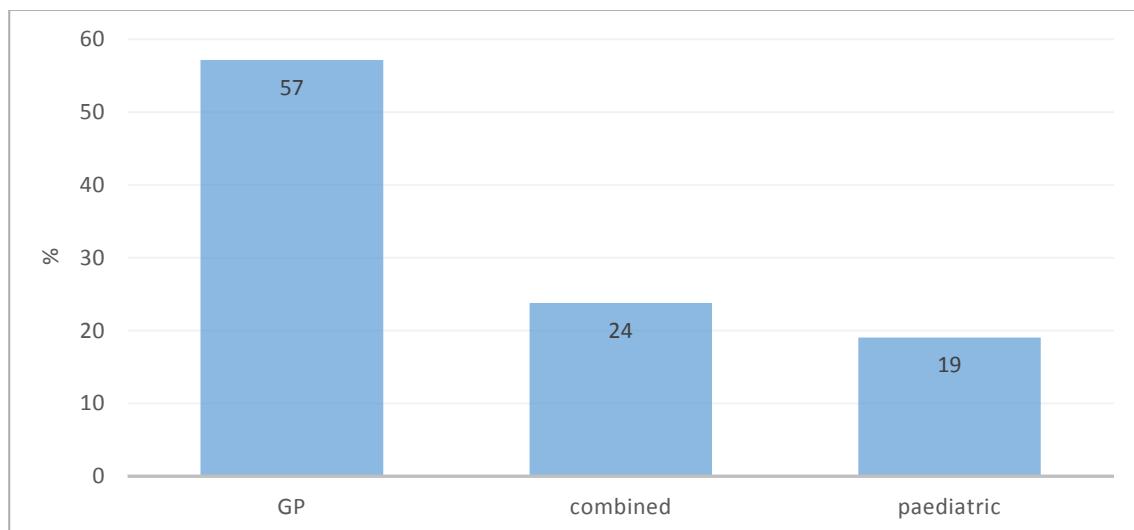
The clinical scenarios and surveys were sent to a CA in each of the 30 countries, having first been checked and agreed by the MOCHA Expert Advisory Group (EAB).

#### **1.2.3 Analysis**

Data from the CA questionnaire was transferred onto a spreadsheet to facilitate management of the large volumes of information. This spreadsheet forms a case study database with the full complement of primary source data, to facilitate any subsequent analyses and review. Data analysis of CA responses was conducted using narrative themes and descriptive statistics including frequency and frequency percent.

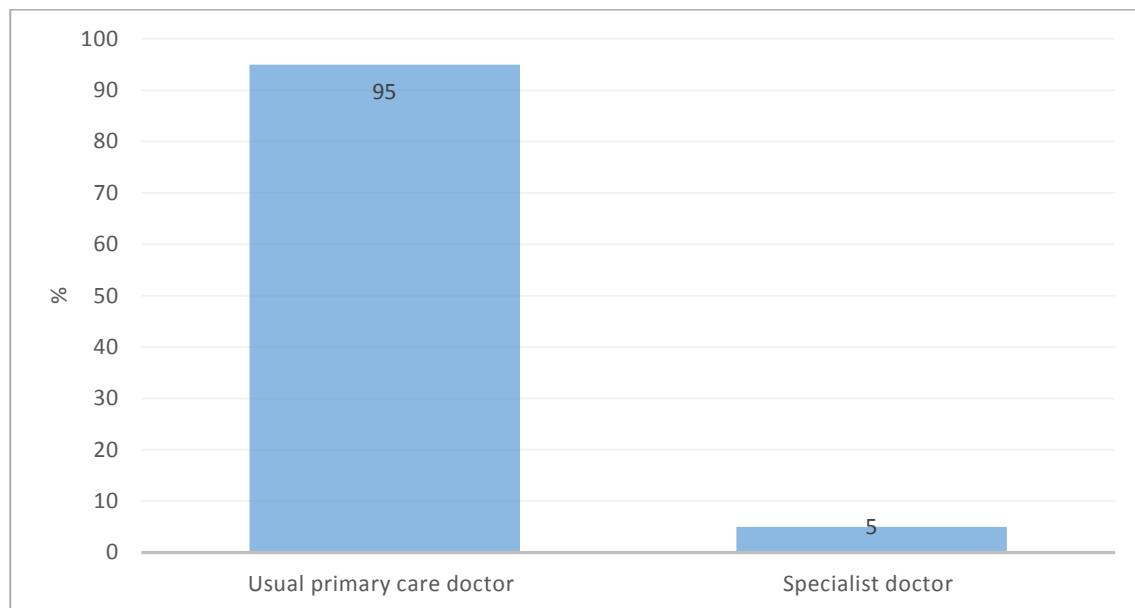
### **1.3 Results**

There was a seventy percent response rate ( $n=21$ ) to questionnaires regarding the structures and processes of care at the primary–secondary care interface, among eligible MOCHA countries, and all were included in the analysis. Data illustrating the type of primary care model, as defined by professional type responsible for providing care, is presented here as important for shaping the nature of the primary-secondary care interface. Fifty-seven percent ( $n=12/21$ ) of countries in our sample reported a General Practitioner (GP) led primary care system, 24% ( $n=5/21$ ) countries reported a combined system in which children could attend either a GP or a paediatrician for the management of minor illnesses, and 19% ( $n=4/21$ ) of countries reported a paediatrician-led system (See Figure 1.1).



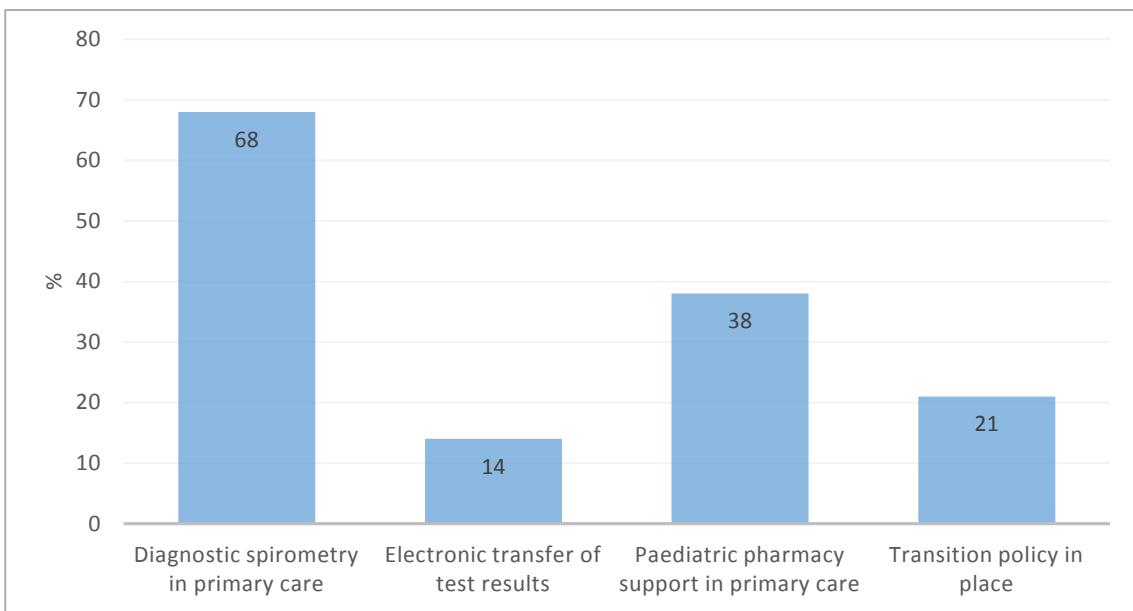
**Figure 1.1 Primary care model types in European countries by lead medical professional**

In most countries (95.2%; n=20/21) the first contact professional for a minor illness in a child with a complex condition would be the same healthcare professional from whom a healthy sibling would seek support (Figure 1.2). Specialist support was routinely available for primary care providers providing care for a child with complex conditions, most commonly by telephone (95%; n=19/20).



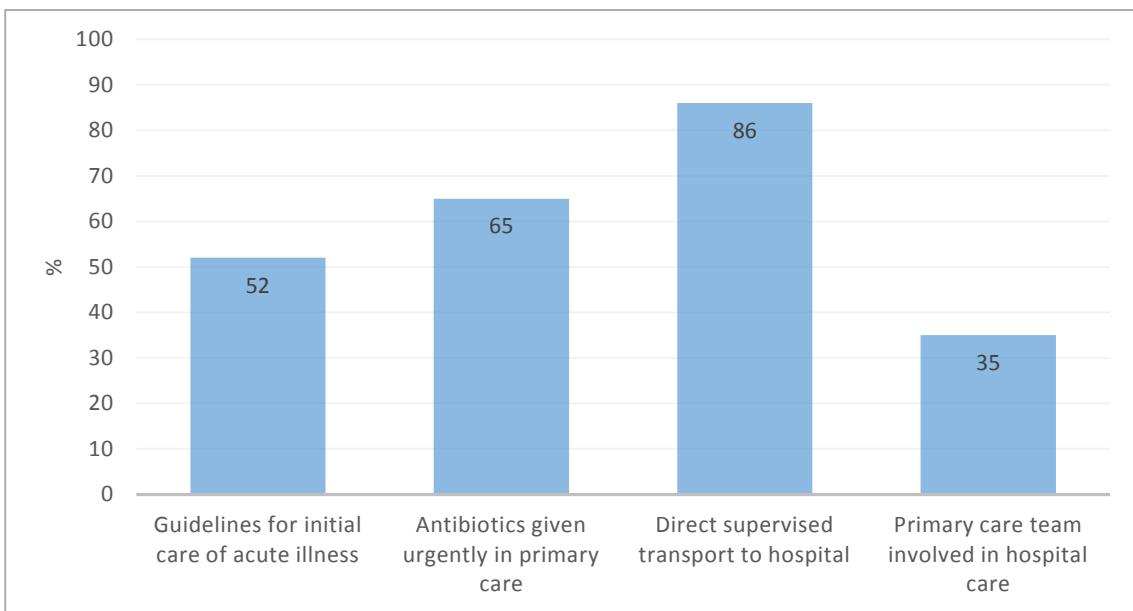
**Figure 1.2. Care provider for minor illness in a child with a complex condition**

Diagnostic and pharmaceutical services are important aspects of care that span the interface between primary and secondary care. In addition, the transition from children's to adults' healthcare is an important feature of care for adolescents with chronic conditions (Figure 1.3). Sixty-eight percent (n=13/19) of MOCHA countries could provide spirometry for a child of 16 years in primary care, as an example of a diagnostic test. Of those countries that provide specialist diagnostics, six countries reported that the primary care provider would receive extra financial support for this. Three countries would transfer this information to secondary care via electronic health record, with a written letter sent in the post being the usual option. Over a third, 38.1% (n=8/21) of MOCHA countries identified pharmacy support in urgent care. Pharmacists provide support through the dispensing and counselling of prescribed medications. Estonia and Portugal reported a community-based pharmacy system whereby the pharmacist would be a part of the primary care team, aware of the child's background and illness. In contrast, Finland reported pharmacist support being largely hospital-based. Policies surrounding transition to adult services were identified by only four countries (21.1%; n=4/19). Most countries reported transition to adult services at 18 years (50%; n=8/16) with Croatia starting as low as 7 years of age. No countries reported the availability of transition clinics, for children with asthma, to enhance the handover between adult and child services.



**Figure 1.3. Planned care processes at the primary-secondary care interface**

Management of acute potentially serious illness illustrates the interface between primary and secondary care (Figure 1.4). Standardised guidelines supporting the initial consultation were reported by 50% (n=10/20) of the responding countries. All countries reported that standard processes in their countries would enable recognition of the urgency of the child's condition and immediate contact with specialist support either through a hospital-based paediatrician or the emergency services. For example, an acutely ill and clinically deteriorating child may require urgent antibiotics, as a potentially life-saving intervention. Of responding countries, 68% (n=13/19) reported that the first dose of these antibiotics could be provided in primary care. For those that would not provide the first dose in primary care, the child would be referred to the emergency services and provided with antibiotics. The provision of antibiotics in primary care largely depended on the expertise of the practitioner – “*In the event when the GP may feel uncomfortable with administering the antibiotic empirically, then the EMS [emergency medical service] is called to transport the patient to the nearest hospital*”. After emergency referral from primary to secondary care, most countries’ health systems would include directly supervised transport of the child via an ambulance service or alternative emergency service (90%; n=18/20). After referral to secondary care, the primary care team would be involved in the child’s on-going care in only seven countries (36.8%; n=7/19).



**Figure 1.4. Urgent care processes for management of an acutely ill child at the primary-secondary care interface**

## 1.4 Discussion

Primary and secondary care are key organisational components of all healthcare services across Europe, but their structure and processes vary and are influenced by their current and historical societal, political, cultural, and economic contexts. Consequently, the nature of the primary-secondary care interface varies substantially between countries. This chapter provides a description and comparative analysis of the primary-secondary care interface for children and young people across a range of European countries and lays foundations for further exploration of the differential outcomes between countries regarding how health systems may be strengthened to support improved care.

Previous cross-sectional surveys, published in 1999 and 2010, explored the types of primary healthcare models for children and young people among European countries (Katz et al., 2002, van Esso et al., 2010). The type of primary healthcare model is an important consideration in describing the interface with secondary care because the degree of hierarchy and separation between tiers of healthcare may affect the barriers and facilitators for sharing care between community and hospital. Katz and van Esso divided countries into different systems according to the main provider of primary care. There were substantial differences between Katz's and van Esso's findings, and our findings differ again. We report that 57% of responding MOCHA countries described a GP-led system, 24% reported a combined system with both types of professionals working at the front line of care, and 19% of the described a paediatric led first line support model. In contrast, van Esso et al in 2010 sampled 31 countries, had a 94% response rate, and reported that 41% had GP model, 35% of countries had a combined model, and 24% of countries had a paediatric model. Katz et al in 2002 sampled 34 European countries and found that 18% had a GP system, 47% had a combined model, and 35% of countries had a paediatric system (Katz et al., 2002). Van Esso highlighted apparent changes in primary care provision in the years after Katz's paper in 2002 (van Esso et al., 2010). A cautious interpretation of the typologies of models in countries is advisable, however, since definitions of professions vary. For example, GPs received substantially more paediatric training in some countries compared to others, and the barriers between primary and secondary care are more porous in some countries than others.

Paediatric expertise has been identified as an important factor which influences the appropriateness of referrals from primary to secondary paediatric care, which may arise from risk aversion and from the challenges of making a diagnosis in children (Busby et al., 2017). This is supported by Australian research in which '*knowledge of specific conditions*' and '*experience with similar patients*' were the most commonly cited reasons which influenced GPs decision to refer children to specialist services (Freed et al., 2016). Similarly, differing working arrangements may support closer cooperation and sharing of skills. For example, Swedish GPs and paediatricians work in teams with children's nurses in urban community-based children's centres. Since shared working, rapid referrals, and consultations are commonplace and easy, the distinction between types of models and different types of professionals has less impact, so this system could plausibly be defined as a GP or combined model. Similarly, in the Netherlands, the transmural care model enables GPs and paediatricians to work more closely together than is the case for example in the UK, through aligning financial and managerial incentives. Hence, although defining these countries as having a GP model for children's first-access is correct, it is also an incomplete explanation as they have advanced further along the road to integrating primary and secondary care than many other countries. If the type of primary care model is to be defined by the type of professional delivering first contact care, then a more complete and accurate description of professional training, competence, and confidence is required than has been available hitherto. A GP model delivered by doctors without specialist training in paediatrics, working in a separate setting with little systematic reliable contact with secondary care colleagues, is likely to provide different quality of care than a more joined up model delivered by GPs trained in paediatrics, working closely with their specialist colleagues. The work described here contributes towards a more comprehensive understanding of the nature of sharing and handing over patient care between professionals across the primary and secondary care boundaries, along with other work in the MOCHA programme.

The pathway for patients to move back and forth between primary and secondary care appears largely consistent between MOCHA participating countries. Referral to secondary care is usually managed by the primary care physician via telephone and supported where necessary by ambulance services. Only six countries reported the use of an electronic care record to enable this transition by supporting safe effective communication. This is surprising given the evidence for electronic referral formats which have been shown to improve the quality and timeliness of communication between primary and secondary care (Graetz et al., 2014, Motamedi et al., 2011). Furthermore, such a system offers advantages for the coordination of care of children with CCN who may attend multiple healthcare professionals across different sites. Patient health records have evolved in the UK and the USA from a paper document, designed for communication among healthcare professionals, to electronic documents that both patients and healthcare professionals can access (Greenhalgh and Keen, 2014). However, data protection legislation across Europe poses a significant barrier to the use of electronic health care records. In Denmark, the national e-health portal (Sundhed) enables collaboration between all individuals involved in the patient's care; allows the patient to interact with the healthcare provider, allows healthcare providers to access up-to-date information to enable evidence-informed practice, and promotes patient self-management through a system of online forums.

The importance of access to expertise and safe transfer of accurate and timely information is highlighted through two examples: diagnostics, and children's medication. There is growing interest in point of care testing and diagnostics in primary care. There is considerable variation in our findings regarding whether diagnostics could be provided for children by the primary care service. While there is inconclusive evidence for effectiveness or cost-effectiveness, there are suggestions that diagnostic availability in primary care may prevent unnecessary referrals to secondary care (Harris et al., 2016), and evidence that suggests the presence of diagnostic services, for example, ultrasound, in primary

care may influence early diagnosis and survival for children with Wilms' tumour (Pritchard-Jones et al., 2016).

Pharmacy is another important aspect of a comprehensive primary care service for children and is illustrative of the nature of interactions with secondary care. Medication management is more complex in children than adults for several reasons, for example, prescribing dosages by weight or surface-area, the widespread use of unlicensed and off-label medications, and the variable ability of children to communicate effects or side effects of medication. The transfer of accurate and timely information about children's medication regimes and prescription changes is important for delivering high-quality care for children moving between primary and secondary care. In a review by Huynh et al. (2013), rates of discrepancies in medication histories of children at admission and discharge from hospital ranged from 22%-72% of patients (Huynh et al., 2013). Kwan et al. (2013:400) suggest that failure to interrogate or reconcile a patient's medication history at each transition of care can result in misinformation becoming '*hard-wired*' into a patient's healthcare record, further perpetuating the risk of error (Kwan et al., 2013). Integrating pharmacy into the primary teams, with the ability to prescribe, offers potential to support primary care healthcare professionals in providing better healthcare for patients, and in preventing ill-health. Integration of pharmacy services with primary care can provide more accessible healthcare, reduce prescription errors, and facilitate better medication use, which all contribute to better management of health within the community and reductions in inappropriate hospital admissions. The incorporation of pharmacy services with primary care, however, was limited across MOCHA countries. Only 38% of CAs identified pharmacist support in primary care. Given these findings, the lack of pharmacy support, as a key primary care function, across MOCHA countries represents a key opportunity for strengthening primary care.

The importance of a smooth transition between paediatric and adult services, and the most effective way to achieve this has become a subject of considerable debate. In most European countries, adolescent medicine is not recognised as a separate subspecialty, and a lack of sufficient focus on caring for this age group, in either paediatric or adult medicine training, has resulted in adolescents historically being a neglected group (Viner, 2003). The transition between children and adults' healthcare for an adolescent is a potential risk in continuity and quality of healthcare. Appropriate provision of specific transition support services from child to adult services is variable across MOCHA countries. No country in our study identified standard transition clinics for adolescents with asthma, and policies surrounding transition were identified in only 21% of participating countries.

Management of the acutely ill and deteriorating child who presents to primary care is a helpful test case for the interface between primary and secondary care. Guidelines can support effective safe management of acutely ill children in community care settings, but they must be supported by appropriately trained staff and safety netting processes. Half of the MOCHA respondent countries used guidelines for managing the acutely ill child in primary care. Antibiotics given promptly at the first presentation of meningococcal sepsis can save lives; our findings that 68% of countries reported complying with this guidance suggests significant room for improvement. After urgent transfer to secondary care, the primary care team would be involved in the child's on-going care in only six countries. Coordination of care is critical for those children who travel back and forth between sectors, as there is a risk of duplication of care, or conversely of '*falling through the net*' and not being appropriately followed up by either sector (McHugh et al., 2013).

#### **1.4.1 Strengths and Limitations**

Clinical scenarios were chosen carefully to illustrate universal clinical problems, nonetheless, they do still present a hypothetical patient subject to real-world contexts. The CA system of respondents is a

pragmatic means of acquiring primary and secondary care data from countries in the MOCHA programme. The system does also present a potential bias, contrasted with a validated survey tool and systematic sampling method, since respondents may describe not what actually happens in practice, but what they feel *should* happen (Schwappach and Gehring, 2014, Converse et al., 2015). This can create a '*social desirability bias*' (Peabody et al., 2000) as respondents attempt to portray the ideal rather than the real situation.

## **1.5 Conclusions and Implications**

Successful hand-overs of healthcare for children across the interface between primary and secondary care relies on the timely, effective, and consistent transfer of information to support the continuity and coordination of care. There are considerable variations in the structures and functions of the primary-secondary care interface for children's healthcare in European countries participating in the MOCHA study. An important next step is to determine whether there are systematic differences in relevant health outcomes for children and young people, and if so, to what extent they may be attributed to the differences in the primary-secondary care interface.

We identified several examples where countries may learn from each other's progress in strengthening the processes of care at the boundaries between primary and secondary care, for example through diagnostic processes, electronic transfer of information, transition policies, and specialist support in primary care.

Our findings identify areas where further research would be helpful. Further detailed information is needed on the nature of primary care models and their impact on the interface with secondary care. It is not yet understood whether the management of minor illness in children with CCNs is better delivered by usual primary care doctors, or whether additional specialist support is helpful, and if so, how this should be delivered. The barriers and facilitators to the use of digital technology for hand-over of care between primary and secondary healthcare should be more clearly described. Further evidence for effective and cost-effective practice and policy supporting paediatric pharmacy, transition, and diagnostics as integral part of children's healthcare is required. Evidence is needed to support effective use of existing guidelines and care processes for the management of acutely ill children in primary care settings.

## **Chapter 2 Management of a Child with Complex Care Needs**

**Maria Brenner, Phil Larkin, Miriam O'Shea, Jay Berry, Daniela Luzi, Fabrizio Pecoraro, Oscar Tamburis, Manna Alma**

*It should be let's use the whole remit of all of the services because all the children are different.  
What suits one won't suit the other. (Father, UK)*

### **2.1 Introduction to the Management of a Child with Complex Care Needs**

This chapter builds on the work presented in our earlier report on managing the care of the child with CCNs (Brenner et al., 2017). In that report, we presented three 'in-principle' complex health issues that are representative of population trends across childhood, and we presented findings on the first part of our survey, which explored the structures and processes of care in place for children with CCNs. At that point, we suggested that CCNs that are more 'established', and which are anecdotally known to have a larger population, have specific facilitators of optimum care that may not reflect those of all children with CCNs. In this chapter, we explore this in more detail. The chapter presents our findings from our comparison of data across all three exemplars, including findings on the development of services and socio-cultural influences. This is followed by a discussion of the key themes that emerged and consideration of limitations of the study. We begin this chapter with a reprieve of the exemplars and methods used to explore the integration of care for children with CCNs across the EU/EEA.

### **2.2 Design**

In our earlier report, we identified that this is the first time that the issue of CCNs in children has been examined across the EU/EEA. To address this we employed a mixed-method approach, which was informed by a discussion on post-positivism advocating a realist perspective on healthcare research. For this part of the project, three vignettes were developed for children requiring integrated care, in each of the following areas: Traumatic Brain Injury (TBI), Long-Term Ventilation (LTv) and Intractable Epilepsy. The selection of these exemplar conditions was guided by consideration of previous work in the area including: epidemiological trends; findings of burden of care and the completion of systematic and integrative reviews. The importance of the need for coherence with other work across the wider MOCHA project and exploration of care across a variety of ages from infancy to 18 years was also taken into account during the selection process. The decision on the specific areas to be explored was initially made by a team comprised of clinical and academic expertise including senior nursing academics with backgrounds in critical and palliative care, and physicians in complex and community care. These areas were subsequently ratified by the EAB.

Our overall survey consisted of three sections - a vignette, questions adapted from the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (Association of Maternal and Child Health Programs, 2014) and the Complex Care European Survey of Change, adapted from the Eurobarometer Survey (Centeno et al., 2013). Detail of the survey development and deployment is presented in our earlier report (Brenner et al, 2017). The three scenarios are as follows:

#### **Scenario 1 Adolescent following a Traumatic Brain Injury**

*Luke, a 15 year old previously healthy adolescent, suffered a head injury in a skateboard accident. Initially he had no loss of consciousness but fifteen minutes later he was unresponsive with dilating and slow reacting pupils bilaterally. Following initial assessment in the ED he was transferred to the Paediatric Intensive Care Unit where he was ventilated and sedated. An MRI showed a left-sided extradural bleed with no midline shift and he had surgery for evacuation of the bleed on Day 2. He did not have any spinal injury. He was extubated after 6 days and was discharged to the neurological*

*ward. After four weeks in hospital he was transferred to a rehabilitation centre where he spent five months. On his recent discharge to home he has ongoing right-sided weakness and has facial palsy, which is slowly improving. He is very anxious and is aggressive towards his parents and his twin sister. His care involves input from a large number of multidisciplinary healthcare professionals. In the coming months it is hoped that he will resume his education and in the coming years he will need to transfer to adult care services.*

### **Scenario 2 Child assisted with Long-Term Ventilation**

*Max is an eighteen month old boy with a diagnosis of chronic lung disease due to bronchopulmonary dysplasia. Max was born at 26 weeks gestation weighing less than 1kg. He had a diaphragmatic hernia, a gastrostomy tube placement at three months of age, and a Grade IV intraventricular haemorrhage requiring a cerebrospinal fluid ventricular shunt. Max has been ventilator dependent since he was born and is considered to have a life-threatening condition. A tracheostomy tube was placed at six weeks of age due to the need for ongoing ventilation. Max spent the first three months of his life in intensive care, followed by four months in a step-down/transitional care unit. At present Max has the following: impaired pulmonary function, developmental delay in fine and gross motor skills, and speech and language difficulties. His prognosis for weaning off the ventilator does not seem favourable at the moment and ideally he requires the healthcare input of the following healthcare professionals: community nurses, specialist consultants (respiratory, paediatrician, neurology), community general practitioner, pharmacist, speech and language therapist, physiotherapist, occupational therapist, social worker, dentist, home care nursing team and respite care services. He lives with his two sisters, aged 5 and 7 years, and his mother and father. He lives 120kms from the main children's hospital and 40kms from his nearest regional hospital which has a small paediatric unit.*

### **Scenario 3 Child with intractable epilepsy**

*Lara is a 7 year old girl who lives at home with her mum, dad, and younger brother, aged 18 months. Lara has developmental delay and initially presented with infantile spasms. The infantile spasms resolved with treatment, however, Lara has been presenting with generalised seizures for the last three years and has intractable epilepsy. She is currently on a ketogenic diet administered through a gastrostomy tube but is not responding to it. She is waiting surgery for insertion of a vagal nerve stimulator. Lara has seizures at least three times a day and has presented in the Emergency Department more than 20 times in the last year. She is confined to a wheelchair and has significant physical and emotional care needs and requires the input of the following: epilepsy specialist nurses (inpatient and community), community nurses, specialist consultants (neurology, paediatrician), community general practitioner, pharmacist, speech and language therapist, physiotherapist, psychologist, occupational therapist, and social worker. Lara's parents are non-EU migrants who settled in your country 9 years ago. Her Dad only speaks his native language while her Mum has basic knowledge of the official language of your country.*

#### **2.2.1 Identification of survey instruments**

We adapted the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (Association of Maternal and Child Health Programs, 2014), which were originally developed in the United States of America, and which address the core components of the structure and process of an

effective system of care for these children. Table 2.1 lists the domains we explored for each of the exemplars:

**Table 2.1 Domains for exploration for each exemplar condition**

	TBI	LTV	Intractable epilepsy
Screening, assessment and referral		X	X
Access to care	X	X	X
Care coordination	X	X	X
Community-based services	X	X	X
Family-professional partnerships	X	X	X
Transition to adulthood	X		
Quality assurance and improvement	X	X	X

The final part of the survey focused on gathering data on the socio-cultural context for the responses given for each of the 30 countries. The *Complex Care European Survey of Change* was adapted from a specific Eurobarometer Survey (Centeno et al., 2013). In this survey, the integration of care of children with CCNs at the acute/community/primary interface was considered within the wider milieu of health care policy, as well as social and cultural factors. This section of the data collection tool included questions on the management of children with CCNs, questions on policy, and questions on the future of care delivery at the acute community interface to children with CCNs in each country.

### **2.2.2 Sample**

The vignettes and surveys were sent to a CA in each of the 30 countries.

### **2.2.3 Validity and reliability**

Although face validity does not provide strong evidence of validity, it is a helpful means of encouraging participation in the study (Moore, 2010). Face validity was established through consultation with other researchers and clinical experts to determine professional appearance and layout. To address content validity the vignettes were sent to two experts who had experience in vignette development. The vignettes and surveys were also presented and discussed with a large group of stakeholders including: clinical experts in acute and community settings; healthcare managers and discharge coordinators; a number of European patient advocacy groups including the European Association of Children in Hospital and the European Patient Forum Youth Group; a professional membership organisation for those working with and allied to palliative care, the European Association of Palliative Care; and other MOCHA researchers who would subsequently require the results of our work to progress modelling of processes of care. Qualitative measures of rigour (credibility, authenticity, accuracy, confirmability and transferability) were applied to these data (Denzin and Lincoln, 2011).

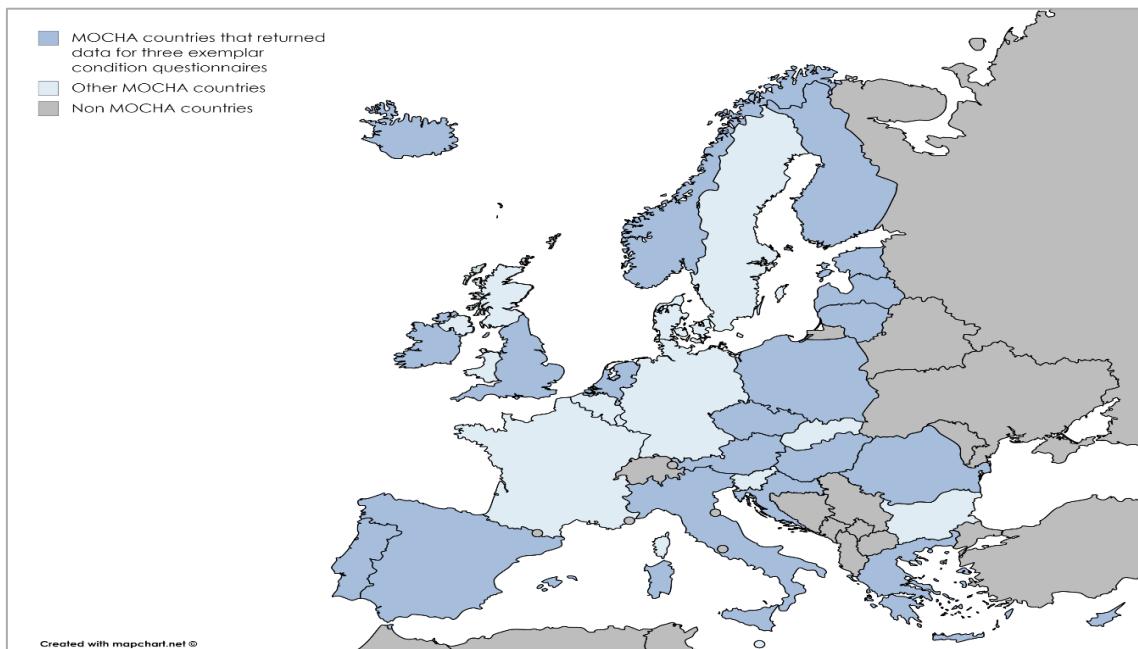
### **2.2.4 Analysis**

Data were analysed using descriptive statistics; frequency and frequency percent are also reported. A number of countries provided additional text data in the commentary boxes at the end of each section of the survey. A thematic analysis was undertaken of the free text data provided. Attriide-Stirling's thematic analysis network (Attride-Stirling, 2001) was applied to the textual data and descriptive meaning extracted and reported on in the context of the findings of the wider study into complex care.

## 2.3 Findings

### 2.3.1 Comparisons of key findings from across the three exemplars

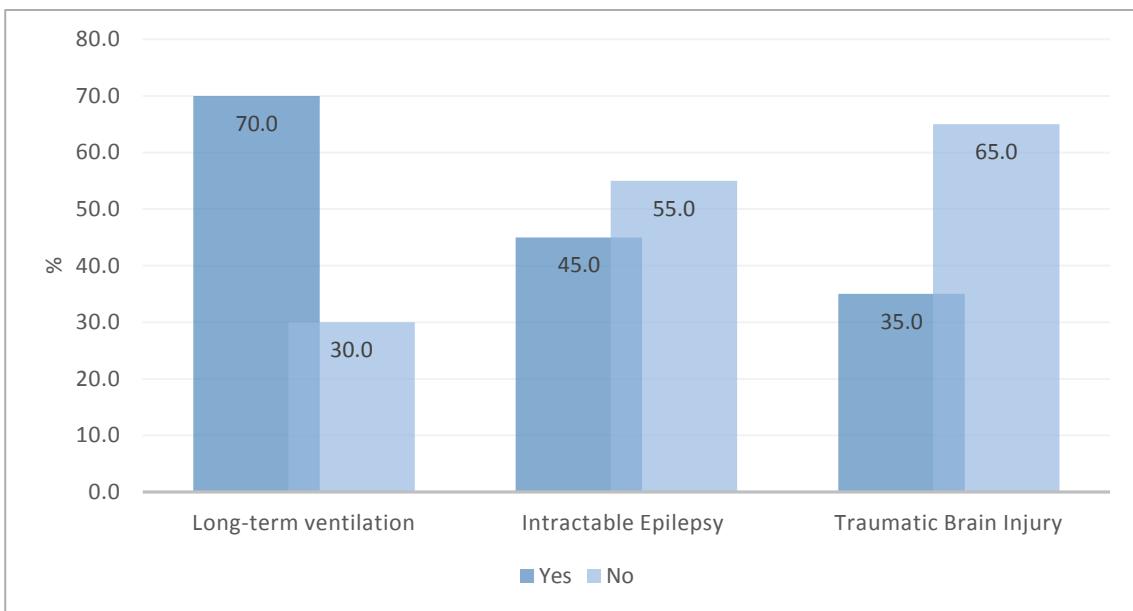
Ten questions, corresponding to five subsections of the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (Association of Maternal and Child Health Programs, 2014), were asked in a similar manner across the three exemplars. The five sub-sections were: access to care; care coordination; community-based services and supports; family-professional partnerships; and quality assurance. Two-thirds (66.6%, n=20) of participating countries provided categorical data that could be analysed for each of the ten similar questions (Figure 2.1).



**Figure 2.1 Countries (N=20) that provided data for similar questions across all three exemplars**

### Access to care: identification of healthcare providers

A higher proportion of countries had a system in place to identify all healthcare providers who care for children assisted with LTV (70.0%, n=14), than for those who care for children with intractable epilepsy (45.0% n=9) or TBI (35.0%, n=7) (Figure 2.2)



**Figure 2.2 Presence/absence of systems to identify all healthcare providers**

### Care coordination: access to care coordination and personalised plans

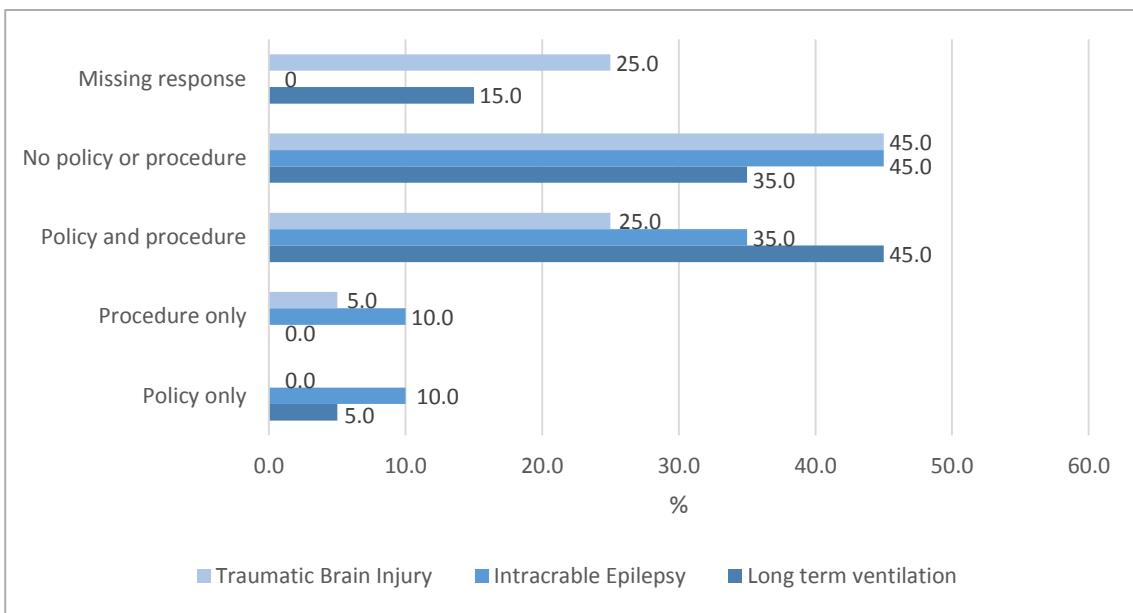
Almost half of participating countries (45.0% n=9), have no policies or procedures that promote care coordination for children with intractable epilepsy or adolescents with TBI. A smaller proportion of respondents (35.0%, n=7) indicated that their country did not have care coordination policies or procedures for children assisted with LTV (Figure 2.3). The benefit of having access to an individual who can assist parents/guardian with the coordination of services was raised by the parents of a child with TBI during one of the DIPEx interviews:

*Mother: Vulnerable... it would be nice to have someone who give you a helping hand.*

*Father: For my part, a coach who stands next to you and says 'you can call me if there is anything'.*

*Mother: Yes, or a family coach.*

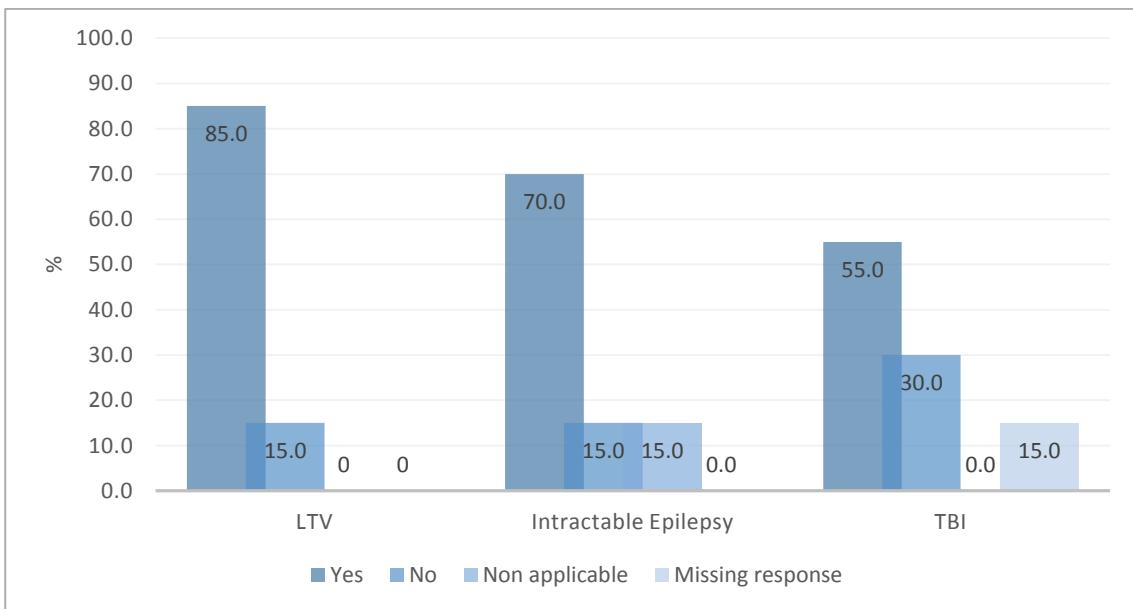
*Father: And like, "I will help you. Is there something we should arrange? Do you know what? I will arrange a physiotherapist who will visit you at home; I will call for you. Or I will do this and this for you. (Father and mother of a child with TBI, Netherlands)*



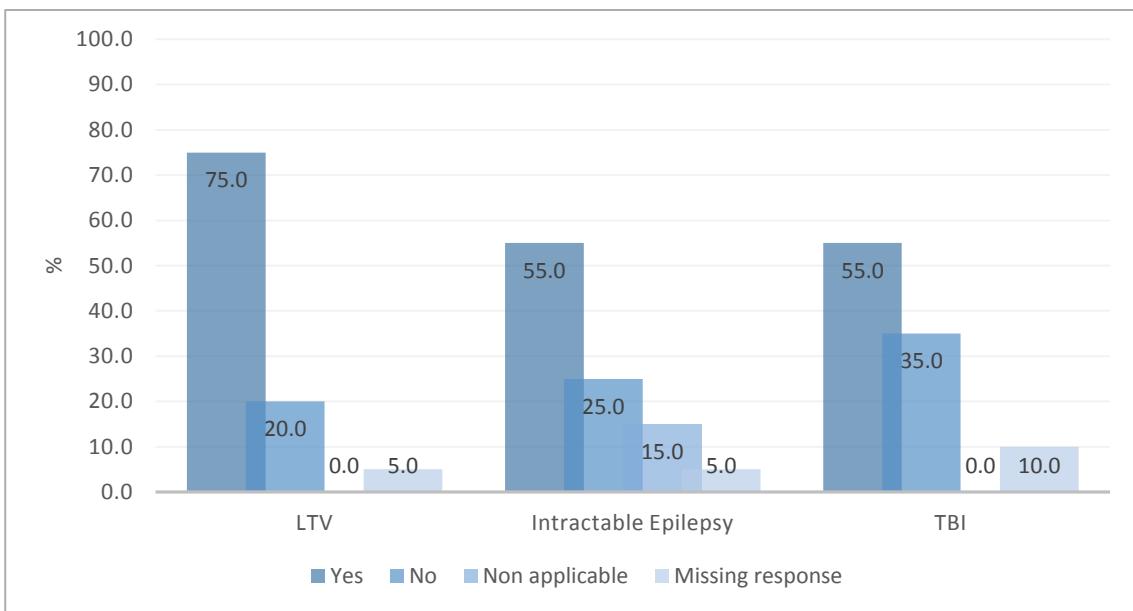
**Figure 2.3 Proportion of countries with policies and/or procedures in place promoting care coordination**

The majority of respondents indicated that personalised care plans for children assisted with LTV (85.0%, n=17) or with intractable epilepsy (70.0%, n=14) are developed in consultation with the parents/guardians of these children in their respective countries. A smaller proportion of respondents indicated that parents/guardians were included in the development of personalised care plans for adolescents with TBI (55.0%, n = 11) (Figure 2.4).

Members of the healthcare team are consulted about the development of personalised care plans for children assisted with LTV in three-quarters of participating countries (75.0%, n=15), and for over half (55.0%, n=11) of countries in relation to the other two exemplar complex conditions (Figure 2.5).

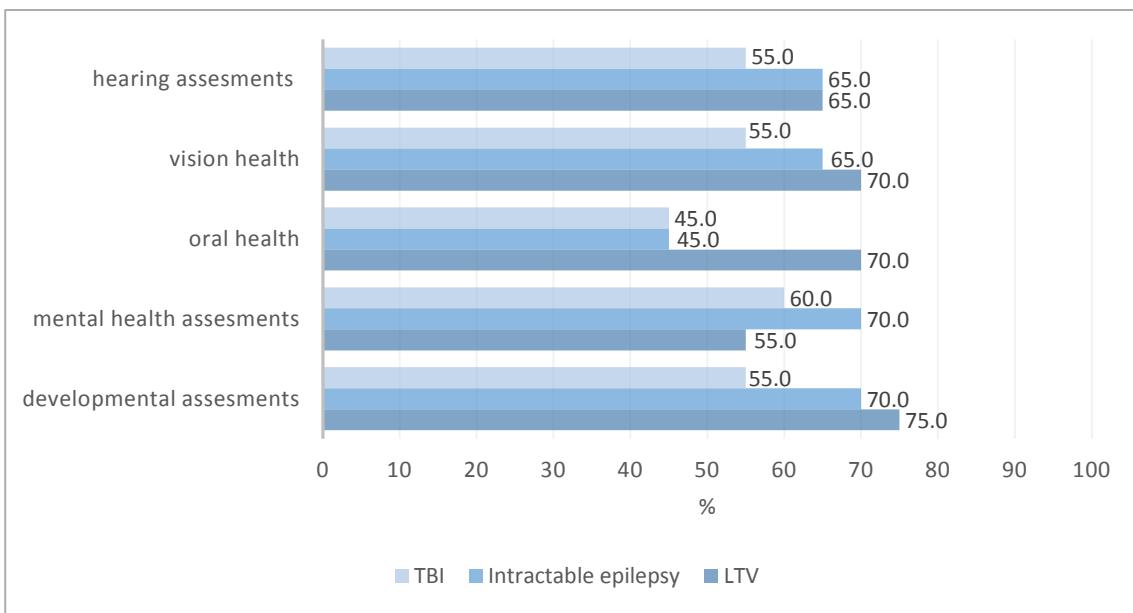


**Figure 2.4 Individuals consulted regarding the development of a personalised care plan**



**Figure 2.5 Healthcare team consulted regarding the development of a personalised care plan**

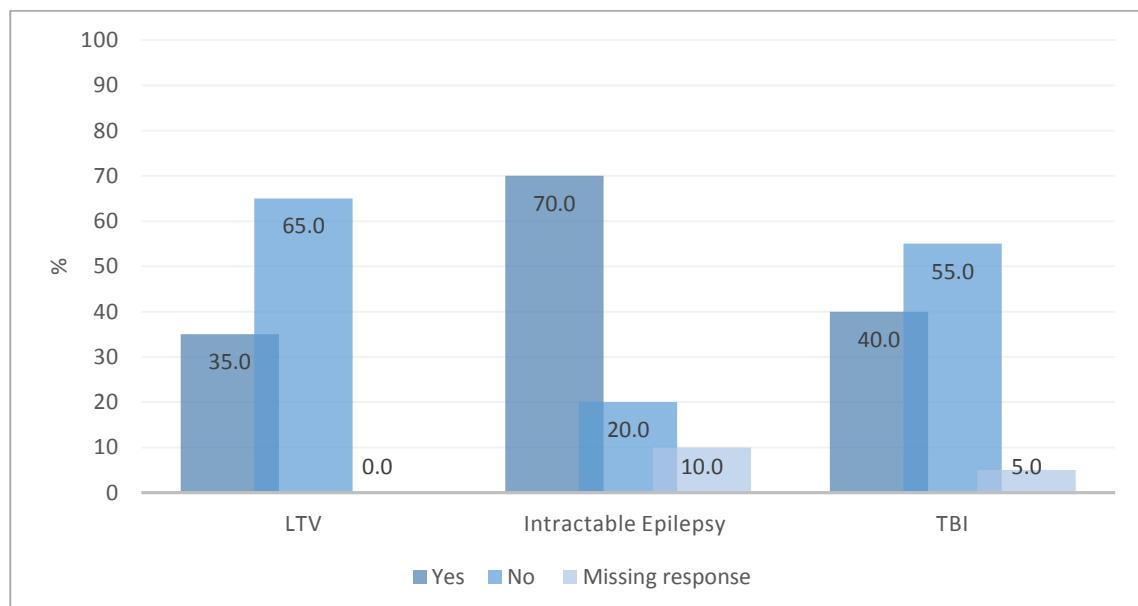
The majority of participating countries incorporate developmental assessments into the personalised written care plan for children assisted with LTV (75.0%, n=15), with intractable epilepsy (70%, n=14) and for adolescents with TBI (55.0%, n=11). Over two-thirds of participating countries include mental health assessments in the written personalised care plan for children with intractable epilepsy. Twelve countries (60.0%) include mental health assessments in the care plan of adolescents with TBI, while eleven countries (55.0%) include mental health assessments in the care plan of children assisted with LTV. Oral health assessments are included in the care plan for children assisted with LTV in fourteen (70.0%) participating countries. A smaller number of countries (45.0%, n=9) include oral health assessments for children with intractable epilepsy and adolescents with TBI. Vision health assessments are integrated into the personalised care plans for children assisted with LTV in over two-thirds of participating countries (70.0%, n=14), while nearly two-thirds of respondents reported that children with intractable epilepsy received integrated vision health assessments as part of their personalised care plans (65%, n=13). Vision health assessments are included in the personalised care plans for adolescents with TBI in a smaller proportion of participating countries (55%, n=11). Nearly two-thirds of participating countries include hearing assessments in the written personalised care plan for children assisted with LTV and for those with intractable epilepsy (65.0%, n =13). In addition, over a half of the countries also reported the inclusion of hearing assessments in the personalised care plan of adolescents with TBI (Figure 2.6).



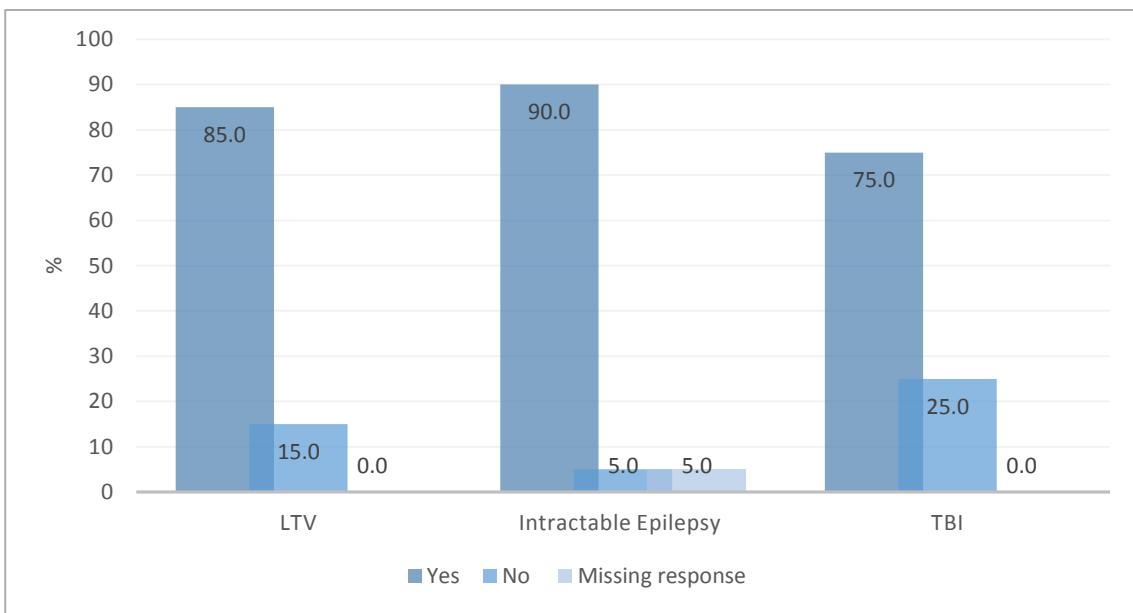
**Figure 2.6 Participating countries where the personalised written care plan integrates healthcare assessments according to exemplar condition**

### Community-based services and supports: family advocacy and psychological support

Family advocacy groups for children with intractable epilepsy have greater involvement in making recommendations to community services (70.0%, n= 14), than advocacy groups for adolescents with TBI (40.0%, n=8) and children assisted with LTV (35.0%, n=7) (Figure 2.7). Families of adolescents with TBI are reported to have less access to psychological support than for the other two exemplars (Figure 2.8).



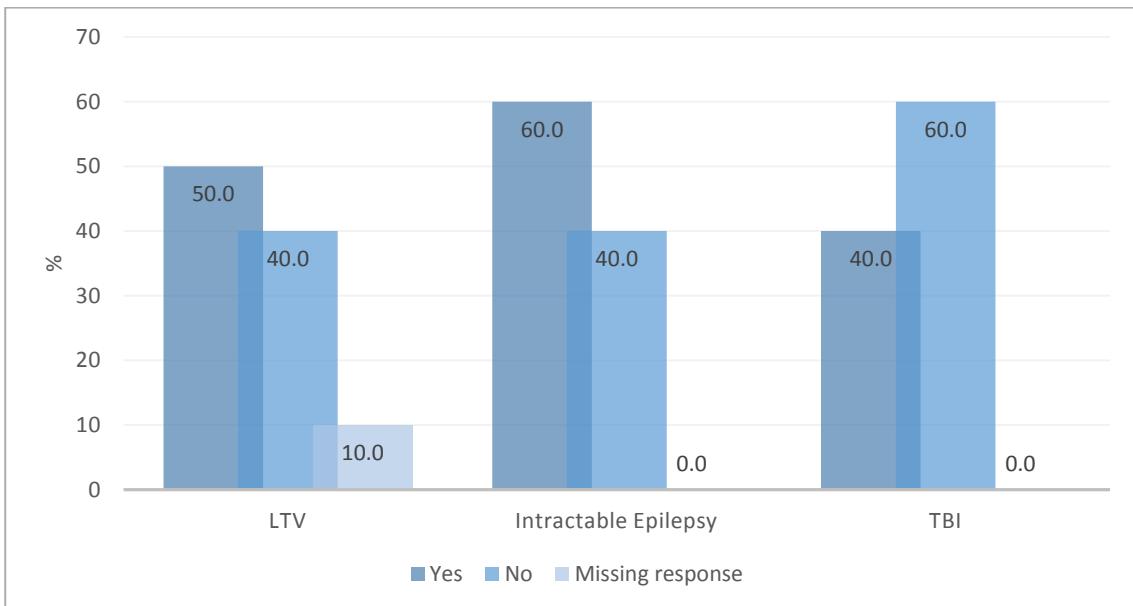
**Figure 2.7 Involvement of family advocacy groups in making recommendations to home and community-based services**



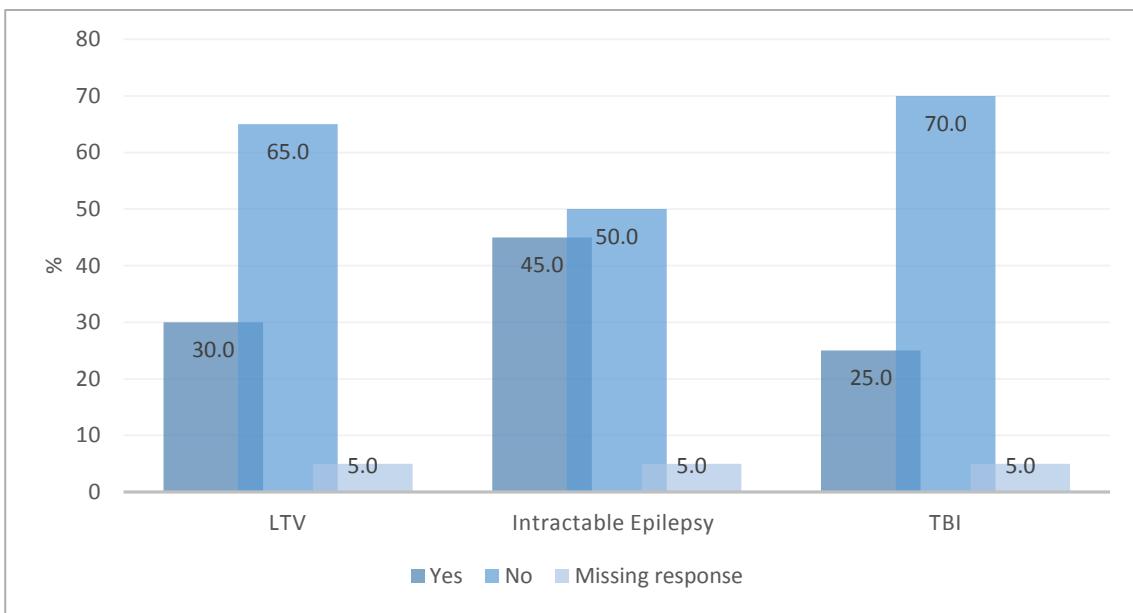
**Figure 2.8 Access to psychological support with paediatric expertise for parents/guardians and siblings of children/adolescents**

#### Family-professional partnership: policy development, quality initiatives and information material

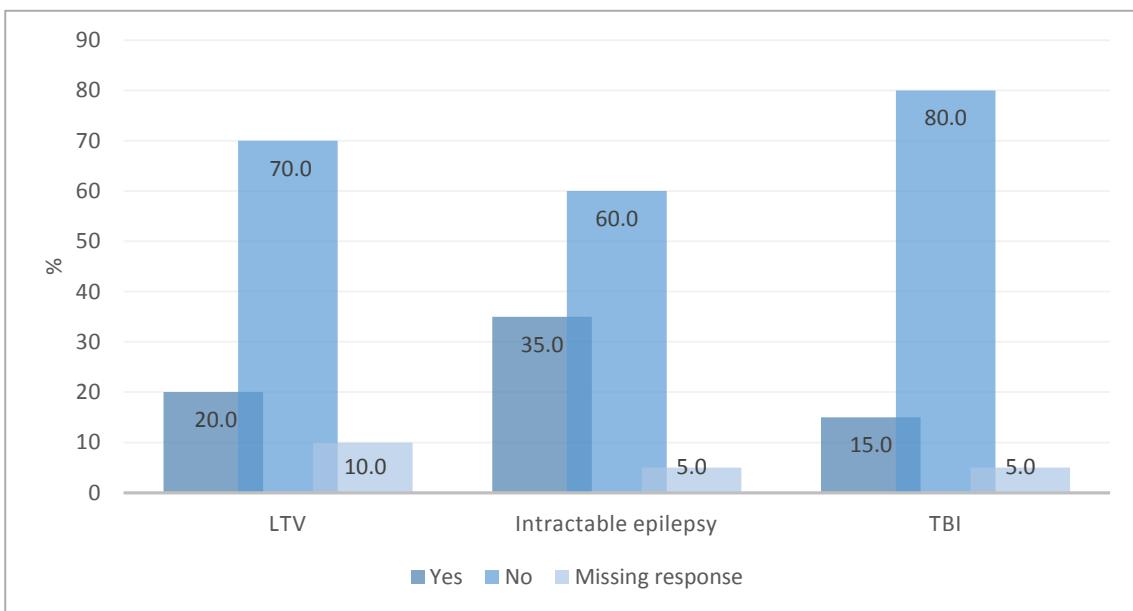
Parents/guardians of children with intractable epilepsy have a greater opportunity to participate in the development of policies and/or procedures affecting their children and in national quality improvement initiatives than parents/guardians of children on LTV or parents/guardians of adolescents following a TBI (Figures 2.9 and 2.10). Overall, parents across all three exemplars are poorly represented in the review of information material (Figure 2.11).



**Figure 2.9 Parents/guardians of children/adolescents invited to participate in the development of policies and/or procedures affecting their children**



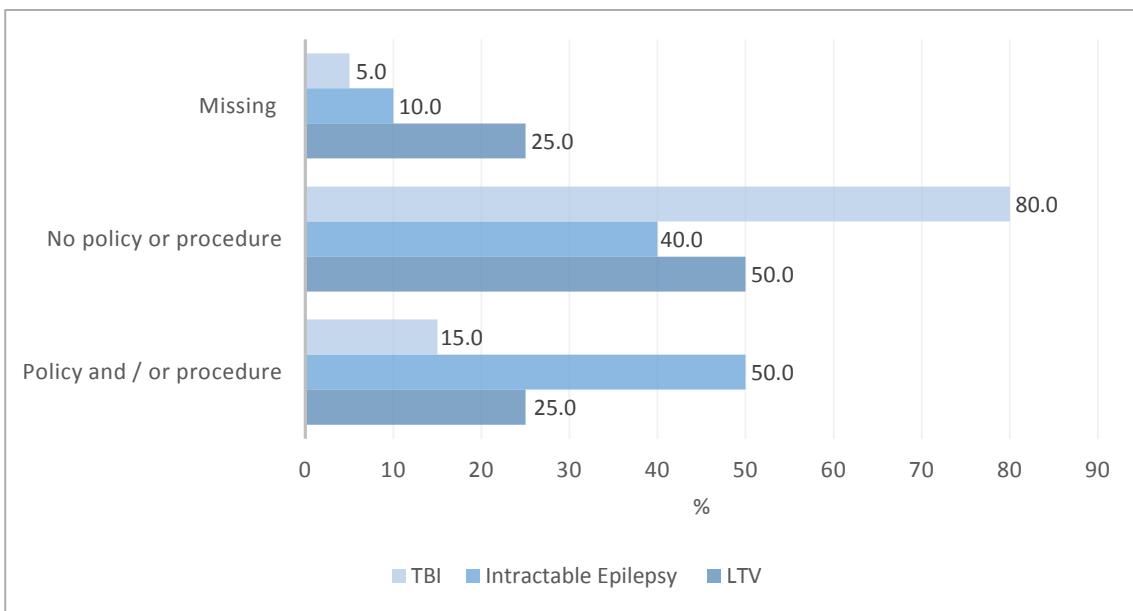
**Figure 2.10 Parents/guardians invited to participate in national quality improvement initiatives**



**Figure 2.11 Parents/guardians involved in the review of information material**

### Quality Assurance: service providers and parents/guardians

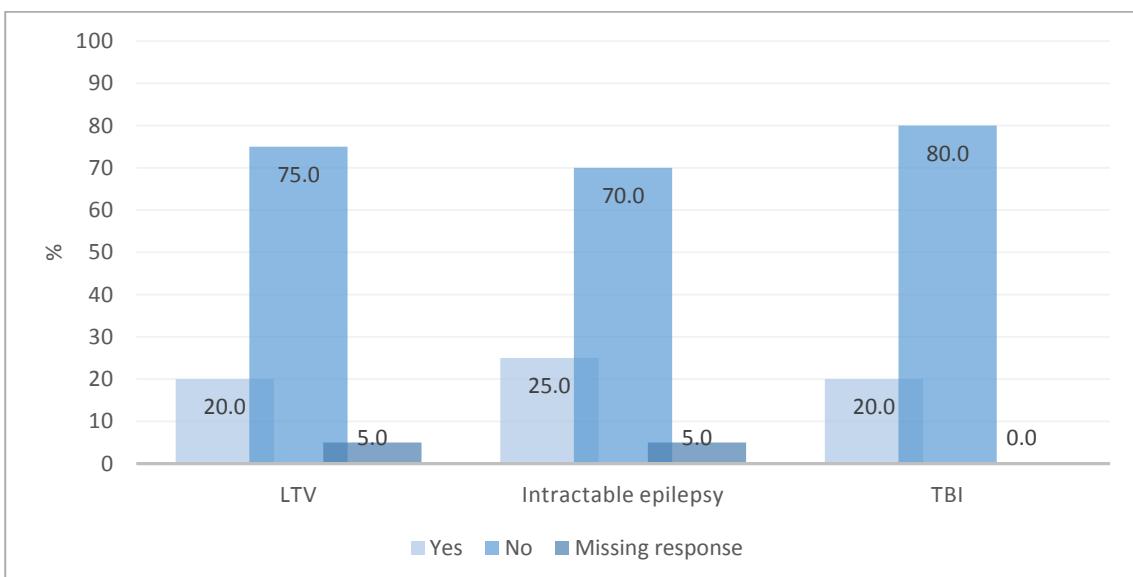
The majority of participating countries (80.0%, n=16) do not have any quality assurance mechanisms (policy and/or procedure) in place to ensure that services providers caring for adolescents with TBI provide quality care. Half (50.0%, n=10) of the participating countries do not have any quality assurance mechanisms to ensure quality care is provided to children assisted with LTV, while 40.0% (n=8) do not have quality assurance mechanisms for the care of children with intractable epilepsy (Figure 2.12).



**Figure 2.12 Quality assurance policies and/or procedures for service providers**

One-quarter (25.0% n=5) of participating countries collect data from the parents/guardians of children with intractable epilepsy relating to quality of care, while one-fifth (20.0%, n=4) of participating countries collect related data from the parents/guardians of children assisted with LTV and from the parents/ guardians of adolescents with TBI (Figure 2.13). Data collected by the DIPEX consortium suggests that parents/guardians would value the opportunity to provide feedback about their child's care:

*That there is just with any GP or preventive health care services or specialist a kind of survey, or something like that, a questionnaire that you can fill in. Like a kind of satisfaction ...Yes, but also after you are ready (when you have your diagnosis), after 4 years, that you then fill in that questionnaire. About your experiences. And of course you should get a questionnaire in between as well. But if you are still in the process and you are still worried about your child, then you experience things differently. (Mother, Netherlands)*



**Figure 2.13 Data collection on the experience of care from the perspective of parents/guardians**

### **2.3.2 Summary of comparisons of key findings from across the three exemplars**

- A higher proportion of countries have a system in place to identify all healthcare providers for children assisted with LTV than for the other two exemplars.
- There is little standardisation of care coordination regardless of exemplar.
- Fewer countries have personalised care plans for adolescents with a TBI than for children assisted with LTV or with intractable epilepsy.
- Children assisted with LTV have less access to mental health assessments than adolescents following a TBI or children with intractable epilepsy.
- Families of children assisted with LTV or adolescents with a TBI have less engagement in community services and less opportunity to participate in policy development than parents of children with intractable epilepsy.
- Families of children with a TBI have less access to psychological support than other families.
- Quality assurance mechanisms are more established for the care of children with intractable epilepsy than the other two exemplars.
- Experience of care is not captured for 75-80% of all families, regardless of CCN.

### **2.3.3 Business process analysis**

The aim of task 6 on WP2 was to analyse the process of complex care treatment across the countries participating in this study, reconstructing the child's care pathway through the identification of the actors and the activities performed to address child's care needs. The methodology adopted to describe the care process using the Unified Modelling Language (UML) has been described in the deliverable D1.4, while the analysis outlining TBI and LTV was performed respectively in the deliverables D2.5 and D2.7.

In the following subsections, the major focus is on tracing whether a pattern of collaboration between care professionals is present and its influence on the performance of the related activities in the delivery of complex care. The use of the UML methodology allowed us to depict a general pattern of activities performed in the treatment of complex care conditions (Figure 2.14), showing that the main differences among countries can be identified by the presence of a multidisciplinary team, especially in the activities related to the development of a personalised written plan as well as in its implementation. When this is the case, the process is more straightforward, suggesting a better communication and collaboration in the child's care. For these reasons, to get a deeper insight into the different combinations of the multidisciplinary team involved in the process, the analysis of the CAs' answers, especially those provided in the narratives, were used to classify some patterns of collaboration that may be considered indicators of continuity of care. This was achieved using the UML use case diagram (subsection 2.3.5). Based on this analysis, bubble charts were developed to analyse countries' organisational features in the treatment of complex care, as well as differences between TBI and LTV.

### **2.3.4 High-level UML activity diagram for complex care**

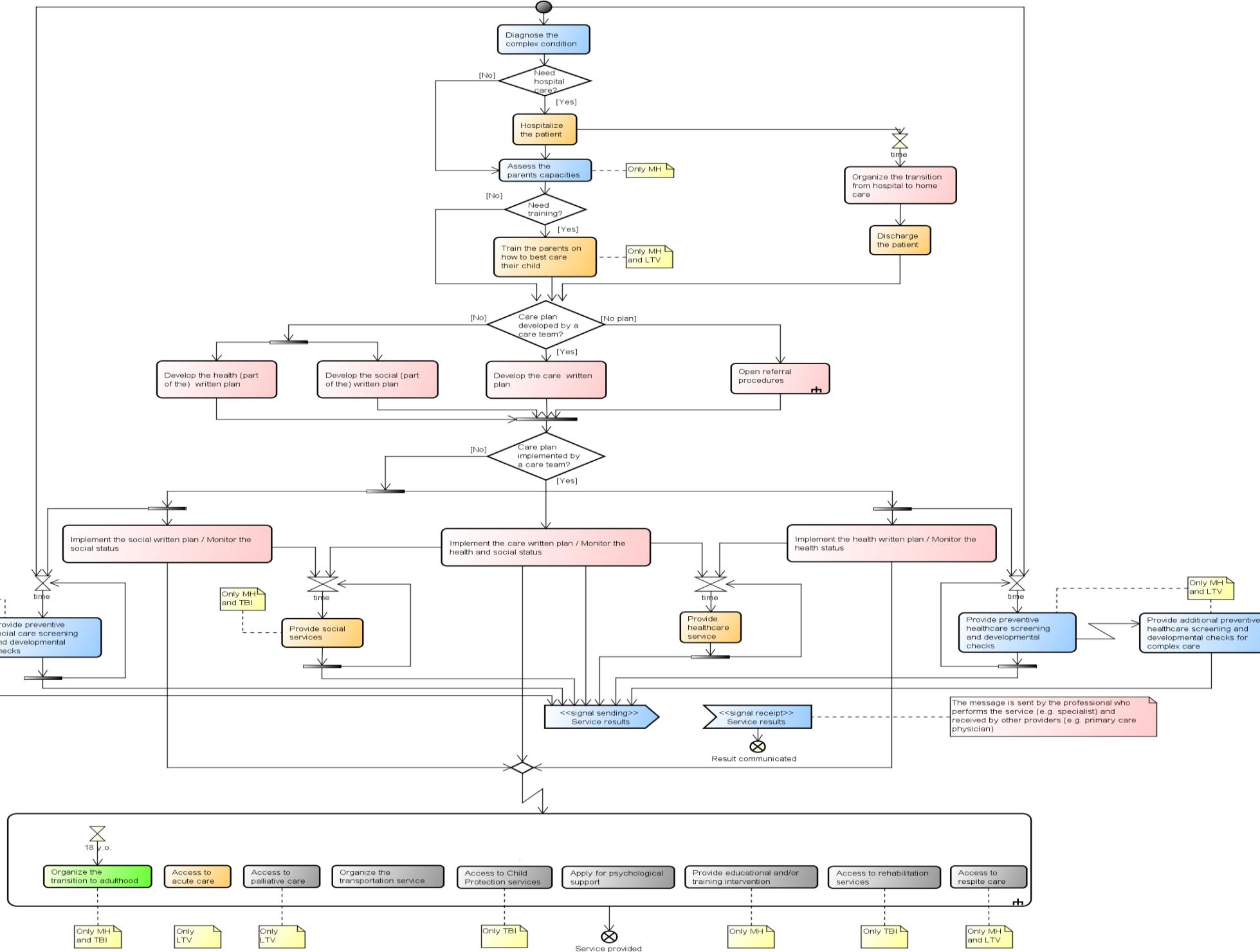
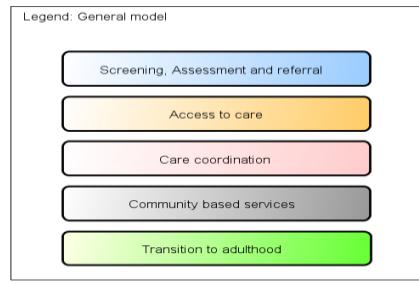
This subsection reports a general, not country-specific UML activity diagram that reconstructs the process of complex care on the basis of the questionnaires on TBI and LTV, reporting all the possible activities that are likely to be performed within these conditions. To provide a comprehensive view of complex care, the diagram also maps the activities performed in the treatment of autism and ADHD. To specify which activity is analysed in specific conditions yellow notes have been added to the diagram. Each activity has been also classified within the domains of the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (Association of Maternal and Child Health Programs, 2014). The first part of the diagram is focused on the assessment of the child's conditions to

determine the severity of the complex condition and define the diagnosis. Depending on this analysis an important part of the process is to determine whether the child needs to be hospitalised and the relevant transition from hospital to home that represents a set of actions that include the medical indications to monitor child health as well as the checking that all the conditions are met to host the child at home.

The central part of the diagram is focused on the development and implementation of the personalised written plan. Considering that the development of the plan can include the identification and organisation of health and/or social care services the diagram highlights two main patterns of performing this task: 1) the care plan is developed of a team composed by a diverse combination of health and social professionals working in a collaborative way; 2) the care plan is developed either by health or social care individual professionals each one developing their own specific plan. In addition, to represent the countries, which do not have a formal written plan, a macro-activity highlighting a set of steps related to referral procedures to access services is added.

The same pattern has been used to represent the implementation of the written plan where the monitoring of the health and social status can be performed: 1) by a care team comprising professionals from different settings (primary, secondary and/or social care); 2) by single professionals not working in a team each one implementing their own specific plan. Depending on the organisation pattern, the provision of health and social services in the community, as well as health and social screening services, presents different degrees of collaboration that are represented in the use case diagrams. Furthermore, the information exchange is depicted by signal sending/receipt elements of the activity diagram that can represent a form of collaboration between professionals sharing information on child's health status. Moreover, during the child's pathway a set of community-based services as well as the access of acute care in case of medical crisis can be triggered (lower part of the diagram).

As shown in the diagram, the conditions (represented by diamonds) that highly influence the flow of activities are determined by the presence of a multidisciplinary team that develops and/or implements the care plan in a collaborative way. When health and social professionals do not work in a team or when there are teams that are either specialised in health or in social care, two parallel activities are performed making the health and social care activities more fragmented. In this case, additional efforts are needed to communicate the results of each activity and coordinate the child's care.



**Figure 2.14. High-level UML activity diagram describing the process of care for a child with a complex condition**  
**(LTV = Long Term Ventilation, TBI = Traumatic Brain Injury, MH = mental health)**

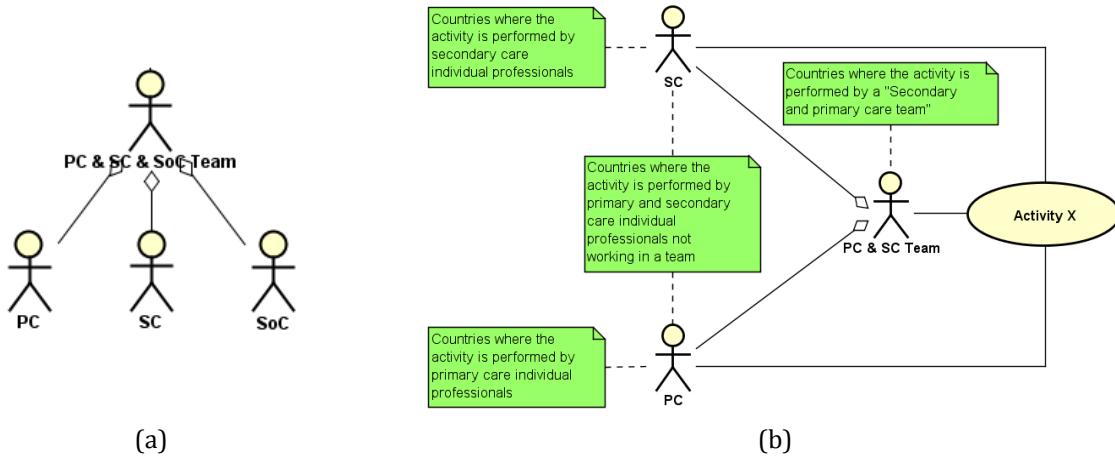
### **2.3.5 Organisation pattern in complex care.**

This subsection analyses the questions that report the type of professionals who are involved in the process of developing and implementing the personalised written plan for a child with a CCN. Focusing on the process of developing and implementing the personalised written plan we gathered information on whether care professionals work as a team or as individuals carrying out specific professional-related activities. Moreover, given that these activities represent a crucial point in care coordination, we further specialised the multidisciplinary team to capture the different combinations of teams taking into account their care specialisation, generally closely related to the setting they belong to. These teams may also provide indications of the interface between primary, secondary and social care comprising also the school care professionals. Therefore, the different levels of collaboration have been identified and classified as following:

1. *Professional collaboration*, which is a multidisciplinary team composed by secondary, primary and social care professionals that may also comprise school care professionals.
2. *Mixed team* that is composed as follows: a) secondary care professionals (e.g. neurologist) and social professionals (e.g. social worker) or b) primary care physicians and social professionals.
3. *Secondary and primary care team* composed by specialists (e.g. pneumologist) and primary care physicians (e.g. GP, paediatrician).
4. *Care team* that is composed by professionals belonging to the same setting: a) secondary care professionals or b) primary care professionals or c) social professionals.
5. *Individual professionals* that identify more than one health and/or social care providers not working in a team.
6. *Single professional* who is the sole provider of the activity.

### **2.3.6 UML use case diagram.**

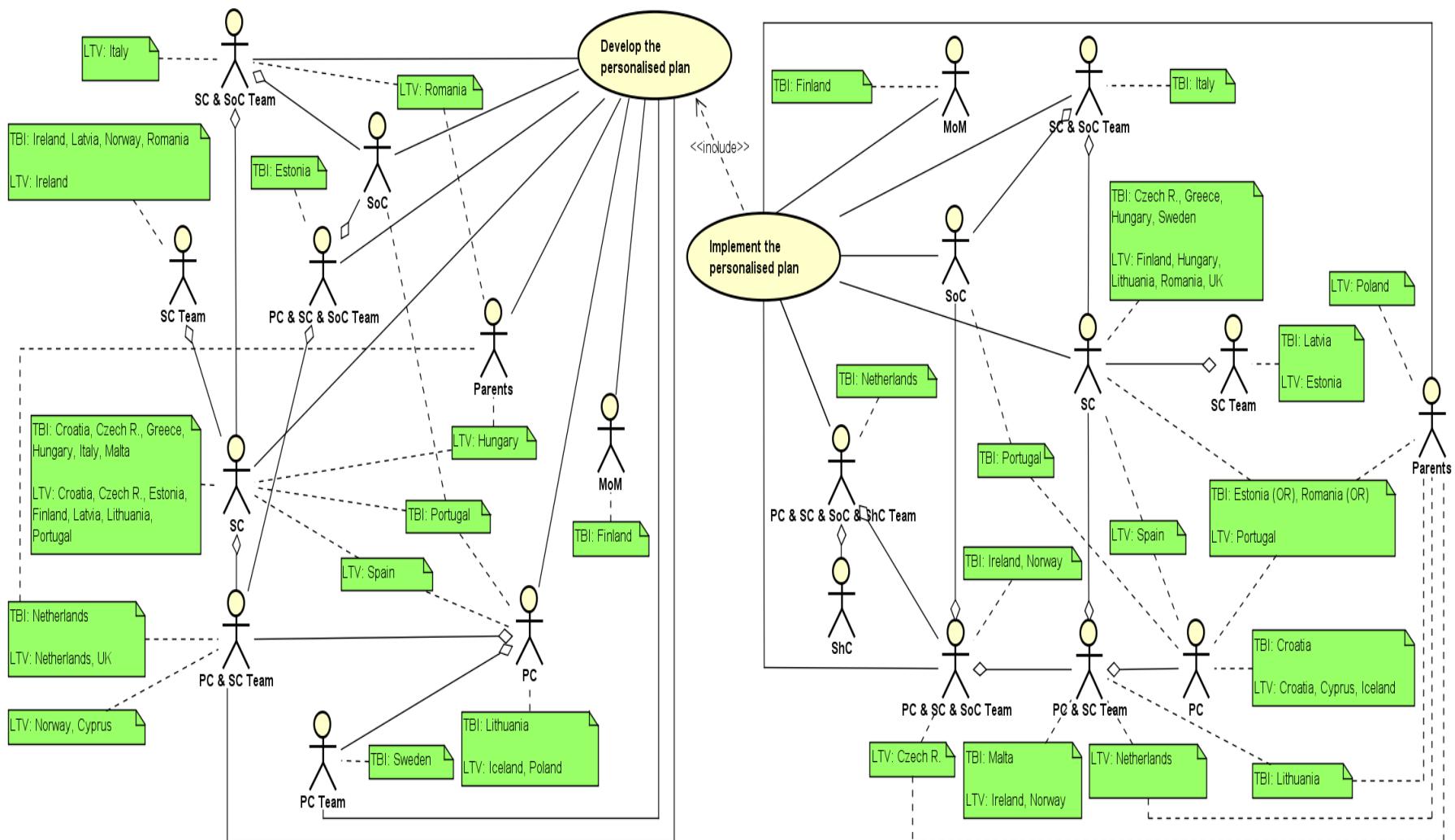
The level of collaboration in the development and implementation of the plan is represented using the UML composition symbol . For instance, as shown in Figure 2.15a, the PC & SC & SoC Team is a *composition* of PC (Primary Care), SC (Secondary Care) and SoC (Social Care) professionals. They are an example of what we defined Professional Collaboration. The diagram also provides green notes (see Figure 2.15b) that report for each country the types of actors involved in the related activity as highlighted by the dotted lines.



**Figure 2.15 Example of UML use case diagram elements**

**Showing a) professional collaboration where a PC & SC & SoC Team is a composition of PC (Primary Care), SC (Secondary Care) and SoC (Social Care) professionals; b) green notes reporting the types of actors participating to the relevant Activity X.**

The UML use case diagram in Figure 2.16 provides a static description of the activities related to the development and implementation of the personalised written care plan, each of which, is represented by ellipse.



Note: Data from Luxembourg will be included in the final updated report following further clarification

**Figure 2.16 UML use case diagram: development and implementation of the personalised plan**

**PC = Primary care professionals; SC = Secondary care; SoC = Social care; ShC = School care; MoM = member of the municipality**

Considering both activities (“*Develop the personalized written plan*” and “*Implement the personalized plan*” use cases) there is a high variety of team composition across countries and also between health conditions. These activities are performed only in a few countries by a professional collaboration (Czech R. for LTV; the Netherlands, Ireland, Norway and Estonia for TBI) or by a mixed team (Italy for both pathologies and Romania for LTV). A relatively higher number of secondary and primary care teams as well as of care teams is present in both activities. However, both activities are mainly performed by individual professionals not working as members of a team. Moreover, the diagram highlights the involvement of parents in the development and implementation of the written plan as a possible interface between professionals.

### **2.3.7 Analysis of level of collaboration in complex care.**

In this subsection the analysis of the level of collaboration in the MOCHA countries is reported for TBI and LTV. To represent this information a bubble chart (Figure 2.17) is developed for each complex condition highlighting both the development (horizontal axis) and the implementation (vertical axis) of the personalized plan. The criteria to determine the scale of values reported in the chart to represent the level of collaboration among professionals in the performance of the relevant activities is based on the assumption that: the lowest level of collaboration occurs when the relevant activity is performed by a single professional, while the highest level takes place when the activity is performed by a professional collaboration among providers coming from secondary, primary as well as social care settings. Table 2.2 reports the scale of values used to develop the bubble charts, taking into account the different groups described previously.

**Table 2.2. Scale of values of the different levels of collaboration**

Level of Collaboration	Value
Mixed team (PC + SoC or SC + SoC)	5
Secondary and Primary Care team	4
Care team (SC or PC or SoC)	3
Individual professionals	2
Single professional	1

*Note:* PC= primary care / SC = secondary care / SoC = social care

The size of each bubble is proportional to the number of countries classified in the specific level of collaboration. Moreover, two dotted red lines have been added to the figure to specify the coordinates of the barycentre that highlights the average level of collaboration in a specific complex condition. The barycentre has been calculated using the weighted arithmetic mean where the weights are the number of countries detected for a specific level of collaboration. As an example, the formula to determine the level of collaboration in the development of the plan is reported below. The same formula has been applied to assess the level of collaboration to implement the plan.

$LoC_{development}$

$$= \frac{n_{single-prof} + (2 \cdot n_{individual-profs}) + (3 \cdot n_{care-team}) + (4 \cdot n_{SC&PC-team}) \cdot (5 * n_{mixed-team}) \cdot (6 * n_{prof-coll})}{n}$$

Note: LoC = Level of collaboration / PC= primary care / SC = secondary care

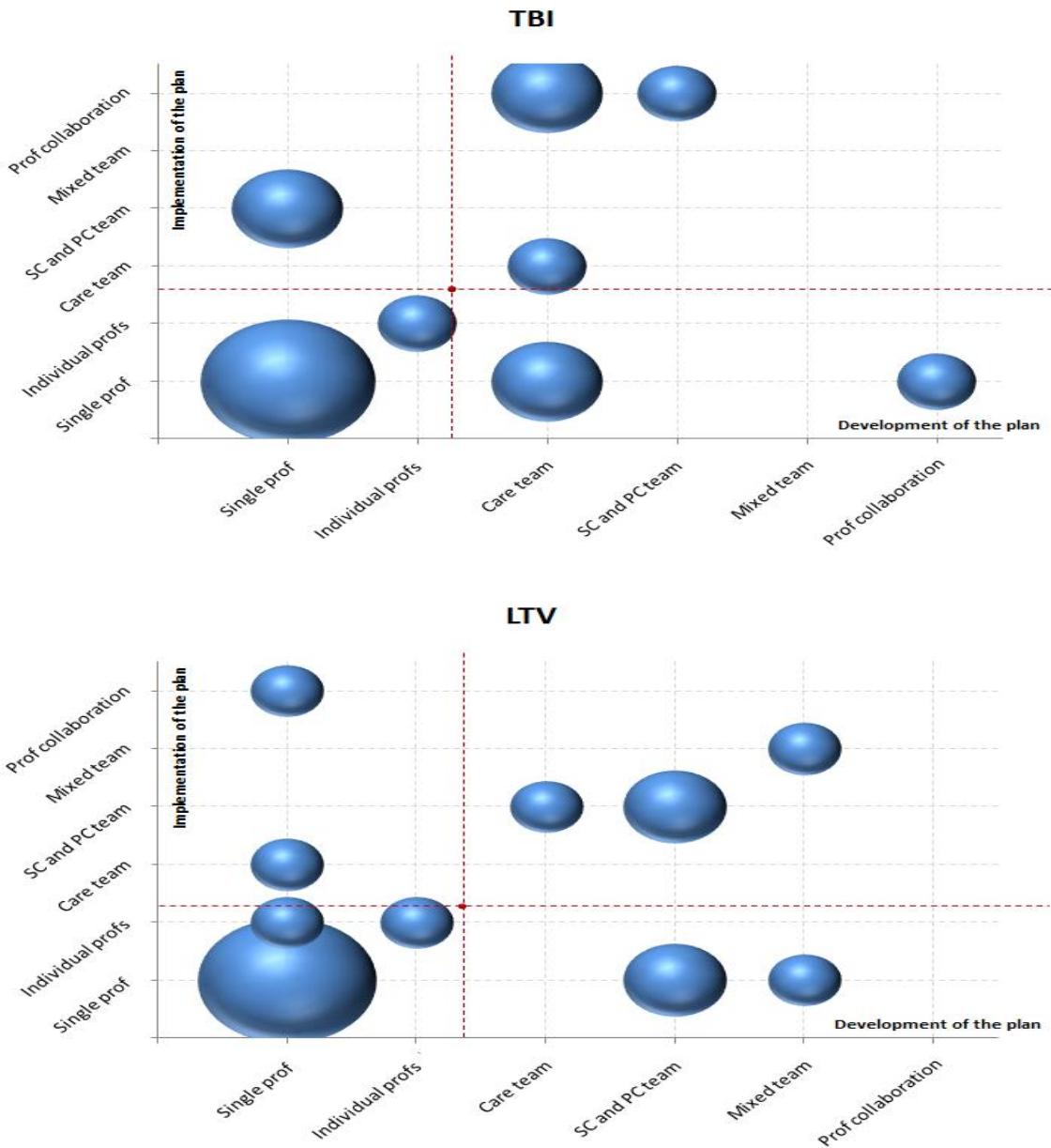
Charts have been developed on the basis of the results shown in Table 2.3, where the number of countries for each specific level of collaboration and for each complex condition is reported.

As highlighted in the table and the diagrams, in a significant proportion of countries both activities are performed by single and/or individual professionals not working in a team. This is more evident considering the LTV condition than in the TBI where a lower number of countries shows this pattern.

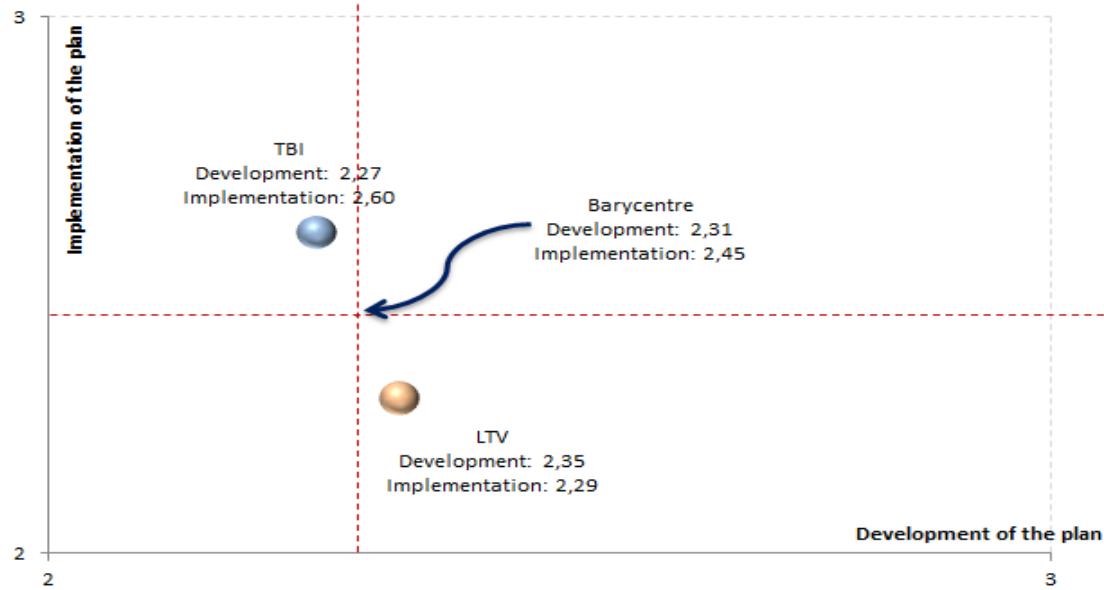
Starting from these results an additional bubble chart has been developed putting together the barycentre values of the two complex conditions, as shown in Figure 2.18. Furthermore, in this case two dotted red lines have been added to specify the coordinates of the barycentre that highlight the average level of collaboration of complex care.

**Table 2.3 Number of countries performing the planned activities with the different levels of collaboration**

	Development	Implementation	TBI	LTV
Level of collaboration	Mixed team	Mixed team	0	1
	SC-PC team	Professional collaboration	1	0
	Care team	Professional collaboration	2	0
	Mixed team	Care team	0	0
	SC-PC team	SC-PC team	0	2
	Professional collaboration	Single professional	0	0
	Mixed team	Individual professionals	0	0
	Care team	SC-PC team	0	1
	Single professional	Professional collaboration	0	1
	Mixed team	Single professional	0	1
	Care team	Care team	1	0
	SC-PC team	Single professional	0	2
	Single professional	SC-PC team	2	0
	Care team	Single professional	2	0
	Individual professionals	Individual professionals	1	1
	Single professional	Care team	0	1
	Single professional	Individual professionals	0	1
	Single professional	Single professional	5	6



**Figure 2.17 Level of collaboration for TBI and LTV**



**Figure 2.18. Level of collaboration for each complex condition**

### 2.3.8 Summary of comparisons of key findings from the business process analysis.

- A slightly higher level of collaboration is present in the development of the plan for a child assisted with LTV than on TBI, while the reverse is true for TBI, where there is a higher level of collaboration in the implementation of the plan.
- In the majority of the countries, the development and implementation of the plan are generally provided by single and/or individual professionals not working in a team, both in LTV and TBI. Generally, these professionals are hospital-based specialised physicians, such as neurologists or pulmonologists.
- In a few countries a professional collaboration is in place limited to the implementation of the plan and only for TBI.
- The involvement of primary care physicians is higher during the implementation of the plan than in its development. Their role either working in a team or not seems to be focused on the delivery of general health services.
- In a minority of countries social aspects of child's care are implemented by a collaboration that includes social workers.

### **2.3.9 Complex Care European Survey of Change**

The *Complex Care European Survey of Change* was adapted from a specific Eurobarometer Survey (Centeno et al., 2013). In this survey, the integration of care for children living with CCNs at the acute/community/primary interface is considered within the wider milieu of healthcare policy, as well as social and cultural factors. CAs were asked about the current state of development of services for children with each of the tracer conditions including the most significant changes in the integration of care in the last five years, the overall progress in the integration of care services in the last five years, and the main barriers and facilitators to the integration of care for each tracer condition. Finally, they were asked about the current state of policy and socio-cultural issues pertaining to each of the three areas regarding: strategies used to improve political awareness and government recognition of the need for integration of care services; any special funding initiatives for each group; any involvement between their country and the EU on initiatives to enhance integration of care; and they were asked to identify any major public discussion, debate or controversy about the needs of children with CCNs in the last five years.

#### **Significant changes in the integration of care in the last five years**

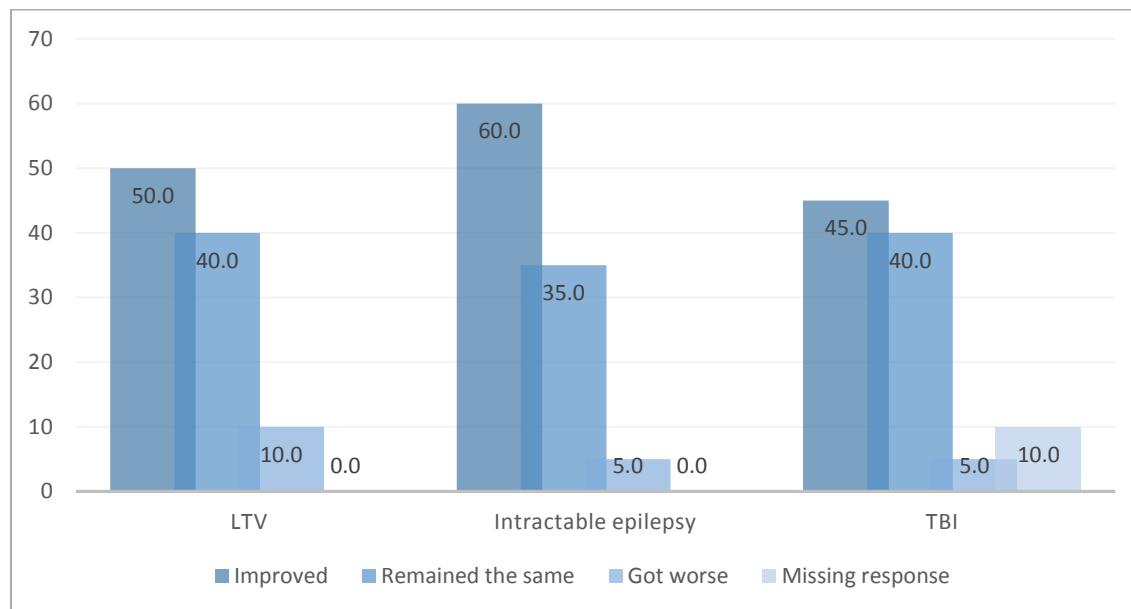
Two significant changes were found in data on all three exemplars, enhanced care coordination and establishment of integrated care programmes (Table 2.4), while one other change, the establishment of specialist centres, was noted for two exemplars. The other changes noted are all specific to each particular complex health issue.

**Table 2.4 Significant changes in the integration of care in the last five years**

Changes	TBI	LTV	Intractable Epilepsy
Enhanced care coordination	X	X	X
Establishment of integrated care programmes	X	X	X
Establishment of specialist centres and care pathways	X		X
Specialised training for school teachers	X		
Enhanced rehabilitation	X		
Enhanced adolescent care	X		
Availability of written information	X		
Use of electronic health records	X		
Reduction in funding		X	
Establishing expertise in clinical care		X	
Discussion on limits of care		X	
Introduction of digital prescriptions		X	
Introduction of a palliative care strategy		X	
Establishment of advocacy groups			X
Increased participation in care delivery			X
Development of the role of Advanced Nurse Practitioners			X
Increased awareness of needs of siblings			X
Increase in number of paediatric neurologists			X
Cross-border initiatives			X

## Progress in the integration of care services in the last five years

The greatest progress reported on the integration of care services pertained to the care of children with intractable epilepsy. There was a greater perception that things had disimproved for children assisted with LTV than for the other two exemplars (Figure 2.19).



**Figure 2.19 Progress in the integration of care for the three exemplar conditions during the preceding five years**

## Main barriers to the integration of care for each tracer condition

Similar barriers to the integration of care were identified across all three exemplars. The majority of countries commented on lack of awareness of adolescents needs while one country commented on over treatment of children assisted with LTV.

**Table 2.5 Main barriers to the integration of care for each tracer condition**

Barrier	TBI	LTV	Intractable Epilepsy
Poor care coordination	X	X	X
Lack of clinical expertise and specialist training	X	X	X
Insufficient funding	X	X	X
Absence of standards of care	X	X	X
Absence of clinical pathways to specialist care	X	X	X
Geographical variation in care	X	X	X
Insufficient development of e health	X	X	X
Insufficient access to psychosocial support	X	X	X
Lack of awareness of adolescent needs		X	
Over diagnosis and over treatment		X	

### **Main facilitators to the integration of care for each tracer condition**

Training and retention of skilled healthcare staff was identified as a facilitator of integration of care across all three exemplars. The need for a national data base, timely transfers to specialist services and enhanced family and school support were identified for two of the three exemplars.

**Table 2.6 Main facilitators to the integration of care for each tracer condition**

Facilitator	TBI	LTV	Intractable epilepsy
Training and retention of skilled healthcare staff	X	X	X
Timely transfers to home and specialist services	X	X	
Increased political awareness			X
Adolescent specific care	X		
National data base	X	X	
Enhanced family support	X		X
Enhanced school health	X		X
Enhanced technology support		X	
Increased political awareness		X	

### **Strategies used to improve political awareness and government recognition of the need for integration of care services**

Media campaigns, parent lobby groups and conference debates were used as strategies across all three exemplars, while the variation between strategies in LTV and intractable epilepsy may reflect the maturity of public and professional understanding of the respective CCNs.

**Table 2.7 Strategies used to improve political awareness and government recognition**

Strategy	TBI	LTV	Intractable epilepsy
Media campaigns	X	X	X
Parent lobby groups	X	X	X
Conference debates	X	X	X
Increase in NGOs		X	
EU campaigns			X
Medical expert lobby group			X

### **Special funding initiatives**

The standard funding arrangements were similar for all three groups, with additional funding sourced for children with intractable epilepsy through pharmaceutical and private enterprises, families and volunteers and EU funding channels. This may again be explained by the maturity of public and professional understanding of the respective CCNs.

**Table 2.8 Funding initiatives**

Funding	TBI	LTV	Intractable epilepsy
NGOs	X	X	X
State funding	X	X	X
National Lottery	X	X	X
Insurance company		X	X
Pharmaceutical and private enterprises			X
Families and volunteers			X
EU funding			X

**Involvement with the EU on initiatives to enhance integration of care**

Overall, there seemed to be cross country medical/academic partnerships across the EU to support the management of the CCNs, while professional networks and research programmes were also utilised to support the integration of care.

**Table 2.9 Involvement with the EU on initiatives to enhance integration of care**

Involvement	TBI	LTV	Intractable epilepsy
Professional networks	X	X	
Cross country clinical/academic partnerships on treatment options	X	X	X
Research programmes		X	X

**Major public discussion, debate or controversy about the needs of children with CCN in the last five years.**

While a variety of debates occurs, there was no uniting issue or common approach used for debate across all three exemplars.

**Table 2.10 Public discussion, debate or controversy**

Discussion, debate or controversy	TBI	LTV	Intractable epilepsy
Academic/scientific conferences		X	X
National awareness days	X		X
Media campaign by parents		X	X
TV debates by medical experts			X
Ethical debate on ventilation		X	
Public debate on UN Convention on rights of persons with a disability			X

**2.3.10 Summary of key findings from the Complex Care European Survey of Change**

- The majority of significant changes that occurred were specific to each individual complex health issue.
- The greatest progress on the integration of care over the last five years pertained to children with intractable epilepsy.

- There was a disimprovement in care coordination in the last five years for children assisted with LTV compared to the other two exemplars.
- The absence of care coordination was identified as a barrier to integration of care.
- Training and retention of skilled healthcare staff was identified as a facilitator of integration of care across all three exemplars.
- Media campaigns, parent lobby groups and conference debates are used across all three exemplars to improve political awareness of the needs of children and adolescents.
- In addition to the standard provision of funding from Non-Governmental Organisations (NGOs) and the state, children with intractable epilepsy in some countries also benefit from funding from pharmaceutical and private enterprises, family and volunteer fundraising and the EU.
- Cross country medical and academic partnerships are utilised to enhance the management and integration of care for children across all three exemplars.
- The fora for discussion, and the topics for debate, about the needs of children with CCN varied across all three exemplars, highlighting different issues of public concern.

## **2.4 Discussion and Limitations**

The comparison of findings across the three exemplars from the initial survey presented at the start of this chapter suggests that the integration of care for children with CCNs across the EU/EEA is not favourable. Overall, reflective of the findings presented in our earlier report in July this year (Brenner et al., 2017), the integration of care for children with intractable epilepsy seems to be at a more evolved stage than the integration of care for children assisted with LTV or adolescents with a TBI. This pattern is continued in the findings on the development of services and the socio-cultural influences on the integration of care. While our early findings identified the two cross-cutting themes of parents as catalysts of optimum integration of care, and pathways to specialist care, a further three facilitators were identified from the findings presented in this chapter: enhancing care coordination; national integrated care programmes; and cross country clinical/academic partnerships. We continue to propose that there is no ‘one-size-fits-all’ when it comes to facilitating optimum care for such a diverse group of children and their families and that it is reasonable to suggest that CCNs that are more ‘established’ and which are anecdotally known to have a larger populations have specific facilitators of optimum care at the acute community interface that may not reflect those of all children with CCNs. This is important in understanding that one size will not fit all in the future planning for healthcare provision in the acute services, in the community and at the acute community interface. This has relevance across the EU/EEA, as it raises issues of resources, specialism, and important issues in terms of equity of access, geographical variation and geographical isolation.

### **2.4.1 Limitations**

The ‘complexity’ of measuring the structures and processes of complex care across 30 countries cannot be underestimated and a number of limitations were identified in the study. Similar to our earlier findings we urge caution with interpretation of the data as: not all countries reported on all sections of the questionnaires; some responses were sparse; and some of the findings suggest that responses may have reflected general issues on TBI, LTV or epilepsy, as opposed to the specific scenarios presented. While the use of vignettes affords the possibility to create a variety of care

delivery situations pertaining to complex care, there is concern about the use of hypothetical situations to elicit opinion. This is considered a threat to external validity in the study as there was the potential that participants' responses would not reflect the reality of clinical work. This reflects concerns raised in previous studies (Ludwick and Zeller, 2001, Brenner, 2013). Nonetheless, we consider that we received rich contextual data from the CAs. We were reliant on a large number of respondents to feed into this process, across a number of countries. This had the potential to yield a wide variety of responses, in an area previously unexplored, with informants providing commentary to CAs in very specialist areas of practice. However, structures were put in place across the MOCHA project to facilitate this: the glossary of terms was available to support consistency in terminology and the key informant in each country was a local expert in child health services, who collated and conveyed the responses from their country.

## **2.5 Conclusion**

This chapter presented the findings from our comparison of data across all three exemplars, TBI, LTV and intractable epilepsy, building on the work from our earlier report presented to the European Commission in July this year. Although some commonalities exist across the findings from the three exemplar conditions, we remain convinced, after this further analysis, that there are individual critical junctures in care delivery that will demand care provisions that are specific to particular cohorts of children and their families. It is also realistic to presume that optimum facilitators of care in one jurisdiction may not transfer very well to another.

## **Chapter 3 Social Care Interface**

**Austin Warters, Rebecca McHugh, Manna Alma**

*I may say that I spent my childhood in a hospital. I went to the hospital several times in a row or twice a year... (...) I was frustrated, I couldn't see my friends, nothing (...) When I came to school, I sat on a wheelchair. I couldn't do anything (...) I couldn't do what I liked to do. My classmates did not accept me. They didn't help me when I had a foot in cast. I had to do everything by myself, even my assistant did not help me. It was just terrible. (Girl with epilepsy, 16 years, Czech Republic)*

### **3.1 Introduction to the Social Care Interface**

The aim of task 3 was to explore the interface between social care and primary care for children with CCN across the countries participating in this study; a report outlining the findings from this task was completed and submitted to the EU Commission in July 2017. Social care needs are defined in this task as including 'a wide range of everyday needs such as the ability to enjoy friends and family, participate in school, engage in leisure and social activities and have a safe and happy home environment' (Marchant, 2007). The earlier task 3 report found considerable variation in how and to what extent social care and primary care are integrated throughout the MOCHA countries. A detailed account of the findings of task 3 are not incorporated into this chapter, rather the purpose of this chapter is to further explore the main themes emanating from the report. The context in which these themes will influence the care process of a child with CCNs and their family is the current landscape of social care provision in Europe. This is explored within this chapter with the aim of considering what it can tell us about the future of social care provision throughout Europe. While social care needs were identified at the beginning of work on this project from the literature, in this chapter the perspectives of children with CCNs and their parents/guardians are also represented, as provided by data from the DIPEX team. The introductory quote captured by the DIPEX team illustrates the social care needs of a child with CCNs through her own words. Though this child is undergoing acute interventions her preoccupation is with her friends and how she will fit in when she is back in school. In other words, her preoccupation is not just with her health status but also with her wider world.

### **3.2 Methods**

Questionnaires on social care for children with CCN were sent to the 30 MOCHA CAs in May 2016 and data collection was completed between June 2016 and March 2017 (see WP2 survey compendium on MOCHA website). Twenty four countries responded and the findings are presented in Chapters 3-5 of the social care report published in July of this year. Four related themes were identified from the data collected: information provision; participation; flexible support, and; equity of access. In this chapter each of these themes are discussed alongside the DIPEX data, which represents the views of children and families. The inclusion of findings from the DIPEX data is an addition to the previous social care report. In this chapter contextual issues affecting contemporary social care provision within Europe are also explored through a consideration of the CA data in light of the relevant literature.

### **3.3 Direction of Future Social Care Provision in Europe**

Within Europe, contributions to the 'mixed economy' of personal social services are made from four sectors; the informal sector (families, friends etc.), the state, the voluntary non-profit sector, and the for-profit sector (Munday, 2003; p.5-6). As the MOCHA data shows, the extent of each of these four sectors can be difficult to define within a country. In many the combination of publicly-provided and externally-provided social supports is hard to fully establish. In Croatia, for example, the respondent outlines how the multiple supports that are available for parents/guardians and siblings of children with CCNs are provided; 'through a combination of NGOs, primary care, social care and mental health services'. Voluntary organisations will often have been contracted by the state, but some of the time the work of voluntary organisations is to provide organisation-funded care where public provision is not sufficient. In Lithuania, for example, while counselling and support for a child with an ABI, would be available through school, access to support for his parents and siblings (parenting skills courses, practical support and counselling, for example) would be available within the NGO network only. As Anheier explains, the reason for the creation of non-profits initially is often to provide care that is 'difficult' (2000); in some cases, it seems that non-profits are functioning as a provider to ameliorate gaps in the provision of social care.

Previous work has identified four 'types' of social care system - the Scandinavian model of public services, where the principle of universalism is fundamental and services are paid for through general taxation (e.g. Sweden, Denmark, Norway and Finland); the family care model, where state-provision of services is limited and the responsibility of the family to provide care emphasised (e.g., in the Mediterranean countries of Greece, Spain, Portugal, Italy, Cyprus and Malta); the means-tested - sometimes Beveridge – model, where the state withdraws from a role of direct service provision and contracts services for a targeted population of the most dependent service users (associated with the United Kingdom and to some extent Ireland), and; the northern European subsidiarity model, where the subsidiarity principle is stronger and the state will often provide services through NGOs (Germany, Austria, Netherlands and – less so – France and Belgium) (Munday, 2003; 6). In the absence of comparable data, there is a lack of research looking at whether any one of these types will contribute to the generation of better outcomes for children with CCNs.

Globalisation, as defined by the drive for increased competitiveness, has created a market-orientation, which, along with the de-institutionalisation of social services, holds considerable influence over the provision of social services in Europe (Munday, 2003; Gilbert, 2005). The outsourcing of social care to both non-profit and for-profit organisations has increased dramatically in Europe (Gilbert, 2005); outsourcing to non-profit organisations, in particular, is encouraged by the EU (Cunningham, 2011). The reduction in the size of the informal sector, in the wake of the growing participation of women in the labour market, as well as the increased need for social care provision within Europe, have, in all likelihood, also contributed to this trend (Kautto, 2002). Explaining social care provision in terms of de-institutionalisation meanwhile, understands states as being on a continuum moving away from an institution-based model. Within Europe, countries in Central and Eastern Europe in particular have been found to be among the most dependent in the world on residential care for children. (This is believed to be due to a lack of adequate support for parents/guardians, especially in disability services, as, in many countries, up to 60% of children in

residential care are children who have a disability (UNICEF, 2010)). However, the drive towards de-institutionalisation is dominant within social care provision in all Europe, including in Central and Eastern European countries with the assistance of expertise and finance from the EU and the UN (Eurochild, 2014; UNICEF, 2010).

More consistent across Europe is the social service approach to child welfare. Children's services policy does not simply focus on protecting children from abusive environments but emphasises promotion of their welfare and that of their families through addressing their developmental needs (Thoburn, 2013). Part of the impetus for effective integrated health and social care for children is their vulnerability, and children with CCNs are more vulnerable than other children to risk of harm or abuse. Coordination in safeguarding planning (for example facilitating the sharing of information regarding known risk factors etc.) is vital, and efforts towards inter-sectoral approaches are visible throughout MOCHA. As external providers of personal social services are coming to be more heavily relied upon within Europe, an important consideration for the future of social care is considering how private providers will coordinate effectively with publicly-provided services, particularly health services, and how they will approach the task of child safeguarding within their own organisations. An example of a state regulating external providers through mandating compliance with existing policies is in the case of England where guidelines laid out in 'Working Together to Safeguard Children' are applicable for services contracted by the National Health Service (NHS), while in Germany, where informal non-profit institutions have a large role to play in social care, the respondent notes that such organisations are required to have a written concept for child protection.

The concept of integrated care relates to children's lives more broadly than as described above. As outlined in the UN Convention on the Rights of the Child (1989), children with CCNs have the right to the supports which will enable them to 'achieve the greatest possible self-reliance and to lead a full active life in society' (United Nations General Assembly, 1989). Integrated care has taken on significant relevance throughout Europe, being prioritised by the WHO in addition to the EU, and is believed to have the potential to provide a high standard of care for all children, in particular, those with CCN. (The different layers of integrated care are covered extensively in the previous social care deliverable; a health or social care professional taking on a care coordination role is a common mechanism for the provision of integrated care.) It is likely that those countries which have moved furthest away from an institutional model will be best equipped to move towards a more complete model of integrated care (having more developed social care supports). The MOCHA data does show that some countries have been able to pay more consideration to building a system of integrated care than others. Overall, while the drive to integrated care is likely to superordinate the 'type' of social care system which a country belongs to (as described above), and remain a priority for all of the MOCHA countries, the most appropriate arrangements to enact such care in practice will likely differ between the MOCHA countries according to system type.

### **3.4 Discussion of Findings**

#### **3.4.1 Information provision**

As is clear from the previous social care deliverable, adequate information provision is at the root of effective support for children with CCNs, and for their families. Information provision is explored

in the DIPEX report (Alma et al., 2017), and both children with CCNs and their parents had much to say on the issue. From the point of view of both children with CCNs and their parents, there was a wide variety of experiences regarding access to information from across the DIPEX data. It was clear that for parents of children with complex mental health conditions in the UK, experiencing difficulty getting information on services, as well as information on strategies for dealing with changes in family life, had the potential to lead to intense frustration. Parents talked about how they were not given any information regarding referral options to a mentor, or courses that their children could attend. Some of these parents mentioned how they would appreciate something akin to a 'spider diagram' which could point them towards appropriate services. One mother of child with in the UK describes how there is no pathway of care;

*There's no pathway, there's no road...there's no kind of, right OK we're coming under this umbrella; there's loads of things we could be looking at (...) you're in desperate need and then someone goes, 'Well actually if you were thinking about this we could access that.' And it's like, 'Well if you'd told me that six months ago we could have started that process and got into line and got all our paperwork ready for whatever. (Mother, UK)*

A positive example from the Czech Republic was presented for parents of children with complex mental health conditions, where support groups for parents/guardians of children with Attention Deficit Hyperactivity Disorder (ADHD) were found to be beneficial by parents. From the point of view of children with complex physical needs, experiences across the five DIPEX countries were varied; some participants in the Czech Republic and Germany found it helpful that more information on living with TBI or epilepsy was provided by their GP than by a specialist, which made it easier for them to talk about their private life, while one Czech participant described having an excellent channel of communication with her specialist with whom she can discuss any issues she has by email.

In the MOCHA data, there are examples of excellent facilitators of information provision. These include various means of providing information on the child's complex need (e.g. information days for parents/guardians; websites dedicated to the provision of information on a complex condition) and on entitlements (e.g. handbooks outlining entitlements for families which include a child with CCNs). A number of respondents pointed to professionals as a source of information; the Finnish respondent, for example, outlines how practical information for parents in their caring role, as well as referrals (to child welfare services, housing services, mental health services, family counselling for example), would be provided by a social worker. In a number of MOCHA countries, a care coordinator is available to facilitate the passing of information between a health or social care professional and the family – this role is discussed under the theme of 'Flexible support'. The significant role that NGOs often play in providing care for children with CCN is again highlighted under this theme as in both Croatia and Ireland, for example, the respondent notes that practical advice should be available from both health professionals and NGOs or advocacy groups.

The importance of information-providing supports for families has been outlined in the literature - as Sartore G. et al point out, part of the value of information provision for parents/guardians is knowing that they are not alone; hearing stories from others 'that give them hope for the future and

make them feel less alone' are very valuable (2013;3). There are examples of peer support groups<sup>1</sup> within MOCHA; while a few respondents point to access to peer support groups, some of the other MOCHA respondents point to the availability of peer support through online parenting forums. Both internet-based and face-to-face support groups are found to be beneficial to parents/guardians by Marchant et al. (2007). From the DIPEX and task 3 data it is clear that in some cases social care support for the wider family is difficult to access as there is a lack of support available – however, the DIPEX data shows that in some cases what is lacking is adequate signposting to family supports.

### **3.4.2 Enabling participation**

The right for children with CCNs to participate in decisions about their care is outlined in the previous social care deliverable as a right enshrined in the UN Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. The issue of participation is apparent in the report presented by DIPEX in which it is noted that 'children and young people felt that they should be involved in managing their care' (Alma et al., 2017; 133). A positive example in a healthcare setting illustrating the issue of participation is presented where a teenage girl in the Netherlands with TBI stated that she feels her views are listened to, and, importantly, that if health professionals decide not to do things her way, they have a reasonable approach and outline their reasons to her;

*With the doctors: I sometimes make suggestions and then they actually find it good, or even better. And otherwise, I agree with them. (Girl with TBI, 18 years, The Netherlands)*

There are positive examples from MOCHA at both the policy level and at implementation level of prioritisation of the right to participate. The Estonian respondent, for example, points to a youth forum held once a year; '101 children to Toompea' is an event held in Estonian Parliament where children can express their views on issues affecting children. Additionally, children and representative organisations are involved in the drafting of child-related strategies and legislation, as in the case in a number of the other MOCHA countries. In Norway meanwhile, specialist health care services administer what are called 'Centres for Learning and Mastery'. Found throughout the country these centres employ an educational approach incorporating user involvement and empowerment; cooperation between users and health and care professionals is facilitated through group work and dialogue. This example illustrates the importance of information provision in empowering people to participate.

In contrast, frustration at a lack of participatory decision-making is clear from an account from the Polish respondent of protests held by parents/guardians of children with CCNs who were frustrated at the rate of pay for carers - in this case, the protest led to a change in policy with an increase in payments to carers. Participation outside the political process through protest is a phenomenon not limited to this example. In Ireland for example, a number of protests demanding better services for children with disabilities have been held in recent years. A lack of speech

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<sup>1</sup> Peer support is defined by Sartore et al., (2013) as "the existence of a community of common interest where people gather (in person or virtually by telephone or computer) to share experiences, ask questions, and provide emotional support and self-help".

therapists, respite, mental health services and early intervention supports have been highlighted (RTE, 2017b, RTE 2017a).

Although support services for parents/guardians has been found to be empowering, increasing their ability to take part in decisions about their child's care (Banach, 2010<sup>2</sup>; Solomon et al<sup>3</sup>, 2001) there is much variation in the amount of support available for families throughout MOCHA countries, and in many cases a lack of supports for parents/guardians of children with CCNs, as well as their siblings, is evident. The necessity of the parent/guardian acting as the catalyst for accessing social care support for their child is apparent in a number of MOCHA countries and both the Polish and Portuguese respondents made reference to the fact that parents/guardians will have different levels of capability. The Polish respondent acknowledges that the capacity of the parent will be a significant factor in the treatment of a child with CCNs; "Activity, competence, awareness, and socio-economic status of parents are crucial in relation to further treatment and development of the child with health problems". The provision of support services for parents/guardians may help to bridge the gap between those who find it easier to participate in the caregiving process and those who find it more difficult.

### **3.4.3 Flexible support tailored depending on the needs of the child and family**

Examples of flexible support delivered in a manner that best suits the child and parent/guardian were presented in the previous social care deliverable. The value of flexible support that meets individual needs is clear from the data collected by DIPEX (Alma et al., 2017), which includes accounts from parents explaining how they would like their child's age and capabilities to be taken into account by health professionals who they come into contact with. Having their needs and those of their child taken into account over what protocol may dictate is valued; 'It is important that a GP takes actions and does not automatically follow the protocol' (2017; 80). The above quote illustrates very well how this theme is connected to the theme of participation - the views of children with CCN and their parents/guardians must be listened to for their wishes to be accommodated. It is clear from Alma et al. (2017) that flexible support from the GP was valued; in some cases, this meant the GP taking on roles beyond what is required of them (for example, helping with applications for rehabilitation or for financial support) if a family really needed their help.

Data gathered from the CAs illustrate a number of ways in which care is delivered in a flexible manner. These include provision of solutions to overcome barriers to provision of care (for example, the innovative approach to the care of those who are unable to travel to access counselling in Poland where specialised counselling may be given by telephone, or over the internet) and provision of a number of options for care (for example, when accessing rehabilitation care), as well as the provision of services to ease family life (such as relief services in the home) and the work/life balance of parents/guardians of a child with a complex care needs (such as in Lithuania, where employees raising a disabled child have one additional rest day during the month). Having a

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<sup>2</sup> In a study on parenting children with autism.

<sup>3</sup> In a study on parenting children with disabilities.

flexible choice of services was also raised by parents of children with complex mental health needs in the DIPEX report;

*You [should] have 'choose and book' appointments at the hospital for certain services [um] and I get that you can't choose and book everything, but there should be a certain element of being able to pick and choose. (Mother, UK).*

A common example of individualised support throughout MOCHA is care coordination. It should be noted that for this mechanism to effectively provide individualised support it is essential that, firstly, the health or social care professional in the role of care coordinator is responsive to the needs and wants of the child and their family, and additionally, that children's social care needs are understood as holistic and interdependent (the Framework for the Assessment of Children in Need and their Families (Department of Health, England, 2000), covered in the previous social care deliverable is based on the well-established work of Bronfenbrenner (Bronfenbrenner, 1986) and is an example of a useful facilitator when attempting to view a child's needs in a holistic manner). A lack of definitional rigidity in the role of a care coordinator nationally and internationally has been noted by Hillis et al. (2016), and throughout MOCHA professionals acting in a care coordinator capacity drawn from a wide range of health/social care roles perform work that is not standard across the different countries but rather varies considerably. In a few countries the professional in charge of care coordination is drawn from whichever area is most relevant according to the child's need. For example, in Estonia, a child such as Luke (an adolescent with a TBI, the subject of our case scenario) may have his after-hospital care coordinated by a neurologist, paediatrician, or nurse, depending on his principal needs when leaving secondary care.

### **3.4.4 Equity in access<sup>4</sup>**

The issue of regional inequity is highlighted in the previous social care deliverable as the geographical spread of services throughout MOCHA countries will in some cases preclude equity of access. Examples of regional inequity are also present in the DIPEX data (Alma et al., 2017:58) where it's noted that accessing appropriate treatment is more difficult in rural areas;

*Getting the right treatment was [...] highly time-consuming due to the high number of appointments children needed. This was especially a problem for families living in rural areas or small cities, where some of the different specialists were unavailable (2017; 58)*

The exacerbation of existing financial inequities due to regional inequity in service provision is clear as parents of children with CCNs in the Czech Republic and Germany outlined how financial strain, and problems with time management, resulted from the fact that they needed to travel a long way in order to visit their specialist (Alma et al., 2017).

Regional inequity in service provision is a prominent theme in the task 3 data, with the provision of care in rural areas scarcer in a number of countries than in urban areas. Financial difficulties are often a concern for parents/guardians of children with CCN and the potential of regional inequity to

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<sup>4</sup> The issue of equity in the provision of primary health care for children as a whole is the focus of WP 7 of the MOCHA project. In that task, the influence of socio-economic status on health care for children, and health care provision for children in care and for migrant children are examined.

exacerbate existing financial inequity is clear. In the case of Lithuania, for example, the respondent notes that huge inequalities throughout the country when it comes to rehabilitation services have led to the opening of some private centres. (Resorting to private provision is referred to in the DIPEx report (Alma et al., 2017) where a Spanish parent reports using a private psychiatrist due to long public waiting lists.) Long waiting lists, as a result of insufficient provision, are also mentioned in task 3 data as a barrier to access in two MOCHA countries (Estonia and Poland); another barrier preventing equity in access to care includes the necessity of expertise in order to overcome bureaucracy (Germany).

Facilitators to equity in access to care are apparent. In Finland for example, the respondent notes that it is possible to receive compensation for travel and overnight accommodation costs in order to help with a child and an accompanying person's travel costs if the child needs to travel in order to receive rehabilitative care, while four of the respondents pointed to rehabilitation facilities being offered as field services (Czech Republic, Latvia, Netherlands, Poland). In Austria meanwhile, a child rehabilitation plan has very recently been launched which will provide a total of 343 beds for children and adolescents and 50 beds for relatives in rehabilitation centres (previous to this resources for rehabilitation for children and adolescents were limited, with adult services sometimes utilised as a consequence).

It is important to highlight the fact that the themes discussed in this chapter are interconnected. Flexible support, which will meet the needs of a family, for example, is only achievable with the participation of children and their families in the discussion on the supports required. Participation, in turn, cannot be properly facilitated without provision of adequate information to children and their parent/guardian. Each of the themes discussed below must thus be understood as part of the wider picture of needs for children with CCN and their families.

### **3.5 Conclusion**

Four 'types' of social care system in Europe have been identified in previous work; categorisations are based on the 'mixed economy' of personal social services with contributions from four sectors; the informal sector (families, friends etc.), the state, the voluntary non-profit sector, and the for-profit sector (Munday, 2002). It might be reasonable to assume that differences in social care system will lead to differences in experience of social care supports being provided. An exploration of provider-effects on the identified themes is beyond the scope of this task but would benefit from further analysis. However, what should be prioritised, regardless of system-type, is the meeting of the needs of children with CCN and their families with regard to the four themes identified from the work of this task; information provision; enabling participation; flexible tailored support, and; equity of access. These can be thought of as akin to the dynamics that can determine or influence a child and family's experience of negotiating their way through the care process and they are essential to consider when planning a system where social care and primary care are effectively integrated; it is clear that throughout the MOCHA countries there are examples of facilitators for meeting the needs of children with CCN and their families as they relate to these four themes.

## **Chapter 4 Nursing Preparedness for Practice**

**Anne Clancy, Elena Montañana Olaso, Philip Larkin**

*It always depends on the nurse... (Girl, 15 years, Czech Republic)*

### **4.1 Introduction to Nursing Preparedness for Practice**

Globally, nurses are the largest professional group in the health force. They play a key role in delivering care to children in the community and provide prevention and health promotion as well as curative services to children, young people and their families. Advances in the field of medicine have increased the number of children living longer with complex conditions, and with that, the need for an optimal environment with high-quality health care. The move towards primary care (WHO, 2008) attempts to facilitate the psychosocial needs of children with CCN and their families. The knowledge and training acquired by the nurses working with these children and their families have to be targeted in order to deliver optimal and high-level care (WHO, 2008).

The WHO has stressed nurses' role in public health and sees the need to focus on family health and community health nursing and to renew and upgrade education and training in this respect (WHO, 2013). In order to provide optimal care, it is vital that nurses receive timely and optimal training. Education plays a key role in developing nursing competencies. Nurses who have a higher level of education have been found to deliver care that leads to better patient outcomes (Praxmarer-Fernandes et al., 2017). The right to care is also acknowledged by the Paediatric Nursing Associations of Europe (PNAE):

*Children and adolescents (young people) have the right to be cared for by appropriately qualified and educated nursing staff. Children and their families/guardians have a right to know that the nurse who cares for their child is specifically educated and competent to do so [...] (Paediatric Nursing Association of Europe, 2015).*

However, the level of education offered for nurses across Europe varies considerably (Praxmarer-Fernandes et al., 2017). Article 31 of The Professional Qualifications EU Directive 2005/36/EC amended by the Directive 2013/55/EU, regulates the undergraduate training of nurses responsible for general care. This is based on a minimum of three years of study and "*shall consist of at least 4600 hours of theoretical and clinical training*". Furthermore, it specifies that this training shall include several areas of knowledge, in which is included "child care and paediatrics", either as specific area of focus or integrated within other subjects (European Parliament and Council Directive, 2005, 2013). This EU Directive provides a general framework for nursing curricula across Europe, giving a general description of the competencies required for a general nurse. However, it does not address differences between countries and does not give guidance on the specific content and skills that are necessary for each of the areas that it mentions, including the nursing care of children. Each country can interpret the Directive as they see fit.

Specialist/postgraduate nurse training is not standardised at EU level. PNAE has mapped paediatric nursing education across Europe, identifying the different options available that nurses have in order to deliver specialised care to children and young people. However, they do not focus on the training that nurses receive in general nursing programmes regarding children care, and in particular to children with CCNs.

Benner, Sutphen, Leonard and Day (2010) calls out for a radical transformation of nurse education at national levels in order to meet today's CCNs (Benner et al., 2010, Benner, 2012). In order to propose change, it is important to map existing educational requirements and study the content of nursing curricula, being aware that professional practice is more than the sum of these parts. A better understanding of the curricula at nursing schools can contribute to the further development of nursing education. This development can result in improved preparedness for practice, and in consequence, the improvement of health care delivery to children and their families.

#### **4.1.1 Aims and objectives**

The purpose of this task was to analyse nurses' preparedness for the care of children with CCNs and their families in the community in 30 European countries. This involved examining respective educational requirements and the curriculum documents of undergraduate nursing programmes. The specified research objectives were to:

1. Map nursing qualifications required in each country to work with children with CCNs in the community.
2. Identify and analyse nursing curricula documents, for content on child care, paediatrics, and children with CCNs.
3. Identify European standards in general nursing programmes for delivering care to children with CCNs.
4. Identify and describe possible breaches in optimal nursing education for delivering care to children with CCNs in the European context.

### **4.2 Methodology**

A questionnaire, for distribution by CAs, was developed in order to explore the qualifications required for nurses caring for children with CCNs in the community. The questionnaire also included a request for nursing curriculum documents. According to Smith and Morgan (2010), there is a paucity of research on university curricula. Nursing curriculum documents detail the units in a programme of study that is taught over time (the hours of which may be prescribed either nationally or through EU directives) and that lead to accreditation as a nurse (Smith and Morgan, 2010). It was postulated that an analysis of curricula documents with a focus on children would give information on how nursing care of children is described within the programme. We acknowledge that some countries require specialised training to deliver care to children with CCN, but for the purposes of this study, only general nursing curricula were examined.

#### **4.2.1 Design**

A non-experimental descriptive study design with a qualitative element was adopted. It incorporated an inductive summative content analysis (Hsieh and Shannon, 2005) to investigate child-related content in nursing curriculum documents. This method was chosen to facilitate the analysis process, as it takes into consideration variations in the document styles with both narrative texts and bullet point lists (Sjolin et al., 2014).

#### **4.2.2 Questionnaire description**

The authors developed the questionnaire (See WP2 survey compendium on the MOCHA website) with a focus on subjects related to children and child health. The questionnaire was divided into two main sections. Section 1 explored the curriculum documents of undergraduate

and postgraduate nursing programmes. Original or English translated versions of general and/or paediatric nursing curricula were requested from CAs in 30 countries. To ensure that the document requested adequately represented nurse training in the country, it was specified that, as far as possible, documents from the university department or nursing school with the largest number of nursing graduates per year were required. A link to an example curriculum with the type of detail requested was sent in order to achieve consistency in the sample of documents requested for analysis.

Information on paediatric nursing education available across Europe is accessible from the PNAE. The European Observatory has also compiled information on nursing education within their Health in Transition reports (European Observatory on Health Systems and Policies, n.d<sup>5</sup>).

In order to understand which paediatric options were available across countries, a table with information gathered from these two sources were incorporated in Section 1 (See compendium on the MOCHA website). The CAs sourcing the data were asked to confirm that the information provided in the table was correct and updated for their country. In addition, the CAs were also asked to obtain the number of nurses that complete paediatric nurse education each year for their country.

Section 2 sought information on the qualifications required for nurses to deliver care to children with CCN. To achieve this information, a general question was asked: *In your country, can nurses with a general nursing qualification look after children with complex health care needs in the community?* A dichotomous answer was requested (Yes/No). If the answer was No, the agents had to specify which qualification was required, if it was compulsory, and to provide an original or an English translation of the curriculum document.

#### **4.2.3 Validation**

A protocol for sending questions to the CAs was developed within the MOCHA project. Two different review procedures were established before circulating the surveys. First, the document had to be ratified by the Principal Investigator (PI), Deputy PI and Research Coordinator. Then, an EAB discussed the questions and provided feedback to the research team. To validate the answers presented in the questionnaires and the content of the curricula documents, further clarifying questions were sent to the CAs. This gave the research team the possibility to achieve a more accurate interpretation of the information provided.

#### **4.2.4 Data collection and distribution**

Following established protocol, once the survey was reviewed, it was sent to the CAs through the Research Coordinator in July 2016. The agents were responsible for either delivering the questions to appropriate experts in their respective countries or finding the required data from other sources (ex. national documents). When the CA completed the questionnaire, it was sent back to the Research Coordinator, who returned it to the research team between August 2016 and March 2017.

#### **4.2.5 Sample**

The questionnaire was sent to the CA in each of the 30 countries. Responses were received from 23 countries (79%) at the time of the analysis. Belgium, Luxembourg, Slovakia, Slovenia and United Kingdom did not provide any responses to the questionnaire within the specified

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<sup>5</sup> No date

time frame. Denmark responded after the analysis for this chapter had been processed and is not included in the analysis.

#### 4.2.6 Data analysis

Descriptive statistics were used for analysing the results of the survey on nursing qualifications. Corrections, comments and specifications in the free text boxes offered supplementary information on paediatric training options available for nurses. For example, from one country it was stated, “[...] *there is a specific Paediatric Nursing Specialization established in 2008. It is 40 weeks long*”. From this statement, the research team extracted that paediatric nursing was a specialised/postgraduate programme of 40 weeks duration.

In the curricula analysis, several steps were taken. Firstly, the curriculum content received from each country was transferred to a Word document and, if necessary translated to English using an online tool (<https://www.onlinedoctranslator.com/>). Secondly, an overarching analysis of the curricula documents was performed in order to get an overview of all modules that focused on child care. To achieve this, core modules related to children (e.g. Paediatrics) and other modules on other subjects where children were mentioned (e.g. pharmacology, mental health care) were also examined. The core modules related to children were identified by examining the titles of all modules in the curricula. The identification of child related topics mentioned within other modules was conducted by searching child-related search terms previously agreed on by the research team (Appendix 3).

A summative inductive content analysis of each curriculum was then carried out in order to understand better the written content related to the child. The content related to the care of the child formed the units of analysis. These units were then transferred to an Excel sheet and relevant keywords were extracted. An example of this process is shown in Table 4.1. A grouping process was then carried out in order to categorise and give contextual meaning to the keywords obtained (Cavanagh, 1997). This process generated several subcategories, which were named using content-characteristic words. Following the same procedure, the subcategories were then grouped together into main categories. In order to understand the use of the keywords in their context, a process of quantification was conducted. According to Hsieh and Shannon (2005), “*this quantification is an attempt not to infer meaning but, rather, to explore usage*” (Hsieh and Shannon, 2005). The research team discussed the categorisation in depth before reaching consensus on the interpretation, categorisation and extraction of keywords.

**Table 4.1 Example of keywords extracted from the units of analysis**

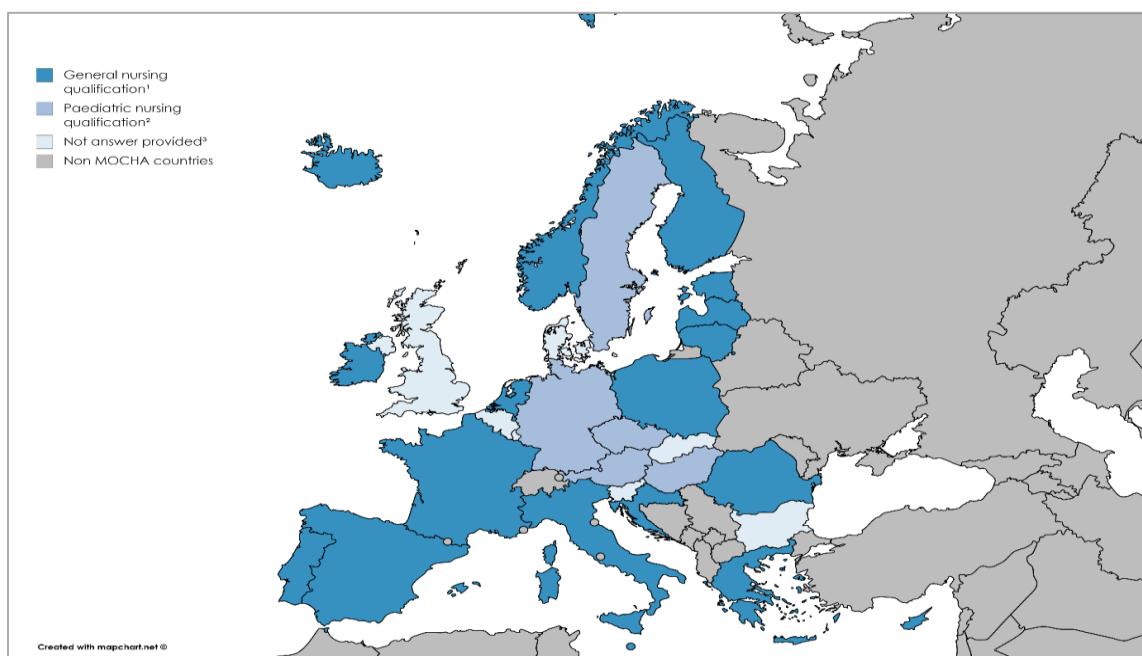
Unit of analysis	Keywords
The <u>nature</u> , <u>diagnosis</u> and <u>treatment</u> of childhood diseases. The main emphasis is on the <u>clinical signs and symptoms</u> and the <u>prevalence</u> of childhood disease in the populations and the <u>most common medical and surgical treatments</u> of these diseases.	Nature of childhood diseases Diagnosis childhood diseases Treatment childhood diseases Clinical signs and symptoms of childhood diseases Prevalence of childhood disease Common medical treatments of childhood diseases Common surgical treatments of childhood diseases

## 4.3 Results

The results are divided into two sections: 3.1 on *Nursing qualifications* and 3.2 on *General nursing curricula*. The nursing qualifications section provides an overview of the nursing training requirements for caring for children with CCNs in the community in Europe. The general nursing curricula section will present a contextual examination of the content related to child care and paediatrics in the curriculum documents provided by the respondent countries.

### 4.3.1 Nursing qualifications

Identifying the training requirements for nursing children with CCN in the community provides background information on the level of education required to provide nursing care for these children. Figure 4.1 is a visual overview of the training requirements across Europe. The findings presented in here are based on the responses from the CA questionnaire<sup>6</sup>.



<sup>1</sup> Cyprus stated that paediatric nursing was not offered in the community.

<sup>2</sup> Sweden stated that either community or paediatric nursing training was required to look after children with CCN in the community.

**Figure 4.1 Nursing training requirements to look after children with CCN**

No specialised training is required to deliver community nursing care to children with CCN in 73.9% ( $n = 17$ ) of the countries. Croatia, Estonia, Finland, France, Greece, Iceland, Ireland, Italy, Latvia, Lithuania, Malta, Netherlands<sup>7</sup>, Norway, Poland, Portugal, Romania and Spain reported that a general nursing qualification was the only requirement. General nursing training was of four years duration in eight countries (47.1%), three years for seven countries (41.2%), and three and a half years for two countries (11.8%) (Table 4.2).

<sup>6</sup> The duration of the general nursing programmes was extracted from the curricula or from the links provided in the questionnaire.

<sup>7</sup> In Netherlands, it was specified that general nurses are allowed to work with these children only for performing general tasks. A specialisation is required for tasks that are more complex.

**Table 4.2 Duration of general nursing programmes for countries where this is the only qualification required for caring for children with CCN**

Duration	Countries
3 years	Croatia, France, Italy, Malta, Norway, Poland, Romania
3.5 years	Estonia, Finland
4 years	Greece, Iceland, Ireland, Latvia, Lithuania, Netherlands, Portugal, Spain

Although a specific paediatric training is not required in these countries, the majority (70.6%, n = 12) offer undergraduate and/or specialised/postgraduate programmes with a focus on children's nursing. The most common being a specialised/postgraduate training of one year duration (Table 4.3). Only Estonia, Finland, Lithuania, Malta and Romania (29.4%) stated that no paediatric options were available for further training.

**Table 4.3 Availability of undergraduate and postgraduate paediatric nursing options in countries where general nursing is the sole requirement for working with children with CCN**

Country	Paediatric nursing options available	Duration
Croatia	- Specialisation/postgraduate training in paediatric nursing	40 weeks
France	- Specialisation/postgraduate training in paediatric nursing	1 year
Greece	- Specialisation/postgraduate training in paediatric nursing	1 year
Iceland	- Specialisation/postgraduate training in paediatric nursing	2 years
Ireland	- Undergraduate in paediatric nursing <sup>a</sup> - Specialisation/postgraduate training in paediatric nursing	4.5 years (undergraduate) 1 year (postgraduate)
Italy	- Undergraduate in paediatric nursing - Specialisation/postgraduate training in paediatric nursing	3 years (undergraduate) 1 year (postgraduate)
Latvia	- Undergraduate specialisation in paediatric nursing	1 year <sup>b</sup>
Netherlands	- Specialisation/postgraduate training in paediatric nursing	13 - 16 months
Norway	- Specialisation/postgraduate training in paediatric nursing	1.5 years
Poland	- Specialisation/postgraduate training in paediatric nursing	810 hours
Portugal	- Specialisation/postgraduate training in paediatric nursing	1.5 years
Spain	- Specialisation/postgraduate training in paediatric nursing	2 years

<sup>a</sup> In Ireland, the undergraduate in children's nursing degree includes modules for both general nursing and children's nursing. The successful completion of this degree provides the right to practice as either a children's nurse or as a general nurse.

<sup>b</sup> This one year of specialisation in Latvia is performed in the fourth year of the general nursing studies. Nurses ending with a specialisation different to paediatrics (for instance surgical nursing, mental health nursing, etc.) are also allowed to work with children with CCN.

Austria, Czech Republic, Germany, Hungary and Sweden (21.7%) stated that a paediatric nursing qualification was required to care for children with CCNs in the community. In Austria<sup>8</sup>, this qualification is achieved by either studying a paediatric undergraduate degree of three years duration at bachelor's level (direct entry) or as a paediatric postgraduate programme of one year duration. In the Czech Republic, a postgraduate training in paediatric nursing is mandatory for delivering care to children with CCN. General nurses with a bachelor degree (BSc) and twelve months of general nursing practice in the field of child care can access this specialisation. Diploma Specialised nurses (DiS) (trained at vocational schools) can access this

<sup>8</sup> In Austria, nurses with a general nursing qualification can work with children with CCN. However, in practice only paediatric nurses look after children with CCN in the community.

specialisation by doing a BSc in nursing. They are usually<sup>9</sup> admitted directly into the second or third year. After completing the BSc degree and with twelve months of general nursing practice in the nursing care of children they can access the paediatric nursing specialisation. In Germany<sup>10</sup>, the specific paediatric qualification is reached by doing a three year paediatric undergraduate degree at a vocational school. If the applicant is a general nurse, this training is reduced to one and a half years. In Hungary, a three year paediatric undergraduate degree at a vocational school is mandatory. In Sweden<sup>11</sup>, after completion of a three years general nursing degree at bachelor level, a specialisation/postgraduate training in paediatric or community nursing is necessary in order to work with children with CCN. The duration of the paediatric training is one year, and applicants need one year of nursing experience to access this training.

Only Cyprus (4.3%) stated that they do not have paediatric nursing service in the community. However, school nurses (called health visitors) are responsible for the primary health care of the children in school settings. For this country, general nursing programmes have a duration of 4 years.

#### **4.3.2 General nursing curricula**

Due to the high number of countries that only require a general nursing qualification for delivering care to children with CCNs in the community (73.9%, n = 17), a comprehensive analysis of these curricula was performed. Documents provided by the CAs come from the institution with the largest number of nursing graduates per year<sup>12</sup>. Despite not having paediatric nursing services in the community, general nursing curriculum from Cyprus was provided by the CA and has been included in this section.

From the seventeen curricula documents gathered, almost half (47.1%, n = 8) were provided in English language. All the documents came from public institutions, as opposed to private academic centres or healthcare facilities.

##### **4.3.2.1 Overarching analysis**

This analysis was performed in order to get an overview of the modules that had a focus on childcare. Appendix 4 contains a glossary of terms with definitions of such modules. Figure 4.2 shows the distribution across countries of the modules that have content related to the care of children within their curricula.

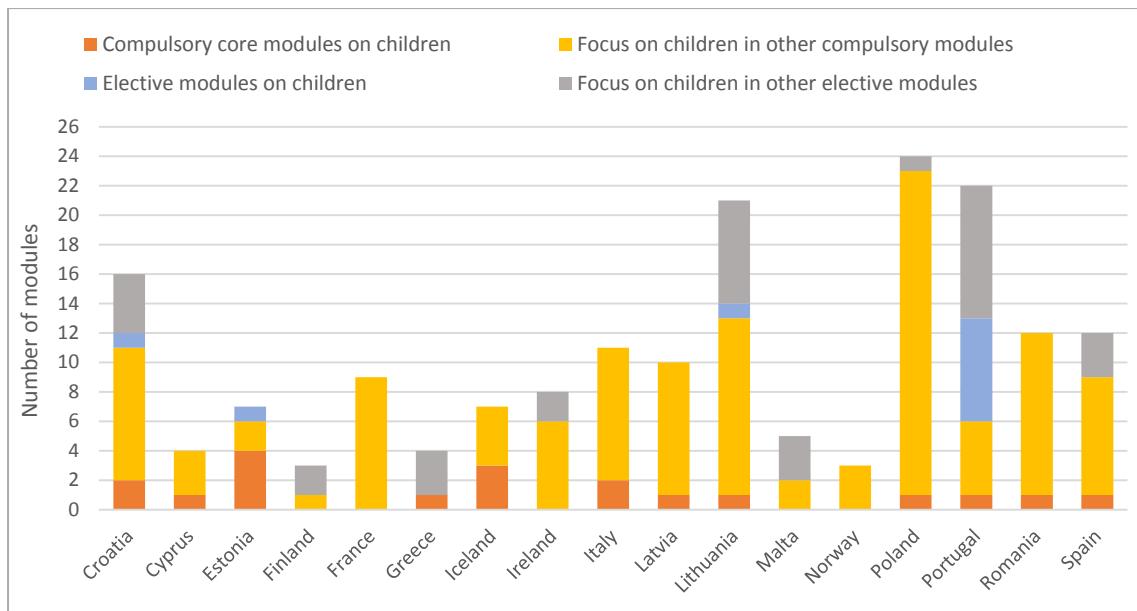
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<sup>9</sup> "Usually" implies that not all DiS students are entitled to start a nursing BSc at the second or third year of the degree. It will depend on the study plan of the previous vocational school. If the DiS nurse ended his/her nursing studies 5-7 years ago this entitlement it is not applicable.

<sup>10</sup> In Germany, a specific paediatric qualification was stated as not being mandatory. However, paediatric nurses normally work with these children, general nurses can be assigned in certain cases. From 2020 the vocational training for the first two years will be a generalist training. Paediatric nursing specialization will be possible from the third year of this vocational training. However, generalist nurses will be also allowed to care for children (the first nurses that will have gone through this program will start working in 2023).

<sup>11</sup> In Sweden, the required qualifications were stated as not mandatory. That is because of a lack of specialised nurses, doing quite common to hire nurses without paediatric specialisation. In preventive care for children, many nurses have community specialisation instead of a paediatric specialisation.

<sup>12</sup> In **Italy**, the general nursing curricula proposed by the CA do not provide a description for all the modules or for the module focus on child care. The research team suggested seeking a curriculum document from Florence University. CA agreed on this curriculum before performing the analysis. In **The Netherlands**, the document proposed by the CA does not provide detailed information on the modules. For that reason, it has not been included in the general nursing curricula analysis. In **Spain**, the university department with the largest number of nursing graduates per year had no available data on the different modules. The curricula chosen for analysis is from the Universidad Autónoma de Madrid, as suggested by the CA.



**Figure 4.2 Distribution of child related content across the different modules in the curriculum**

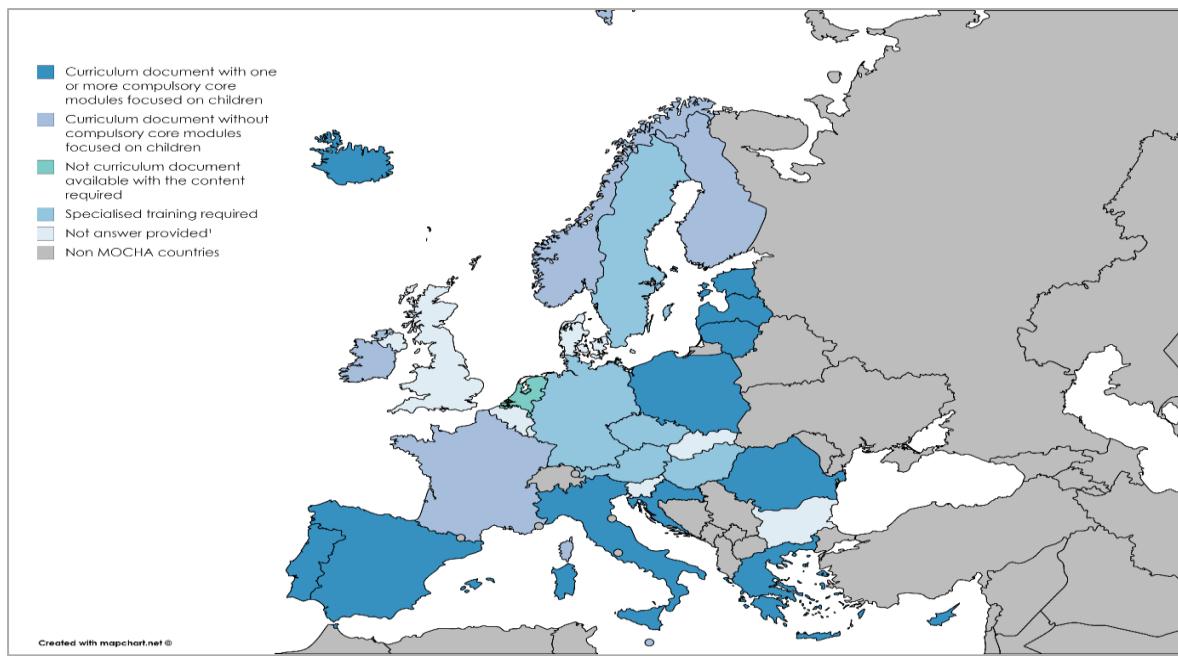
In twelve of the seventeen countries (70.6%) the main bulk of the child related content was within other compulsory modules (ex. children mentioned as part of a pharmacology module). In four countries, (23.5%) it was mainly within other elective modules. Only Estonia (5.9%) had the main child related content as compulsory core modules.

#### Compulsory core modules

This section describes the characteristics of all the compulsory core modules that focused on the care of the child. Almost three-quarters of the curricula (70.6%,  $n = 12$ ) offered one or more of these modules (Figure 4.3). The emphasis in the modules (paediatrics) was similar for the majority of countries. The workload assigned to each module was variable, having from one to sixteen ECTS. More than two-thirds of the modules analysed across countries (73.7%,  $n = 14$ ) differentiated between hours expended on theoretical and practical training<sup>13</sup>. In nine of the countries (75%), the modules on the care of the child were concentrated in one specific year. In three countries, (25%) they were spread across the duration of the training (Table 4.4). In the remaining six countries<sup>14</sup>, content related to paediatrics and child care was only found in the context of other disciplines (Finland, France, Ireland, Malta and Norway) or the curriculum document was not available with the content required (The Netherlands).

<sup>13</sup> Practical hours were not specified in four of the nineteen modules (21.1%). Six modules (60%) showed a greater number of hours dedicated to practical training, and four (40%) had a greater number of hours for theoretical training.

<sup>14</sup> The other five remaining countries to complete the sample ( $n = 23$ ) are the ones that require specialised training for caring for children with CCN in the community.



<sup>1</sup> Denmark responded after the analysis for this chapter had been processed and is not included in the analysis.

**Figure 4.3 Overview of the compulsory core modules on children within the curriculum documents provided by the participating countries**

**Table 4.4 Characteristics of the compulsory core modules by country**

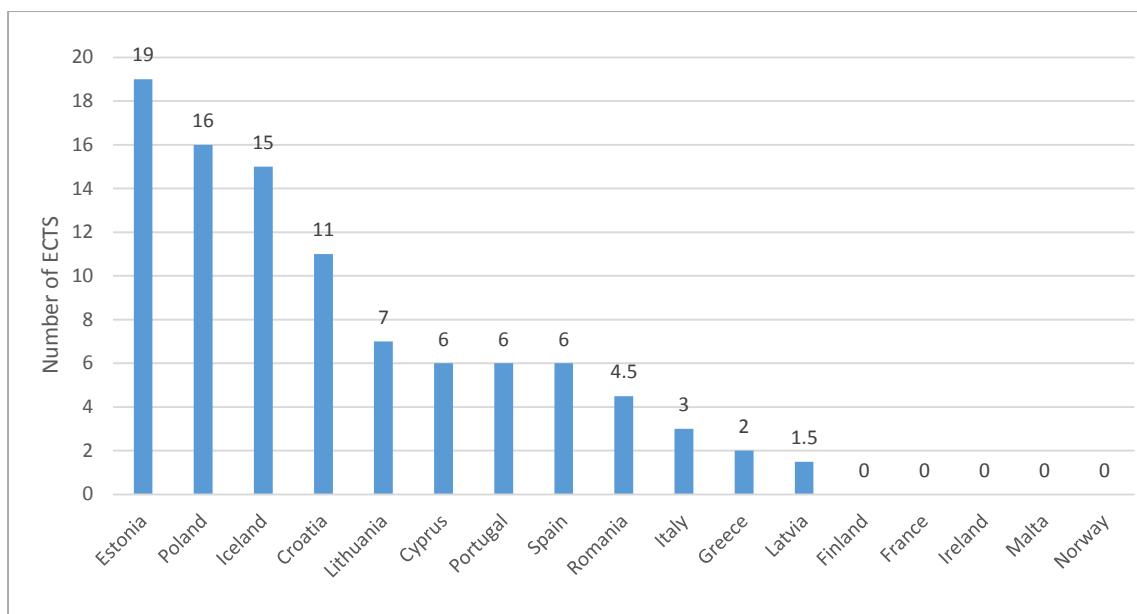
Country	Title of the module	ECTS	Theoretical hours	Practical hours	Year
<b>Croatia</b>	- Paediatrics	2	30	n/a	2 <sup>nd</sup>
	- Nursing a child	9	45	90	2 <sup>nd</sup>
<b>Cyprus</b>	- Child care nursing	6	-	-	3 <sup>rd</sup>
<b>Estonia</b>	- Healthy child nursing	5	36	8	1 <sup>st</sup>
	- Internship - A healthy baby	3	6	56	1 <sup>st</sup>
	- Nursing sick children	5	40	20	3 <sup>rd</sup>
	- Internship - Children's nursing	6	6	150	3 <sup>rd</sup>
<b>Finland</b>	Child care only taught in the context of other modules				
<b>France</b>	Child care only taught in the context of other modules				
<b>Greece</b>	- Paediatrics	2	50-60 <sup>a</sup>	n/a	2 <sup>nd</sup>
	- Nursing care of children and their families	8	24	50	4 <sup>th</sup>
<b>Iceland</b>	- Paediatrics	4	17.3	n/a	4 <sup>th</sup>
	- Growth and development of children and teenagers	3	11.9	n/a	2 <sup>nd</sup>
<b>Ireland</b>	Child care only taught in the context of other modules				
<b>Italy</b>	- Paediatric nursing	2	-	-	2 <sup>nd</sup>
	- Paediatrics	1	-	-	2 <sup>nd</sup>
<b>Latvia</b>	- Paediatrics and patient care	1.5	-	-	3 <sup>rd</sup>
<b>Lithuania</b>	- Children's health, illness and nursing	4	30	15	2 <sup>nd</sup>
<b>Malta</b>	Child care only taught in the context of other modules				
<b>Netherlands</b>	No curriculum document available with the content required				
<b>Norway</b>	Child care only taught in the context of other modules				
<b>Poland</b>	- Paediatric nursing	16	95	320	1 <sup>st</sup> , 2 <sup>nd</sup> , 3 <sup>rd</sup>
	- Nursing of children's health and paediatrics	6	63	18	3 <sup>rd</sup>
<b>Romania</b>	- Childcare and paediatric nursing	4-5 <sup>b</sup>	48	72	3 <sup>rd</sup>
<b>Spain</b>	- Nursing of children and adolescents	6	-	-	3 <sup>rd</sup>

Note: n/a is stated when practical hours are not available in the module. The symbol (-) is stated when differentiation between theoretical and practical was not available either in the whole curriculum or in the specific module.

<sup>a</sup> Theoretical training was only stated in ECTS. The researcher calculated the number of theoretical hours for 2 ECTS taking into account that 1 ECTS is between 25 and 30 hours.

<sup>b</sup> Workload used in the module was only expressed in hours. The researcher calculated the number of ECTS for 120 hours taking into account that 1 ECTS is between 25 and 30 hours.

A figure to illustrate the number of ECTS on compulsory core modules that are related to child care and paediatrics is shown in Figure 4.4.



**Figure 4.4 Total number of ECTS in compulsory core modules that focused on child care and paediatrics**

Estonia, Poland, Iceland and Croatia had curriculum documents with the highest number of ECTS in child and paediatric compulsory core modules, followed by Lithuania, Cyprus, Portugal and Spain, with core modules that had more than six ECTS. Romania, Italy, Greece and Latvia had less than six ECTS in their compulsory core modules related to children. The submitted curricula from the remaining five countries had no compulsory core modules that focused on children.

#### Child care mentioned within the context of other compulsory modules

Childcare was also mentioned within other subjects. Table 4.5 shows the different compulsory modules where the care of the child was mentioned.

In thirteen curriculum documents provided by the participating countries (76.5%), child-related search terms were found in compulsory modules with a focus on the *public health, community and family nursing, health promotion and prevention, and primary care*. Child-related search words were also found within *mental health and psychology disciplines* (64.7%,  $n = 11$ ), in *gynaecological, maternal and children care* (52.9%,  $n = 9$ ), *clinical nursing* (47.1%,  $n = 8$ ), and (35.3%,  $n = 6$ ) within *biomedical science disciplines*. Less than one-fourth included these words within modules with a focus on *other populations* (23.5%,  $n = 4$ ), *legislation/ethical issues* (23.5%,  $n = 4$ ), *growth and development* (17.6%,  $n = 3$ ), *nutrition* (17.6%,  $n = 3$ ) and *pedagogy* (17.6%,  $n = 3$ ). Lower proportions were found in other specialised disciplines such as *surgical nursing or internal medicine* (11.8%,  $n = 2$ ; 5.9%,  $n = 1$ ), and other contextual disciplines such as *protection and safety or management* (5.9%,  $n = 1$ ) (Table 4.5).

**Table 4.5 Other compulsory disciplines<sup>15</sup> where child care was mentioned**

Disciplines	Countries
<b>Public health, community and family nursing, health promotion and prevention, primary care</b>	Croatia, Cyprus, Estonia, France, Iceland, Italy, Latvia, Lithuania, Norway, Poland, Portugal, Romania, Spain
<b>Mental health and psychology</b>	Cyprus, Estonia, France, Iceland, Italy, Lithuania, Malta, Norway, Poland, Romania, Spain
<b>Gynaecological, maternal and children care</b>	Croatia, Cyprus, Finland, Latvia, Lithuania, Malta, Poland, Portugal, Romania
<b>Clinical nursing</b>	Croatia, Ireland, Italy, Latvia, Lithuania, Norway, Poland, Spain
<b>Biomedical science<sup>a</sup></b>	Croatia, France, Italy, Latvia, Poland, Portugal
<b>Other populations<sup>b</sup></b>	Croatia, Ireland, Lithuania, Poland
<b>Legislation/ethics</b>	France, Poland, Romania, Spain
<b>Growth and development</b>	Croatia, Iceland, Portugal
<b>Nutrition</b>	Poland, Romania, Spain
<b>Pedagogy</b>	France, Poland, Romania
<b>Emergency care</b>	Poland, Portugal
<b>Infectious care</b>	Latvia, Poland
<b>Surgical care</b>	Lithuania, Poland
<b>Internal medicine care</b>	Poland
<b>Neurology</b>	Poland
<b>Rehabilitation and physiotherapy</b>	Poland
<b>Management skills</b>	France
<b>Relationships</b>	France
<b>Environment and health</b>	Romania
<b>Protection and safety</b>	Romania
<b>Languages<sup>c</sup></b>	Latvia

<sup>a</sup> Medical knowledge disciplines include modules such as anatomy, physiology, genetics, biochemistry, etc.

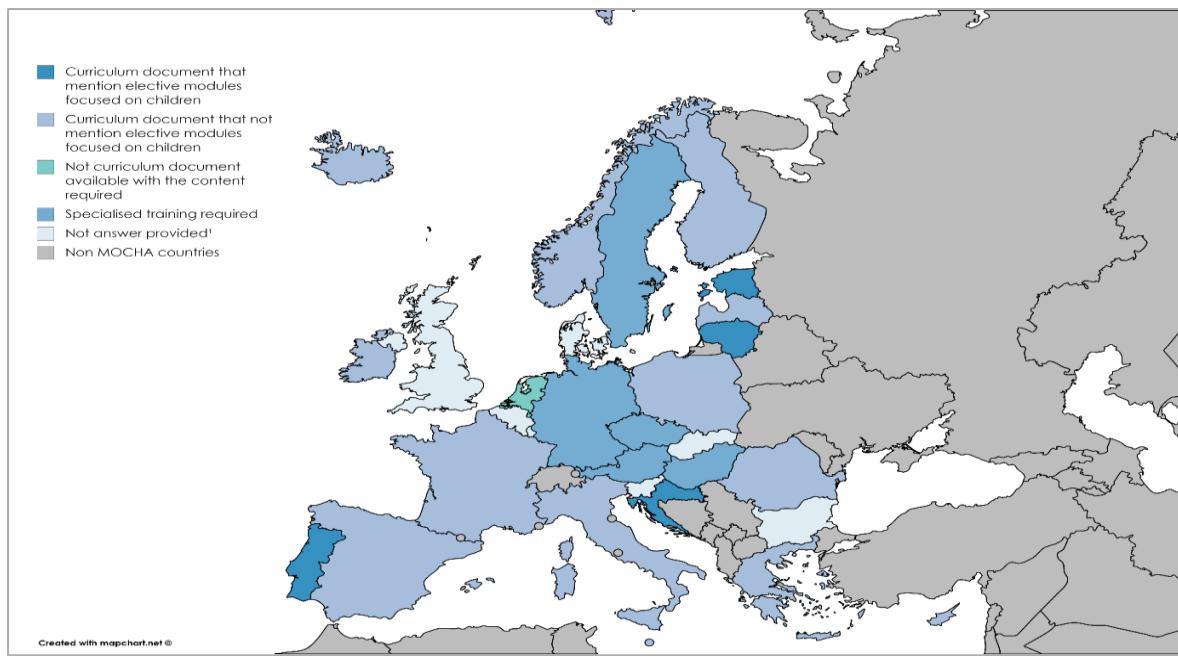
<sup>b</sup> Other populations disciplines include modules such as geriatrics or nursing of adults.

<sup>c</sup> Languages disciplines include the module English for nursing.

### Elective modules

This section describes the characteristics of all the elective modules that focused on the care of the child. These modules were mentioned in less than one-quarter of the curricula (23.5%, n = 4) (Figure 4.5). It is interesting to note that countries that reported having child-related elective modules also had compulsory core modules with a focus on children.

<sup>15</sup> The name of each discipline has been assigned by compiling modules of the same area of study from all the curricula provided by the responding countries.



<sup>1</sup> Denmark responded after the analysis for this chapter had been processed and is not included in the analysis.

**Figure 4.5 Overview of the elective modules focused on children within the curriculum documents provided by the participating countries**

The content of the elective modules varied. Diverse specialised areas on child care such as school nursing, intensive care, mental health or special needs were identified. These modules were usually two or three ECTS, except for Estonia and Portugal who had modules comprising five and eighteen ECTS respectively. The differentiation between hours expended for theoretical and practical training was identified in all the modules analysed across the countries. Nevertheless, practical hours were not specified in four of the eleven modules (36.4%), all coming from the Portuguese curriculum. The elective modules were usually offered in the third or fourth year, except in Lithuania where elective modules were imparted in the second year (Table 4.6).

**Table 4.6 Characteristics of the elective modules by country**

Country	Modules' title	ECTS	Theoretical hours	Practical hours	Year
<b>Croatia</b>	- Nursing care of school children	2	15	15	3 <sup>rd</sup>
	- Paediatric nursing in intensive care unit	2	15	15	3 <sup>rd</sup>
<b>Estonia</b>	- In-depth knowledge in children's nursing	5	20	8	4 <sup>th</sup>
<b>Lithuania</b>	- Socio-cultural work with young people in the community	3	15	15	2 <sup>nd</sup>
	- Children/adolescents with emotional and behavioural disorders	2	27	n/a	3 <sup>rd</sup>
	- Mental health challenges in childhood and adolescence	2	27	n/a	3 <sup>rd</sup>
	- The child with special needs: diagnosis and intervention in paediatric nursing	3	16	12	4 <sup>th</sup>
	- Clinical teaching in the optional area of child health nursing	18	4	385	4 <sup>th</sup>
<b>Portugal</b>	- Paediatric nutrition - assessment and nursing intervention	2	27	n/a	3 <sup>rd</sup>
	- Neonatal nursing	2	27	n/a	3 <sup>rd</sup>
	- Community nursing intervention in school context	3	16	12	4 <sup>th</sup>

Note: n/a is stated when practical hours are not available in the module.

#### Children mentioned within the context of other elective modules

Child care was mentioned in the context of other elective modules (Table 4.6). No more than a quarter of the curricula contained words related to the child in disciplines addressed to *public health, community and family nursing, health promotion and prevention, and primary care* (23.5%, n = 4), *rehabilitation* (17.6%, n = 3), *emergency care* (17.6%, n = 3), *health by gender and sexuality* (17.6%, n = 3), and *pain management* (17.6%, n = 3). Minor proportions of these search terms were identified in subjects such as *oncological care, anaesthesiology*, etc. (11.8%, n = 2; 5.9%, n = 1) (Table 4.7).

**Table 4.7 Other elective disciplines<sup>16</sup> in which child care was mentioned**

Discipline	Countries
<b>Public health, community and family nursing, health promotion and prevention, primary care</b>	Croatia, Greece, Lithuania, Portugal
<b>Rehabilitation and physiotherapy</b>	Croatia, Greece, Lithuania
<b>Emergency care</b>	Lithuania, Malta, Spain
<b>Health by gender and sexuality</b>	Ireland, Portugal, Spain
<b>Pain management</b>	Croatia, Portugal, Spain
<b>Oncological care</b>	Finland, Malta
<b>Transfusion medicine</b>	Croatia
<b>Anaesthesiology</b>	Poland
<b>Obesity</b>	Portugal
<b>Language a</b>	Portugal

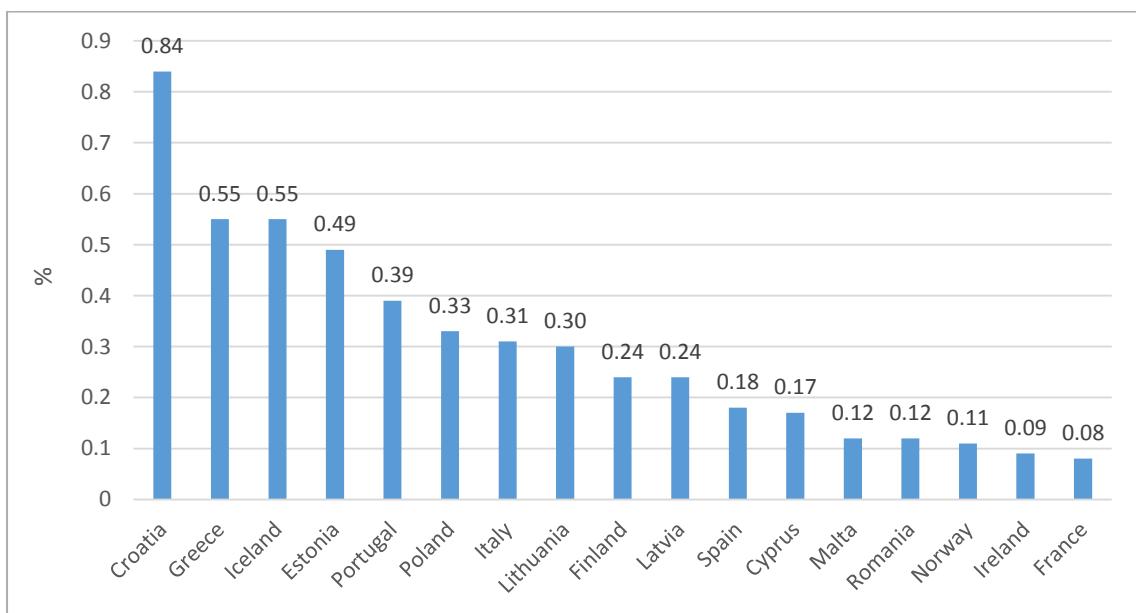
<sup>16</sup> The name of each discipline has been assigned by compiling modules of the same area of study from all the curricula provided by the responding countries.

<b>Lifespan health</b>	Ireland
<b>Dietetics</b>	Lithuania
<b>Obstetrical and child care</b>	Greece
<b>Nursing in basic health</b>	Finland
<b>Biomedical science</b>	Lithuania
<b>Mental health</b>	Portugal

<sup>a</sup>Languages disciplines include the module Portuguese sing language.

#### Quantification of child related search terms in the curricula documents

In order to provide an overview of child-related content in each curriculum, a quantification of child-related search terms (Appendix 5) and comparison with the total number of words in the curriculum documents was conducted. Figure 4.6 shows the results in percentages.



**Figure 4.6 Percentage of child related search terms within the whole curricula by country**

No curriculum document from the respondent countries presented more than one percent of child-related search terms within the whole curricula. The Croatian curriculum had the majority of search terms. In the documents from Greece and Iceland, the percentages dropped to 0.55%. The percentages on the remaining countries was below 0.50%, lowest in Ireland and France. For more information on the number of child-related search terms and total words count in each curriculum see Appendix 5.

#### **4.3.2.2 In-depth analysis of each curriculum**

The inductive content analysis conducted in the curricula documents detected a total number of 1173 keywords related to the care of the child. Twenty-one subcategories and three main categories were identified. The main categories that contained most of the keywords were *Nursing Care of Children* ( $n = 622$ ) and *Paediatrics* ( $n = 440$ ), the category that focused on the *Psychosocial Aspects* had the least number of keywords ( $n = 111$ ) (Table 4.8).

**Table 4.8 Child-related content categorisation**

<b>Subcategory</b>	<b>N</b>	<b>Main category</b>	<b>n</b>
Provision of nursing care	167	Nursing care of children	622
Medical treatment, interventions and procedures	141		
Identification of diseases and nursing diagnosis	79		
Assessment and planning	77		
Prevention and health promotion	60		
Other knowledge and skills to work with children	17		
Ethics and law	17		
Family nursing	15		
Accidents and emergencies	12		
School nursing	12		
Children with complex/special healthcare needs	9		
Nurses roles	9		
Pain management	7		
Pathologies and injuries	257	Paediatrics	440
Growth and development	109		
Child health specific characteristics	45		
Basic needs	29		
Children's and family experiences	32	Psychosocial aspects	111
Support and preparation	29		
Communication and relationships	27		
Health education and counselling	23		
<b>Total</b>			<b>1173</b>

Note: n = number of keywords

- *Nursing care of children*

This category described the content that focused on the knowledge that nurses need in order to deliver effective nursing care to children. It included nursing processes such as nursing assessment, identification and intervention, the study of specific areas such as pain management, family nursing, and ethics.

*Provision of nursing care* ( $n = 167$ ) subcategory incorporated content with a general approach (e.g. effective care provision, paediatric nursing care, etc.), related to specific health conditions (e.g. intestinal infections, respiratory diseases, etc.) and in different child-stages (e.g. newborn, adolescent, etc.). It also comprised provision of care for the child undergoing surgery and for the healthy child. In *medical treatment, interventions and procedures* ( $n = 141$ ), content was addressed to providing knowledge on major interventions, treatments and procedures for some of the most frequent pathological conditions in children. *Identification of diseases and nursing diagnosis* ( $n = 79$ ) contained keywords related to the recognition of deviation in children's health along with the use of appropriate tools and methods for detection. *Assessment and planning* ( $n = 77$ ) covered both, the evaluation of the child, and the assessment of nursing care, including necessary tools. Development of a nursing care plan was also part of this subcategory. *Prevention and health promotion* ( $n = 60$ ) included all content related to vaccinations, prevention of specific problems and diseases, prevention of further complications and risk factors affecting the child. The promotion of healthy development and principles for promoting health were also incorporated. *Other knowledge and skills required to work with children* ( $n =$

17) covered areas such as safety and organisational regulations, the child in his/her context, knowledge on specific units such as intensive care or outpatient clinics, research methods, and several skills like calculation or critical thinking. *Ethics and law* ( $n = 17$ ) incorporated those keywords focused on broad ethical and legal aspects of childhood, children's rights, and the respect for them and their parents. *Family nursing* ( $n = 15$ ) encompassed the family-centred care approach, support to the family, family roles on the child's health, and the skills development to work effectively with their families. *Accidents and emergencies* ( $n = 12$ ) covered areas related to childhood emergencies, including Basic Paediatric Life Support, and factors encouraging accidents on the child. *School nursing* ( $n = 12$ ) embraced several themes, such as health education and promotion, epidemiological risks, or health in school settings. *Child with complex/special healthcare needs* ( $n = 9$ ) introduced keywords related to the child with life-threatening conditions, chronic and malignant diseases, disabilities, and the child with special needs. *Nurses roles* ( $n = 9$ ) content was addressed to provide knowledge on the functions that nurses have related to the care of the child and family, on specific situations (e.g. in the admission to the hospital or in the community), and on specific illnesses (e.g. mental health disorders). *Pain management* ( $n = 7$ ) contained keywords related to the pain concept and the use of tools for its measurement and regulation.

- *Paediatrics*

This category included stages of growth and development, pathologies and injuries, basic needs, and issues related specifically to children.

*Pathologies and injuries* ( $n = 257$ ) was the subcategory with the highest number of keywords related to the child. The content was related to common child health problems (e.g. children's pathologies of all body systems, childhood pathologies, etc.), and related to specific systems (e.g. Diabetes Mellitus, respiratory diseases, etc.). Child psychopathologies were included in this subcategory. *Growth and development* ( $n = 109$ ) incorporated content focus on the normal development of the child, deviations and factors affecting growth. *Child health specific characteristics* ( $n = 45$ ) included particular features in several areas (e.g. anatomical characteristics, body structural characteristics, etc.), and the differences to the adult patient. *Basic needs* ( $n = 29$ ) incorporated keywords focused on children's nutrition and sleep.

- *Psychosocial aspects*

This category described the knowledge available in the curricula related to psychosocial aspects. It included children's and family experiences, support and preparation, communication and relationships, as well as health education and counselling.

*Children's and family experiences* ( $n = 32$ ) related to issues such as illness or hospitalisation. *Support and preparation* ( $n = 29$ ) included content that focused on the provision of both psychological and physical support to children and families for specific aspects like clinical examinations, performing procedures, etc. *Communication and relationships* ( $n = 27$ ) covered both, areas focused on the skills required for an effective communicative process (e.g. communication strategies, methods or evaluation), and areas addressed to the effective establishment of relationships (e.g. children-parent interaction, relationships with children and parents, etc.). *Health education and counselling* ( $n = 23$ ) contained keywords related to the process of teaching and advising children and families, its methodology, and evaluation.

## **4.4 Discussion and Conclusion**

### **4.4.1 Introduction**

This section discusses the main themes emerging from this study, providing key points at the end of each theme. It also includes the limitations that the study and the research team had to face and the conclusion reached.

### **4.4.2 Key themes emerging from this work**

From the data analysed in this study (nursing qualifications and general nursing curricula), three main themes have been identified as important for enhancing nursing preparedness when delivering care to children with CCN in the community: *the need for specialised knowledge, need for standardisation and importance of focus of psychosocial aspects*.

#### **4.4.2.1 The need for specialised knowledge**

The results of this study show that for the majority of European countries, a general nursing qualification is all that is required to work with children with CCN in the community. According to the PNAE, children are entitled to be cared for by nursing staff who are adequately prepared and qualified. Thus, given that specific learning regarding child health may be tacit rather than explicit in general nurse education programmes, they are potentially insufficient in preparing nurses to perform their roles on infants, children and young people (Paediatric Nursing Association of Europe, 2015).

The need for further education for nurses caring for children with CCN has been manifested in the literature (Carver and Sloper, 2004, Fletcher et al., 2011, Pearson, 2013, Summers, 2013, Europe, 2015). In a study performed by Pearson (2013) focusing on palliative nursing care for children, general nursing education was deemed insufficient to provide the specific skills and knowledge that this type of care required. The need for acquiring skills and knowledge through postgraduate programmes was highlighted (Pearson, 2013). Other studies also concur that specific training is essential for nurses to feel prepared for delivering care to children, as a lack of appropriate training can lead to a lack of nurses' confidence (McCloskey and Taggart, 2010, Neilson et al., 2010, Pearson, 2013). Inadequately met educational needs from health professionals was also detected as being one of the main causes for limited engagement with children and young people (Carver and Sloper, 2004, Fletcher et al., 2011). Summers (2013) affirmed that educational programmes have the duty to prepare children's nurses so that they can respond effectively to the needs of children and young people.

Reports in other WP2 tasks also emphasise the importance of specialised care. Having paediatric expertise was noted as being an important factor in appropriate referrals from primary to secondary paediatric care. Additionally, early contact with health professionals with specific education and experience in paediatrics, increases the probability of detecting tumours before they become symptomatic (Wolfe et al., 2017). Having access to specialist care and improving education of nursing and other health professionals was considered as optimal to the integration of care for children with LTV and intractable epilepsy (Brenner et al., 2017). Moreover, young people (16-24 years), although satisfied with health care, consistently report poorer experience of care than older adults and are significantly less likely than adults to feel respected or have necessary confidence and trust in their doctors (Alma et al., 2017).

However, even though the growing body of evidence would suggest that specialist training is of vital importance in providing care for children with CCN, five of the respondent countries

expressed that they have no paediatric options available for further or enhanced graduate nurse education.

#### Key Point

- The need to promote specialist children's nurse education in order to enhance the skills and competence of nurses who deliver care to children living with CCN.

#### **4.4.2.2 Need for standardisation**

Findings in this study showed wide variation across European countries in general nursing qualifications. One issue detected was the variation in number of years training. The Professional Qualifications Directive 2005/36/EC amended by the Directive 2013/55/EU, states that a general nursing degree should consist of at least three years of study. As seen in the results, duration varied between three and four years of study. The difference may depend on the ECTS weighting of the course. In some countries, the variation could be related to the level of education (diploma or bachelor degree) available for nurses. In a study carried out by Praxmarer-Fernandes et al. (2017) on current levels of nursing and midwifery education, wide variations were identified across the European Region, finding that half of the sample (EU or European Free Trade Agreement (EFTA) countries) offered nursing education at both, diploma and bachelor's degree level. However, a bachelor's degree in nursing has been related to better health outcomes, decreasing the rates of patient mortality in hospital settings (Aiken et al., 2014, Praxmarer-Fernandes et al., 2017).

Other main issues identified from the analysis of the general nursing curricula was the wide variation in the focus on children within the curricula. The results showed that child care and paediatrics is addressed within the context of other non-childcare focused modules. Only twelve out of seventeen countries had compulsory core modules on children. It is interesting to note that elective modules focused on children were only available in those countries with one or more compulsory core modules on children.

Article 31 of The Professional Qualifications EU Directive 2005/36/EC amended by the Directive 2013/55/EU, regulates the undergraduate training of nurses responsible for general care (European Parliament and Council Directive, 2005, 2013). As mentioned in the introduction, this Directive gives a general description of the training and competences required for a general nurse. However, it does not give guidance on the specific content and skills that are necessary for each of the areas that it mentions, including the nursing care of children. The implications of this broad directive are visible in the results of this study. The results show the wide variation in the different countries. The countries have adopted and implemented the directive based on their interpretations of what the standard should be.

An integrative review of the literature for this study (March 2016 - February 2017) reveals no current European competence framework for how the nursing care of children should be taught or what the content should be for general nursing programmes. Despite the fact that children comprise a significant part of patient populations in primary care. Wolfe and McKee (2013) in the DIPEX report notes that children in England make up 25% of a typical primary care population, and are associated with 40% of the workload (Alma et al., 2017).

In this study, the content related to the child within general nursing programmes was identified. Three themes were detected: *nursing care of children*, *paediatrics* and *psychosocial aspects*. *Nursing care of children* and *paediatrics* held the greatest number of keywords related to children in the documents analysed. The lack of a European competency framework makes it difficult to regulate which specific knowledge and skills should be endorsed and fostered to ensure the highest possible quality care for children. This would hold even greater importance in the context of the children with CCNs, where this care has to be targeted to the child's specific health condition. In the curricula analysed, very little content focus on children with CCNs was identified. A possible explanation for this is that there is no common definition for children with CCNs across countries. This could be the reason it is difficult to find reference to these children in the curriculum documents. Elements of children with CCNs appeared mainly in modules that focused on the specifics of physiological illnesses, with reference to their care, treatment, aetiology, etc. This concurs with the view of Whitehead (2007) who expressed the long continuing tradition of nursing curricula as being grounded within a disease-focused paradigm (Whitehead, 2007). Such an approach impedes a deeper understanding of complexity, since study of the specific characteristics of these illnesses mitigates against the 'bigger picture' of the social and political determinants of health, with a negative impact on the care of the child with CCNs.

#### Key points

- These considerations demonstrate the need for standardisation, of principal aspects of general nursing education such as the level of education, ECTS per course and the number of years training across European countries.
- The importance of creating a European competency framework for regulating the nursing care of children within general nursing programmes, regarding content and number of hours for theoretical and clinical instruction. A common framework will need to take into consideration the variability of health system across countries.
- Within a European competency framework, it is important to dedicate learning modules to the care of the child. This is particularly important for children with CCN, so that focus on these children and their families will not get lost in the wider curricula.

#### **4.4.2.3 Importance of focus on psychosocial aspects**

Results in this study showed that a large proportion of curricula content is devoted to biomedical knowledge such as *pathologies and injuries* or *medical treatment, interventions and procedures*. Although it is not possible to interpret that larger amounts of time are dedicated to biomedical knowledge, it can give an idea of how the content is distributed and how the subjects are presented in the curriculum. A possible explanation for this could be the long tradition of targeting nursing curricula within a disease-focused paradigm (Sjolin et al., 2014, Whitehead, 2007).

In contrast, psychosocial aspects related to child health were less visible in the curricula documents. In particular, few keywords were found in psychosocial aspects linked to children's and family experiences, communication, creating trusting relationships, counselling, support, and health education.

In the study carried out by the DIPEX group in this WP, children with several health conditions and their parents were asked: What makes a good health professional? Communication and relationships with health professionals were considered key elements (Ahuja and Williams, 2010, Alma et al., 2017, Curtis et al., 2004, Freake et al., 2007, Robinson, 2010, Schaeuble et al., 2010, Schalkers et al., 2014). Children and families reported the need for improvement on these issues. According to the DIPEX study on the recommendations raised by the participants for solving problems experienced with health professionals, "*avoid jargon, show interest on the feelings and life impact of the health condition, explaining to the child, giving information adjusted to the age, listen and facilitate open reassuring communication*" will help to improve communication skills (Alma et al., 2017). These skills were very much appreciated in difficult situations, such as "*when doing tests or uncomfortable explorations*" or "*when asking sensitive questions*" (Alma et al., 2017). As suggested by Griffin et al. (2004), an improved communication between health professional and patients will lead to better outcomes (Griffin et al., 2004, Alma et al., 2017). Moreover, one patient suggested being considered an equal partner in relationships between health professionals and patients, as this enhanced confidence and helped the patients to share their thought (Alma et al., 2017).

The importance of communication and relationships were also highlighted in other tasks in the WP. One of the findings in the management of care of children on LTV and with TBI was that there was: "*limited support for the provision of linguistically appropriate or culturally appropriate information*". Furthermore, "*good personal and professional relationships*" was considered as optimal to the integration of care on children with IE (Brenner et al., 2017).

Other elements found as important for families in the DIPEX group and in other tasks of this WP was the need for health education and support. Parents need more information not only on the diseases of their children, but also on economic support; support for siblings; counselling for families; education, skills and strategies to cope with the child's disease; support for the child to have peer relationships; and services, associations or courses linked with the child health condition (Alma et al., 2017, Brenner et al., 2017, Keilthy et al., 2017).

Importance of the psychosocial aspects is also visible in the literature, where children and families see a partnership with nurses and her/his personal attributes as key characteristics for performing high-quality nursing care. Essential for creating partnership with children and families is the establishment of trusting relationships, where the nurse advocates on behalf of the family, respect their beliefs and values and communicates in an effective way. Personal attributes such as being friendly, empathetic, kind, supportive and with a sense of humour are key elements for enhancing the relationships with the child and family (Fletcher et al., 2011, Hale et al., 2008, Pearson, 2013, Summers, 2013).

In summary, the importance of a psychosocial focus is highlighted strongly by children and their families when describing important characteristics in nurses caring them. However, this focus is barely visible in the sample of general nursing curricula included in this study. Nurse education should prepare nurses so that they can play an important role in promoting trust and alleviating unnecessary suffering in these families. While it is true that nurses need to have appropriate biomedical training in the care of the child, and in particular children with CCN; there is a need for nurses to develop communication and relational skills and personal attributes as highlighted by parents and children. The research team acknowledges that if

nurses do receive appropriate training in these areas, it was not manifest in the curricula content that were analysed in this study.

#### Key points

- It is necessary to focus more specifically on psychosocial aspects related to the care of children and their families in general nursing curriculum documents.
- The lack of emphasis on these aspects highlight the need for the inclusion of children and families when developing educational programmes. This will provide direction for nursing skills and training necessary for the care of the child.

#### 4.4.3 Limitations

The study has limitations. The questionnaire was sent to CAs who had the responsibility of obtaining the required data from nursing experts in their countries. The validity of the responses was dependent on the agents' and respondents' interpretation of the questions. Subtle differences in the meaning of words can create problems in interpreting survey questions (Squires et al., 2013). English is not the native language of many of the respondents. This can also lead to possible misunderstandings. The strength of the research findings must be evaluated in relation to the procedures used to generate the findings (Graneheim and Lundman, 2004). The questions went through a process of validation before the questionnaire was sent. In order to ensure the reliability of the researchers' interpretation, the responses were sent back to the CAs for validation. Issues related to language can influence the validity of the results. The responses from nine countries were in their native language and translated by the team using a translation tool. The members of the research team are proficient in a number of languages and uncertainties related to the meaning of words and sentences were discussed until clarity was attained. Native speakers and experts in the field were also consulted.

The analysed curricula were from institutions who educated the largest number of student nurses in the respondent countries. Content analysis reveals the content of the documents analysed. It does not provide information on how the content is interpreted and used in practice. A text can have numerous meanings and there are always elements of interpretation when deciphering a text (Graneheim and Lundman, 2004). The intention is to explore usage, not to assume meaning. It is essential to take this into account when considering the trustworthiness of the findings. A team of three researchers were involved in process of identifying the keywords and categorising the content. This adds credibility to the analysis process.

The study is descriptive in nature and only the manifest content of terms related to child care is presented. Fairclough (2010) maintains that the articulation of knowledge by the use of certain terms and the absence of others can be indicative of specific discursive strategies (Fairclough, 2010). Describing something in a certain way can ensure the relevance of certain topics and render other topics irrelevant or unimportant (Jørgensen and Phillips, 2006).

Initially, it was planned to study paediatric nursing curricula from countries that required specialised training to deliver care to children with CCNs in the community. The small number of countries requiring specialised training along with the even smaller number of specialised

curriculum documents ( $n = 2$ ) presented for analysis made this plan redundant. In the same way, the data gathered for the number of nurses that complete paediatric nurse education each year was not consistent across countries, making difficult the analysis and posterior comparison. For that reason, this analysis was rejected.

A further limitation is that not all countries responded and we are missing data from Belgium, Denmark<sup>17</sup>, Luxembourg, Slovakia, Slovenia and the United Kingdom. The responses, however, provide a descriptive analysis from 23 countries. The data was collected in 2016-2017. Due to educational reforms, the results of education surveys will need to be monitored for continued relevance in the future (Praxmarer-Fernandes et al., 2017). The study does, however, give a descriptive overview of nursing qualifications required to look after children with CCNs in the community, and the curricula content related to children and paediatrics in 2016-2017 in 23 European countries.

#### **4.4.4 Conclusion**

Benner et al. (2010) called out for a radical transformation of nurse education at national levels in order to meet today's CCN (Benner et al., 2010, Benner, 2012). This section of the MOCHA project has investigated nurses' preparedness for practice in relation to the nursing care of children in the community, and in particular children with CCNs. Existing educational requirements have been mapped and the content of nursing curricula has been studied. The report gives us a better understanding of nursing training in Europe and the opportunity to suggest how to improve education for nurses in order to meet the needs of children and their families. A general nursing degree is all that is required in most countries. Great variations have been detected across countries in the emphasis placed on the child in general nursing programmes. There is no uniform mandatory system to ensure clinical nursing competence (Bradshaw and Merriman, 2008) and without such a system, it is difficult to confirm that nurses are prepared sufficiently to meet the requirements of a child with complex needs. Although a paediatric specialisation would be the ideal training for caring for children with CCNs, the reality is that political and social conditions across Europe can be a hindrance to this goal.

There is, however, a need for European standards in order to agree on content and focus dedicated to children inside general nursing programmes. These standards should incorporate the holistic care of the child. The results of this study have clinical and theoretical implications. There is a need to investigate further discourses in curricula documents and to carry out qualitative studies on how to care for children with CCNs with a number of stakeholders (nurses, student nurses, parents, children and members of national bodies involved in regulating nursing education). Children and parents should be involved at all levels when considering the creation of new standards for practice.

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<sup>17</sup> Denmark responded after the analysis for this chapter had been processed and is not included in the analysis.

## **Chapter 5 Discussion and Conclusions**

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### **5.1 Introduction**

The aim of our work in this section of the MOCHA project was to illuminate facilitators for an optimum acute community interface for children with complex health and social care needs, informing the overall model building for MOCHA in WP9. The first four chapters presented key findings on the Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care across the EU/EEA. This is the first time this has been explored across the EU/EEA and is a very timely piece of work considering the concept of a complex care team is not yet an established entity in the majority of countries in this region. This chapter presents the *Core Principles and Standards of Care for Children with Complex Care Needs in the EU/EEA*.

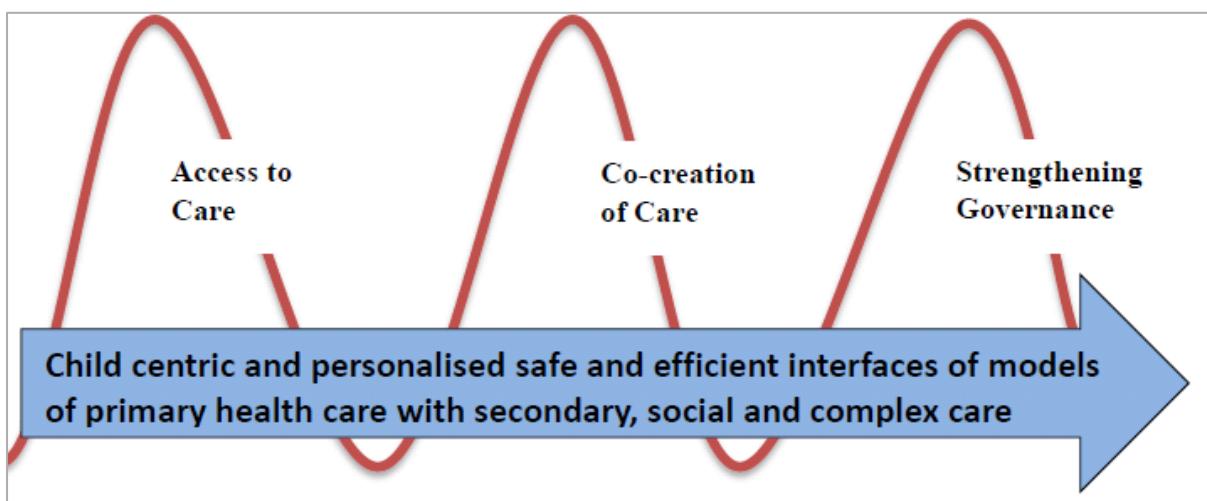
### **5.2 Core Principles for the Successful Integration of Care for Children with Complex Care Needs**

To identify the core principles we, first of all, mapped the collective findings to the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (Association of Maternal and Child Health Programs / The National Academy for State Health Policy, 2017). Given the breadth of data gathered and analysed across this large WP we held two workshops, one in November 2016 and another in September 2017, to explore in detail the potential themes emerging, and to identify the core facilitators of optimum integration of care at the acute community interface for children with complex health and social care needs. Each workshop included presentations from each area of WP2 and discussion with the wider MOCHA team on the issues emerging. While many of the areas from the initial Standards for Systems of Care for Children and Youth with Special Health Care Needs were deemed relevant to the EU context we were also very mindful that it is of foremost importance that our findings have meaning across the EU/EEA with its cultural, socio-political and legal diversity. From these workshops core principles and standards of care for children with CCNs emerged. Considering the variety of needs across a child's life there is clearly no 'one-size-fits-all' when it comes to facilitating optimum care for such a diverse group of children and their families. However, there are core principles, which when applied, will enhance safe and effective care. The core principles are: access to care, co-creation of care, and strengthening governance (Figure 5.1).

- **Access to care:** equitable access to consistently high quality, prompt and accessible services across the country to meet the needs and improve health of all groups within the population.
- **Co-creation of care:** Co-creation in health and social care refers to equipping the child and family in partnership with the professional to design, create and deliver health and social care services. In the drive to improve the efficiency and effectiveness of healthcare services, there has been a growing interest in co-creation as a way of redesigning services to achieve these objectives.
- **Strengthening governance:** Effective governance is necessary to enhance accountability and to support the provision of safe, equitable, accessible and responsive

cross-sectoral care to children with complex care needs. Governance is strengthened by effective communication, access to suitably skilled healthcare professionals, transparent decision-making processes, and the inclusion of children and their families in the design and evaluation of services.

The key standards for each principle are presented below.



**Figure 5.1: Core principles**

## Principle 1: Access to Care

Access to health and social care for the child with CCN refers to equitable access to consistently high quality, prompt and accessible services across the country to meet the needs and improve health of all groups within the population.

### Standards.

- Each child with CCNs is afforded access to age-specific and developmentally appropriate care.
- There is a pathway in place to access non-urgent specialist care in the community 24/7 when a child has CCNs.
- Where possible children with CCNs and their family should be cared for by the same doctor and nurse on each consultation.
- Consideration should be given to the establishment of community complex care centres where the population and specialist expertise exists to support this.
- There is technical support in the community to assist parents caring for a child with CCNs in the home.

- 
- Electronic health records are in operation to support shared care.
  - Community pharmacists provide support to the child with CCN and their parent(s)/guardian(s).
  - A child with CCNs receives ongoing preventative care screening and developmental checks.
  - The results of all screening are disseminated to all health services caring for the child.
  - The results of all screening are communicated to the child's parent(s)/guardian(s).
  - There is a transportation service that can accommodate the child and their assisted technology devices to access the child's daily activities and to attend health and social care visits.
  - All information provided to families of children with CCNs is linguistically appropriate.
  - All information provided to families of children with CCNs is culturally appropriate.
  - When a child with CCNs has a medical crisis there is direct access to, and discharge from, a Paediatric ED and/or a Paediatric Intensive Care Unit.
  - There is timely assessment for, and access to, rehabilitation services.
  - Paediatric palliative care services are available to the child and family when required.
  - There is timely access to respite care services.
  - There is facilitated support in primary care for diagnostic tests that enable prevention and early detection of health concerns.
-

## Principle 2: Co-creation of Care

Co-creation in health and social care refers to equipping the child and family in partnership with the professional to design, create and deliver health and social services. In the drive to improve the efficiency and effectiveness of health and social care services, there has been a growing interest in co-creation as a way of redesigning services to achieve these objectives.

### Standards

- A discharge planning coordinator is available to the child and family when transitioning from the acute to the community setting.
- There is a standardised system to identify the clinical support needs for the child transitioning to home.
- Parents are supported to be clinically ready to care for their child in an incremental manner.
- There is a written personalised plan of care for the child, developed in consultation with the child's parent(s)/ guardian(s) and members of the healthcare team.
- A named care coordinator is appointed to the child with CCNs and their family to support multidisciplinary engagement and care in the community.
- Family advocacy groups are involved in making recommendations to home and community-based services.
- There is a standardised assessment of sibling support needs.
- Parent(s) / guardians(s) and siblings have access to psychological support from professionals with paediatric expertise.
- Children are included in national quality improvement initiatives for their care.
- Data is collected on the overall experience of care for children with CCNs.
- Data is collected on the experience of care from the perspectives of parents(s), guardians(s) and siblings.
- A plan of care is prepared with adult healthcare services before an adolescent is transferred from paediatric services.
- Data is collected on the experience if transitioning from paediatric to adult services from the perspective of the adolescent.
- Data is collected on the experience of transitioning from paediatric to adult services from the perspective of the parent(s) / guardians(s).

## Principle 3: Strengthening Governance

Effective governance is necessary to enhance accountability and to support the provision of safe, equitable, accessible and responsive cross-sectoral care to children with CCNs. Governance is strengthened by effective communication, access to suitably skilled healthcare professionals, transparent decision-making processes, and the inclusion of children and their families in the design and evaluation of services.

### Standards

- Primary care providers have access to specialist support when caring for a child with CCNs.
- Consideration should be given to the development of specialist advanced nurse practice roles in the community for children with CCNs.
- There are standardised systems in place for the assessment of the child with CCNs in the community, including the deteriorating child.
- There is a standardised process for the clinical handover of the child with CCNs to and from secondary care services.
- There is a system in place to identify all of the health and social care providers who care for a child with CCNs.
- There is a system in place to identify all of the voluntary agencies who care for children with CCNs.
- There is a system in place to govern all care delivery to the child with CCNs in the home.
- All primary care providers caring for children with CCNs have specialist training in the care of children with CCNs, relevant to the individual complex needs of the child they present to care for.
- Education for all social care staff caring for children with CCNs is standardised.
- There is a retention policy for skilled healthcare staff who care for children with CCNs.
- There is a national data base of children with CCNs.
- There are quality assurance mechanisms in place for service providers caring for children with CCNs.
- Cross-border initiatives are in place where no specialist centre exists nationally for children with CCNs.
- National integrated care programmes are in place to support care delivery at the acute community interface.

- 
- There is a school health system in place to support the child with CCNs.
  - There is specialised training for school teachers and education support staff when a child has CCNs.
  - There is special reference to promoting the welfare of children with disabilities within wider child protection legislation.
  - Safeguarding training for children with communication difficulties is provided to all health and social care staff caring for these children.
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As detailed in our previous reports, children with CCNs and their families place great challenges on health and social care delivery for many reasons: they require dynamic and responsive health and social care over a long period of time; they require organisational and delivery coordination functions; health issues such as minor illnesses, which are normally presented to primary care, must be addressed in the context of the complex health issues; and finally the clinical presentation individual to the child may be rare and therefore challenge care management. Our collective findings from our work in WP2 are that the integration of health and social care services are generally found to be insufficient, with wide variation in access to, and governance of care for these children. It is acknowledged that some initiatives are beginning in this area across the EU, however, there remain extensive challenges. These include communication of a child and family's needs at the acute-community interface, confusion over points of accessing care and no defined system of documenting care needs and care delivery in a manner that can be accessible for the family and the multi-disciplinary team when families cross between acute and community care services. The challenges found in the EU/EEA context are shared internationally for this population, with recommendations for the need for a seamless service to avoid overburden on parents and more effective communication processes to enhance continuity of care (Robert et al. 2012). Adopting appropriate processes is essential for continuity of care, the absence of which can lead to difficulty delivering safe and efficient care.

It is previously documented that parents are significantly challenged when becoming the primary caregivers of a child with CCNs (Brenner et al. 2015, 2016a, b). There are known challenges in establishing funding arrangements, with recruiting, training and retaining appropriate community-based carers reported as frequently problematic (Law et al. 2011). The establishment of the role of a discharge coordinator has been found to be extremely beneficial in supporting co-creation of care with parents as they leave acute care services, while the ongoing support through the role of a care coordinator for families when they are in the community has been found to reduce parents stress and enhance their trust in the health service. It also serves to reduce their time commitment to coordinating the care of their child (Ehrlich et al. 2012, Hillis et al 2016). On a wider international field, there are very interesting advances in innovative co-creation practices in the United States for specific complex health issues (Weier et al., 2017), which would be extremely worthwhile exploring while addressing and establishing the core components of safe and effective care delivery. One of the key issues in the governance of care pertains to concern around the quality of care delivery available in the

community for children and their families. The governance of care for children with CCNs in the community was unclear across the majority of the countries who responded to our surveys. This focus on governance is supported by Greer et al. (2015) and aligns with wider work on governance in primary care in MOCHA in WPs 1 and 9. To address the issue of governance of care for children with CCNs there is a need for direction at the policy level, with agreement on the criteria for competent care delivery and clarity in the organisation of services for children with CCNs and their families and in the regulation of training and education of health and social care staff caring for these children.

### **5.3 Conclusion**

The growing trajectory of children with CCN places great challenges on healthcare delivery. However, prior to the instigation of the MOCHA project little was known about the management of care of these children at a critical juncture in care delivery, the acute community interface. This ties closely into the primary care function of coordination and continuity of care, as described in WP1. This final report from WP2 has illuminated facilitators for an optimum acute community interface for children with complex health and social care needs, informing the overall model building for MOCHA in WP9. In doing so we have identified and presented the first core principles and standards for the care of children with CCN in the EU drawing on all of the constituents of WP2.

## References

- AHUJA, A. S. & WILLIAMS, R. 2010. Telling stories: learning from patients' and families' experiences of specialist child and adolescent mental health services. *International Journal of Consumer Studies*, 34, 603-609.
- AIKEN, L. H., SLOANE, D. D., BRUYNEEL, L., VAN DEN HEDE, K., GRIFFITHS, P. & BUSSE, R. E. A. 2014. Nurse staffing and education and hospital mortality in nine European countries: a retrospective observational study. *Lancet*, 383, 1824-1830.
- ALMA, M., MAHTANI, V., PALANT, A., KRACMAROVA, L. K. & PRINJHA, S. 2017. Work Package 1: Report on Patient Experiences of Primary Care in 5 DIPEX countries (Unpublished manuscript).
- ANHEIER, H. 2000. Managing non-profit organisations: Towards a new approach. *Civil Society Working Paper 1*. London England.
- ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS. 2014. Standards for Systems of Care for Children and Youth with Special Health Care Needs. Washington DC: Association of Maternal and Child Health Programs.
- ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS / THE NATIONAL ACADEMY FOR STATE HEALTH POLICY. June 2017. Standards for Systems of Care for Children and Youth with Special Health Care Needs: Version 2.0. Washington DC: Association of Maternal and Child Health Programs.
- ATTRIDE-STIRLING, J. 2001. Thematic Networks: An Analytic Tool for Qualitative Research.. *Qualitative Research*, 1, 385-405.
- BANACH, M., LUDICE, J., CONWAY, L. & COU, L. J. 2010. Family Support and Empowerment: Post Autism Diagnosis Support Groups for Parents. *Social Work with Groups*, 33, 69-83.
- BENNER, P. 2012. Educating Nurses: A Call for Radical Transformation-How Far Have We Come? *Journal of Nursing Education*, 51, 183-184.
- BENNER, P., SUTPHEN, M., LEONARD, V. & DAY, L. 2010. *Educating nurses: a call for radical transformation*. Stanford, CA, Jossey-Bass.
- BRADSHAW, A. & MERRIMAN, C. 2008. Nursing competence 10 years on: fit for practice and purpose yet? *Journal of Clinical Nursing*, 17, 1263-1269.
- BRENNER, M. 2013. Development of a factorial survey to explore restricting a child's movement for a clinical procedure. *Nurse Researcher*, 21, 40-48.
- BRENNER, M., LARKIN, P. J., HILLIARD, C., CAWLEY, D., HOWLIN, F. & CONNOLLY, M. 2015. Parents's perspectives of the transition to home when a child has complex technological health needs. *International Journal of Integrated Care*, 15, e035.
- BRENNER, M., CONNOLLY, M., CAWLEY, D., HOWLIN, F., BERRY, J. & QUINN, J. 2016a. Family and healthcare professionals' perceptions of a pilot hospice at home programme for children: a qualitative study. *BMC Palliative Care*, 2016, 89.
- BRENNER, M., COTE, S.M., BOIVIN, M., TREMBLAY, R.E. 2016b. Severe congenital malformations, family functioning and parents' separation/divorce: a longitudinal study. *Child: Care Health and Development* 42(1), 16-24.
- BRENNER, M., O'SHEA, M. & LARKIN, P. 2017. MOCHA Work Package 2: Final Report on the Current Approach to Managing the Care of Children with Complex Care Needs in Member States. Brussels: EU Commission.
- BRONFENBRENNER, U. 1986. Ecology of the family as a context for human development: Research Perspectives. *Development Psychology*, 22, 732-742.
- BUSBY, J., HOLLINGWORTH, W. & PURDY, S. 2017. The role of general practice in reducing unplanned hospital admissions. *British Journal of Hospital Medicine*, 78, 186-187.
- CARVER, J. & SLOPER, P. 2004. The participation of children and young people in decisions about service development. *Child: Care, Health and Development*, 30, 613-621.
- CAVANAGH, S. 1997. Content analysis: concepts, methods and applications. *Nurse Researcher*, 4, 5-16.

- CENTENO, C., LYNCH, T., DONEA, O. & ROCAFORT, J. D. C. 2013. EAPC Atlas of Palliative Care in Europe 2013 - Full edition. Millan, Italy: European Association for Palliative Care.
- CONVERSE, L., BARRETT, K., RICH, E. & RESCHOVSKY, J. 2015. Methods of Observing Variations in Physicians' Decisions: The Opportunities of Clinical Vignettes. *Journal of General Internal Medicine*, 3, 586-594.
- CUNNINGHAM, I. & NICKSON, D. 2011. A gathering storm: Re-tendering and the voluntary sector workforce. . *International Journal of Public Sector Management*, 24, 662-672.
- CURTIS, K., LIABO, K., ROBERTS, H. & BARKER, M. 2004. Consulted but not heard: a qualitative study of young people's views of their local health service. *Health Expectations*, 7, 149-156.
- DENZIN, N. & LINCOLN, Y. 2011. *The Sage Handbook of Qualitative Research*, New York, NY, SAGE.
- ELO, S. & KYNGAS, H. 2008. The qualitative content analysis process. *Journal of Advanced Nursing*, 62, 107-115.
- DEPARTMENT OF HEALTH, ENGLAND. 2000. Framework for the Assesment of the Needs of Children and their Families. London, England: Department of Health, England
- EHRLICH, C., KENDALL, E. & MUENCHBERGER, H. 2012. Spanning boundaries and creating strong patient relationships to coordinate care are strategies used by experienced chronic condition care coordinators. *Contemporary Nurse: A Journal for the Australian Nursing Profession* 42, 67-75.
- EUROCHILD 2014. Deinstitutionalisation and quality alternative care for children in Europe Lessons learned and the way forward. Working paper.
- EUROPEAN PARLIAMENT AND COUNCIL DIRECTIVE on the Recognition of Professional Qualifications 2005. *Official Journal of the European Union*. L 255/22, Article 31. Retrieved from: <http://eur-lex.europa.eu/legal-content/en/%20TXT/?uri=CELEX%3A32005L0036> (accessed 12 October 2017).
- EUROPEAN PARLIAMENT AND COUNCIL DIRECTIVE 2013/55/EU amending Directive 2005/36/EC on the recognition of professional qualifications and Regulation (EU) No 1024/2012 on administrative cooperation through the International Market Information System ('the IMI Regulation'). 2013. *Official Journal of the European Union*. L 354/132. Retrieved from: <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32013L0055&from=EN> (accessed 12 October 2017).
- EUROPEAN OBSERVATORY ON HEALTH SYSTEMS AND POLICIES. *Health Systems in Transition*. [Online]. Available: <http://www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits> [Accessed 12th October 2017].
- EUROPEAN OBSERVATORY ON HEALTH SYSTEMS AND POLICIES. 2013. European child health services and systems: lessons without borders. In: WOLFE, I. & MCKEE, M. (eds.) *European Observatory on Health Systems and Policies Series*. Maidenhead, Berkshire, England: European Observatory on Health Systems and Policies.
- FAIRCLOUGH, N. 2010. *Critical discourse analysis: the critical study of language*, New York, NY, USA, Routledge.
- FLETCHER, T., GLASPER, A., PRUDHOE, G., BATTRICK, C., COLES, L., WEAVER, K. & IRELAND, L. 2011. Building on the future: Children's views on nurses and hospital care. *British Journal of Nursing*, 20, 39-45.
- FREAKE, H., BARLEY, V. & KENT, G. 2007. Adolescents' views of helping professionals: a review of the literature. *Journal of Adolescence*, 30, 639-653.
- FREED, G. L., TURBITT, E., KUNNIN, M., GAFFORINI, S., SANCI, L. & SPIKE, N. 2016. General practitioner perspectives on referrals to paediatric public speciality clinics. *Australian Family Physician*, 45, 747-753.
- GARRIDO, M. V., ZENTNER, A. & BUSSE, R. 2011. The effect of gatekeeping: A systematic review of the literature. *Scandinavian Journal of Primary Health Care*, 29, 28-38.
- GILBERT, N. 2005. The "Enabling State?" from Public to Private Responsibility for Social Protection: Pathways and Pitfalls. *OECD Social, Employment and Migration Working Papers*. Paris, France: OECD.

- GRAETZ, I., REED, M., SHORTELL, S. M., RUNDALL, T. G., BELLOWS, J. & HSU, J. 2014. The next step towards making use meaningful: electronic information exchange and care coordination across clinicians and delivery sites. *Medical Care*, 52, 1037-1041.
- GRANEHEIM, U. H. & LUNDMAN, B. 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.
- GREENHALGH, T. & KEEN, J. 2014. "Personalising" NHS information technology in England. *BMJ* (Clinical Research Edition), g7341.
- GREER, S.L., WISMAR, M. & FIGUERAS, J. 2015. Strengthening health system governance: better policies, stronger performance. England: Open University European Observatory on Health Systems and Policies Series.
- GRIFFIN, S. J., KINMONTH, A. L., VELTMAN, M. W., GILLARD, S., GRANT, J. & STEWART, M. 2004. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. *Annals of Family Medicine*, 2, 595-608.
- HALE, C., LONG, T., SANDERSON, L. & CARR, K. 2008. Identifying the attributes of threshold and higher level nursing practice for children's cancer and palliative care nurses: The views of children, their parents and other stakeholders. *Journal of Research in Nursing*, 13, 9-20.
- HARRIS, M., FREY, P., ESTEVA, M., GASPAROVIC-BABIC, S., MARZO-CASTILLEJO, M., PETEK, D., PETEK STER, M. & THULESIUS 2016. How health system factors influence referral decisions in patients that may have cancer: European symposium report. *Journal of Cancer Research and Therapy*, 4, 7-10.
- HILLIS, R., BRENNER, M., LARKIN, P. J., CAWLEY, D. & CONNOLLY, M. 2016. The Role of Care Coordinator for Children with Complex Care Needs: A Systematic Review. *International Journal of Integrated Care*, 16, 12.
- HSIEH, H. F. & SHANNON, S. 2005. Three approaches to qualitative content analysis. *Qualitative Health Research*, 15.
- HUYNH, C., WONG, I. C. K., TOMLIN, S., TERRY, D., SINCLAIR, A., WILSON, K. & JANI, Y. 2013. Medication discrepancies at transitions in pediatrics: a review of the literature. *Paediatric Drugs*, 15, 203- 215.
- JONES, C. D., VU, M. B., O'DONNEL, C. M., ANDERSON, M. E., PATEL, S., WALD, H. L., COLEMAN, E. A. & DEWALT, D. A. 2015. A failure to communicate: a qualitative exploration of care coordination between hospitalists and primary care providers around hospitalizations. *Journal of General Internal Medicine*, 30, 417-424.
- JØRGENSEN, M. W. & PHILLIPS, L. 2006. *Diskursanalyse som teori og metode. (Discourse analysis as theory and method)*. Roskilde: Universitetsforlag/samfunds litteratur.
- KATZ, M., RUBINO, A., COLLIER, J., ROSEN, J. & EHRICH, J. H. H. 2002. Demography of pediatric primary care in Europe: delivery of care and training. *Pediatrics*, 109, 788-796.
- KAUTTO, M. 2002. Investing in services in West European welfare states. *Journal of European Social Policy*, 12, 53-65.
- KEILTHY, P., WARTERS, A., BRENNER, M. & MCHUGH, R. 2017. MOCHA Work Package 2: Final report on models of children's social care support across the EU and the relationship with primary health care. Brussels: EU Commission.
- KWAN, J. L., LO, L., SAMPSON, M. & SHOJANIA, K. G. 2013. Medication reconciliation during transitions of care as a patient safety strategy: a systematic review. *Annals of Internal Medicine*, 158, 397-403.
- LAW, J., MCCANN, D. & O'MAY, F. 2011. Managing change in the care of children with complex needs: healthcare providers' perspectives. *Journal of Advanced Nursing*, 67, 2551-2560.
- LEE, A. C. K., BLANK, L., PAYNE, N., MCSHANE, M. & GOYDER, E. 2013. Demand management: misguided solutions? *The British Journal of General Practice*, 63, e589-e591.
- LUDWICK, R. & ZELLER, R. A. 2001. The factorial survey: an experimental method to replicate real world problems. *Nursing Research*, 50, 129-33.

- MARCHANT, R., LEFEVRE, M., JONES, M. & LUCKOCK, B. 2007. Necessary stuff: The social care needs of children with complex care needs and their families. London, England: Social Care Institute for Excellence.
- MCCLOSKEY, S. & TAGGART, L. 2010. How much compassion have I left? An exploration of occupational stress among children's palliative care nurses. *International Journal of Palliative Nursing*, 233-240.
- MCHUGH, S. M., O'MULLANE, M., PERRY, I. & BRADLEY, C. 2013. Barriers to, and facilitators in, introducing integrated diabetes care in Ireland: A qualitative study of the views in general practice. *BMJ Open*, 3, e003217.
- MOORE, D. 2010. *The Basic Practice of Statistics*. New York, NY, WHM Freeman & Co.
- MOTAMEDI, S. M., POSADAS-CALLEJA, J., STRAUS, S., BATES, D. W., LORENZETTI, D. L., BAYLIS, B., GILMOUR, J., KIMPTON, S. & GHALI, W. A. 2011. The efficacy of computer-enabled discharge communication interventions: A systematic review. *BMJ Quality & Safety*, 20, 403-415.
- MUNDAY, B. 2003. European Social Services: Map of Characteristics and Trends. Strasbourg, France: Council of Europe.
- NEILSON, S., KAI, J., MACARTHUR, C. & GREENFIELD, S. 2010. Exploring the experiences of community-based children's nurses providing palliative care. *Journal of Paediatric Nursing*, 22, 31-36.
- PAEDIATRIC NURSING ASSOCIATION OF EUROPE. 2015. Paediatric nurse education in Europe: a position statement by the Paediatric Nursing Associations of Europe (PNAE). Available at:[https://www2.rcn.org.uk/\\_data/assets/pdf\\_file/0003/634530/Paediatric-Nurse-Education-in-Europe2015.pdf](https://www2.rcn.org.uk/_data/assets/pdf_file/0003/634530/Paediatric-Nurse-Education-in-Europe2015.pdf) [Accessed 19th September 2017].
- PEABODY, J. W., LUCK, J., GLASSMAN, P., DRESSELHAUS, T. R. & LEE, M. 2000. Comparison of vignette, standardized patients, and chart abstraction: a prospective validation study of three methods for measuring quality. *JAMA*, 283, 1715-1722.
- PEARSON, H. N. 2013. You've only got one chance to get it right": children's cancer nurses' experiences of providing palliative care in the acute hospital setting. *Issues in Comprehensive Pediatric Nursing*, 36, 188-211.
- PRAXMARER-FERNANDES, S., MAIER, C. B., OIKARAINEN, A., BUCHAN, J. & PERFILIEVA, G. 2017. Levels of education offered in nursing and midwifery education in the WHO European region: multi-country baseline assessment. *Public Health Panorama*, 3, 357-536.
- PRITCHARD-JONES, K., GRAF, N., VAN TINTEREN, H. & CRAFT, A. 2016. Evidence for a delay in diagnosis of Wilms's tumour in the UK compared with Germany: implications for primary care for children. *Achieves of Disease in Childhood*, 101, 417-420.
- ROBERT, R., ZHUKOVSKY, D. S., MAURICIO, R., GILMORE, K., MORRISON, S. & PALOS, G. R. 2012. Bereaved Parents' Perspectives on Paediatric Palliative Care. *Journal of Social Work in End-of-Life & Palliative Care*, 8, 316-338.
- ROBINSON, S. 2010. Children and young people's views of health professionals in England. . *Journal of Child Health Care*, 14, 310-326.
- RTE. 2017a. *Protest over 'broken promises' on disability rights* [Online]. Available: <https://www.rte.ie/news/2017/0919/905954-disability-protest/> [Accessed 19th September 2017].
- RTE. 2017b. *Protesters seek better services for children with disabilities* [Online]. Available: <https://www.rte.ie/news/health/2017/0403/864795-marches-enough-is-enough/> [Accessed 19th September 2017].
- RUTH, J. L., GESKEY, J. M., SHAFFER, M. L., BRAMLEY, H. P. & PAUL, I. M. 2011. Evaluating communication between pediatric primary care physicians and hospitals. *Clinical Pediatrics*, 50, 932-928.
- SARTORE, G., LAGIOIA, V & R., M. 2013. Peer support interventions for parents and carers of children with complex needs (Protocol). *Cochrane Database of Systematic Reviews*. Issue 6. Art. No.: CD010618.

- SCHAEUBLE, K., HAGLUND, K. & VUKOVICH, M. 2010. Adolescents' preferences for primary care provider interactions. *Pediatric Nursing*, 15, 202-210.
- SCHALKERS, I., DEDDING, C. H. M. & BUNDERS, J. F. G. 2014. '[I would like] a place to be alone, other than the toilet' – Children's perspectives on paediatric hospital care in the Netherlands. *Health Expectations*, 18, 2066-2078.
- SCHWAPPACH, D. L. B. & GEHRING, K. 2014. Silence that can be dangerous: a vignette study to assess healthcare professionals' likelihood of speaking up about safety concerns. *PLoS One*, 9, e104720.
- SJOLIN, H., LINDSTROM, V., HULT, H., RINGSTED, C. & KURLAN, L. 2014. What an ambulance nurse needs to know: A content analysis of curricula in the specialist nursing programme in prehospital emergency care. *International Emergency Nursing*, 23, 127-132.
- SMITH, N. V. & MORGAN, M. 2010. Politics and pedagogy: discursive constructions in the IB Theory of knowledge – Guide. *The Curriculum Journal*, 21, 299-312.
- SNOW, V., BECK, D., BUDNITZ, T., MILLER, D. C., POTTER, J., WEARS, R. L., WEISS, K. B. & WILLIAMS, M. V. 2009. Transitions of Care Consensus policy statement: American College of Physicians, Society of General Internal Medicine, Society of Hospital Medicine, American Geriatrics Society, American society of Emergency Physicians, and Society for Academic Emergency Medicine. *Journal of Hospital Medicine*, 4.
- SOLOMON, M., PISTRANG, N. & BARKER, C. 2001. The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology*, 29, 113-132.
- SQUIRES, A., AIKEN, L. H., VAN DEN HEEDE, K., SERMEUS, W., BRUYNEEL, L., LINDGVIST, R., SCHOOVENHOVEN, L., STROMSENG, I., BUSSE, R., BRZOSTEK, T., ENSIO, A., MORENO-CASBAS, M., RAFFERTY, A., SCHUBERT, M., ZIKOS, D. & MATTHEWS, A. 2013. A Systematic Survey Instrument Translation Process for Multi- Country, Comparative Health Workforce Studies. *International Journal of Nursing Studies*, 50, 264-273.
- SUMMERS, K. 2013. Children's nurse education - what is important to the service user? *British Journal of Nursing*, 22, 747-750.
- THOBURN, J. 2013 Services for vulnerable and maltreated children. In Wolfe, I. and McKee, M. eds., 2013. European Child Health Services and Systems: Lessons without borders. Maidenhead, UK: Open University Press/McGraw-Hill, pp.219-239.
- UNITED NATIONS GENERAL ASSEMBLY. 1989 Convention on the Rights of the Child, United Nations, Treaty Series, vol.1577.
- UNICEF CEE-CIS. 2010. At home or in a home? Formal care and adoption of children in Eastern Europe and Central Asia, UNICEF: Regional Office for Central and Eastern Europe and the Commonwealth of Independent States.
- VAN ESSO, D., DEL TORSO, S., HADJIPANAYIS, A., BIVER, A., JAEGER-ROMAN, E., WETTERGREN, B., NICHOLSON, A., PRIMARY-SECONDARY, (PSWG), WORKING GROUP OF THE EUROPEAN ASSOCIATION OF PAEDIATRICS (EAP). 2010. Paediatric primary care in Europe: variations between Countries. *Achieves of Disease in Childhood*, 95, 791-795.
- VERMEIR, P., VANDIJK, D., DEGROOTE, S., PELEMAN, R., VERHAEGHE, R., MORTIER, E., HALLAERT, G., VAN DAELE, S., BUYLAERT, W. & VOGELAERS, D. 2015. Communication in healthcare: a narrative review of the literature and practical recommendations. *International Journal of Clinical Practice*, 69, 1257-1267.
- VINER, R. 2003. Bridging the gaps: transition for young people with cancer. *European Journal of Cancer*, 39, 2684-2687.
- WEIER, R.C., GARDNER, W., CONKOL, K., KELLEHER, K.J. 2017. Partners for kids care coordination: lessons from the field. *Pediatrics*, 139(Suppl 2):S109-S116.
- WHITEHEAD, D. 2007. Reviewing Health promotion in nursing education. *Nurse Education Today*, 27, 225-237.
- WOLFE, I., THOMSON, M., GILL, P., TAMBURLINI, G., BLAIR, M., VAN DEN BRUEL, A., EHRICH, J., PETTOELLO-MANTOVANI, M., JANSON, S., KRANANIKOLOS, M. & MCKEE, M. 2013. Health Services for Children in Western Europe. *Lancet*, 6, 1224-1234.

- WOLFE, I., LIGNOU, S., SATHERLEY, R. October 2017. Referral – Discharge Interface (Unpublished Work). MOCHA Project.
- WORLD HEALTH ORGANIZATION. 2007. Conceptual framework for the international classification of patient safety: Version 1.0 for use in field testing. Geneva, Switzerland: World Health Organization.
- WORLD HEALTH ORGANIZATION 2008. Primary Health Care: Now More Than Ever. Geneva, Switzerland: World Health Organization.
- WORLD HEALTH ORGANIZATION 2013. WHO nursing and midwifery progress report 2008–2012. Geneva, Switzerland: The World Health Organization.
- YIN, R. K. 2013. Case study research: design and methods. Los Angeles: SAGE Publications.

## Appendix 1. Glossary of Terms

TERM(S)	PROPOSED DEFINITION
<b>ACUTE CARE</b>	Acute care refers to the secondary/tertiary care centre from which a child may be admitted or discharged to the community/primary care service. It includes “the health system components, or care delivery platforms, used to treat sudden, often unexpected, urgent or emergent episodes of injury and illness that can lead to death or disability without rapid intervention. The term <i>acute care</i> encompasses a range of clinical health-care functions, including emergency medicine, trauma care, pre-hospital emergency care, acute care surgery, critical care, urgent care and short-term inpatient stabilization” (Hirshon et al., 2013).
<b>ACTIVITY DIAGRAM</b>	A diagram that shows the decomposition of an activity into its constituents (Rumbaugh et al., 2005)
<b>BUSINESS MODEL</b>	An abstract representation of an organization, be it conceptual, textual, and/or graphical, describing a set of strategic choices and alternatives to support an organization to create, deliver and capture different forms of value according to its purpose, goals, plans, processes, resources and rules (Errikson and Penker, 2000).
<b>BUSINESS PROCESS</b>	A collection of activities designed to produce a specific output for a particular customer or market (Sparks, 2000)
<b>CARE COORDINATION</b>	Care coordination may be defined as the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care (McDonald et al., 2007, Schultz and McDonald, 2014).

<b>CARE PATHWAY</b>	<p>A care pathway is a complex intervention for the mutual decision making and organization of care processes for a well-defined group of patients during a well-defined period. Defining characteristics of care pathways include:</p> <ul style="list-style-type: none"> <li>(i) An explicit statement of the goals and key elements of care based on evidence, best practice, and patients' expectations and their characteristics;</li> <li>(ii) the facilitation of the communication among the team members and with patients and families;</li> <li>(iii) the coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, patients and their relatives;</li> <li>(iv) the documentation, monitoring, and evaluation of variances and outcomes; and (v) the identification of the appropriate resources. The aim of a care pathway is to enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources (Vanhaecht et al., 2007, Panella and Vanhaecht, 2010).</li> </ul>
<b>CHILD</b>	A child refers to anyone under the age of 18 years old (United Nations General Assembly, 1989).
<b>CHILD PROTECTION/SAFE GUARDING</b>	Child protection/safe guarding refers to methods aimed at preventing and responding to violence, exploitation and abuse of children (UNICEF, 2006).
<b>CHRONIC ILLNESS</b>	Long term condition that can be treated but not cured (Health Service Executive, Ireland, 2008)
<b>CLASS DIAGRAM</b>	A diagram that shows a collection of declarative (static) model elements, such as classes, types, and their contents and relationships (Rumbaugh et al., 2005)
<b>CLINICAL CARE</b>	Clinical care is confined to diseases and symptomatic therapeutics, which involve medical remedies and treatments. As these days patients are discharged home earlier in the course of recovery, the

	<p>need for continuing clinical/medical care has escalated. Most people who are homebound under a physician's plan of treatment, and have an unstable acute or chronic illness require care and services that respond to their clinical care demands. A philosophy that guides the practice of health professionals in meeting clinical care demands is community-based health care. Clinical care demands in community health may include:</p> <ul style="list-style-type: none"> <li>• delegated medical treatment and observation</li> <li>• – symptom management</li> <li>• – wound care</li> <li>• – surveillance and referrals/follow up for acute and critical illnesses</li> <li>• – tube feeding, etc. (WHO Regional Office for South East Asia, 2010).</li> </ul>
<b>CLINICAL PATHWAY</b>	A standardized plan of care against which progress towards health is measured. A clinical pathway is applied based upon the results of a patient assessment. A clinical pathway shows exact timing of all key patient care activities intended to achieve expected standard outcomes within designated time frames. A clinical pathway includes documentation of problems, expected outcomes/goals, and clinical interventions/orders (Cohen et al., 2011, Elias and Murphy, 2012).
<b>COMPLEX CLINICAL CARE NEEDS</b>	Children with complex clinical care needs have substantial care needs as a result of one or more congenital, acquired or chronic conditions, with need of access to multiple health and social support services. These children may have functional limitations that often required tailored technological assistance (Cohen et al., 2011, Elias and Murphy, 2012). In the context of this WP technology includes therapeutic interventions, which may be orientated to communication within a mental health setting or the use of clinical care appliances and aids.
<b>COMPLEX HEALTH STATUS REQUIRING SOCIAL CARE</b>	Complex health status requiring social care support: This refers to the support and care required by children (and their families) with complex health needs that enables them to have an 'ordinary life' (Merchant et al., 2007). This includes supports that facilitates children to live at home in a safe environment, go to school, make friends and take part in community and leisure activities. For parents of children with complex health needs, social care services may prepare parents for an enhanced caring role, provide

	assistance with breaks from caring, and emotional and financial support.
<b>COLLABORATION DIAGRAM</b>	A diagram that shows interactions organized around the structure of a model, using either classifiers and associations or instances and links. Unlike a sequence diagram, a collaboration diagram (Rumbaugh et al., 2005)
<b>COMPONENT DIAGRAM</b>	A diagram that shows the organizations and dependencies among components (Rumbaugh et al., 2005).
<b>COMMUNITY CARE</b>	Community care is defined as 'the blend of health and social services provided to an individual or family in his/her place of residence for the purpose of promoting, maintaining or restoring health or minimizing the effects of illness and disability'(WHO, 2004)
<b>CONGENITAL MALFORMATION</b>	Congenital anomalies are also known as birth defects, congenital disorders or congenital malformations. Congenital anomalies can be defined as structural or functional anomalies (e.g. metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth or later in life (WHO, 2016)
<b>CONTINUITY OF CARE</b>	Continuity of care component of patient care quality consisting of the degree to which the care needed by a patient is coordinated among practitioners and across organizations and time (ISO/TR 18307:2001)
<b>COMMUNITY-BASED NURSING</b>	Community-based nursing covers nursing care provided to individuals, families and groups wherever they live, work, play or go to school. Community-based nursing is a philosophy of care that is characterized by collaboration, continuity of care, client and family responsibility for self-care, and preventive health care (Hunt, 2005). Community-based nursing focuses on an individual and is family-centred in orientation. Partnerships with clients are developed and awareness created on the influences of the community on the health and care of individuals and families. Community-based nursing applies to all nurses who practice

	<p>outside the hospital. Major activities include case management, patient education, individual and family advocacy, and an interdisciplinary approach (Zotti et al., 1996). According to this definition, community-based nursing is not a specialty in nursing but a philosophy that guides care, design and delivery of all nursing specialties (WHO Regional Office for South East Asia, 2010).</p>
<b>COMMUNITY HEALTH NURSING</b>	<p>Community health nursing is synonymous with public health nursing. Community health nursing relies heavily on the systematic process of designing and delivering health services and nursing care to improve the health of the entire community.</p> <p>Community health nursing is a specialty in nursing. According to the American Nursing Association (ANA), public health nursing is the practice of promoting and protecting the health of populations using knowledge from nursing, social and public health sciences (Waldorf, 1999). The primary goal of community health nursing is to help a community protect and preserve the health of its members, while the secondary goal is to promote self-care among individuals and families. In the health-care reform environment, the community health nurse will probably continue to care for individuals and families, particularly high-risk clients and those with communicable diseases. Community health nursing involves the identification of high-risk aggregates in the community, and the development of appropriate and workable policies and interventions to ensure accessible services for all groups of the population (WHO Regional Office for South East Asia 2010).</p>
<b>COMMUNITY NURSES KNOWLEDGE AND SKILLS REQUIRED</b>	<p>Knowledge and many diverse skills are required for community health nurses to function effectively. These are primarily related to each of the two core competencies. Clinical content incorporates knowledge from the nursing sciences and public health science, while practical knowledge relies on work experiences in the actual practice of community health nursing. Furthermore, knowledge from other community health allies is required. To gain all the knowledge required, contents and resources for learning, both as texts and from experts, must be mapped out to lay down the architecture of the courses (WHO Regional Office for South East Asia, 2010).</p>
<b>COMPETENCIES OF NURSES WORKING IN</b>	<p>At least two sets of competencies – core competencies and the complementary competencies – are required to practice community health nursing. There are two core competencies; the</p>

<b>THE COMMUNITY HEALTH-CARE</b>	core competencies for clinical care, and the core competencies for implementing the four functions of community health care. Competencies for clinical care range from health assessment, disease management, case finding, case management, observation and treatment according to delegated responsibility, etc. Competencies for the four functions rely heavily on the means and methods employed to implement each function. Complementary competencies may include cultural sensitivity, participatory research, leadership, development of tools and guidelines for data collection and analysis, and experiential learning through action. Competency mapping is crucial for designing both the theory and practice aspects of community health nursing courses (WHO Regional Office for South East Asia, 2010).
<b>CONTACT</b>	Healthcare activity period during which a subject of care interacts, directly or indirectly, with one or more healthcare professionals (ISO 13940:2015)
<b>EPISODE OF CARE</b>	Time interval during which healthcare activities are performed to address one health issue and as identified and labelled by one healthcare professional (ISO 13940:2015)
<b>FAMILY MEDICINE (FM) OR PRIMARY CARE TEAMS</b>	Family medicine (FM) or primary care teams can vary between countries and in size: the core team usually is the general practitioner and a nurse, but can comprise a multidisciplinary team of up to 30 professionals including community nurses, midwives, dentists, physiotherapists, social workers, psychiatrists, speech therapists, dieticians, pharmacists, administrative staff and managers. In 2003, WHO defined a primary care team as a group of "fellow professionals with complementary contributions to make in patient care". This would be part of a broader social trend away from deference and hierarchy and towards mutual respect and shared responsibility and cooperation". By definition primary care/family medicine teams are patient centred, so their composition and organizational model can change over time (WHO website). Available at: <a href="http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology">http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology</a>
<b>FOSTER CARE</b>	Foster care is where children are placed by a competent authority for the purpose of alternative care in the domestic environment of

	a family other than the children's own immediate family that has been selected, qualified, approved and supervised for providing such care (United Nations, 2009).
<b>GENERAL PRACTICE</b>	General practice is a term now often used loosely to cover the general practitioner and other personnel, and is therefore synonymous with primary care and family medicine. Originally, it was meant to describe the concept and model around the most significant single player in primary care: the general practitioner or primary care physician, while family medicine originally encompassed the notion of a team approach. Whenever the concept of solo practitioner (general practice) versus team-based approach (family medicine) is relevant, the distinction is still made (and important). The specificity of the general practitioner is that he/she is: "the only clinician who operates at the nine levels of care: prevention, pre-symptomatic detection of disease, early diagnosis, diagnosis of established disease, management of disease, management of disease complications, rehabilitation, palliative care and counselling" (Atun, 2004).
<b>HEALTH CARE</b>	Health care represents diverse direct health services and care provided to individuals, families and groups, by the community health centre or similar facility. Examples of health-care demands include the following: <ul style="list-style-type: none"> <li>• day-to-day basic medical care for common ailments</li> <li>• health assessment and outreach/case finding</li> <li>• screening and surveillance for both communicable diseases such as tuberculosis (TB), HIV, dengue haemorrhagic fever (DHF), influenza; and non-communicable diseases such as hypertension, diabetes mellitus, cardiovascular diseases, etc.</li> <li>• immunization for vaccine-preventable diseases for all age groups including pregnant women and children</li> <li>• medication management for persons with chronic and stable illnesses <ul style="list-style-type: none"> <li>• – disease investigations</li> <li>• chronic disease management</li> <li>• health education</li> <li>• health counselling/family counselling</li> </ul> </li> <li>• interventions for family planning and birth spacing, etc (WHO Regional Office for South East Asia 2010).</li> </ul>

<b>HEALTH CARE ACTIVITY</b>	Activity performed for a subject of care with the intention of directly or indirectly improving or maintaining the health state of that subject of care (ISO 13940:2015)
<b>HEALTH CARE ACTIVITY PERIOD</b>	Continuous period of time during which healthcare activities are performed for a subject of care (ISO 13940:2015)
<b>HEALTH CARE ACTOR</b>	Organization or person participating in healthcare (ISO 13940:2015)
<b>HEALTH CARE PROFESSIONAL</b>	Healthcare personnel having a healthcare professional entitlement recognized in a given jurisdiction(ISO 13940:2001)
<b>HEALTH CARE PROVIDER</b>	Healthcare actor participating in the direct provision of healthcare (ISO 13940:2015)
<b>HEALTH CARE ORGANISATION</b>	Organisation whose healthcare personnel participate in the direct provision of healthcare(ISO 13940:2015)
<b>HEALTH CARE THIRD PARTY</b>	Healthcare actor other than a healthcare provider or the subject of care (ISO 13940:2015)
<b>HEALTH ISSUE</b>	Issue related to the health of a subject of care, as identified and labelled by a specific healthcare actor(ISO 13940:2015)
<b>INITIAL CONTACT</b>	Contact that establishes a clinical process (ISO 13940:2015)
<b>INTEGRATED CARE</b>	Integrated care refers to the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system (WHO, 2015b, WHO., 2015a)

<b>INTERACTION DIAGRAM</b>	A generic term that applies to several types of diagrams that emphasize object interactions. These include collaboration diagrams and sequence diagrams (Rumbaugh et al., 2005).
<b>MODEL</b>	A system of assumptions, concepts and relationships between them allowing to describe (model) in an approximate way a specific aspect of reality. Standard glossary of terms used in Requirements Engineering. Available at: <a href="http://reqb.org/docs/REQB_Standard_glossary_of_terms_used_in_Requirements_Engineering.pdf">http://reqb.org/docs/REQB_Standard_glossary_of_terms_used_in_Requirements_Engineering.pdf</a>
<b>MODELLING LANGUAGE</b>	Any artificial language that can be used to express information or knowledge or systems in a structure that is defined by a consistent set of rules. Standard glossary of terms used in Requirements Engineering. Available at: <a href="http://reqb.org/docs/REQB_Standard_glossary_of_terms_used_in_Requirements_Engineering.pdf">http://reqb.org/docs/REQB_Standard_glossary_of_terms_used_in_Requirements_Engineering.pdf</a>
<b>NON-CONTACT PERIOD</b>	Healthcare activity period without the involvement of the subject of care (ISO 13940: 2015)
<b>NURSING</b>	Nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles.  Nurses include professional nurses, enrolled nurses, auxiliary nurses and other nurses such as dental or primary care nurses (International Council of Nurses). Available at <a href="http://www.icn.ch/who-we-are/icn-definition-of-nursing/">http://www.icn.ch/who-we-are/icn-definition-of-nursing/</a>
<b>OBJECT DIAGRAM</b>	A diagram that encompasses objects and their relationships at a point in time. An object diagram may be considered a special case

	<p>of a class diagram or a collaboration diagram. See: <i>class diagram</i>, <i>collaboration diagram</i> (Rumbaugh et al., 2005).</p>
<b>PRIMARY HEALTH CARE</b>	Primary Health Care is generally defined as first-contact, accessible, continued, comprehensive and coordinated healthcare provided by a single practitioner (GP/nurse practitioner) or a multidisciplinary team of professionals in a community practice (WHO, 2008, Davy et al., 2015)
<b>PRIMARY HEALTH CARE</b>	Primary health care (PHC) refers to the concept elaborated in the 1978 Declaration of Alma-Ata, which is based on the principles of equity, participation, inter-sectoral action, appropriate technology and a central role played by the health system (World et al.) <a href="http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology">http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology</a> accessed 13.11.2015
<b>PROCESS</b>	A set of interrelated activities, which transform inputs into outputs [ISO/IEC 12207: 2008].
<b>PUBLIC HEALTH NURSING</b>	<p>Public health nursing is the practice of promoting and protecting the health of populations using knowledge from nursing, social, and public health sciences. Public health nursing is a specialty practice within nursing and public health. It focuses on improving population health by emphasizing prevention, and attending to multiple determinants of health. Often used interchangeably with community health nursing, this nursing practice includes advocacy, policy development, and planning, which addresses issues of social justice. With a multi-level view of health, public health nursing action occurs through community applications of theory, evidence, and a commitment to health equity. In addition to what is put forward in this definition, public health nursing practice is guided by the American Nurses Association <i>Public Health Nursing: Scope &amp; Standards of Practice</i> 2 and the Quad Council of Public Health Nursing Organizations' <i>Core Competencies for Public Health Nurses</i> (American Public Health Association., 2013)</p> <p><a href="http://apha.org/~media/files/pdf/membergroups/nursingdefinition.ashx">http://apha.org/~media/files/pdf/membergroups/nursingdefinition.ashx</a> accessed 13.11.2015</p>

<p><b>PUBLIC HEALTH NURSING EDUCATION</b></p>	<p>The baccalaureate degree in nursing (BSN) is recommended for entry-level public health nurses.<sup>26</sup> <i>The Essentials of Baccalaureate Education for Professional Nursing Practice</i> emphasize fundamental concepts for public health nursing practice such as clinical prevention, population health, healthcare policy, finance, and regulatory environments, and inter-professional collaboration.<sup>27</sup> The graduate is prepared to conduct community assessments and apply the principles of epidemiology among other competencies. (American Public Health Association, 2013)</p> <p><a href="http://apha.org/~media/files/pdf/membergroups/nursingdefinition.ashx">http://apha.org/~media/files/pdf/membergroups/nursingdefinition.ashx</a> accessed 13.11.2015</p>
<p><b>RESIDENTIAL/INSTITUTIONALISED CARE</b></p>	<p>Residential/institutional care is defined as provided in any non-family-based group setting, such as places of safety for emergency care, transit centres in emergency situations, and all other short and long-term residential care facilities, including group homes (United Nations, 2009).</p>
<p><b>RESPITE CARE</b></p>	<p>Respite care is provided by appropriately trained individual(s) for a specified period of time for older people, children with complex needs, or individuals with disabilities, thus providing a break from caregiving to the usual caregiver usually a parent or family member. Respite care may refer to very different types of interventions providing temporary ease from the burden of care for parents, families and informal care givers. The most common forms of respite care include: day-care services; in-home respite; and institutional respite (Francesca et al., 2011).</p>
<p><b>SCENARIO</b></p>	<ul style="list-style-type: none"> <li>• A projected course of action, events or situations leading to specified result.</li> <li>• An ordered sequence of interactions between specified entities (e.g. a system and an actor).</li> <li>• In UML: an execution trace of a use case (International et al.) Standard glossary of terms used in Requirements Engineering. Available at: <a href="http://reqb.org/docs/REQB_Standard_glossary_of_terms_used_in_Requirements_Engineering.pdf">http://reqb.org/docs/REQB_Standard_glossary_of_terms_used_in_Requirements_Engineering.pdf</a></li> <li>• A specific sequence of actions that illustrates behaviours. A scenario may be used to illustrate an interaction or the execution of a use case instance (Rumbaugh et al., 2005)</li> </ul>

<b>SELF-CARE PERIOD</b>	Healthcare activity period where prescribed self-care is performed (ISO 13940: 2015)
<b>SEQUENCE DIAGRAM</b>	A diagram that shows object interactions arranged in time sequence. In particular, it shows the objects participating in the interaction and the sequence of messages exchanged. Unlike a collaboration diagram, a sequence diagram includes time sequences but does not include object relationships. A sequence diagram can exist in a generic form (describes all possible scenarios) and in an instance form (describes one actual scenario). Sequence diagrams and collaboration diagrams express similar information, but show it in different ways. See: <i>collaboration diagram</i> (Rumbaugh et al., 2005).
<b>SOCIAL CARE</b>	Social care is generally referred to as the care provided for any person of any age who need extra support in some of his/her daily activities (Law and Commission, 2011, WHO, 2004). Social care needs arise when an individual's well-being, ability to live independently, or safety is compromised.
<b>SOCIAL CARE</b>	Social care services encompass <i>personal or targeted</i> support for individuals with specific needs, such as home help, respite care, carer income benefits and allowances, counselling, housing support, disability benefits, family support such as parenting advice, and child protection and welfare services including foster and residential care (Department of Health England, 2012). These services can be provided directly by the state, voluntary bodies, or for profit organisations.
<b>SOCIAL WORK</b>	Social work is "an intervention designed to enhance an individual's physical, mental and social functioning through improved coping skills and use of social supports and community health care services. Those who practise social work are generally called social workers. There are many different types, specialties and grades of social worker" (WHO., 2004).
<b>STORYBOARD</b>	A narrative of relevant events defined using interaction diagrams or use cases. The storyboard provides one set of interactions that the modelling committee expects will typically occur in the domain. (Health Level Seven, 2011) Available at:

	<p><a href="https://www.hl7.org/documentcenter/public_temp_00A09967-1C23-BA17-0C5D93D093BBA31B/calendarofevents/FirstTime/Glossary%20of%20terms.pdf">https://www.hl7.org/documentcenter/public_temp_00A09967-1C23-BA17-0C5D93D093BBA31B/calendarofevents/FirstTime/Glossary%20of%20terms.pdf</a></p>
<b>STAKEHOLDER</b>	<p>Any person who has an interest in an IT project. Project stakeholders are individuals and organizations that are actively involved in the project, or whose interests may be affected as a result of project execution or project completion. Stakeholders can exercise control over both the immediate system operational characteristics, as well as over long-term system lifecycle considerations (such as portability, lifecycle costs, environmental considerations, and decommissioning of the system). Standard Glossary of Terms used in Requirements Engineering. Available at: <a href="http://reqb.org/docs/REQB Standard glossary of terms used in Requirements Engineering.pdf">http://reqb.org/docs/REQB Standard glossary of terms used in Requirements Engineering.pdf</a></p>
<b>STATECHART DIAGRAM</b>	<p>A diagram that shows a state machine (Rumbaugh et al., 2005).</p>
<b>SUBJECT OF CARE</b>	<p>Person seeking to receive, receiving, or having received healthcare (ISO 13940: 2015)</p>
<b>TRIGGER EVENT</b>	<p>Trigger event the event that initiates an exchange of messages is called a trigger event. The HL7 Standard is written from the assumption that an event in the real world of health care creates the need for data to flow among systems. The real-world event is called the trigger event. For example, the trigger event "a patient is admitted" may cause the need for data about that patient to be sent to a number of other systems. There is a one-to-many relationship between message types and trigger event codes. The same trigger event code may not be associated with more than one message type. (Health Level Seven, 2011) Available at: <a href="https://www.hl7.org/documentcenter/public_temp_00A09967-1C23-BA17-0C5D93D093BBA31B/calendarofevents/FirstTime/Glossary%20of%20terms.pdf">https://www.hl7.org/documentcenter/public_temp_00A09967-1C23-BA17-0C5D93D093BBA31B/calendarofevents/FirstTime/Glossary%20of%20terms.pdf</a></p>
<b>USE CASE DIAGRAM</b>	<p>A diagram that shows the relationships among actors and use cases within a system (Rumbaugh et al., 2005).</p>

<b>UNIFIED MODELLING LANGUAGE</b>	A standardized general-purpose modelling language in the field of software engineering. UML includes a set of graphic notation techniques to create visual models of software-intensive systems like use case diagrams, activity diagrams, class diagrams and many more ISO/IEC 19501:2005.
<b>UNIVERSAL SOCIAL SERVICES</b>	Universal social services refers to services such as transport, leisure, health and education that should be available to everyone. These are distinct from social care services as they are not dependent on assessment or eligibility. (Adapted from Think Local Act Personal (TLAP) Care and Support Jargon Buster: <a href="https://www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster/">https://www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster/</a> )

## References

- AMERICAN PUBLIC HEALTH ASSOCIATION PUBLIC HEALTH NURSING SECTION. 2013. The definition and practice of public health nursing: A statement of the public health nursing section. Washington DC: USA.
- ATUN, R. 2004. What are the advantages and disadvantages of restructuring a health care system to be more focused on primary care services? *Health Evidence Network Report*. Copenhagen: Denmark: World Health Organisation Regional Office for Europe.
- COHEN, E., KUO, D., AGRAWAL, R., BERRY, J., BHAGAT, S., TD, S. & R, S. 2011. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*, 127.
- DAVY, C., BLEASEL, J., HUEIMING, L., TCHAN, M., PONNIAH, S. & BROWN, A. 2015. Effectiveness of chronic care models: opportunities for improving healthcare practice and health outcomes: A systematic review. *BMC Health Services Research*, 15.
- DEPARTMENT OF HEALTH, ENGLAND. 2012. Caring for our future: reforming care and support. In: Department of Health: England.
- ELIAS, E. & MURPHY, N. 2012. Home care of children and youth with complex health care needs and technology dependancies. *Pediatrics*, 996-1005.
- ERRIKSON, H. E. & PENKER, M. 2000. Business modeling with uml : business patterns at work. New York: John Wiley & Sons.
- FRANCESCA, C., ANA, L.-N., JEROME, M. & FRITS, T. 2011. OECD Health Policy Studies Help Wanted? Providing and Paying for Long-term Care.
- HEALTH SERVICE EXECUTIVE, IRELAND. 2008. The Health Service Executive 4.1 Chronic Illness Framework. Dublin, Ireland. Available at: [https://www.hse.ie/eng/About/Who/Population\\_Health/Population\\_Health\\_Approach /Population\\_Health\\_Chronic\\_illness\\_Framework\\_July\\_2008.pdf](https://www.hse.ie/eng/About/Who/Population_Health/Population_Health_Approach /Population_Health_Chronic_illness_Framework_July_2008.pdf).
- HEALTH LEVEL SEVEN INTERNATIONAL. 2011 (last update April 2017). HL7 Glossary of Terms. Michigan, USA: Health Level Seven International.
- HIRSHON, J., RISKO, N., CALVELLO, E., RAMIREZ, S., NARAYAN, M., THEODOSIS, C. & O'NEILL, J. 2013. Health Systems and Services: The Role of Acute Care. *Bulletin of the World Health Organisation*, 91, 386-388.
- HUNT, R. 2005. Introduction to Community-based and public health nursing. Philadelphia, USA: Lippincott, Williams and Wilkins.

- INTERNATIONAL COUNCIL OF NURSES. Definition of Nursing [Online]. Available: [www.icn.ch/who-we-are/icn-definition-of-nursing/](http://www.icn.ch/who-we-are/icn-definition-of-nursing/) [Accessed 15th November 2015].
- INTERNATIONAL REQUIREMENTS ENGINEERING BOARD. Standard Glossary of Terms Used in Requirements Engineering [Online]. Available: [http://reqb.org/docs/REQB\\_Standard\\_glossary\\_of\\_terms\\_used\\_in\\_Requirements\\_Engineering.pdf](http://reqb.org/docs/REQB_Standard_glossary_of_terms_used_in_Requirements_Engineering.pdf)
- INTERNATIONAL ORGANIZATION OF STANDARDIZATION. 2001. Interoperability and compatibility in messaging and communication standards - Key characteristics. *Health informatics*. Geneva: International Organization for Standardization.
- INTERNATIONAL ORGANIZATION OF STANDARDIZATION / INTERNATIONAL ELECTROTECHNICAL COMMISSION. 2008. Software life cycle processes. Systems and Software engineering. Geneva: International Organization for Standardization
- INTERNATIONAL ORGANIZATION OF STANDARDIZATION. 2015. System of concepts to support continuity of care *Health Informatics*. Geneva: International Organization for Standardization.
- INTERNATIONAL ORGANIZATION OF STANDARDIZATION & INTERNATIONAL ELECTROTECHNICAL COMMISSION. 2005. Open Distributed Processing - Unified Modeling Lanuage (UML) Version 1.4.2. *Information Technology*. Geneva: International Organization for Standardization.
- LAW COMMISSION. 2011. Adult Social Care. London: England: The Law Commission.
- MCDONALD, K. M., SUNDARAM, V., BRAVATA, D. M., LEWIS, R., LIN, N., KRAFT, S. A., MCKINNON, M., PAGUNTALAN, M. S. & OWENS, D. K. 2007. Closing the quality gap: A critical analysis of quality improvement stratigies. In: KG, S., KM, M., RM, W. & DK, O. (eds.) *Technical review 9*. Rockville, MD: Agency for Healthcare Research and Quality.
- MERCHANT, R., LEFERVE, M., JONES, M. & LUCKOCK, B. 2007. Necessary stuff: The Social Care Needs of Children with Complex Care Needs and Their Families. London: The Social Care Institute for Excellance.
- PANELLA, M. & VANHAECHT, K. 2010. Is there still need for confusion about pathways. *International Journal of Care Pathways*, 14, 1-3.
- RUMBAUGH, J., JACOBSON, I. & BOOCH, G. 2005. The Unified Modeling Language Reference Manual. UK: Pearson Higher Education.
- SCHULTZ, E. M. & MCDONALD, K. M. 2014. What is care coordination? *International Journal of Care Coordination*, 17, 5-24.
- SPARKS, G. 2000. An introduction to modelling software systems using the Unified Modelling Language: The business process model. [Online]. Enterprise Architect. Available: [https://www.oasis-open.org/committees/download.php/3040/The\\_Business\\_Process\\_Model.pdf](https://www.oasis-open.org/committees/download.php/3040/The_Business_Process_Model.pdf)
- THINK LOCAL ACT PERSONAL Care and Support Jargon Buster [Online]. Available: <https://www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster/>.
- UNICEF 2006. Child Protection Information Sheet: What is Child Protection. UNICEF.
- UNITED NATIONS 2009. Guidelines for the Aternative Care of Children. NY: United Nations.
- UNITED NATIONS GENERAL ASSEMBLY. 1989. Convention on the Rights of the Child. United Nations.
- VANHAECHT, K., DE WITTE, K. & SERMEUS, W. 2007. The impact of clinical pathways on the organisation of care processes. PhD, Katholieke Universiteit Leuven.
- WALDORF, M. D. 1999. Scope and standards of public health nursing practice. American Nurses Association.
- WORLD HEALTH ORGANIZATION. 2004. A Glossary of terms for community health care and services for older persons. Geneva: World Health Organisation.
- WORLD HEALTH ORGANISATION, 2008. Primary Health Care - Now More than Ever. Geneva: World Health Organisation.
- WORLD HEALTH ORGANIZATION. 2015a. People-centred and integrated health services: An overview of the evidence - Interim Report. Geneva: World Health Organisation.

- WORLD HEALTH ORGANIZATION. 2015b. WHO Global strategy on people-centred and integrated health service - Interim Report. Geneva: World Health Organisation.
- WORLD HEALTH ORGANIZATION. 2016. Congenital abnormalities [Online]. Available: [www.who.int/mediacentre/factsheets/fs370/en](http://www.who.int/mediacentre/factsheets/fs370/en).
- WORLD HEALTH ORGANIZATION REGIONAL OFFICE FOR SOUTH EAST ASIA. 2010. A framework for community health nursing education. New Delhi: India.
- WORLD HEALTH ORGANIZATION REGIONAL OFFICE FOR EUROPE. Main terminology (Primary Health Care) [Online]. Available: [www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology](http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology) [Accessed 13th November 2015].
- ZOTTI, M., BROWN, P. & STOTTS, R. 1996. Community-based nursing versus community health nursing: What does it all mean. *Nursing Outlook*, 44, 211-217.

## **Appendix 2 DIPEX Methodology**

The specific objective of the work of DIPEX International within the MOCHA project is to provide insight into the experiences of children and parents in terms of primary health care for children and the primary/secondary care interface. The DIPEX study sits within the wider work of Work Package 1 (Identification of models of children's primary health care) and Work Package 2 (Interface with secondary, social and complex care). Qualitative researchers from five different countries that are part of the DIPEX International network worked collaboratively to explore patients' experiences in their respective countries across Europe: Czech Republic, Germany, The Netherlands, Spain and United Kingdom.

In the DIPEX study, the qualitative research methodology (the DIPEX-methodology) developed by the Health Experiences Research Group (HERG) of the University of Oxford was used. This methodology includes narrative and semi-structured interviews (Ziebland & Herxheimer, 2008). The relatively unstructured, open-ended nature of the interview method helps to identify participants' own concerns, meanings and priorities rather than being led by a highly focused research interest.

### ***Participants***

We focused on the experiences of children as well as parents. Children were eligible for inclusion if they were aged 10-18. Parents were eligible for inclusion if they had at least one child under 18. Participants were recruited using maximum variation sampling, which involves including a broad range of experiences and demographic characteristics (Coyne, 1997; Marshall, 1996). We aimed to identify and include the widest range of experiences of children and parents in terms of primary care services for children, rather than to identify the numerical distribution that exists in the wider population. Participants were recruited through a number of different sources including GPs, hospitals, mental and social health care organisations, newspaper adverts, charities, patient associations, rehabilitation centres, schools, snowballing, social media and word of mouth.

In this study, we focused on the experiences of "healthy" children, children with (complex) mental health conditions, and children with (complex) physical health conditions and their parents. A "healthy" child refers to the well-child, i.e., children with no or only occasional minor conditions and without any (complex) physical or mental health condition. We also included children with complex health conditions and their parents as their experiences of primary care services may differ from those of "healthy" children and their parents. Bearing in mind the complex health conditions relevant to Work Package 2 of the MOCHA project, we included children with ADHD, Traumatic Brain Injury (TBI), and epilepsy.

In total, 84 children participated in the study, of which 35 were considered "healthy". Twenty-nine children had ADHD as well as, sometimes, other conditions such as depression and/or autism and 20 had TBI or epilepsy. The majority of participants were boys (58%). Children varied in age between 10 and 18 years. The mean age of all children participating in the study was 14.8 years ( $SD=2.0$ ). Of the children with a complex physical health condition, 25% had a brain injury (traumatic or acquired) and 75% had epilepsy.

We included 88 parents in the study. Thirty-four had a “healthy” child, 30 had a child with ADHD or another mental health condition, and 24 had a child with either a brain injury or epilepsy or another physical health condition. Predominantly, mothers participated in the study as 82% of participants were female.

### ***Data collection***

Data collection consisted of in-depth interviews, focus groups and a secondary analysis of interviews conducted in earlier studies in one of the five countries. In total, 80 in-depth interviews were conducted and 9 focus groups with a total of 52 participants. Furthermore, 40 interviews were used in a secondary analysis.

All interviews were in-depth narratives, conducted with a view to eliciting experiences of primary care services for children. The first part of the interview consisted of a narrative, which allowed participants to talk about their experiences, perspectives and concerns in their own way, unprompted (Riessman, 2008). In the second part of the interview, a semi-structured interviewing approach was adopted to explore some topics that had not been discussed and other topics in more detail. All interviews were audio- or video-recorded with participants’ consent. When interviewing children, alternative methods were sometimes used to elicit data in addition to “normal” conversation. This was particularly the case if a child seemed to have little to say or remembered very little about their experiences. For example, pictures showing fairly typical health care scenes were shown to a child in order to start a conversation with the child, or a child was asked about their views on several statements about primary health care services. Occasionally children were asked to write a letter to their GP or health minister about what they liked and disliked about their appointment with the GP or the surgery.

Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data (Kitzinger, 1995). The group process can help people explore and clarify their views in a way that would be less easily accessible in a one-to-one interview. In total, 9 focus groups were conducted, 5 with children and 4 with parents. A total of 26 children and 26 parents participated in these group discussions. Each focus group consisted of two to nine participants. The focus groups covered a list of topics, formulated using a semi-structured interview guide which was developed by the research team.

In addition to the in-depth interviews and focus groups with children and parents, a secondary analysis of pre-existing narrative interviews was conducted.

### ***Analysis***

All interviews were fully transcribed verbatim. When analysing the interviews, a qualitative interpretative approach was taken. The research team held monthly Skype meetings throughout the recruitment, data collection and analysis phases. Four face-to-face workshops were also held. Interviews and focus group discussions were analysed for themes that structured participants’ experiences using a thematic analysis combined with constant comparison (Glaser and Strauss, 1967; Green and Thorogood, 2014; Pope et al., 2000). All five researchers agreed on the coding frame, based on topics covered in the interview guide and emergent themes, and conducted a separate thematic analysis of their own data. The results of these analyses were compared and checked for differences and similarities and discussed during a face-to-face

workshop. Extracts from the interviews, translated by each country researcher, are used to illustrate the results.

### **References**

- COYNE, I.T. 1997. Sampling in qualitative research. Purposeful and theoretical sampling: merging or clear boundaries? *Journal of Advanced Nursing*, 26, 623-630.
- GLASER, B.G. & STRAUSS, A.L. 1967. The discovery of grounded theory: strategies for qualitative research. Chicago: Aldine.
- GREEEN J & THOROGOOD N.(2014) *Qualitative methods for health research*. Sage Publications Ltd London.
- KITZINGER, J. 1995. Qualitative research: Introducing focus groups. *British Medical Journal*, 311, 299-302.
- MARSHALL, M.N. 1996. Sampling for qualitative research. *Family Practice*, 13, 522-525.
- POPE C., ZIEBLAND Z., & MAYS N. 2000. Qualitative research in health care. Analysing qualitative data. *British Medical Journal* 320(7227), 114-116.
- RIESSMAN, C.K. 2008. Narrative methods for the human sciences. Thousand Oaks, CA: Sage.
- ZIEBLAND, S. & HERXHEIMER, A. 2008. How patients experiences contribute to decision making: illustrations from DIPEx (personal experiences of health and illness). *Journal of Nursing Management*, 16, 433-439.

### **Appendix 3 List of Child-Related Search Terms**

- Child
- Paediatric
- Pediatric
- Newborn
- New-born
- Infant (*note: use the word “infan” instead of infant as it cannot bring the word infancy*)
- School
- Adolescent (*note: use the word “adolescen” instead of adolescent as it cannot bring the word adolescence*)
- Teenager
- Youth
- Young
- All ages (*note: only with the use of the word “ages” it will bring words related to “all ages”*)

## **Appendix 4 Definition of Type of Modules**

- **Compulsory core modules:**

In this study, the term compulsory core modules has been used to denote those modules with a total focus on children care, and that are compulsory for all the students of the general nursing programme. It for example includes modules such as *Paediatric Nursing* or *Nursing a Child*.

- **Child care mentioned within the context of other compulsory modules:**

This term denotes those modules that not have a total focus on children care, but that include any child-related search terms (Appendix 3) in their content description. These modules are focused on other areas of study, such as *Community Nursing* or *Mental Health Care*. These are also compulsory for all the students of the general nursing programme.

- **Elective modules:**

The term elective modules is utilised to name those modules with a total focus on children care, and that are optional within the curricula. This means that not all the students of the general nursing programme will be accessing these modules, if not only the proportion of students that have chosen them. It for example includes modules such as *Nursing Care of School Children* or *Paediatric Nursing in Intensive Care Units*.

- **Children mentioned within the context of other elective modules:**

This term denotes those modules that not have a total focus on children care, but that include any child-related search terms (Appendix 3) in their content description. These are also optional within the curricula, and are focused on other areas of study such as *Emergency Nursing* or *Oncology Nursing*.

## **Appendix 5 Quantification of Child-Related Search Terms**

<b>Country</b>	<b>Total words in the document</b>	<b>Total times child-related search terms have been mentioned</b>
Croatia	11506	97
Cyprus	7688	13
Estonia	5858	29
Finland	9582	23
France	15092	13
Greece	4503	25
Iceland	15319	85
Ireland	12532	12
Italy	17195	53
Latvia	30835	75
Lithuania	25060	76
Malta	16727	21
Norway	7325	8
Poland	44198	148
Portugal	50247	198
Romania	61783	77
Spain	48449	88