



Models of Child Health Appraised
(A Study of Primary Healthcare in 30 European countries)

**Work Package 2:
Final Report on the Current
Approach to Managing
the Care of Children with Complex
Care Needs in Member States**

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Final Report on the Current Approach to Managing the Care of Children with Complex Care Needs in Member States

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Contents

Contents	2
Abbreviations	7
Executive Summary	8
Introduction	11
Chapter 1 Background	12
1.1 Introduction	12
1.2 Background	12
1.3 Aim and objectives	12
1.4 Conceptual framework	12
1.5 Design	13
1.6 Conclusion	17
Chapter 2 Management of an Adolescent with a Traumatic Brain Injury at the Acute Community Interface	18
2.1 Introduction	18
2.2 Structure and processes of care for adolescents with a TBI	18
2.3 Summary of key results in the management of care for an adolescent with a TBI	28
2.4 Identification of facilitators and barriers of the optimum integration of care at the primary and secondary care interface	28
2.5 Summary of optimum integration of care at the acute community interface for an adolescent with a TBI	32
Chapter 3 Management of a Child on Long-term Ventilation at the Acute Community Interface	34
3.1 Introduction	34
3.2 Structures and processes of the care in place for a child on LTV	34
3.3 Summary of key results in the management of care of a child on LTV	45
3.4 Identification of the facilitators and barriers of optimum integration of care at the primary and secondary care interface for a child on LTV	49
3.5 Summary of optimum integration of care at the acute community interface for a child on LTV	56
Chapter 4 Management of a Child with Intractable Epilepsy at the Acute Community Interface	57
4.1 Introduction	57
4.2 Structures and processes of care in place for a child with intractable epilepsy	57
4.3 Summary of key results in the management of care of a child with intractable epilepsy	69



4.4	Identification of facilitators and barriers of the optimum integration of care at the primary and secondary care interface for children with intractable epilepsy.	69
4.5	Summary of optimum integration of care at the acute community interface for a child with intractable epilepsy.	77
Chapter 5	Discussion and Conclusions	78
5.1	Introduction	78
5.2	Key themes emerging on the integration of care for children with complex care needs	78
5.3	Limitations	84
5.4	Conclusion	84
References		85
Appendix 1	Glossary of terms	87
Appendix 2	Acknowledgement of contributions	97
Appendix 3	MOCHA Country Agent Questions – Long-term ventilation	105
Appendix 4	MOCHA Country Agent Questions – Traumatic Brain Injury	124
Appendix 5	MOCHA Country Agent Questions – Intractable Epilepsy	136

Figures

Chapter 2

2.1	Presence / absence of systems to identify healthcare providers caring for adolescents with a TBI	19
2.2	Provision of transport for adolescents with a TBI to accommodate daily activities and healthcare visits	19
2.3	Proportion of countries with policies and/or procedures in place to support the provision of linguistically appropriate and culturally appropriate written information to the families of adolescents with a TBI	20
2.4	Proportion of countries with policies and/or procedures in place promoting care coordination for adolescents with a TBI	21
2.5	Presence / absence of a Discharge Planning Coordinator in paediatric departments / hospitals	21
2.6	Individuals consulted regarding the development of a personalised care plan for an adolescent with a TBI	22
2.7	Health assessments included in the personalised care plan for adolescents with a TBI	23
2.8	Access to psychological support from professionals with expertise in paediatric and adolescent mental health	23
2.9	Proportion of countries where adolescents with a TBI (when cognition allows) and/or their parents/guardians are invited to participate in the development of policies and procedures affecting them and/or their children	24
2.10	The inclusion of parental and guardian opinion in national quality improvement initiatives related to the care of adolescents with a TBI	25



2.11	Inclusion of parents and guardians in the review of written information	25
2.12	Presence or absence of policies and/or procedures relating to the preparation of adolescents with a TBI and their families for the transition from paediatric to adult healthcare services	26
2.13	Preparation of care plans with adult healthcare services prior to the transferal of adolescents with a TBI from paediatric to adult healthcare services	26
2.14	Proportion of countries that collect data from adolescents with a TBI, and their parents/guardians, regarding their experience of the transition from paediatric to adult healthcare services	27
2.15	The proportion of countries with and without quality assurance policies and/or procedures for service providers caring for adolescents with a TBI	28
2.16	The proportion of countries where data are collected from adolescents with a TBI and their parents/guardians on the experience of care	28
2.17	Factors influencing integration of care following a TBI	29
2.18	Emergence of global theme 'adolescent specific care'	31
2.19	Emergence of global theme legal, policy and governance structure	32

Chapter 3

3.1	Proportion of countries with policies and/or procedures in place to support the provision of preventative care screening and developmental checks to children on LTV	34
3.2	Proportion of counties with policies and/or procedures in place to document and communicate the results of screening or developmental checks for children on LTV to all care services	34
3.3	Proportion of countries with policies and/or procedures in place to document and communicate the results of screening or developmental checks for children on LTV to their parents/guardians	35
3.4	Countries with and without systems in place to identify all healthcare providers caring for children on LTV	36
3.5	Provision of transport to accommodate the daily activities and healthcare visits of children on LTV	36
3.6	Proportion countries with policies and/or procedure in place to support the provision of linguistically and / or culturally appropriate information to the families of children on LTV	37
3.7	Proportion of countries with policies and / or procedure in place promoting care coordination for children on LTV	38
3.8	Individuals consulted during the development of personalised care plans for children on LTV in participating countries	38
3.9	Health assessments included in the personalised care plans of children on LTV in participating countries	39
3.10	Presence or absence of a Discharge Planning Coordinator in paediatric departments / hospitals	40
3.11	Presence or absence of a process that facilitates direct access to and/or from the Paediatric Intensive Care Unit (PICU) for children on LTV	40
3.12	Presence or absence of paediatric palliative care and end of life policies	41



3.13	Access to psychological support from professionals with paediatric expertise for parents/guardians and siblings of children on LTV	41
3.14	Countries where parents /guardians of children on LTV are invited/ not invited to participate in the development of policies or procedures affecting their children	42
3.15	Proportion of countries with / without quality assurance policies and /or procedures for service providers caring for children on LTV	43
3.16	Proportion of countries that collect data on the care experience of children on LTV from the perspective of their parents/guardians and siblings	43
3.17	High-level UML activity diagram for LTV	45
3.18	Factors influencing integration of care for a child on LTV	49
3.19	Emergence of global theme 'family preparedness for transitioning to home'	50
3.20	Emergence of global theme coordinated pathway to specialist care	52
3.21	Emergence of global theme legal, policy and governance structures	55

Chapter 4

4.1	Countries with/without national or regional guidance to assist local primary care centres with the care of children with intractable epilepsy.	57
4.2	Proportion of countries with policies and/or procedures in place, which support preventative care screenings and developmental checks for children with intractable epilepsy.	57
4.3	Proportion of countries with policies and/or procedures in place to document and communicate the results of screening or developmental checks for children with intractable epilepsy to all care services.	58
4.4	Proportion of countries with policies and/or procedures in place to document and communicate the results of screening or developmental checks to the parents/ guardians of children with intractable epilepsy.	58
4.5	Countries with/without systems in place to identify all healthcare providers caring for children with intractable epilepsy.	59
4.6	Proportional responsibility for the provision of transport to accommodate the daily activities and healthcare visits of children with intractable epilepsy.	60
4.7	Proportion of countries with policies and/or procedure that support the provision of linguistically appropriate and/or culturally appropriate information to the families of children with intractable epilepsy.	60
4.8	Proportion of countries with policies and/or procedures in place promoting care coordination for children with intractable epilepsy.	61
4.9	Individuals consulted regarding the development of a personalised care plan for a child with intractable epilepsy.	62
4.10	Types of health assessments included in the personalised care plan for children with intractable epilepsy in participating countries.	63
4.11	The involvement of family advocacy groups in making recommendations to home and community based services for children with intractable epilepsy.	64



4.12	Access to psychological support from professionals with paediatric expertise for parents/guardians and siblings of children with intractable epilepsy.	64
4.13	The inclusion of parents/guardians of children with intractable epilepsy in the development of policies and procedures affecting their children.	65
4.14	The inclusion of parental and guardian opinion in national quality improvement initiatives related to the care of children with intractable epilepsy.	66
4.15	The inclusion of parents and guardians of children with intractable epilepsy in the review of information material.	66
4.16	Participating countries with/without quality assurance policies and /or procedures for service providers caring for children with intractable epilepsy	67
4.17	Proportion of participating countries that collect data on the care experience of children with intractable epilepsy from the perspective of their parents/guardians and siblings.	68
4.18	Global themes in context for intractable epilepsy.	69
4.19	Emergence of global theme 'Transitions in care'	71
4.20	Emergence of global theme 'Communication'	73
4.21	Emergence of the global theme 'Care coordination and support'	76

Chapter 5

5.1	Mapping key findings from thematic analysis across exemplars	79
5.2	Potential determinants of specific care needs of each group of children and their families	83

Tables 1.1	Vignette for traumatic brain injury	14
1.2	Vignette for long term ventilation	14
1.3	Vignette for intractable epilepsy	15
1.4	Domains for exploration for each exemplar condition	16
5.1	Mapping key findings of structures and processes across exemplar conditions	77



Abbreviations

AC	Access to Care
BT	Basic Themes
CAs	Country Agents
CBS	Community-Based Services
CC	Care Coordination
EAB	External Advisory Board
ED	Emergency Department
EEA	European Economic Area
EU	European Union
FPP	Family-Professional Partnerships
GT	Global Themes
LTV	Long-Term Ventilation
NGO	Non-Governmental Organisation
OT	Organising Themes
PED	Paediatric Emergency Department
PICU	Paediatric Intensive Care Unit
QA	Quality Assurance
SAR	Screening, Assessment and Referral
TAS	Transitioning to Adult Services
TBI	Traumatic Brain Injury
UML	Unified Modelling Language
WHO	World Health Organisation



Executive Summary

Background

The United Nations Convention on the Rights of the Child (to which all EU and 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 are surviving into adulthood. By their very nature, children with complex care needs, and their families, place great challenges on healthcare delivery in the community. Although a relatively small proportion of the population, the cost of healthcare and support services for this group is very high; figures from the United States show that children with complex health needs account for as much as one-third of healthcare spending for all children. 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 provide an account of the current approach to the management of care of children with complex healthcare needs in 30 European countries and what this means for primary care service delivery. The specific objectives during this period were to: identify 'in-principle' complex health issues that would be representative of population trends across childhood; adapt measurement tools to gather data on systems of care for children with complex healthcare needs; explore the structures and processes of care in place for children with complex healthcare needs; identify those which are part of primary care services; and identify facilitators and barriers of optimum integration of care at the acute community interface for children with complex healthcare needs. Mechanisms to support the structure and processes of integration of care were explored using vignettes, across three exemplar conditions, traumatic brain injury (TBI), long-term ventilation (LTV) and intractable epilepsy. The survey, applied to 30 EU/EEA countries using a local agent, was adapted from the Standards for Systems of Care for Children and Youth with Special Health Care Needs, and the European Survey of Change.

Main Findings

Traumatic brain injury

- The majority of countries have no systems in place to identify all healthcare providers care for adolescents following a TBI.
- There is limited support for the provision of linguistically appropriate or culturally appropriate information on TBI.
- There is limited inclusion of the young person in the planning of their care.
- There is limited engagement of family advocacy groups.
- There is a significant absence of policies and procedures to support transition to adult services.
- The majority of countries report availability of psychological support for adolescents and their families.

Facilitators and barriers of the optimum integration of care following a TBI in an adolescent:

- Seeking and incorporating the voice of the adolescent where possible in care planning.
- Specific sibling support.
- Information for parents on caring for an adolescent following a TBI.
- Care delivery in units equipped to meet the specific needs of adolescents.
- Specialist emergency transport and specialist trauma care.
- Cross-border specialist healthcare initiatives.
- Timely pathway to skilled rehab care.
- Access to respite care.
- Established pathway for transitioning to adult care.



Long-term ventilation

- Less than half of responding countries have policies and procedures in place to support the preventative screening assessment and referral of children on LTV for developmental checks.
- The majority of countries have mechanisms in place which can identify all of the healthcare providers caring for children on LTV.
- There is limited support for the provision of linguistically appropriate or culturally appropriate information.
- Consultation with both parents/guardians and healthcare professionals occurs in the development of personalised care plans in the majority of countries.
- Just over half of the responding countries have discharge planning coordinators.
- There is limited engagement of family advocacy groups.
- The majority of countries do not collect data on the experience of care from the perspective of the parents/guardians or siblings of children on LTV.

Facilitators and barriers of the optimum integration of care for a child on LTV:

- Tailored education programmes to support clinical readiness of parents.
- Phased step-down plan where parents increase input into clinical care prior to discharge.
- Pathways for access to specialist care including access to a PICU and PED 24/7, access to a physician 24/7 and a pathway for accessing respite care.
- Complex care centres which serve as a 'one-stop-shop' for health and social care services.
- Addressing geographical variability in ability to access community care when a child is on LTV.
- Enhanced governance of care delivery in the home.
- Enhanced education of nursing and care staff to care for children on LTV.
- National standards for the care of children on LTV.
- Establishment of national registry of children on LTV.
- Shared documentation to enhance care coordination and integration.
- Official disability status.
- Ongoing NGO advocacy role.

Intractable epilepsy

- There are limited mechanisms in place to support preventative care screening and developmental checks, and to communicate the results of such screening.
- Few countries have a system in place to identify all of the healthcare providers who care for children with intractable epilepsy.
- There is widely reported involvement of family advocacy groups in the development of care plans and in the provision of recommendations to community-based services.
- There are limited mechanisms in place to support care coordination.
- There is widely reported availability of psychological support for parents/guardians and siblings.
- The majority of countries do not collect data on the experience of care from the perspective of the parents/guardians or siblings of children with intractable epilepsy.

Facilitators and barriers of the optimum integration of care for a child with intractable epilepsy:

- Access to a range of clinical diagnostic tests.
- Learning from adult-focused policy development.
- Addressing geographical variability in ability to access community care.
- Enhanced IT support.



- High impact QA measure.
- Enhanced education of healthcare professionals and the general public.
- Community support groups.
- Greater support for parents in care coordination.
- Establishment of greater link roles and advanced nursing practice.
- Enhancing individualised care planning.
- Ongoing voluntary sector support.

Conclusion

Some similar issues emerged across all three exemplar conditions examined, including parents as catalysts of optimum integration of care and pathways to specialist care. However, we would 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. While the links across findings from each area seem to be somewhat obvious, the variance in how they emerged suggests that the specific care needs of each cohort of these children are determined by 1) the dynamic of the specific complex care need and 2) the advancement of understanding of the needs of these children and adolescents. Our next report will therefore consider the socio-cultural context of our findings so as to identify feasible and relevant implications for care delivery across such a diverse group of member states. This work is ongoing and will be presented and discussed in the final report from Work Package 2 in November 2017. This will present the future vision of the care of children with complex care needs, situated within the context of key European and international research and policy documents, drawing on all of the constituents of the Work Package.



Introduction

This report builds on work completed in Work Package 1, with a specific emphasis on the current approach to managing the care of children with complex care needs at the acute community interface. This will allow the services provided to these children to be analysed and, ultimately, appraised, in terms of their relationship to primary care models. Children with complex care needs are defined as those with substantial care needs resulting from one or more congenital, acquired or chronic conditions, which require access to multiple health and social support services (1, 2). The report presents what is known regarding the structures and processes in place to support the management of care for such children at the acute community interface across the European Union (EU) and the European Economic Area (EEA), and presents facilitators for optimum integration of their care. The work presented in this report is conducted in parallel with ongoing work across Work Package 2, on a broad spectrum of interrelated areas of complex health and social care needs. This includes referral/discharge pathways, enduring mental healthcare issues, family experiences, and education and skill requirements to care for these children and their families. This report should, therefore, be read in conjunction with the findings emanating from each of these areas. A final report on the needs and future visions for the care of children with complex conditions will be provided later this year, drawing on all strands of work across Work Package 2. This will present key implications for practice, policy and research, in the context of the socio-economic landscape of the participating countries.

This work was made possible by the contribution of a large number of experts in child health. We would like to acknowledge the input and support of our MOCHA colleagues Prof Mitch Blair, Prof Michael Rigby, Dr Denise Alexander and Ms Christine Chow, the MOCHA Country Agents (CAs) and members of the External Advisory Board (EAB). We would also like to acknowledge the input of Dr Ed Schor and colleagues at the Lucille Packard Foundation for Children's Health, Prof Carlos Centeno-Cortes, the Paediatric Nurses Association of Europe, the European Association of Palliative Care, the European Association of Children in Hospital, the European Patients' Forum Youth Group, and child health colleagues across the EU who provided data to the CAs to make this work possible.



Chapter 1

Background

1.1 Introduction

This chapter presents the background to our examination of the structures and processes that are in place across the EU/EEA to support the management of children with complex care needs and their families. The aim and objectives of this part of the MOCHA project are presented with detail on the methods used to gather and analyse the data. The findings are then presented in the subsequent chapters followed by a discussion of the key themes and details of the next phase of our work.

1.2 Background

The United Nations Convention on the Rights of the Child (to which all EU and EEA countries are signatories) defines the highest attainable standard of healthcare as a fundamental right of every child (3). Improvements in neonatal and paediatric care mean that more children with complex care needs are surviving into adulthood. By their very nature, children with complex care needs, and their families, place great challenges on healthcare delivery in the community (4). While a relatively small proportion of the population, the cost of healthcare and support services for this group is very high; figures from the United States show that children with complex health needs account for as much as one-third of healthcare spending for all children (5). Although the provision of care closer to home for such children is a policy objective internationally (6), integration of health services is insufficient with wide variation in systems of care for these children internationally. The World Health Organisation (WHO) defines integrated care as *“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”* (7). Integrated care may be described in a variety of ways and can occur at different settings and levels of the health service (8). Horizontal integration refers to the coordination of activities across different functioning units and / or organisations that are at the same stage in the delivery of service (e.g. multi-disciplinary teams). In contrast, vertical integration refers to the coordination of services across functioning units and / organisations that are at different hierarchical stages in service delivery (e.g. the integration of healthcare between primary and secondary care providers) (8). Longitudinal integration of care throughout childhood and adolescents is a pertinent issue, which will be explored within the wider context of the MOCHA project. At present, however, the progress towards achievement of care closer to home for children with complex health needs has been slow despite growing evidence that homecare: provides a means of mitigating the barriers and isolation children and their families experience during the transition from hospital to home, can significantly decrease hospital utilisation, and reduces the cost of care for children living with complex care needs (9, 10).

1.3 Aim and objectives

The aim of our work in this section of the MOCHA project was to provide an account of the current approach to the management of care of children with complex healthcare needs in 30 European countries and what this means for primary care service delivery. The specific objectives during this period were to:

- Identify ‘in-principle’ complex health issues that would be representative of population trends across childhood;



- adapt measurement tools to gather data on systems of care for children with complex healthcare needs;
- explore the structures and processes of care in place for children with complex healthcare needs, identifying those which are part of primary care services;
- identify facilitators and barriers of optimum integration of care at the acute community interface for children with complex healthcare needs.

1.4 Conceptual framework

Our work is based within a rights-based framework, in that it was informed by the work of the UN Convention on the Rights of the Child (3) and guided by the following principles: universality and inalienability; indivisibility; interdependence and interrelatedness; equity and non-discrimination; participation and inclusion; empowerment; accountability and respect for the rule of the law. Our work was also informed by a philosophy of family-centred care, which suggests that the care of a child is best delivered in consultation with the child and their family (10). The central tenet of this philosophy of care is that optimum care of a child is achieved through a partnership approach with the child's family. In theory, this recognises the uniqueness of each family and builds on their strengths. However, it is widely acknowledged that policy makers often omit meaningful reference to family engagement and healthcare professionals often struggle to achieve family centred care in practice (11). The framework chosen reflected these underpinnings, while capturing the key constituents for successful integration of care for a child with complex health needs (12), identifying the interface of care as a two-way dynamic process influenced by socio-political, legal and governance issues.

1.5 Design

This is the first time that the issue of complex healthcare needs in children has been examined across the EU/EEA. The challenge, therefore, was to develop a research approach that would be robust to gather foundation data across 30 European states on an area about which little is written. The methods used were influenced by the current move to use both quantitative and qualitative approaches in the exploration of structures and processes of care provision. This is a non-experimental descriptive study with a qualitative element; the decision to use a mixed-method approach was based on a pragmatic and pluralist approach, and was informed by discussion on post-positivism advocating a realist perspective on healthcare research (13).

1.5.1 Vignette and survey development

The criteria for selection of areas for study were steered by the following: consideration of previous work in this area including trends of presentation and findings on burden of care; completion of systematic and integrative reviews; exploring care at a variety of ages between infant and 18 years of age; and congruity with other ongoing work across the wider MOCHA project. Three vignettes were developed for children requiring integrated care for this part of the project, in each of the following areas: traumatic brain injury, long-term ventilation and intractable epilepsy. The decision on the specific areas to be explored was initially made by a team comprised of clinical and academic experts 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 External Advisory Board (EAB) to the project, which is comprised of members of European medical, paediatric and policy bodies, and civil society groups including a young person from the youth sub-group of the European Patients' Forum.



The survey consists of three sections - a vignette, questions adapted from the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (14) and the Complex Care European Survey of Change, adapted from the Eurobarometer Survey (15). The survey was applied in each of the 30 countries, using a local agent. It therefore needed to be clear, using terms and constructs which would be unambiguous, independent of any local structures, or practice styles or conventions.

Writing the vignettes

In the past vignettes were predominantly used in politics and marketing, however, they have recently been used for a variety of reasons in healthcare research including patient preferences in shared decision making (16) and practitioner assessments of parenting (17). This approach is also compatible with the innovations of Yin in using case studies in health services research (18). Guided by best practice in writing vignettes (19-21) the research team drew on their own clinical expertise, findings from previous studies exploring the coordination and integration of care for children with complex health needs, and an extensive search of the literature. This was to ensure that the vignettes would contain sufficient clinically relevant information on the setting, the participants, the problem and the interacting dimensions, to allow participants the clearest possible picture of the situation.

In writing the vignettes for use in 30 countries, we were mindful of the need for clarity in terminology, the need to present a setting that could be widely understood, and the optimum length of the vignettes. The issue of language was particularly important as the official language of the MOCHA project is English and there was no opportunity for translation and back translation within the project (the MOCHA CAs having been selected as being adequately fluent in scientific English as well as the country's indigenous language(s)). To address the issue of terminology we developed a glossary of terms to accompany each survey. This was part of an overall glossary of terms for the work package, which has been made available on the project website (Appendix 1). A choice had to be made regarding whether the vignette was to be a "snapshot" (a static situation) or represent a process with different stages (22). In keeping with best practice the vignettes were of a moderate length, no longer than one paragraph, and reflected a static situation, to avoid over-burden on the respondents (19, 23). The vignettes for traumatic brain injury (TBI), long-term ventilation (LTV) and intractable epilepsy are presented in Tables 1.1, 1.2 and 1.3.

Table 1.1 Vignette for 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.



Table 1.2 Vignette for 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.

Table 1.3 Vignette for 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.

Identification of survey instruments

An extensive review of the literature identified a number of potential instruments, however, the majority of these tools were focused very specifically on care coordination practices as opposed to seeking to explore the integration of care of children with complex care needs at the acute/community/primary interface. We therefore made the decision, with permission of the Lucile Packard Foundation, to adapt the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (14). These standards address the core components of the structure and process of an effective system of care for these children. They were initially derived from a comprehensive review of the literature, expert opinion, and case studies of standards currently in use across the United States of America, with input and guidance from a working group of stakeholders including; paediatric providers, health plans, children's hospitals, families/consumers, health services researchers, and others. There are 10 domains within these standards. The area of health information technology is addressed in Work Package 8 of MOCHA and the issue of eligibility to care and insurance and finance were particular to the American health system so they were not included. Table 1.4 lists the remaining domains, and identifies which areas were chosen to explore care across each of the three exemplar conditions:



Table 1.4 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 (15). In this survey the integration of care of children with complex care needs at the acute/community/primary interface is 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 complex care needs, questions on policy, and questions on the future of care delivery at the acute community interface to children with complex care needs in each country. The findings from this section of the survey will be presented later this year in the next report on the future vision for the care of children with complex healthcare needs.

1.5.2 Sample

The vignettes and surveys were sent to a 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 country agents, please see the MOCHA website <http://www.childhealthservicemodels.eu/partnerlisting/country-agents>).

1.5.3 Validity and reliability

Although face validity does not provide strong evidence of validity, it is a helpful means of encouraging participation in the study (23). 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; health care managers and discharge coordinators; a number of European patient advocacy groups including the European Association of Children in Hospital, the European Patient Forum Youth Group and 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 (24).

1.5.4 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. Attride-Stirling's



thematic analysis network (25) 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.

1.6 Conclusion

This chapter set out the background to our work on the management of care of children with complex care needs at the acute / community interface, with a comprehensive presentation of our approach to this aspect of the MOCHA project. The survey findings on the care of a child with the TBI, LTV and intractable epilepsy are presented in Chapters 2, 3 and 4.



Chapter 2

Management of an Adolescent with a Traumatic Brain Injury at the Acute Community Interface

2.1 Introduction

This chapter reports on the standards and processes in place for the management of an adolescent with a TBI at the acute community interface. A total of 23 surveys were returned from a possible 30 countries (76.6%). The first part of the chapter presents the descriptive analysis of the categorical data relating to responses obtained from the adapted *Standards for Systems of Care for Children and Youth with Special Health Care Needs*. This is followed by the findings of the thematic analysis which was undertaken of the free text data provided by each respondent, to identify facilitators and barriers to optimum integration of care at the acute community interface.

2.2 Structures and processes of care in place for adolescents with a TBI

The structures and processes of care for adolescents with a TBI were explored under six domains of the adapted *Standards for Systems of Care for Children and Youth with Special Health Care Needs*: access to care; care coordination; community-based services and supports; family-professional partnerships; transitioning from paediatric to adult healthcare services; and quality assurance.

2.2.1 Access to care

There are no systems in place to identify all healthcare providers caring for adolescents with a TBI in the majority of participating countries (60.9%, $n = 14$) (Figure 2.1). The State provides some assistance to parents/guardians with the daily transport requirements in nine countries (39.1%). In a further five countries (21.7%) the State and the healthcare providers offer some assistance to the parents/guardians of adolescents with a TBI with daily transport requirements (Figure 2.2).



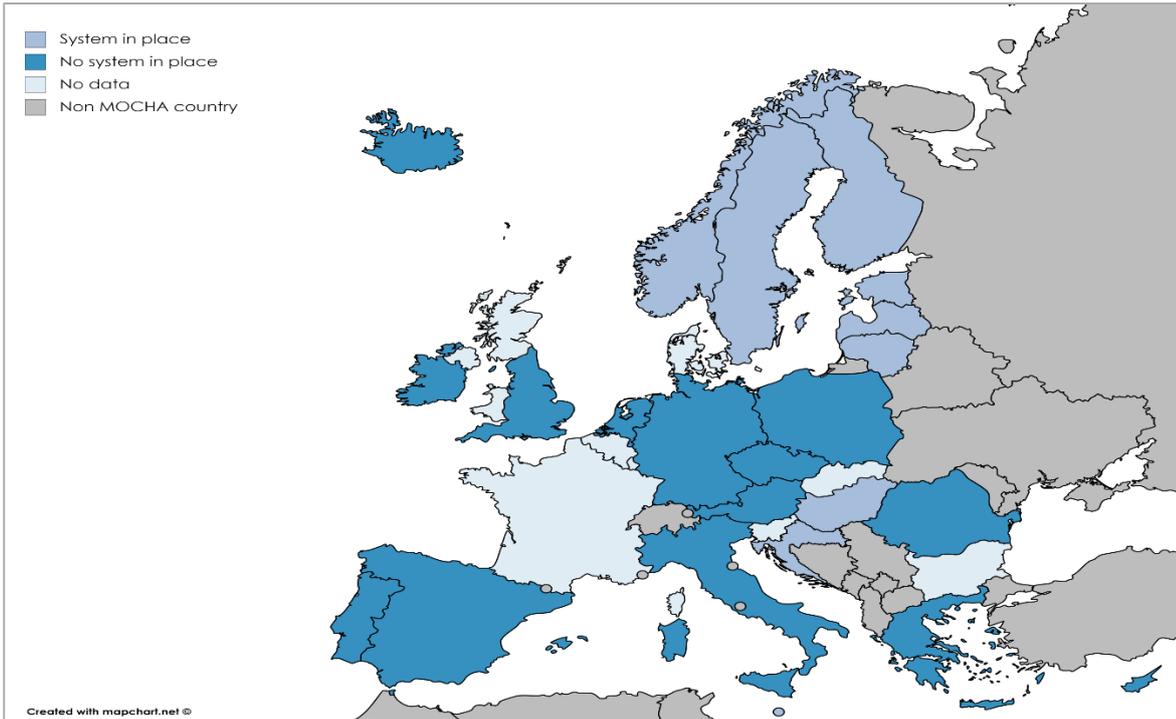


Figure 2.1 Presence / absence of systems to identify healthcare providers caring for adolescents with a TBI

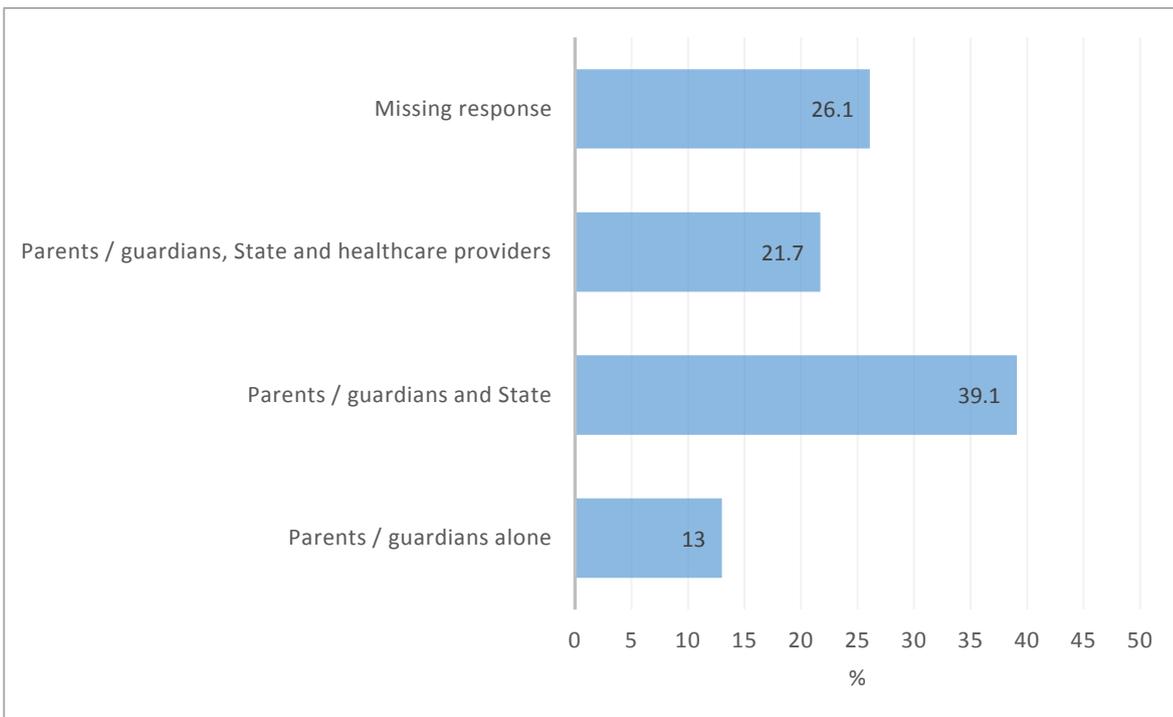


Figure 2.2 Provision of transport for adolescents with a TBI to accommodate daily activities and healthcare visits

Less than one-quarter of respondents (21.7%, $n = 5$) reported that their country has policies and procedures which support the provision of linguistically appropriate written information to the parents/ guardians of adolescents with TBI. Respondents from three countries (13%) reported that their countries have policies or procedures in place to support the provision of linguistically appropriate information (Figure 2.3). Two respondents (8.7%) reported that their countries have policies and procedures in place to support the provision of culturally appropriate information, while a further two respondents (8.7%) reported that there are policies but no procedures in place to support the provision of culturally appropriate care in their country (Figure 2.3).

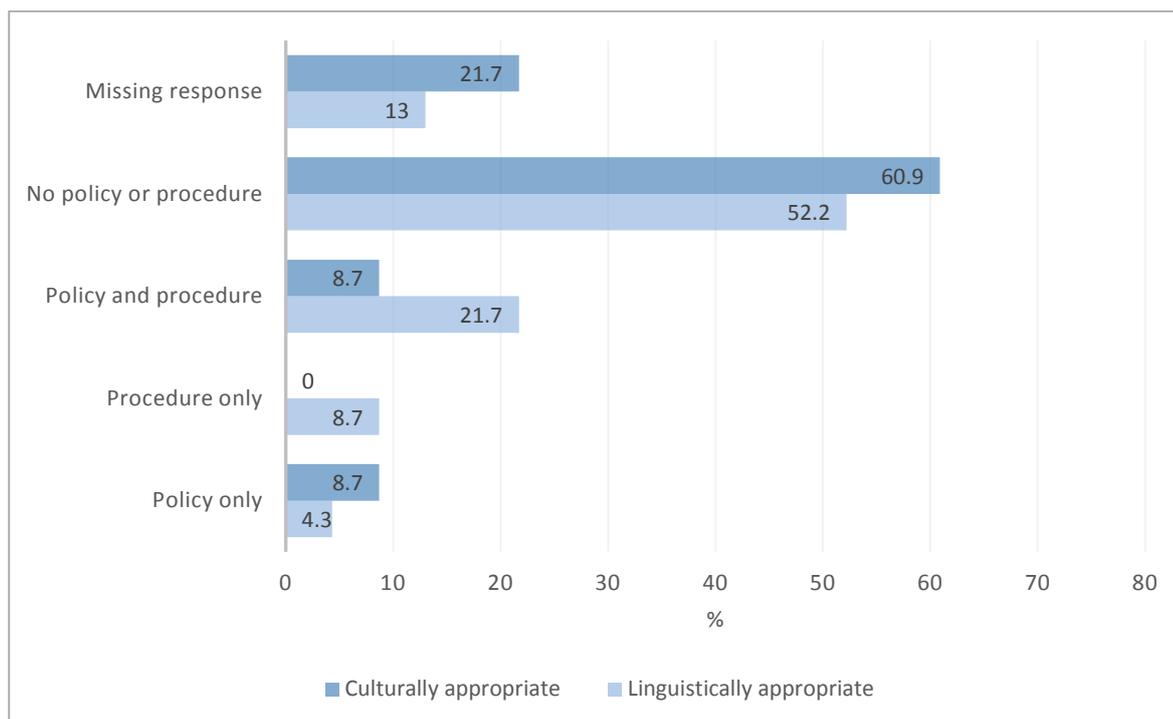


Figure 2.3 Proportion of countries with policies and/or procedures in place to support the provision of linguistically appropriate and culturally appropriate written information to the families of adolescents with a TBI

2.2.2 Care coordination

Less than one-quarter of countries (21.7%, $n = 5$) have policies and procedures in place that supports the coordination of care for adolescents with TBI. One respondent (4.3%) reported that their country has procedures but no policy in place to support care coordination (Figure 2.4). Nearly two-thirds of respondents (65.2%, $n = 15$) reported that the paediatric departments in large hospitals or specialised paediatric hospitals in their countries have a Discharge Planning Coordinator who is responsible for organising the transition of an adolescent with a TBI from the acute hospital environment to the community-based setting (Figure 2.5)

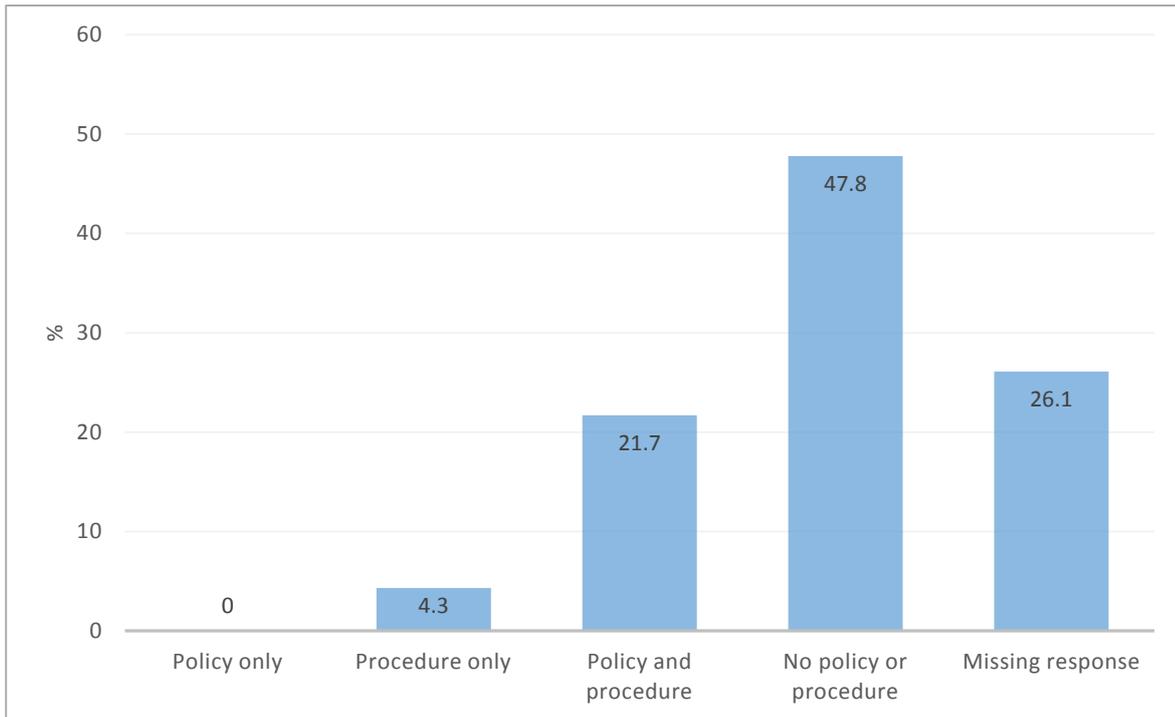


Figure 2.4 Proportion of countries with policies and/or procedures in place promoting care coordination for adolescents with a TBI

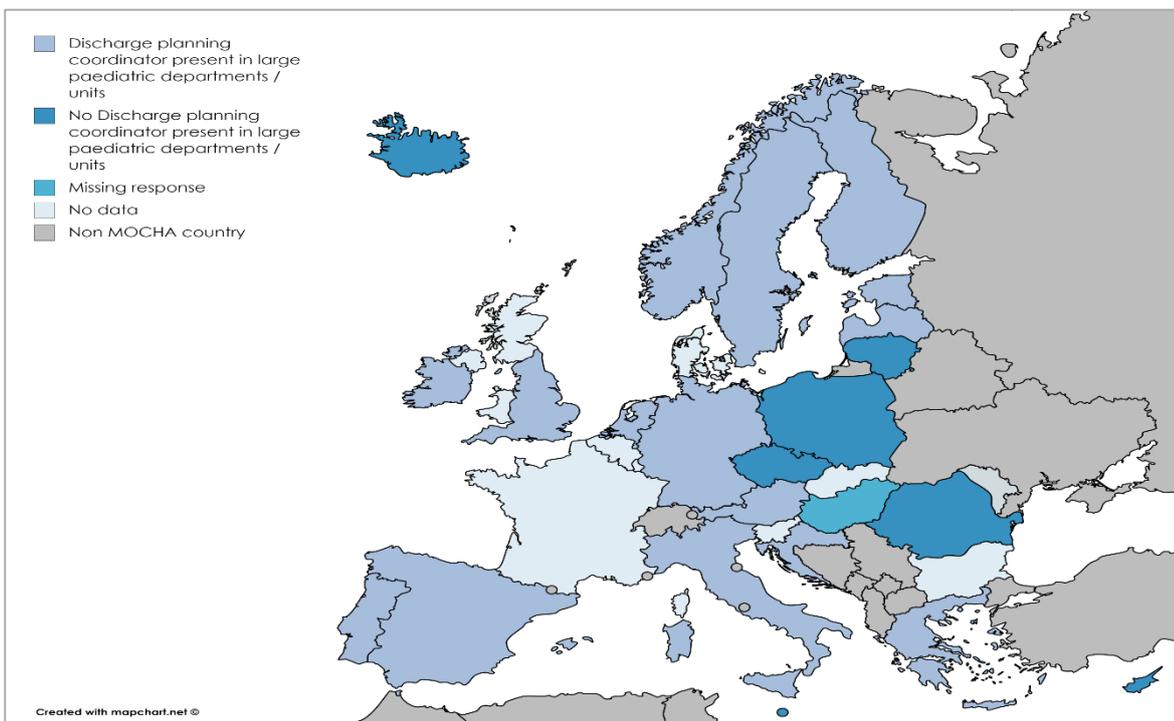


Figure 2.5 Presence / absence of a Discharge Planning Coordinator in paediatric departments / hospitals

Parents/guardians and members of the healthcare team are involved in the development of personalised care plans for adolescents with TBI in over half of the participating countries (52.2%, $n = 12$) (Figure 2.6). Where cognition allows, adolescents with a TBI are involved in the development of their personalised care plan in eleven countries (47.8%).

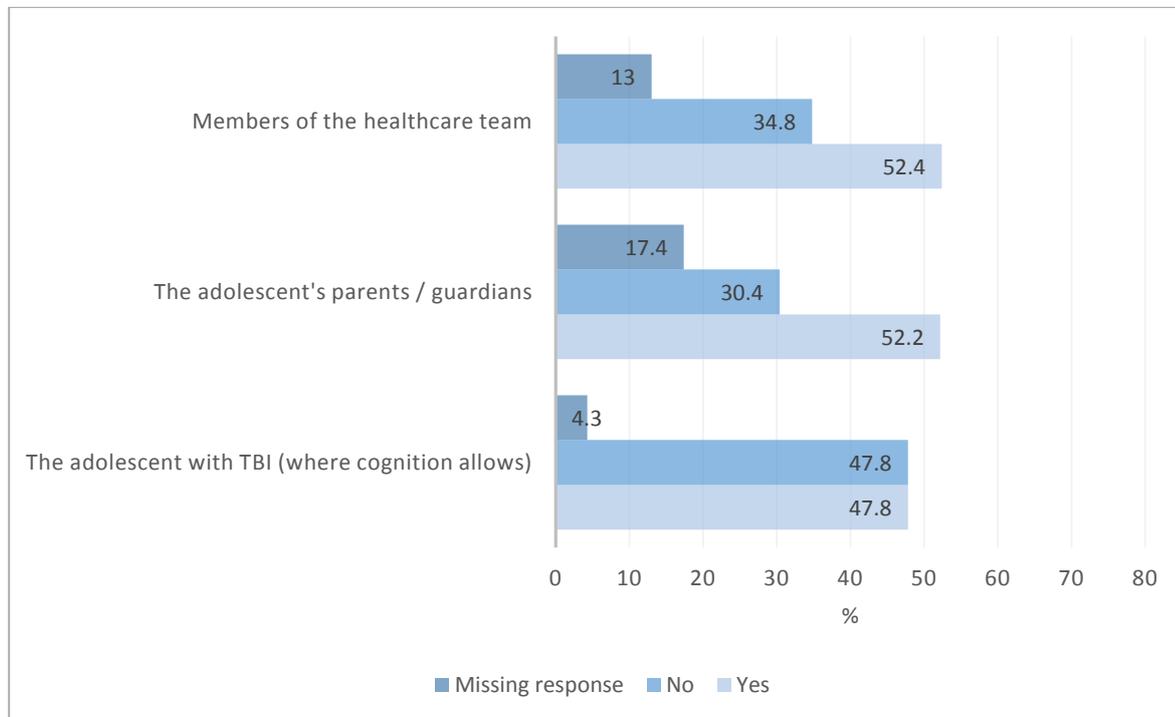


Figure 2.6 Individuals consulted regarding the development of a personalised care plan for an adolescent with a TBI

Developmental and mental health assessments are included in the personalised care plan for an adolescent with a TBI in almost two-thirds of participating countries (60.9%, $n = 14$) (Figure 2.7). In addition, respondents indicated that oral health assessments are included in the personalised care plans of adolescents with TBI in just under a half of participating countries (47.8%, $n = 11$). Vision and hearing assessments are integrated into the care plans of twelve (52.2%) and thirteen (56.5%) countries respectively. The respondents from four countries (17.4%) reported that a personalised care plan is not developed for adolescents with TBI in their country.

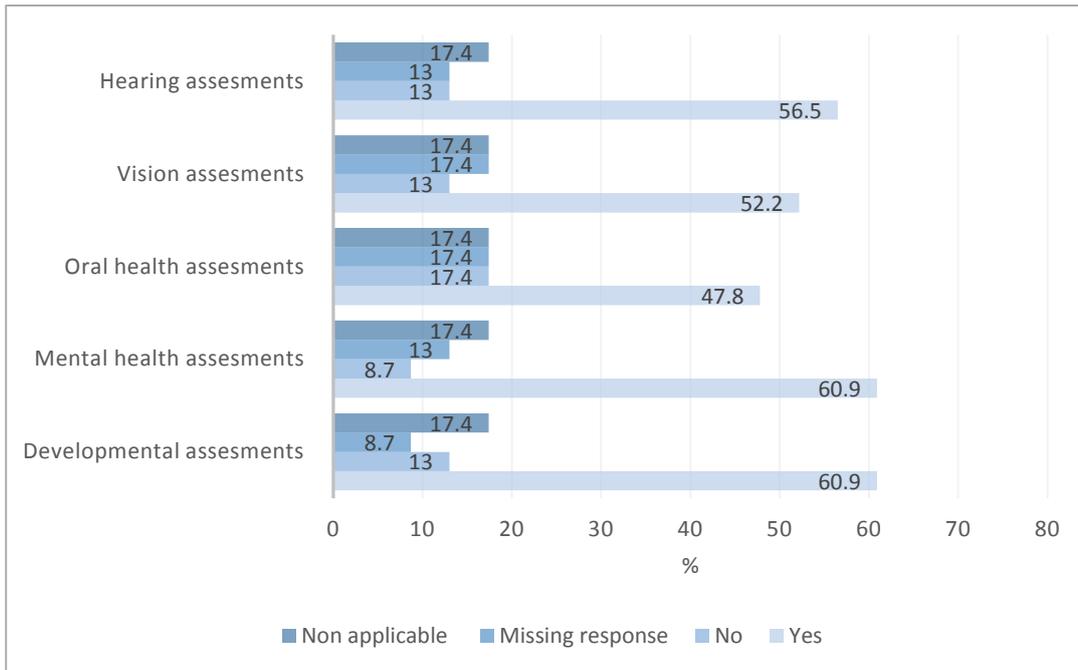


Figure 2.7 Health assessments included in the personalised care plan for adolescents with a TBI

2.2.3 Community-based services and support

Community-based services and supports refers to the structures that are in place to assist adolescents with TBI and their carers following their discharge from the acute hospital setting to the home/community environment. Community-based services may include, but are not limited to; patient advocacy or peer support groups, respite services, home nursing services and community-based health and allied health professionals. Family advocacy groups are involved in making recommendations to home and community-based TBI services in just over one-third (34.8%, $n = 8$) of countries. Adolescents with TBI have access to psychological support from professionals with expertise in paediatric and adolescent mental health in the majority of countries (87%, $n = 20$) (Figure 2.8).

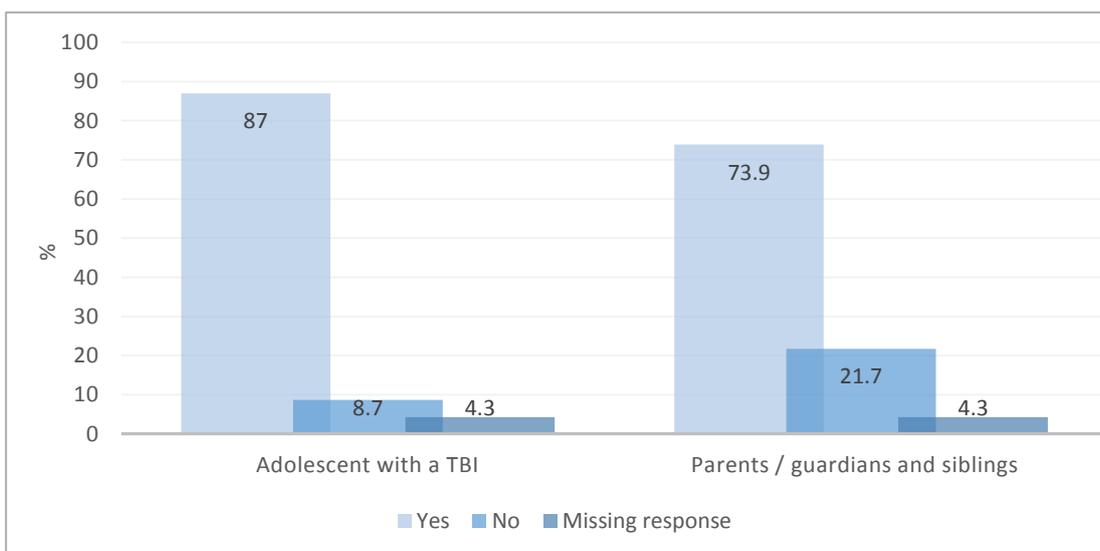


Figure 2.8 Access to psychological support from professionals with expertise in paediatric and adolescent mental health



2.2.4 Family-professional partnerships

Where cognition allows, adolescents with a TBI are invited to take part in the development of policies and procedures, which may affect them, in seven (30.4%) participating countries. The parents/guardians of adolescents with a TBI are invited to participate in the development of policies and procedures affecting their children in nine (39.1%) countries (Figure 2.9).

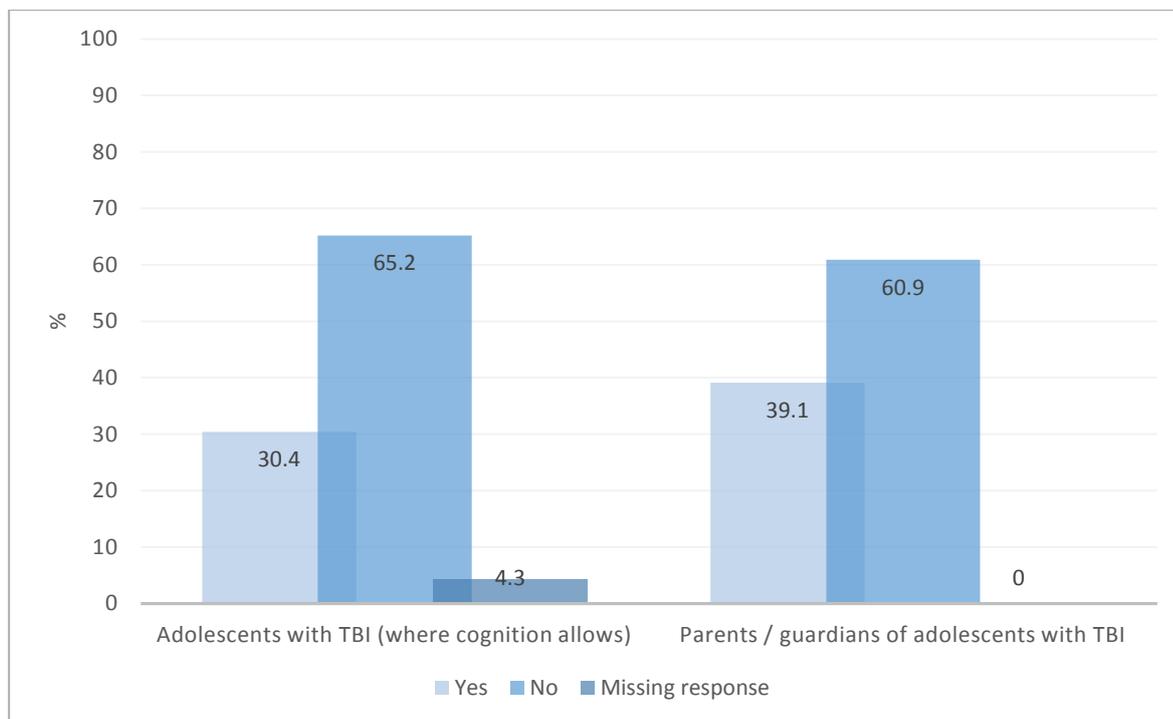


Figure 2.9 Proportion of countries where adolescents with a TBI (when cognition allows) and/or their parents/guardians are invited to participate in the development of policies and procedures affecting them and/or their children

The opinions of parents/guardians of adolescents with a TBI are included in national quality improvement initiatives in just over one-quarter of participating countries (26.1%, $n=6$) (Figure 2.10). Three countries (13%) also involve the parents and guardians in the review of written information pertaining to a TBI to ensure that it is culturally and linguistically appropriate (Figure 2.11).

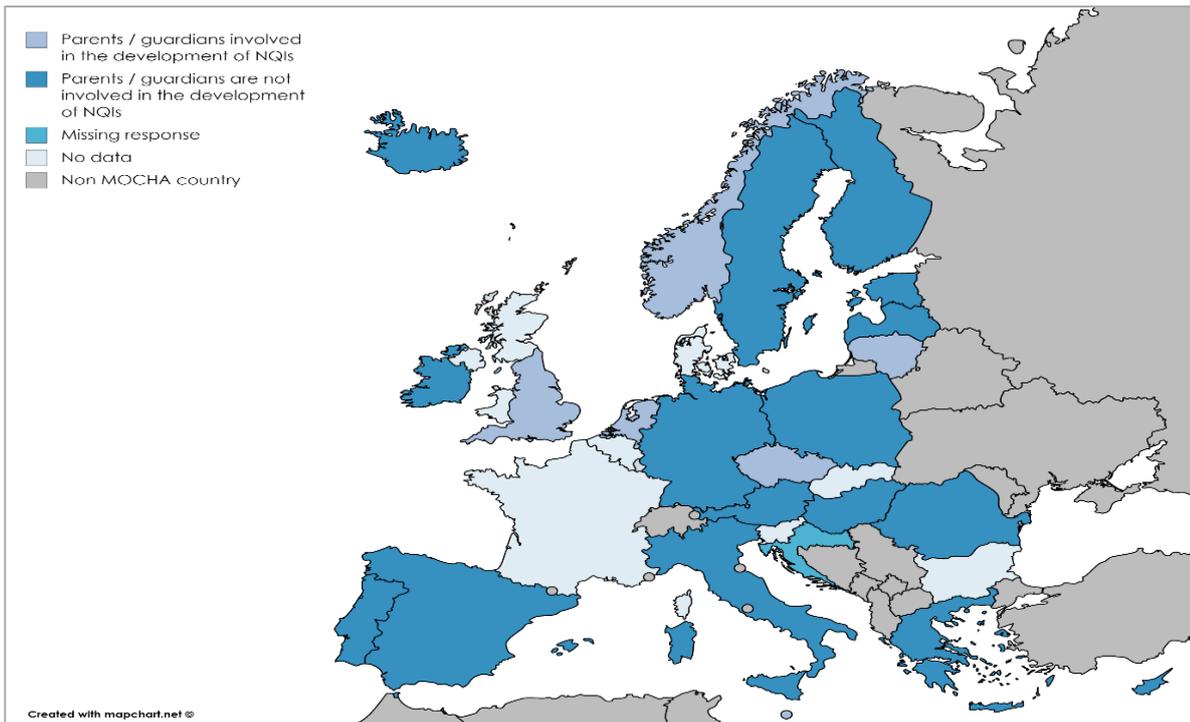


Figure 2.10 Inclusion of parental and guardian opinion in national quality improvement initiatives related to the care of adolescents with a TBI

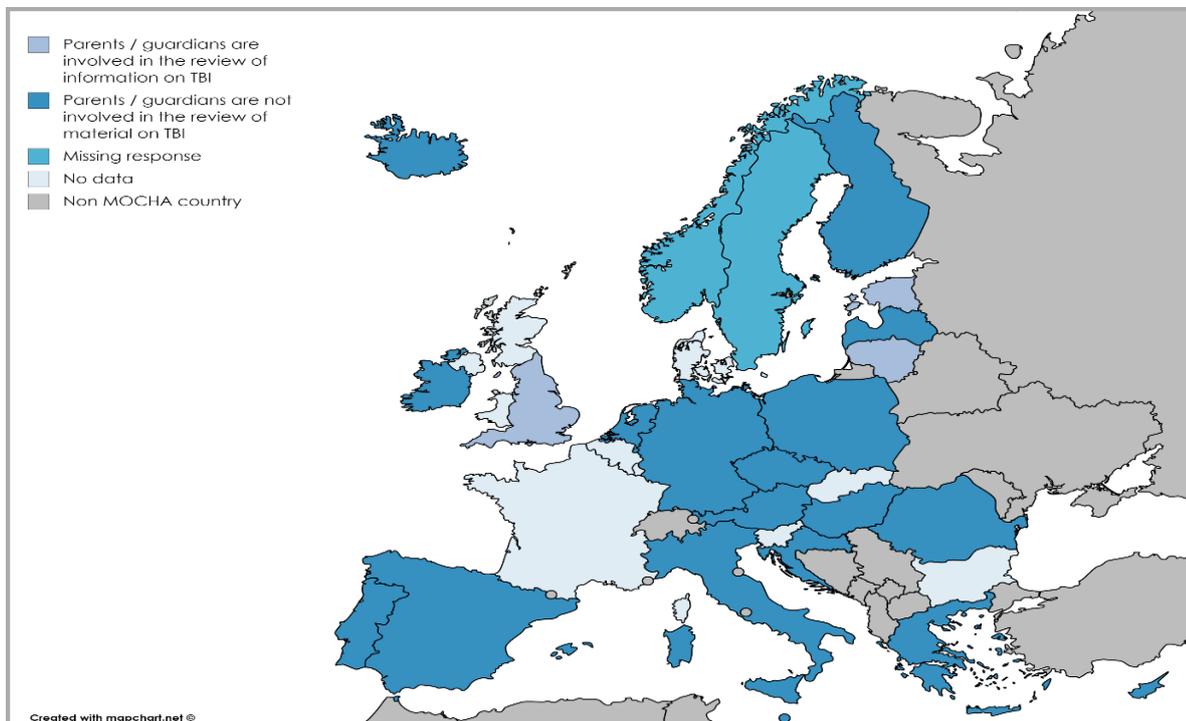


Figure 2.11 Inclusion of parents and guardians in the review of written information.

2.2.5 Transitioning from paediatric to adult healthcare services

The majority of countries do not have policies and/or procedures in place that provide guidance on the preparation of adolescents with TBI and their families as they transition to adult healthcare services (73.9%, $n = 17$) (Figure 2.12).

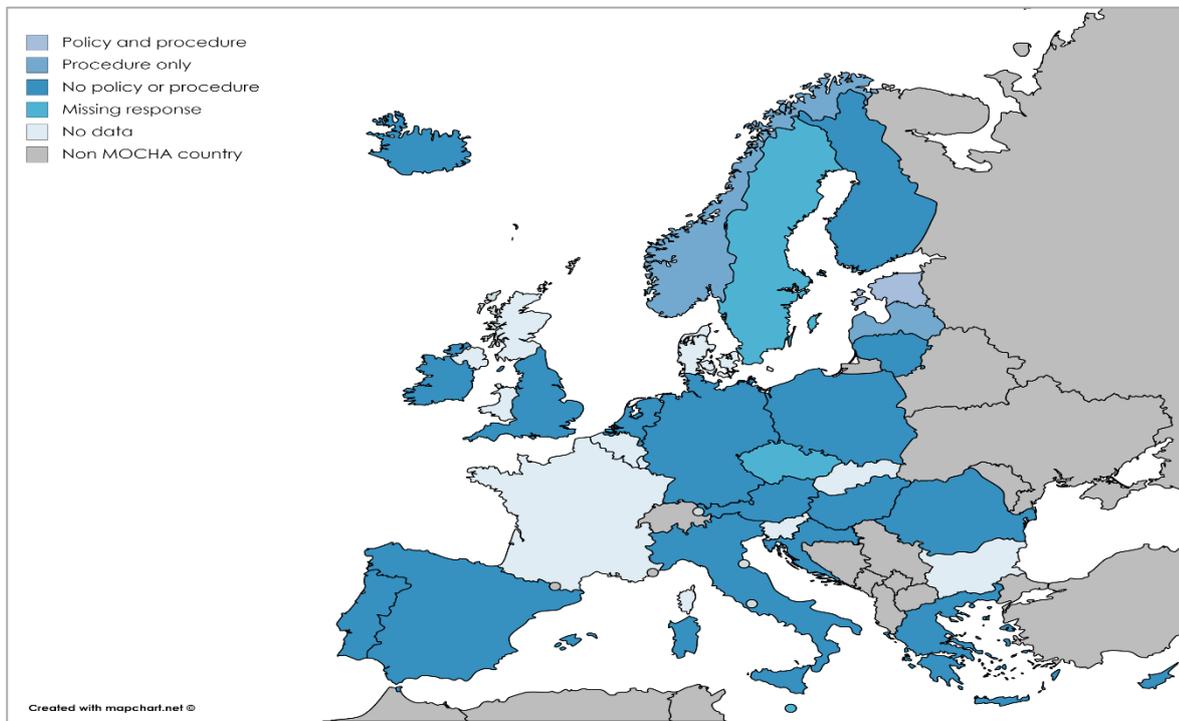


Figure 2.12 Presence or absence of policies and/or procedures relating to the preparation of adolescents with a TBI and their families for the transition from paediatric to adult healthcare services

A plan of care is prepared with the adult healthcare service providers prior to the transfer of the adolescent with a TBI from paediatric to adult services in seven (30.4%) of the participating countries (Figure 2.13). No respondent indicated that their country currently collects data on the experience of transition from paediatric to adult healthcare services from either adolescents with a TBI (where cognition allows) or from their parents/guardians (Figure 2.14).

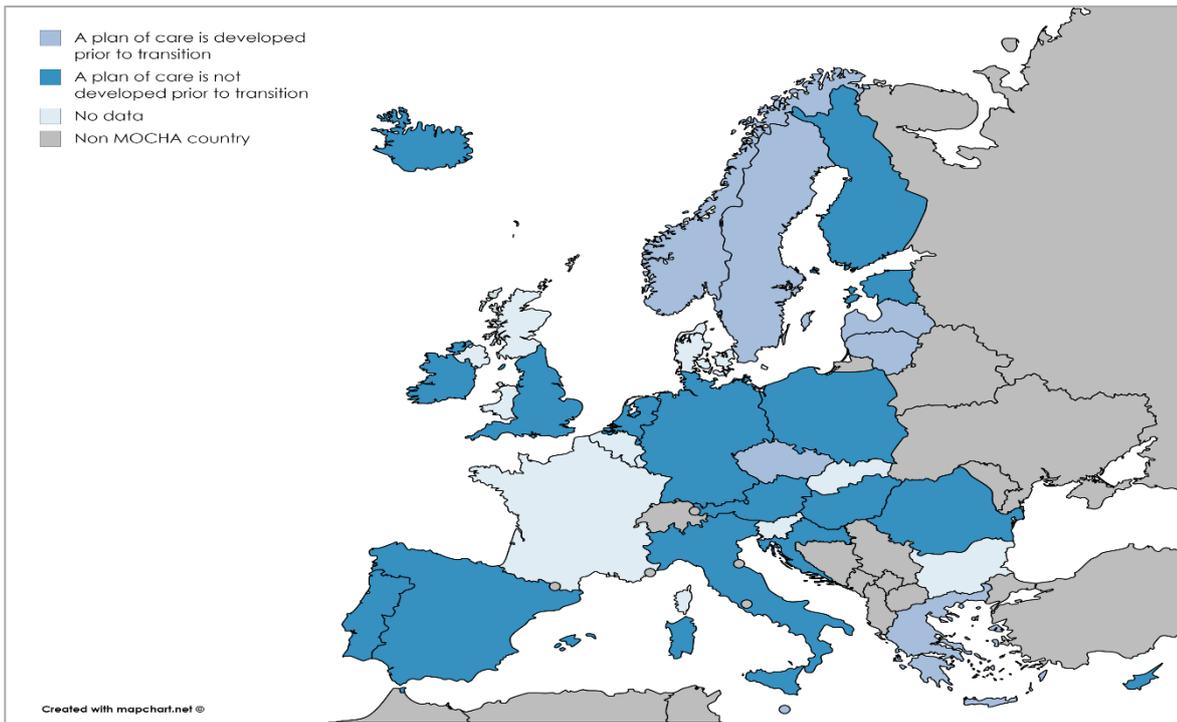


Figure 2.13 Preparation of care plans with adult healthcare services prior to the transfer of adolescents with a TBI from paediatric to adult healthcare services

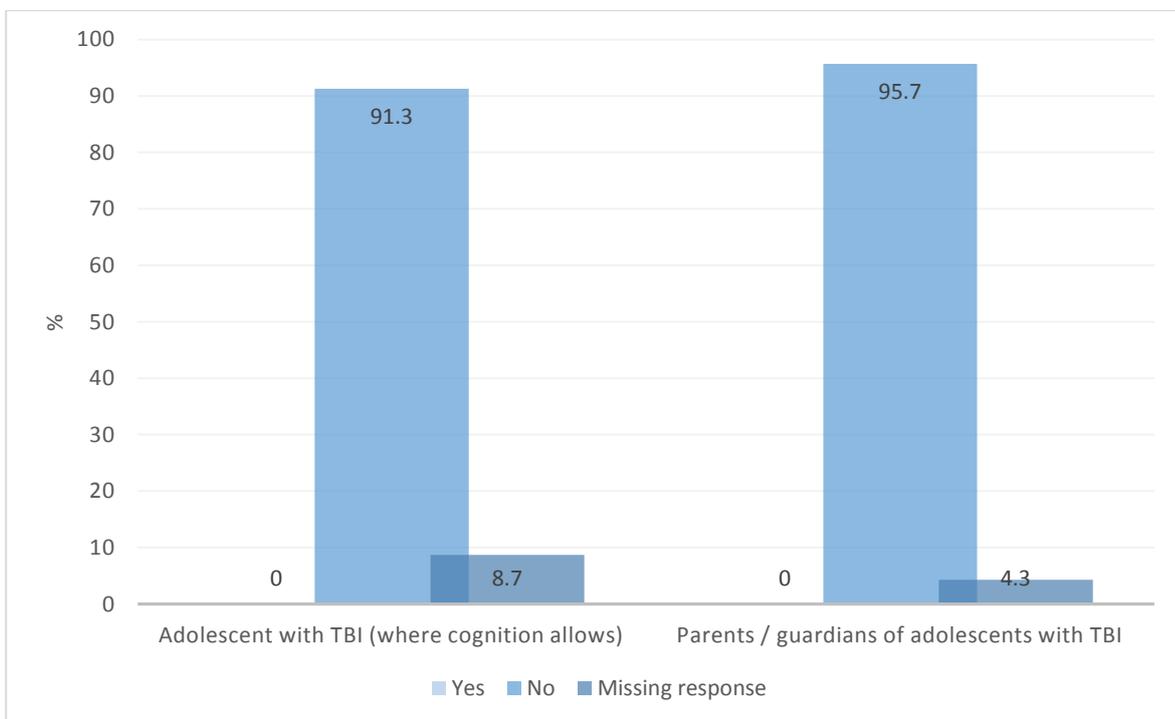


Figure 2.14 Proportion of countries that collect data from adolescents with a TBI, and their parents/guardians, regarding their experience of the transition from paediatric to adult healthcare services

2.2.6 Quality assurance

Nearly a half of all respondents reported that their country does not have policies or procedures relating to quality assurance for service providers caring for adolescents with a TBI (47.8%, $n = 11$) (Figure 2.15). Data on the experience of care is collected from adolescents with a TBI (where cognition allows) and their parents /guardians in less than one-fifth of participating countries (17.4%, $n = 4$) (Figure 2.16).

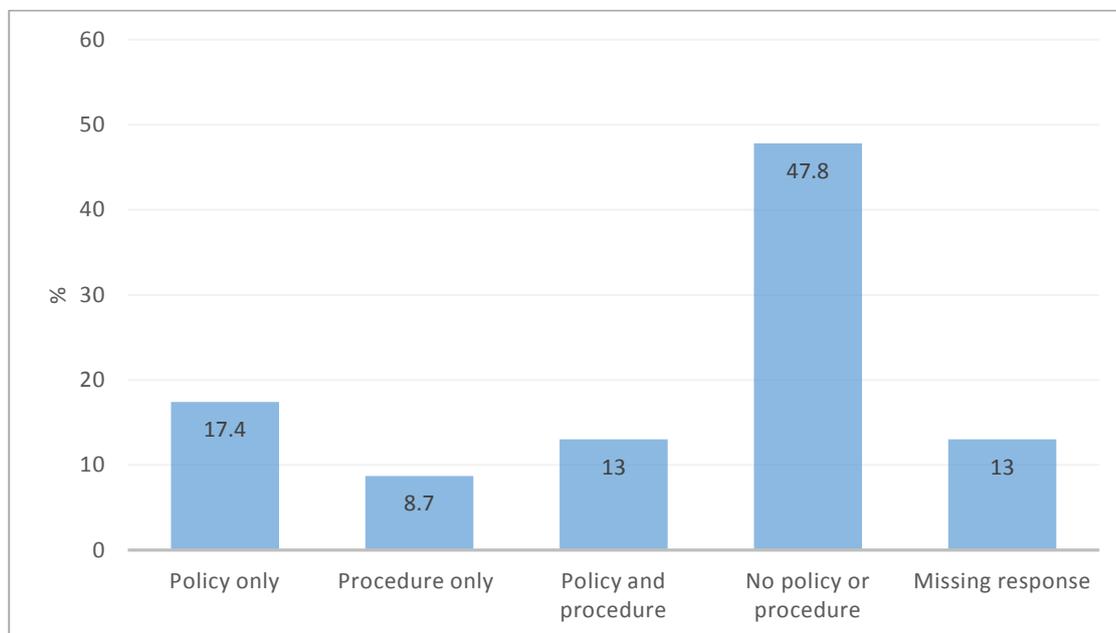


Figure 2.15 Proportion of countries with and without quality assurance policies and/or procedures for service providers caring for adolescents with a TBI

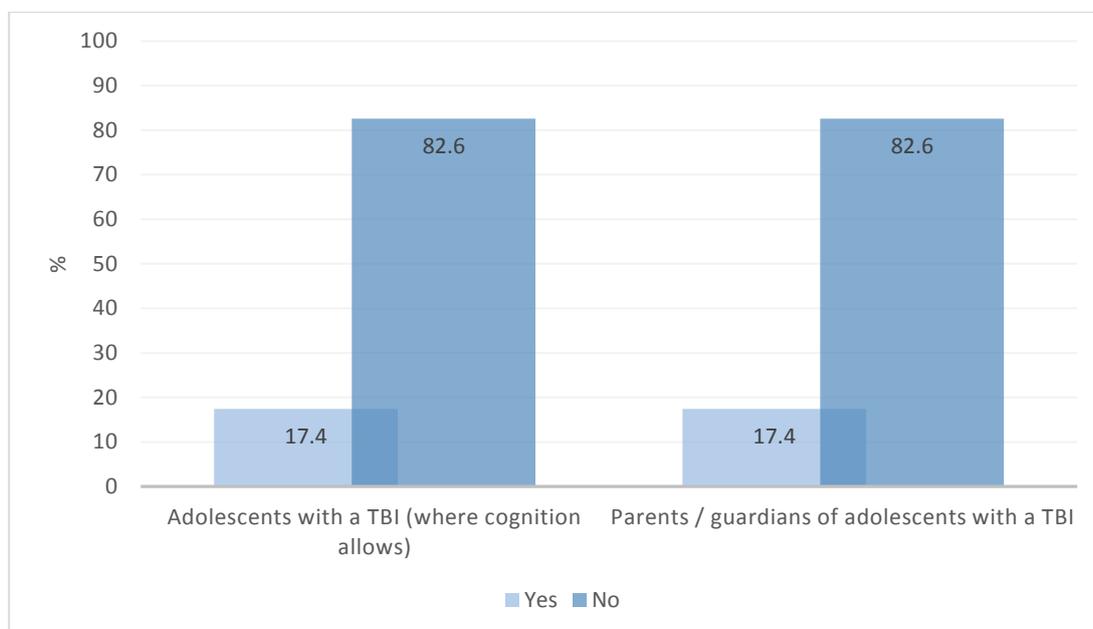


Figure 2.16 The proportion of countries where data are collected from adolescents with a TBI and their parents/guardians on the experience of care

2.3 Summary of key results in the management of care of an adolescent with a TBI

- The majority of countries have no systems in place to identify all healthcare providers care for adolescents following a TBI.
- There is limited support for the provision of linguistically appropriate or culturally appropriate information on TBI.
- There is limited inclusion of the young person in the planning of their care.
- There is limited engagement of family advocacy groups.
- There is a significant absence of policies and procedures to support transition to adult services.
- The majority of countries report availability of psychological support for adolescents and their families.

2.4 Identification of facilitators and barriers of the optimum integration of care at the primary and secondary care interface

Within each domain of the survey there was an opportunity for respondents to provide additional information on the management of care for a child at the acute community interface. The text provided by the CAs was analysed to identify facilitators and barriers of optimum integration of care at this interface. Two Global Themes (GTs) emerged from the qualitative data: 'adolescent specific care', and 'legal, policy and governance structures' (Figure 2.1). Many respondents provided examples of good practice and barriers to good practice in their country; examples are provided in text excerpts from countries across the EU/EEA with summary points at the end of each GT.

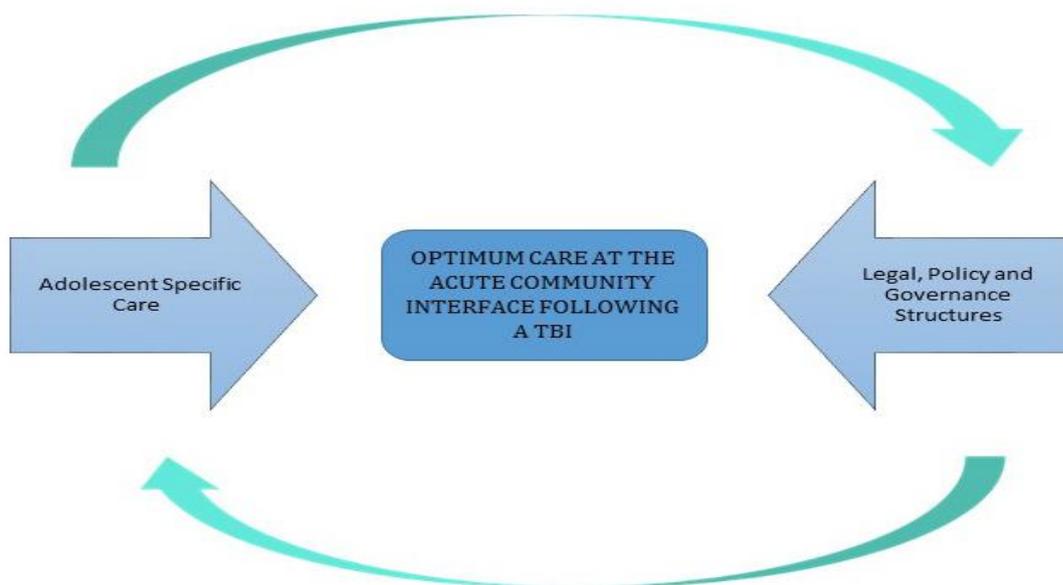


Figure 2.17 Factors influencing integration of care with a TBI

2.4.1 Adolescent specific care

The GT 'adolescent specific care' emerged from two organising themes (OTs) 'environment of care' and 'adolescent and family engagement'. A number of respondents reported that some hospitals have specific adolescent units providing age appropriate care and identified the value of such a unit:

Some general hospitals and child hospitals have specific units devoted to adolescents' health. When this is the case, care is much more adjusted and adolescents get much more integrated care across several areas: developmental/puberty; mental health, oral health, vision health, hearing assessment; sexual health; nutrition; and counselling. (Portugal)

Other respondents identified barriers to optimum care including examples of where adolescents as young as 14 are cared for in adult settings, for either acute care delivery or rehabilitation care.

The second OT 'adolescent and family engagement' emerged from data from a number of countries who offered examples of how the needs of the adolescent and their families are addressed following a TBI. This included seeking their views on care delivery:

The patient (if possible) and the parents are consulted. Adolescents with TBI, through youth councils in hospitals, are involved in the development of policies and procedures. (Norway)

The client input is ensured by the involvement of young people and parents across the development process. There is a digital consultation among young people and parents organized to identify what they consider important in healthcare. (Netherlands)

Overall, the current level of healthcare professionals' engagement with parents to support adolescents' needs post a TBI was identified by CAs as a barrier to optimum care for the family, with many describing a lack of information for parents on managing their child as a particular problem. Sibling support was also identified as a challenge, though some examples were provided of support systems in place:

For siblings of children and/or adolescents with TBI there are 'Siblings -days 'organised several times a year. During these days they get information about TBI and they can share their experiences with each other. (Netherlands)



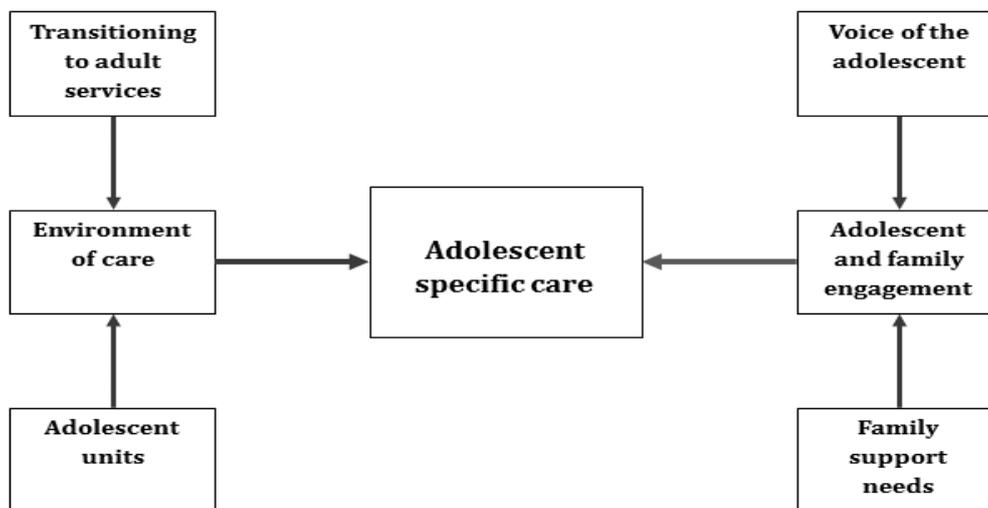


Figure 2.18 Emergence of global theme ‘adolescent specific care’

2.4.2 Legal, policy and government structures

This GT emerged as CAs emphasised the need for access for adolescents, and their families, to specialist services once discharged. The OT ‘infrastructure’ emerged from data from respondents on key issues that are necessary to support optimum care when an adolescent has a TBI. This included emergency transport at the time of injury, cross-border specialist initiatives and centralisation of trauma care facilities. A number of respondents highlighted the importance of an excellent air and road ambulance network to expedite the initial care delivery to an injured child. In some countries cross-border specialist healthcare initiatives were identified as critical infrastructure in the initial treatment period. This was particularly true for island nations:

In complex cases, adolescents may be flown out by air ambulance, usually to London for treatment in a Paediatric Neurosurgical Unit. Teleconsultation with a Maltese Paediatric neurosurgeon working in the UK established over the past years is often performed to assess the needs and advise upon future management. This link has been of great value in enhancing the quality of care and assessment in such cases. (Malta)

While geographical variation in care is often identified as a challenge in care delivery, for adolescents with a TBI centralised specialist care was identified as a positive as it was linked to greater opportunities for enhanced expertise and access to optimum technology in this specialised field of care.

The OT ‘standards of care delivery’ emerged from three Basic Themes (BTs): access to rehabilitation, respite care, and transitioning to adult services. A number of respondents reported variance in care delivery between urban and rural centres, reporting rural centres to have limited appreciation of the need for intensive rehabilitation and limited funding to support such treatment:

The services are well developed at the 5 specialized TBI centres... the accessibility varies a lot throughout the country. In several local rehabilitation centres the staff have very little knowledge



about the need for intensive training after TBI. There is also a lack of resources for this intensive treatment. (Sweden)

The majority of respondents suggested that a national strategy on the management of children /adolescents following a TBI would be important to address many of the issues raised. At present, there is a predominant absence of such a strategy or any associated standards of care, or where national strategies do exist they may not offer guidance on the care of those under 18 years. There was also concern expressed about the absence of respite care available for adolescents following a TBI. Respondents identified the importance for families to have access to respite care, particularly where an adolescent may have behavioural challenges as a result of the injury. It is noted that many respondents raised concern regarding the ad hoc nature of the transfer of care to adult services in their respective countries and they identified this as a critical juncture where key health, social care and education needs could be missed.

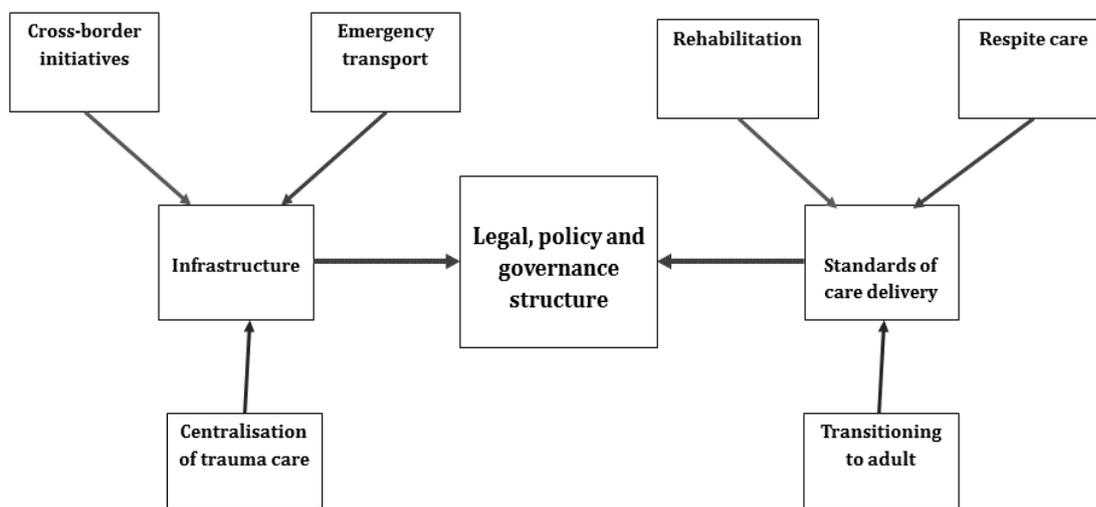


Figure 2.19 Emergence of global theme legal, policy and governance structure

2.5 Summary of optimum integration of care at the acute community interface for an adolescent with a TBI

- Seeking and incorporating the voice of the adolescent where possible in care planning.
- Specific sibling support.
- Information for parents on caring for an adolescent following a TBI.
- Care delivery in units equipped to meet the specific needs of adolescents.
- Specialist emergency transport and specialist trauma care.
- Cross-border specialist healthcare initiatives.
- Timely pathway to skilled rehab care.
- Access to respite care.
- Established pathway for transitioning to adult care.



Chapter 3

Management of a Child on Long-term Ventilation at the Acute Community Interface

3.1 Introduction

This chapter reports on the findings on the standards and processes in place for the management of children on LTV at the acute community interface. A total of 24 surveys were returned from a possible 30 countries (80%) countries. One respondent indicated that their country does not have home LTV, therefore, responses of 23 countries (76.6%) were analysed.

3.2 Structures and processes of care in place for a child on LTV

The structures and processes of care for a child on LTV were explored under six domains of the adapted *Standards for Systems of Care for Children and Youth with Special Health Care Needs*: screening and assessment; access to care; care coordination; community-based services and supports; family-professional partnerships; and quality assurance.

3.2.1 Screening, assessment and referral

The analysis shows that 43.5% ($n=10$) of countries have policies and procedures in place to support the preventative screening, assessment and referral of children on LTV for developmental checks (Figure 3.1). Over one-third of countries (39.1%, $n=9$) have specific mechanisms (policies and procedures/procedures alone) in place to document and communicate the results of the screening assessment, and referral of these children, to the care services who provide care to children on LTV (Figure 3.2). A similar number of countries have a mechanism (policies and procedures/policies or procedures alone) in place to support the communication of screening, assessment and referral findings to the parents/guardians of children on LTV (Figure 3.3).



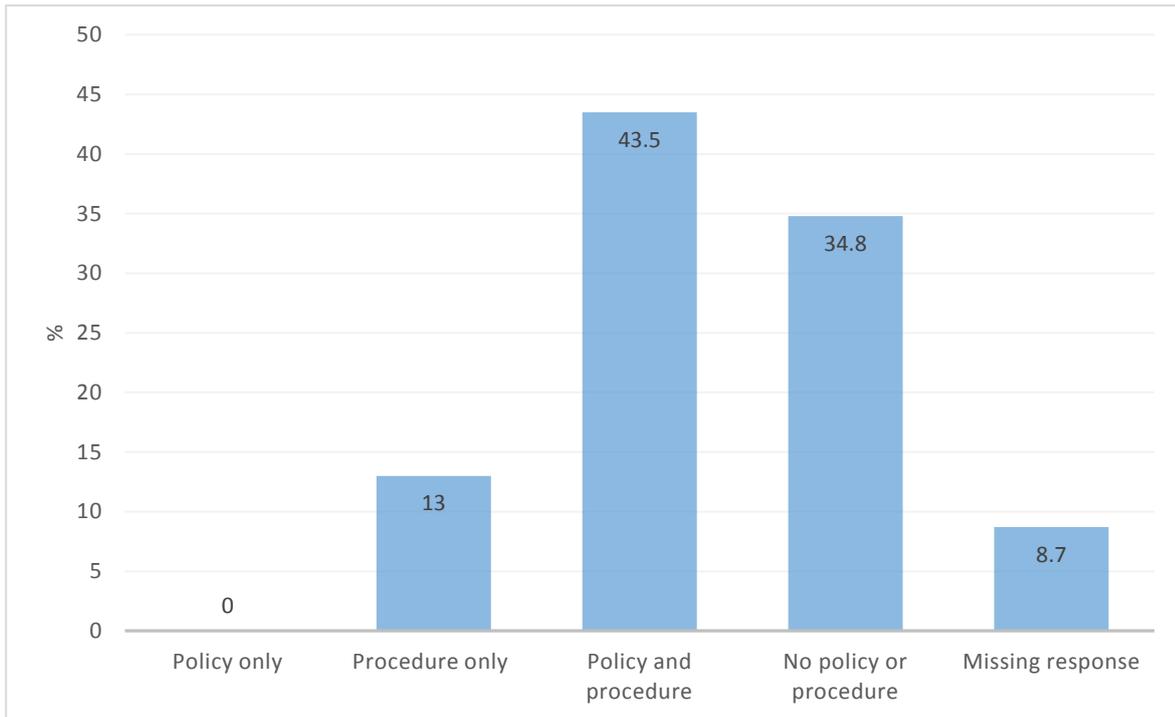


Figure 3.1 Proportion of countries with policies and/or procedures in place to support the provision of preventative care screening and developmental checks to children on LTV

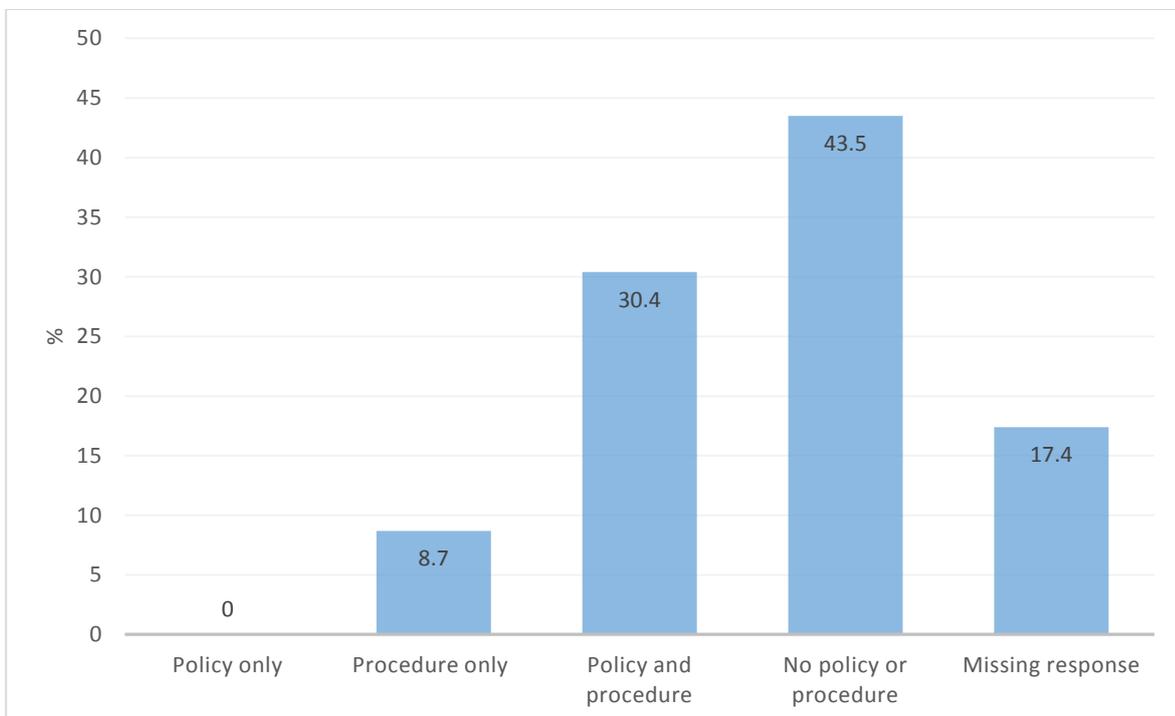


Figure 3.2 Proportion of counties with policies and/or procedures in place to document and communicate the results of screening or developmental checks for children on LTV to all care services



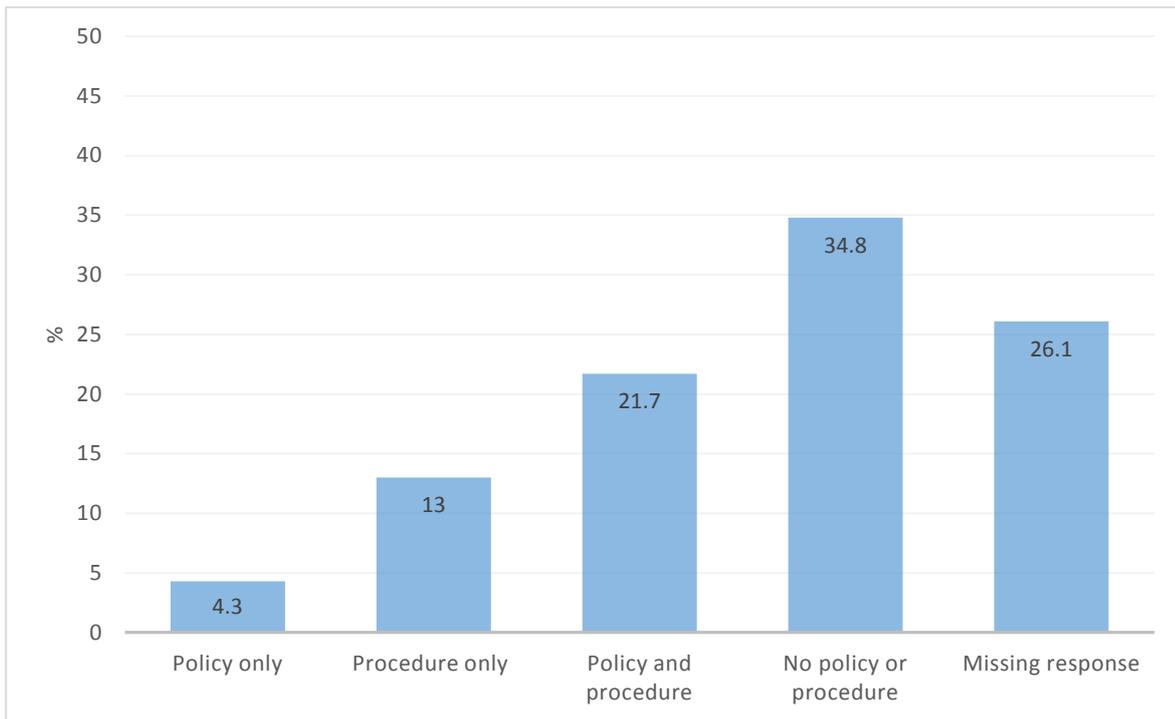


Figure 3.3 Proportion of countries with policies and/or procedures in place to document and communicate the results of screening or developmental checks for children on LTV to their parents/guardians

3.2.2 Access to care

The majority of countries (60.9%, $n=14$) have mechanisms in place that can identify all of the healthcare providers caring for children on LTV (Figure 3.4). The transport of young children on LTV to accommodate regular activities and/or healthcare appointments is facilitated in five countries (21.7%) by their parents/guardians, without support from the State and/or healthcare provider. The State provides some assistance with transport to the parents/guardians of children on LTV in seven countries (30.4%). In one country (4.3%) transport is facilitated by the healthcare provider and in a further five countries (21.7%) the transport of children on LTV is supported by a combination of both the State and healthcare providers (Figure 3.5).

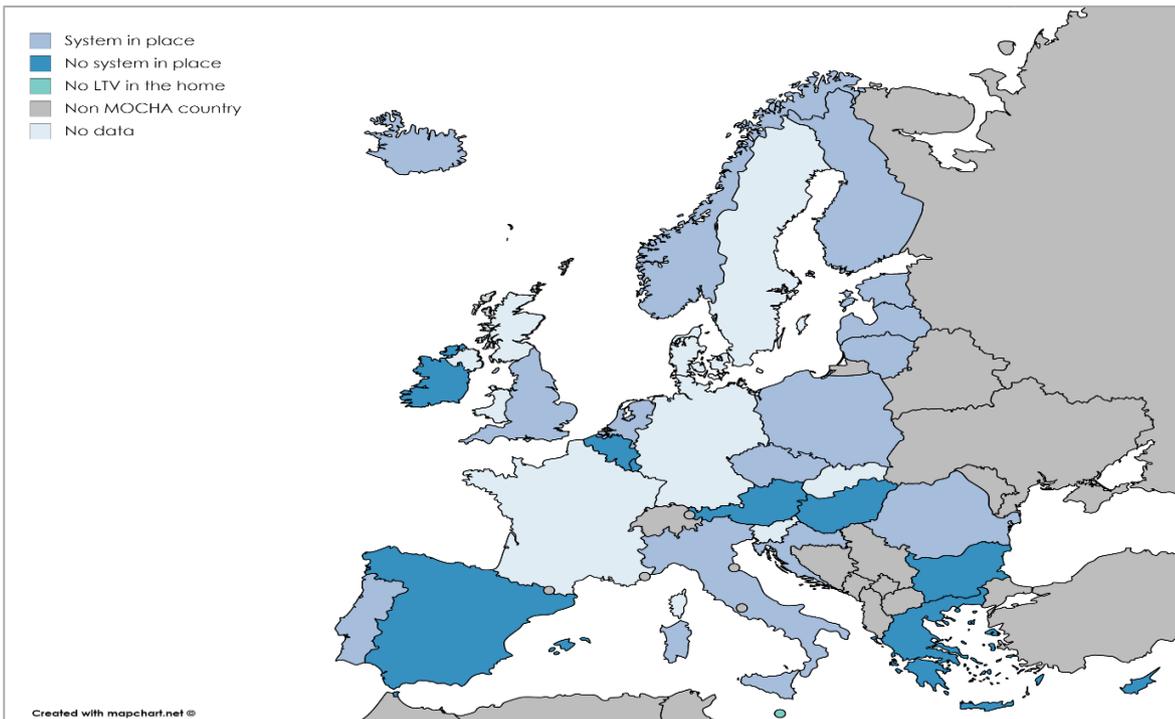


Figure 3.4 Countries with and without systems in place to identify all healthcare providers caring for children on LTV

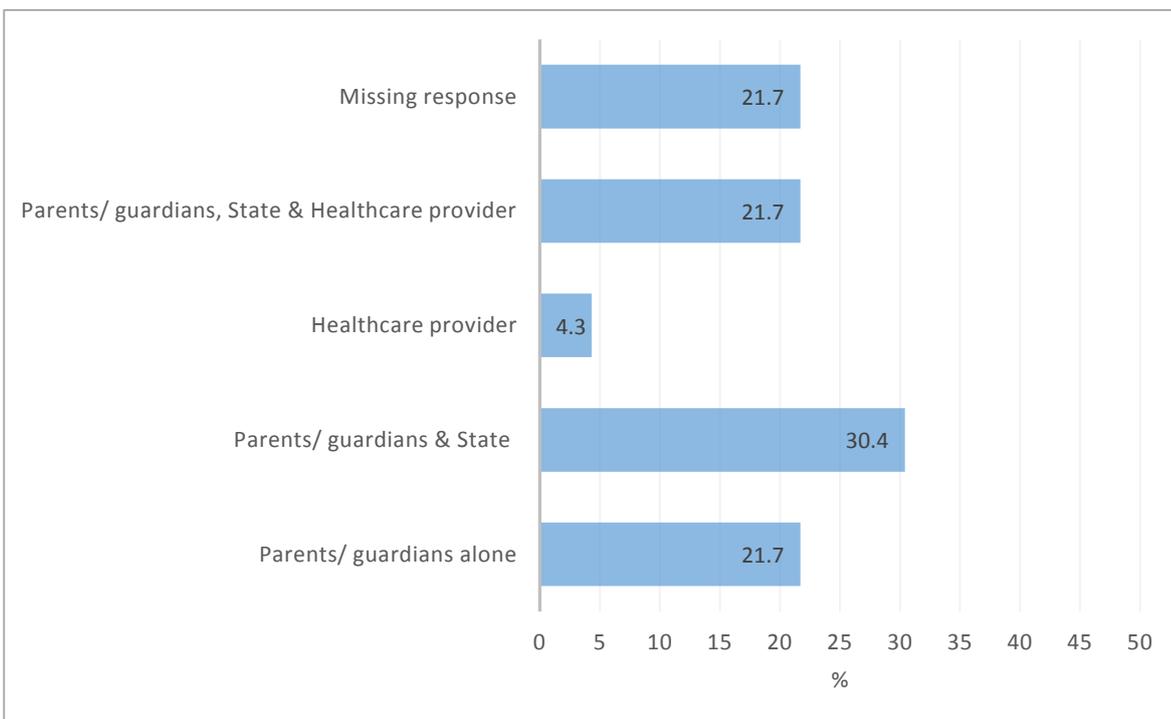


Figure 3.5 Provision of transport to accommodate the daily activities and healthcare visits of children on LTV

Over half of respondents (56.5%, $n= 13$) reported that their country has no policies or procedures in place to support the provision of linguistically and culturally appropriate information to the families of children on LTV (Figure 3.6).

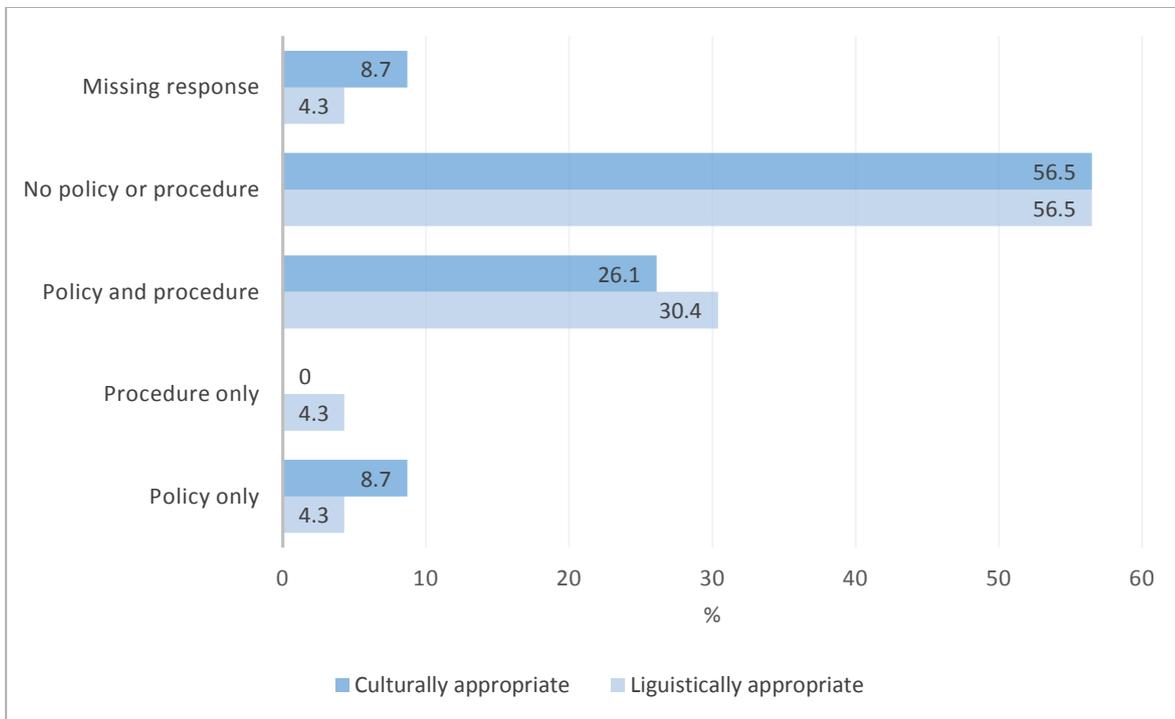


Figure 3.6 Proportion countries with policies and/or procedure in place to support the provision of linguistically and / or culturally appropriate information to the families of children on LTV

3.2.3 Care coordination

There are no policies or procedures in place to support care coordination for children on LTV in 43.5% ($n=10$) of the countries that responded (Figure 3.7). However, consultation with both parents/guardians (82.6%, $n=19$) and healthcare professionals (69.6%, $n=16$) in the development of personalised care plans was reported by the majority of respondents (Figure 3.8).

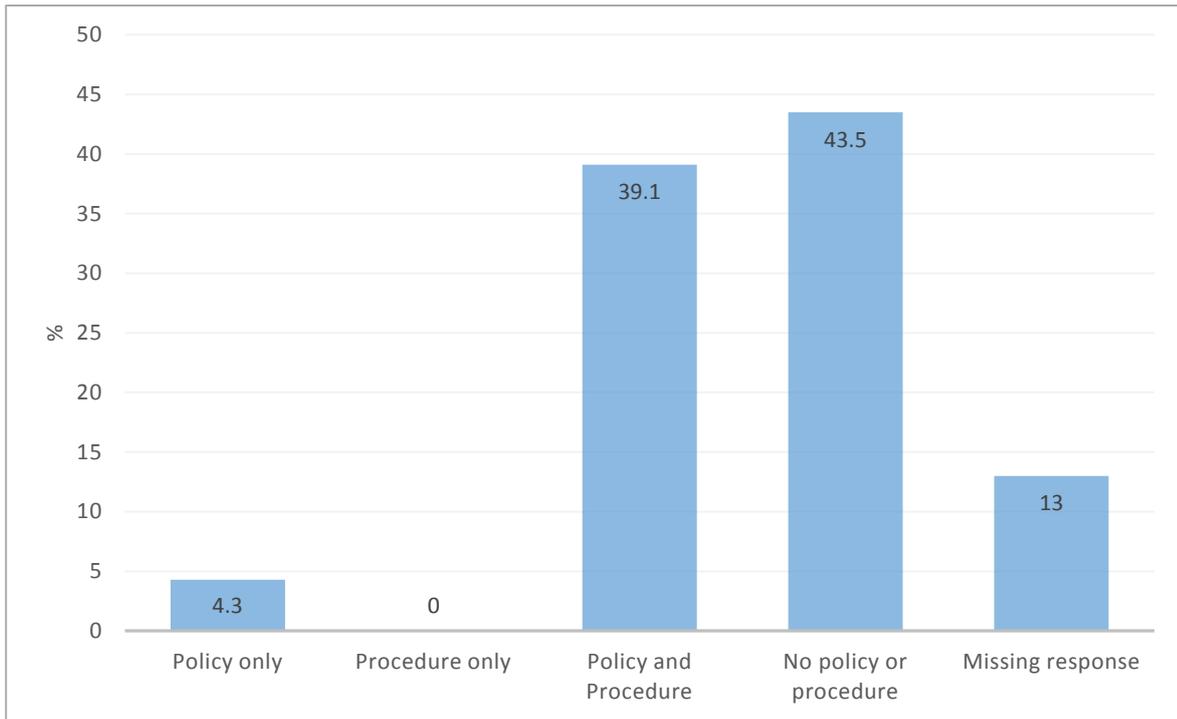


Figure 3.7 Proportion of countries with policies and / or procedure in place promoting care coordination for children on LTV

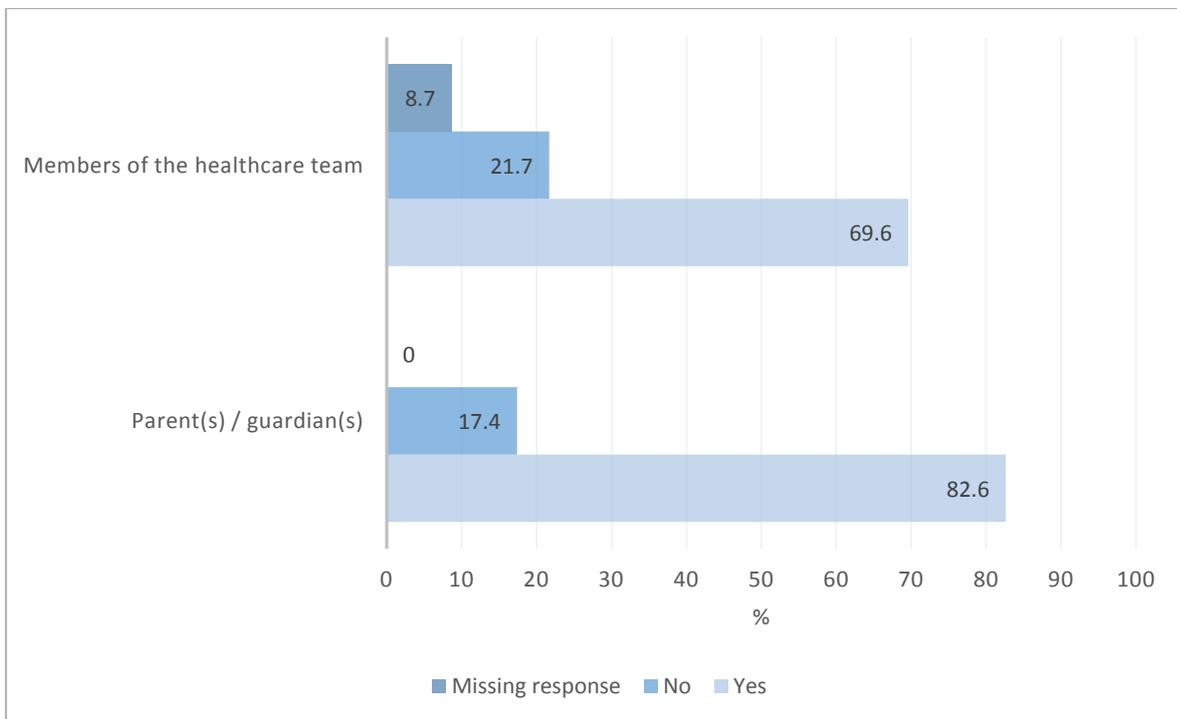


Figure 3.8 Individuals consulted during the development of personalised care plans for children on LTV in participating countries.

A variety of health assessments are contained in the personalised care plans for these children, with a relatively consistent spread of the common assessment health checks evident (Figure 3.9). The representative of one country (4.3%) reported that a personalised care plan is not developed for children on LTV in their country.

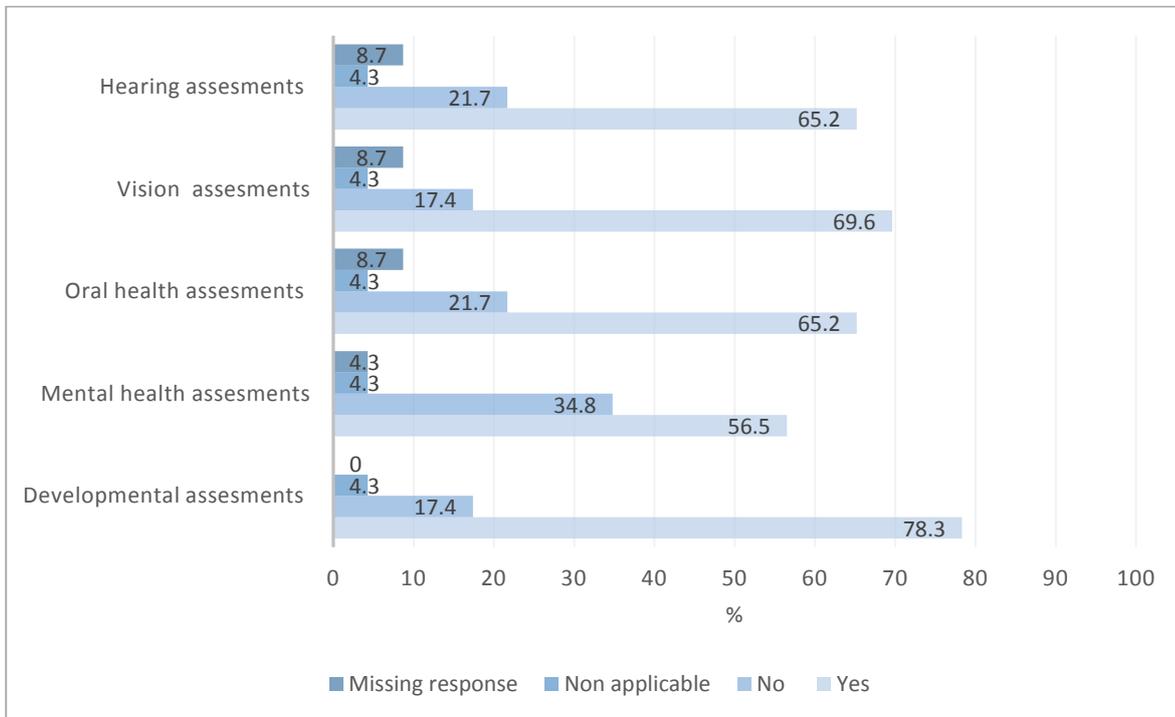


Figure 3.9 Health assessments included in the personalised care plans of children on LTV in participating countries

The point of transfer of care to home is a significant determinant of a successful on-going community acute interface. Respondents from nine countries (39.1%) indicated that there are Discharge Planning Coordinators in place in paediatric departments/hospitals in their countries who oversee the transfer of such a child to their home environment. Nearly half (47.9% $n=11$) of respondents reported that there are no discharge planning coordinators in their respective countries. Three (13%) respondents did not provide an answer to this question (Figure 3.10). The majority of the respondents (73.9%, $n=17$) indicated that their country has a process in place to facilitate direct access to and/or from a paediatric intensive care unit (PICU) for a child on LTV (Figure 3.11).

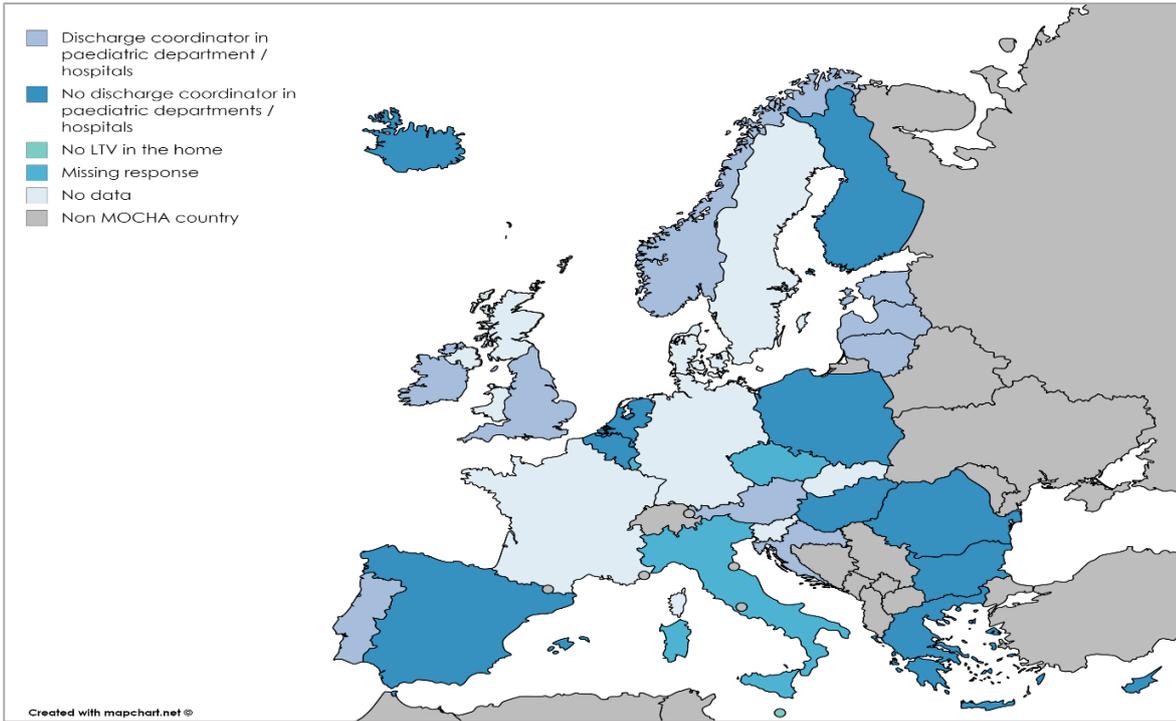


Figure 3.10 Presence or absence of a Discharge Planning Coordinator in paediatric departments / hospitals

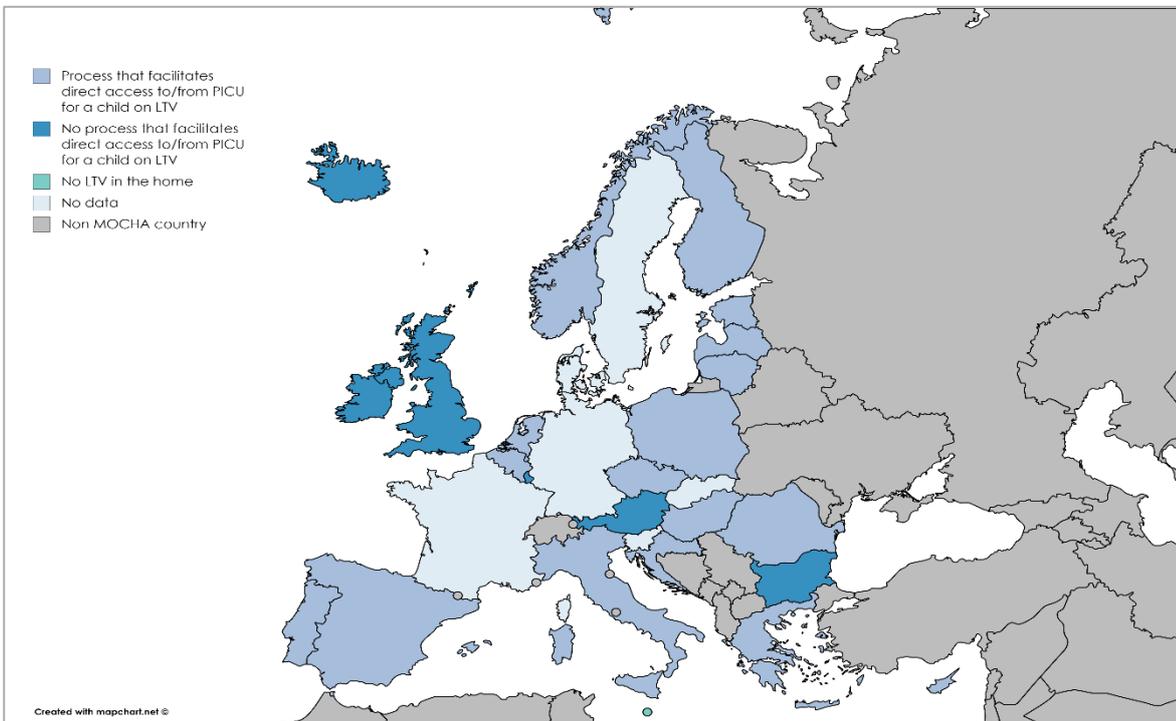


Figure 3.11 Presence or absence of a process that facilitates direct access to and/or from the Paediatric Intensive Care Unit (PICU) for children on LTV

3.2.4 Community-based services and supports

Family advocacy groups are involved in making recommendations to home and community-based services for children on LTV in over one-third of countries (34.8%, $n=8$). Fourteen (60.9%) participating countries have policies in place for paediatric palliative care and end-of-life care (Figure 3.12). The majority (87.1%, $n=20$) reported that their country provides access to psychological support for the parents/guardians and siblings of a child on LTV (Figure 3.13).

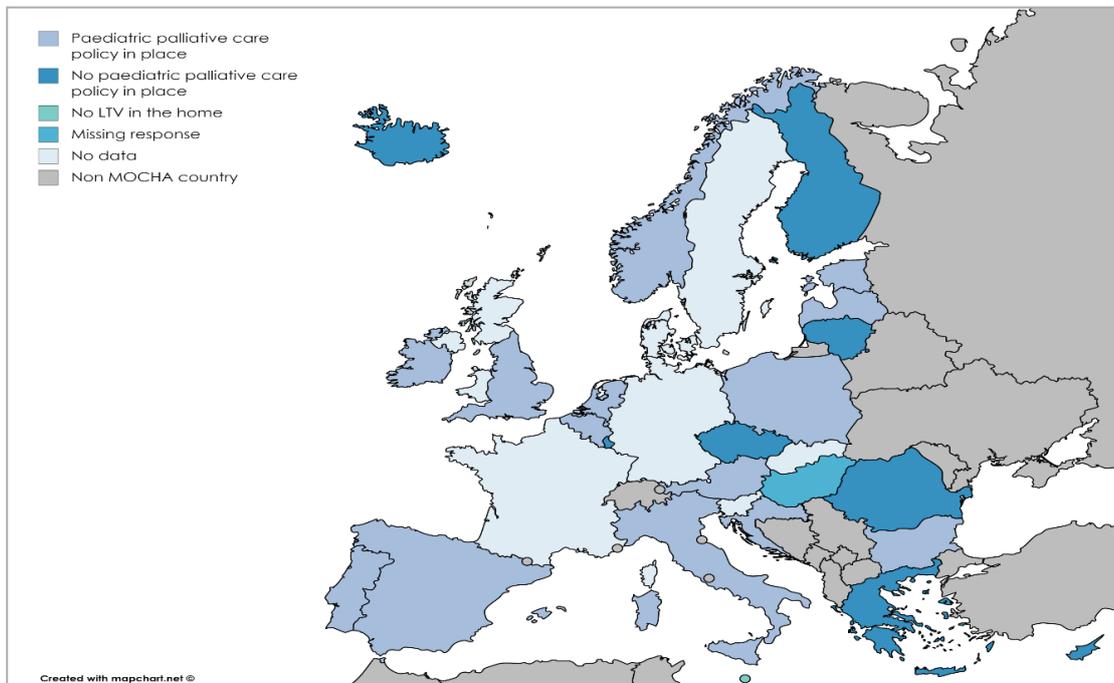


Figure 3.12 Presence or absence of paediatric palliative care and end of life policies

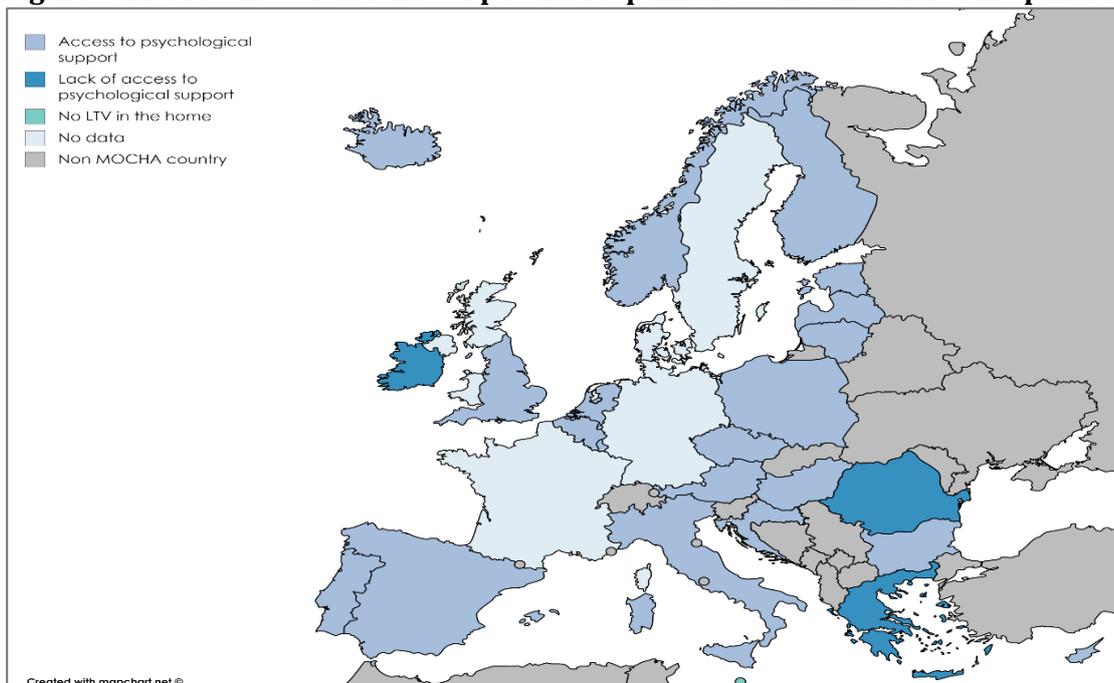


Figure 3.13 Access to psychological support from professionals with paediatric expertise for parents/guardians and siblings of children on LTV

3.2.5 Family-professional partnerships

Family advocacy groups are involved in the development of policies and procedures affecting the care of children on LTV in eleven (47.8%) countries (Figure 3.14). The parents/guardians of children on LTV are included in national quality improvements in only six countries (26.1%), while parents/guardians are not involved in the review of information material in the majority (65.2%, n=15) of countries.

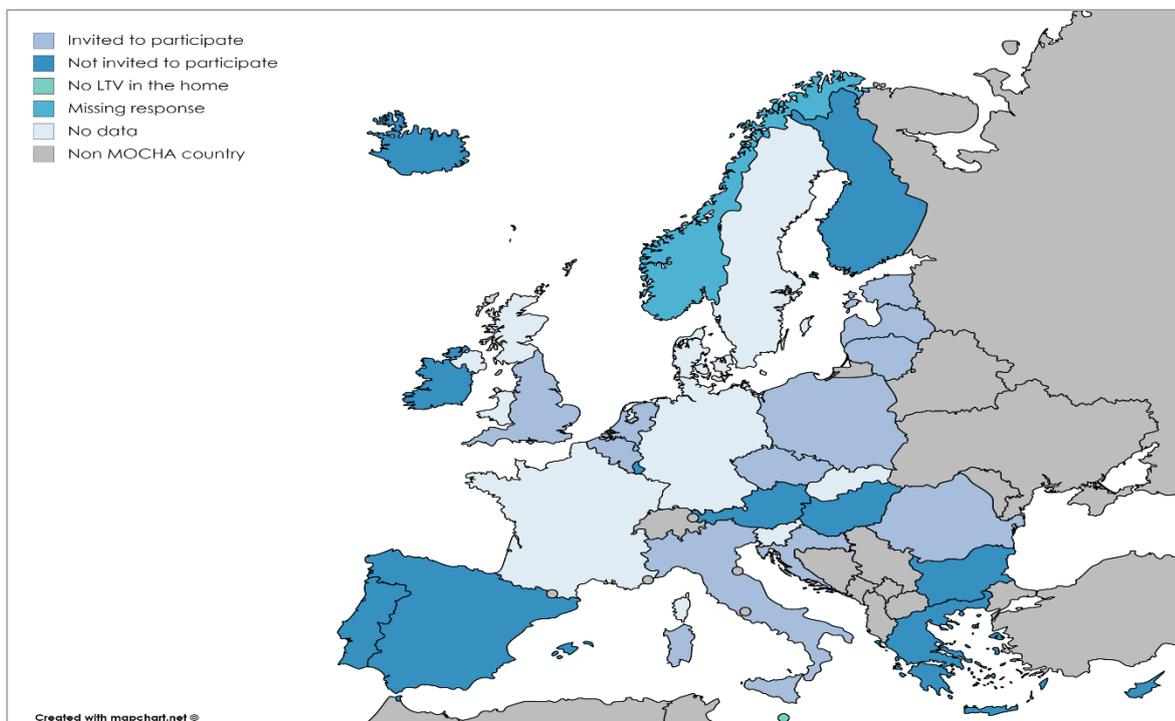


Figure 3.14 Countries where parents /guardians of children on LTV are invited/ not invited to participate in the development of policies or procedures affecting their children

3.2.6 Quality assurance

Almost half of respondents (47.8%, n=11) reported that their countries do not have policies or procedures in place to support quality assurance for service providers caring for children on LTV (Figure 3.15). The majority of countries do not collect data on the experience of care from the perspective of the parents/guardians (78.3%, n=18) or siblings (91.3%, n=21) of children on LTV (Figure 3.16).

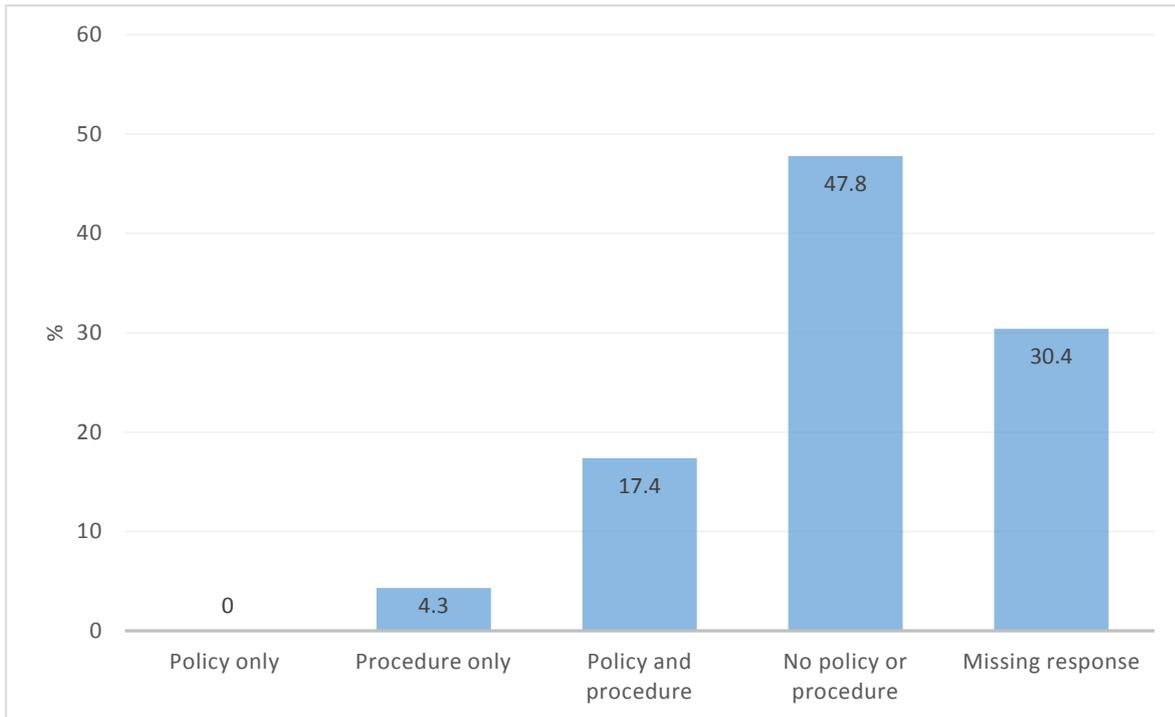


Figure 3.15 Proportion of countries with / without quality assurance policies and /or procedures for service providers caring for children on LTV

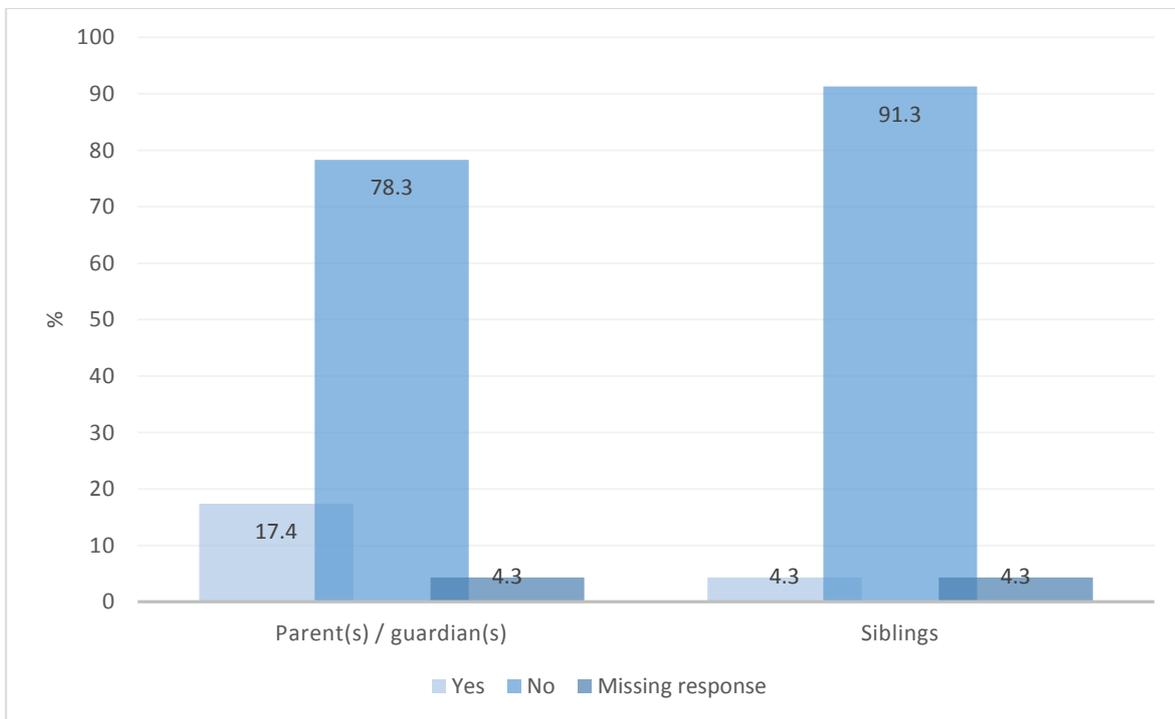


Figure 3.16 Proportion of countries that collect data on the care experience of children on LTV from the perspective of their parents/guardians and siblings

3.3 Summary of key results in the management of care of a child on LTV

- Less than half of responding countries have policies and procedures in place to support the preventative screening assessment and referral of children on LTV for developmental checks
- The majority of countries have mechanisms in place which can identify all of the healthcare providers caring for children on LTV
- There is limited support for the provision of linguistically appropriate or culturally appropriate information.
- Consultation with both parents/guardians and healthcare professionals occurs in the development of personalised care plans in the majority of countries.
- Just over half of the responding countries have discharge planning coordinators
- There is limited engagement of family advocacy groups.
- The majority of countries do not collect data on the experience of care from the perspective of the parents/guardians or siblings of children on LTV.

To further elucidate the structures and processes, the Unified Modelling Language (UML) activity diagram (Figure 3.17) presents a high level of description focusing on the main macro-activities of a child on LTV, like Max in our vignette. Given that this UML diagram is not country specific, it reports all the possible activities that are likely to be performed. In order to map the level of collaboration between professionals, the following actors were identified: 1) a single professional that can work in either the primary care setting or in a hospital; 2) multiple professionals who lead their individual speciality but who do not work in an organised wider multi-disciplinary team; 3) multidisciplinary team which is composed of health professionals who work in the hospital and/or primary care; 4) multidisciplinary team that includes a social worker.

The process starts with the organisation of the transition from hospital to home that represents a set of actions. This includes the medical instruction on monitoring the child's health as well as the planning required to prepare the parents and their home for the child coming home (including equipment such as ventilator, training for parents to use it, etc.). This macro-activity can be carried out by a discharge planning coordinator, an *ad hoc* team that can include health and social care professionals or by a hospital physician. Moreover, it also includes the development of a discharge plan that can be written in collaboration with the parents and/or with members of the health team. Once the child is discharged from hospital, three macro activities start in parallel:

1. Provision of a healthcare service in the community, a series of activities routinely performed at predefined period of time (represented by a circle and an hourglass).
2. Provision of preventive care screening and developmental checks, which are a series of activities routinely performed at predefined periods of time. This should also include the communication of the results to all care services as well as to the parents. Preventive screening may include review visits to monitor the psychological and/or physical development of the child or may be part of prevention specifically organised for preterm children.

The third activity is *implementation of the written plan* that provides the scheduling for monitoring the child's health status. This activity may include access to acute care in the case of an acute deterioration in the child's health state, the availability of psychological support for parents, and access to palliative care, if required.



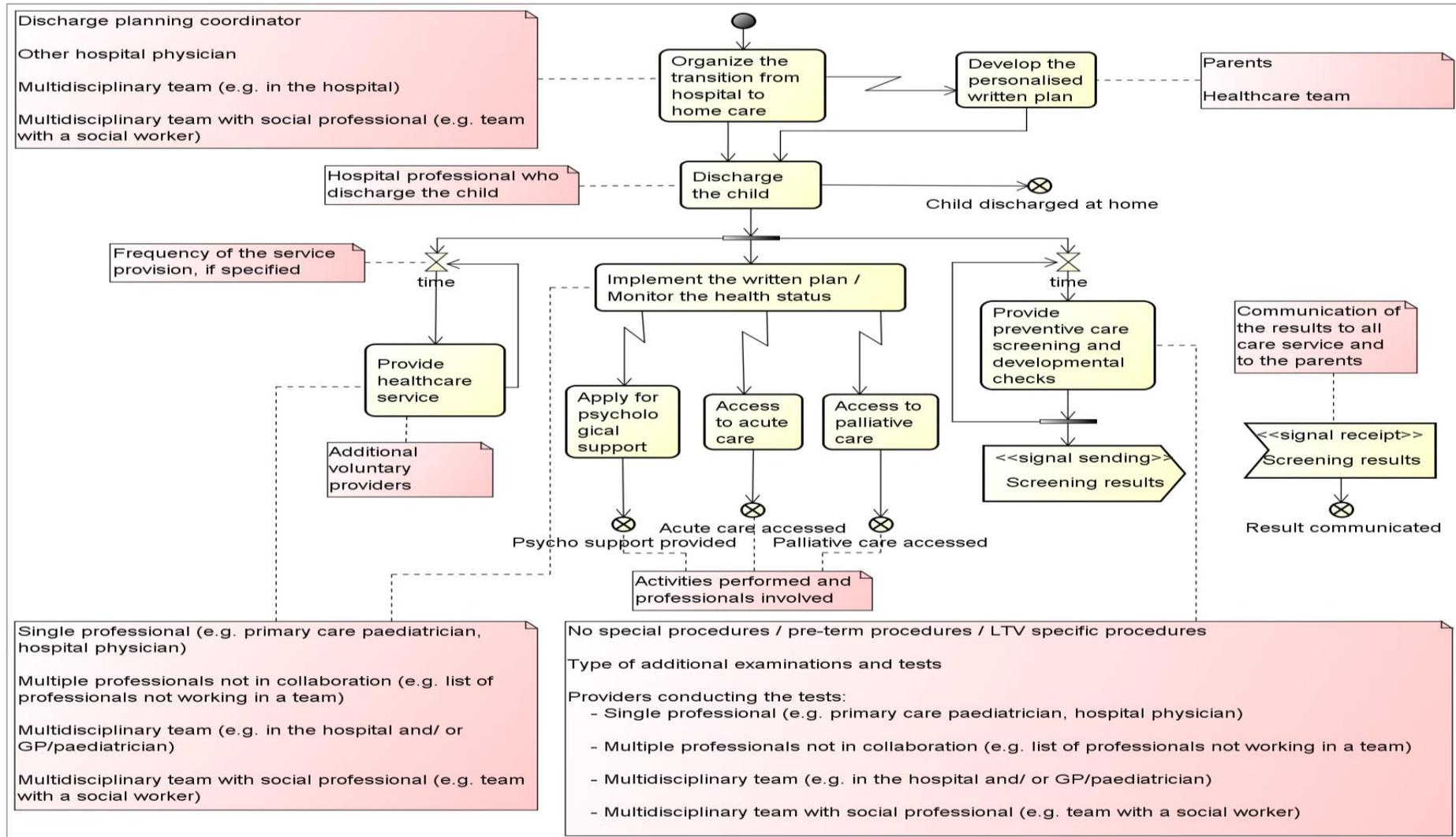
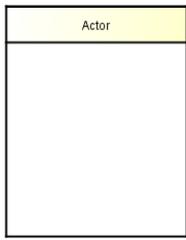
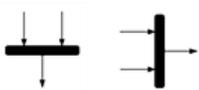
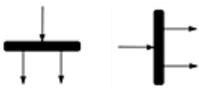


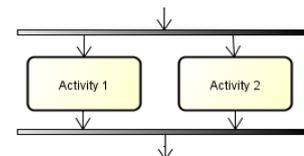
Figure 3.17 High-level UML activity diagram for a child on LTV



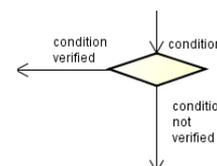
Glossary of UML notation.

Element description	Symbol used in the UML formalism
<p>Actor: represented by a swim lane it indicates the actors and stakeholders that take place in the process to be modelled. An actor can be a person, an information system, a device, etc. Each activity performed by the actor is embedded in the relevant swim lane.</p>	
<p>Initial state: represented by a full black circle it represents the beginning of a process. It can be used by itself or with a note symbol that explains the starting point.</p>	
<p>Activity: represented by a rectangle with rounded corners it defines the single activity performed by the relevant actors of the swim lane where it is placed.</p>	
<p>Call activity (macro-activity): represented by a rake-style symbol within the activity symbol it is used to invoke the execution of another activity diagram.</p>	
<p>Wait time action: represented by a stylized hourglass it introduces a time related event. The note placed next to the symbol specifies the time at which the occurrence happened. Once the time event occurred the related action should be performed.</p>	
<p>Join: represented by a thick vertical or horizontal line it combines two concurrent activities and reintroduces them to a flow where only one activity occurs at a time.</p>	
<p>Fork: similarly to join it is represented by a thick line it splits a single activity flow into two concurrent activities.</p>	

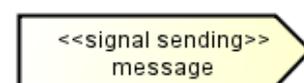
Concurrent activities: represented by a fork symbol followed by a join symbol it describes the split of the main flows into two or more parallel activities that are subsequently reintroduced in the main flow.



Decision: represented by a diamond shape it represents a conditional decision at which a workflow divides into two or more branches. The condition is placed next to the connector depending on the branch that matches the relevant answer. The condition (known as the guard of the activity edge) is shown in square brackets.



Message sent: represented by a convex pentagon labelled with a <<signal sending>> stereotype it describes a signal generated and transmitted to an identified actor, when all the prerequisites of the action execution are satisfied.



Message received: represented by a concave pentagon labelled with a <<signal receiving>> stereotype it describes a signal received by an actor. Each message received shall be accompanied by a message sent.



Final state of the flow: represented by an empty circle with a cross inside it shows the ending point of a single process' flow.



Final state of the process: represented by a solid circle with a hollow circle inside it represents the completion of the whole process. While final state of the flow identifies the end of a process in a single flow, a final state of the process represents the completion of all flows in an activity diagram.



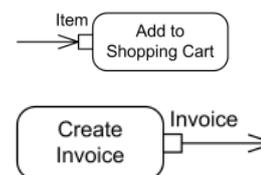
Connector: represented by an arrowed line that shows the directional flow, or control flow, of a set of activities, messages, initial and states, etc. An incoming arrow starts a step of an activity; once the step is completed, the flow continues with the outgoing arrow.



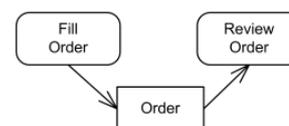
Interrupting connector: represented by a zig-zag arrow it is used to manage an exception that can occur during the execution of a relevant activity.



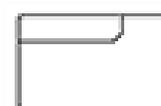
Input and output pin: represented by a small square attached to the activity rectangle it represents objects (such as information, document) that are inputs or outputs of the relevant activity.



Object: represented by a rectangle it describes an object (such as information, document) that is exchanged between two activities.



Loop: represented by a rectangle with a label on its top-left part it allows the creator to model a repetitive sequence of actions within the option loop symbol.



Note: represented by a rectangle with a top-right corner bent it allows the diagram creators or collaborators to communicate additional messages that don't fit within the diagram itself. Each can be related to a specific element (activity, message, actor, etc.) of the diagram.



3.4 Identification of the facilitators and barriers of optimum integration of care at the primary and secondary care interface for a child on LTV

A number of countries provided additional text in the commentary boxes at the end of each section of the survey. We analysed this to identify facilitators and barriers of optimum integration of care at the acute community interface for a child on LTV and their family. Three Global Themes (GTs) emerged from this data: 'family preparedness for transitioning to home', 'coordinated pathway to specialist care' and 'legal and governance structures' (Figure 3.18). The first two GTs are inextricably linked as optimum integration of care is reliant on the key constituent needs of parents being addressed when the child is being cared for in the hospital or in the home, while optimum integration requires the support of appropriate legal and governance structures. Many CAs provided examples of good practice and barriers to good practice in their country; examples are provided in text excerpts from countries across the EU/EEA with summary points at the end of each GT.

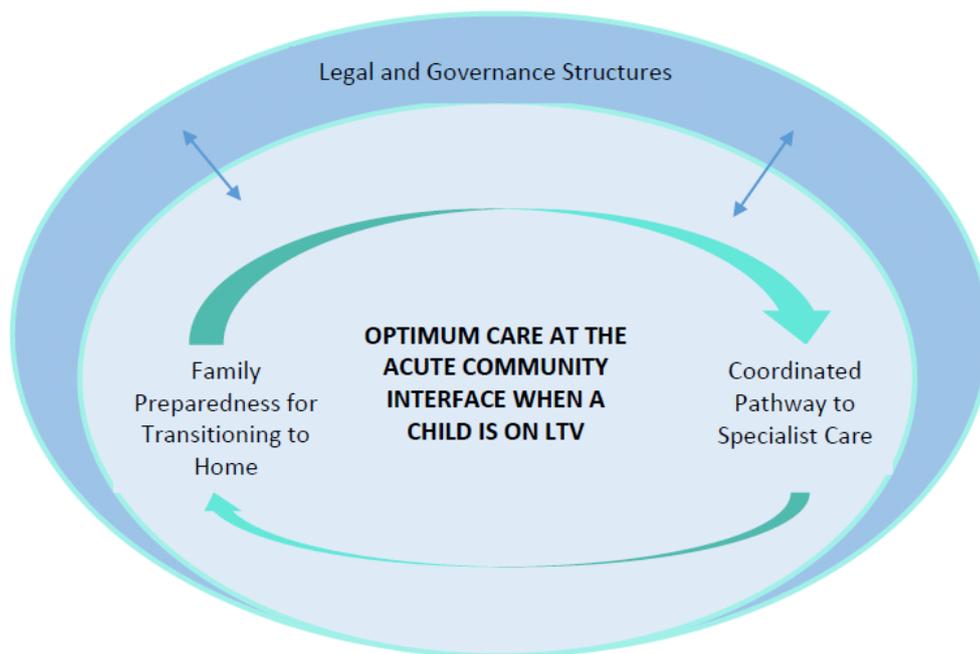


Figure 3.18 Factors influencing integration of care for a child on LTV

3.4.1 Family preparedness for transitioning to home

The GT ‘family preparedness for transitioning to home’ describes the facilitators and barriers of the optimum interface of care for children on LTV and their families, as parents transition to becoming the child’s primary care giver in the home. This GT emerged from accounts from CAs on facilitators of a successful transition to home currently in place in their country and arose from two organising themes (OTs) ‘individualised care’ and ‘discharge coordination’.

The OT ‘individualised care’ refers to the clinical readiness of parents to take care of their child on LTV following their discharge from hospital. A number of CAs reported on specific education programmes that worked well in their country:

Parents will be trained in the ICU in tracheostomy care, equipment, medicines etc. by the physicians and nurses in charge prior to their discharge to home. (Austria)

Accessibility to a translator service was identified as a key constituent to effective individualised care, to support equity of care and optimum readiness for caring for the child at home.

Local organisations have procedures to provide translator services for children and families. Such services are also used to translate information for written material. (Ireland)

It was suggested that parents are best supported in their transition to home when they have the opportunity to gradually increase their care input, according to their own perceived level of readiness to become the child’s primary caregiver. A phased step-down plan was identified as an appropriate way to facilitate this, whereby parents increase their input in to the clinical care of their child in an incremental manner.



If parents feel more secure, the child comes to a step down unit, where the parents share a greater part of care themselves, but know they can always call someone for support. The last step in inpatient care before discharging, is the regular ward, where the parents look after the child more-or-less themselves. There are no time limits for the duration of the stay, neither at the ICU, nor at the other wards. Only when the parents feel safe and do well, and agree, the child will be discharged at home. (Austria)

The second OT ‘discharge coordination’ emerged from data from a number of countries who provided examples of support offered to enhance family preparedness for transitioning to home. Central to this was the role of a Discharge Coordinator, who was identified as being the central point of communication and planning at the acute community interface, for specialist medical and nursing input, and for technical support and allied health input prior to discharge. In terms of specialist medical and nursing input, this refers to linking the acute care team with the community care team, to ensure the community care team would have a full picture of the clinical care needs of the child transitioning to home. In addition the discharge coordinator would ideally be responsible for ensuring all the technical support is appropriately planned and in place prior to the child’s discharge from hospital.

He/she contacts the parents and together with the transitional care person of the hospital and the social worker they discuss and organize all the technical equipment, social support which is needed, additional care...to the last detail. All necessary structures and processes for home ventilation of the child will be planned and will be available before discharge. (Austria)

Many countries who did not have a specific discharge coordinator for these children identified the absence of this role as a significant barrier to integration of care at the acute/community interface.

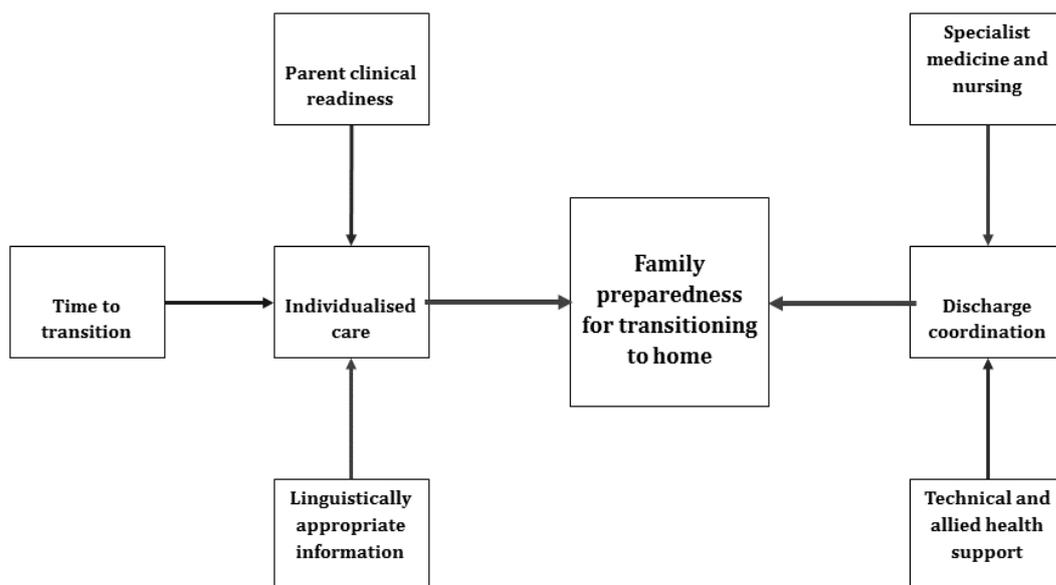


Figure 3.19 Emergence of global theme ‘family preparedness for transitioning to home’



3.4.2 Coordinated pathway to specialist services

This GT emerged as CAs emphasised the need for access for children on LTV, and their families, to specialist services once discharged. Repeatedly there was concern expressed about the inequity in the provision of specialist care, in that pathways to care rarely existed. The GT emerged from two OTs 'access to specialist unscheduled and urgent care' and 'pathway to non-urgent care'.

Timely access to specialist unscheduled care was identified as critical to the safe and effective care of the child on LTV. In the data returned this was referred to as the ability of families to access a PICU and a Paediatric Emergency Department (PED) 24/7. The need for a pathway for care, where the parameters for access were clearly understood was identified as critical to support this. In the event of significant respiratory dysfunction in the community immediate access to a PICU was identified as optimum practice. Many also identified the need for 24/7 access to a PED:

In case of an emergency situation, all patients can visit the emergency room 24 hrs a day 365 days a year. If something happens at home, the ambulance service is available (free for the patients) (Estonia)

A number of countries provided examples of what they considered to be good practice in access to urgent care in the community when a child is on LTV. This predominantly included having 24/7 access to a physician to seek clinical care advice. For example, in Estonia parents can access a physician, in person or by phone 24/7, locally or from abroad, to seek advice.

The OT 'pathway to non-urgent specialist care' emerged from four basic themes (BTs): monthly specialist home visit, psychological and psychiatric support, hospice and respite care, and complex care centres. CAs identified a need for a clear pathway for parents to access this support in the community from healthcare, allied healthcare and social care professionals. A number of CAs identified facilitators of optimum non-urgent access as depicted here:

There is a system called home visitation: medical staff consisting of one intensivist or paediatrician and an enrolled anaesthesiology nurse visits the child on a monthly basis. During this visits not only the tube replacement takes place, but a set of consultations happen. Primary caretakers are highly advised to attend, and welcomed, to meet the hospital staff in place. (Hungary)

There was considerable concern about the need for mental health support for children on LTV and their families. Three countries provided examples of services in this area, however, the majority of CAs reported no provision, or very limited availability, of psychological support:

All parents/.../ have the opportunity to receive professional psychiatric support. Psychology professionals are part of the interdisciplinary teams. (Austria)

The psychologist takes care of parents and siblings even after discharge, also directing them to the territorial referral service (Italy)

There was also concern expressed about the absence of respite care available for children on LTV. CAs reported the importance for families to have access to respite care, either in an unscheduled capacity where there may a family crisis or as non-urgent care to provide respite



for the child and family. For example in Poland it was reported that *there is strong palliative and hospice care network. The hospice care might have two forms home or institutionally based.*

The establishment of complex care centres was identified as an optimum way forward to enhance holistic care of the child on LTV and their families, to support access and availability to a wide variety of health and social care professionals. An example of this was provided by the CA from Bulgaria who described what was in place and described what it involved:

...centres for complex care for children with disabilities and chronic diseases are organisations in which medical and non-medical specialists perform at least one of the following activities: support of the families of children with disabilities and chronic diseases for prescribing and performing early diagnosis, treatment and medical and psychosocial rehabilitation; long term treatment and rehabilitation of children with disabilities and chronic diseases and education of parents for home-care; providing visits of medical specialists for specialised care of children with disabilities and severe chronic diseases, who are looked after at home or at social care residential home; providing specialised palliative care for children.... These centres are currently under construction. Gradually they are starting to function effectively.

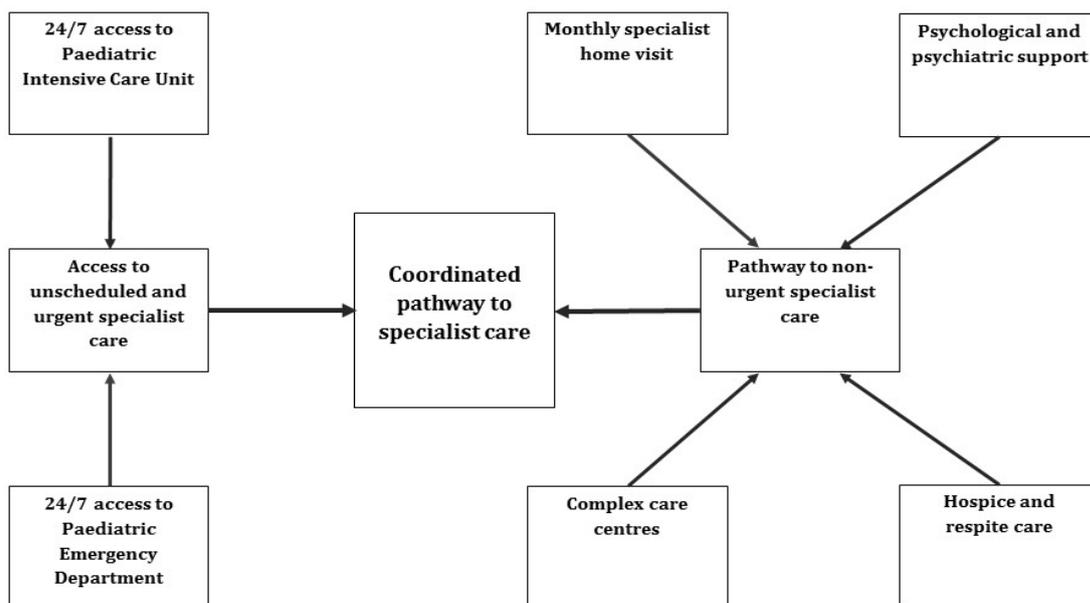


Figure 3.20 Emergence of global theme coordinated pathway to specialist care

3.4.3 Legal, policy and governance structures

The GT ‘legal, policy and governance structures’ emerged from the presentation of a number of areas identified as facilitators and barriers of optimum care delivery at the acute community interface including infrastructure, standards of care delivery, legal status and advocacy.

The OT ‘infrastructure’ emerged from data provided by the CAs on key issues that influence the opportunities for optimum integration of care at the acute community interface. These included



geographical variation in access to care, challenges with transport and difficulties with volunteer support. Many countries highlighted concern about inequity in access to care for children on LTV. The CAs reported that resource allocation to support care for children on LTV can vary according to funding in different geographical areas and they also highlighted that access to specialist care, to support the child transitioning to home, varied considerably between urban and rural locations. In some cases this would mean that if a child lived outside an urban centre the family may not be able to access sufficient care for their child to live at home.

In the event the family lived outside Athens or other large urban centres without a paediatric hospital Max's care could not be undertaken at home. (Greece)

The level of service provision is resource limited and contingent on the availability of services in a geographical area. (Ireland)

Challenges were also identified regarding the transport of children on LTV regardless of the child's geographical location with one CA reporting that *ambulances are often too small for the ventilation material* (Netherlands).

The OT 'standards of care delivery' emerged from three BTs: governance of care in the home, national strategy and data access and communication. The issue of governance of care in the home emerged a number of times in comments from the CAs. Examples of good practice in this area were provided:

Checks in the home care sector will be done by the competence team (Austria)

Trained home carers (beyond family members) are available and funded by the Social Insurance Board. (Estonia)

However, the majority of CAs reported a number of challenges in governance of care in the home including lack of governance of care agencies and inadequate education of nursing and care staff to care for a child on LTV in the home.

The home nurses as well as the 24h nurses are not trained specifically and not familiar with the individual needs of the child. (Austria)

This challenge was explained by some CAs by the fact that the number of children on LTV in their country was not very high, and thereby the experience of caring for them was limited. Lack of available clinical expertise in this area was also attributed to an overall shortage of healthcare professionals in many countries. Nonetheless, where this happens it was highlighted that all of the responsibility falls back to the parents.

The majority of CAs suggested that a national strategy on the management of children on LTV would begin to address many of the issues raised. However, they highlight that at present there is a predominant absence of such a strategy or any associated standards of care. The consequences of the absence of such a strategy or standards of care were explained further by a number of CAs. This included no standardised needs-assessment or re-assessment for children and their families. This was again identified as an issue of potential inequity in access to, and delivery of, care to these children and their families.



There is no standardised needs-assessment for children on LTV which consequently can lead to disparities and variations in services. (Ireland)

A further consequence of this issue is the challenge of data access and communication between families and healthcare professionals. This included the absence of shared documentation, which was identified as problematic by the majority of respondents. A number of suggestions were made regarding how this could be addressed including the establishment of a national registry of patients on LTV and structures to support data access:

There is a registry based on the Respiratory Society of the Portuguese Society of Paediatrics, and an easy communication between peers (Portugal)

The role of care coordinator to support integration at the acute community interface was identified as pivotal to address some of the issues raised.

It was highlighted in a number of CA responses that the child's legal status was important in facilitating integration of care delivery, this included where the child had official disability status and where there was a legal right established in a country affording right to long-term care for patients with respiratory problems.

All persons with disability receive a Disability Card... The purpose of the card is to simplify certification of the degree of disability in connection with exercising the rights granted to the disabled and receiving various concessions. (Estonia)

The right to care is guaranteed.... long term care for patients with respiratory problems is included... guaranteed benefits in the field of nursing and care services for long-term care. Those documents are the legal basis for the services of long-term care. (Poland)

The role of non-governmental organisations (NGOs) was identified as a very important facilitator for integration of care at the acute community interface, by virtue of the many roles they can play in supporting optimum care delivery. Examples of the supportive role of NGOs included: fundraising to support state funding for care delivery; volunteers and staff from NGOs to organise and deliver care to children on LTV and their families; and acting as advocates for the needs of these families. The need for parents of children on LTV to have a voice was very strong in the data gathered and in many countries it was identified that parents had a very limited voice at the policy table. Specifically NGOs were identified as working very well when there was a structured means of communicating parent issues to government representatives, as depicted here in a response from the CA in Bulgaria:

There are many NGOs which are officially recognised as representative organisations. They are asked for opinions and statements for documents under a project by the Ministry of Health (and other Ministries as well like the Ministry of Education, Ministry of Labour and Social Policy etc)

However, in a number of countries 'parents voices in initiatives' were not present. In some countries CAs reported no such system of volunteers or charity organisations to provide care or support for children on LTV and their families. This was identified as a significant barrier to the provision of care for this population.



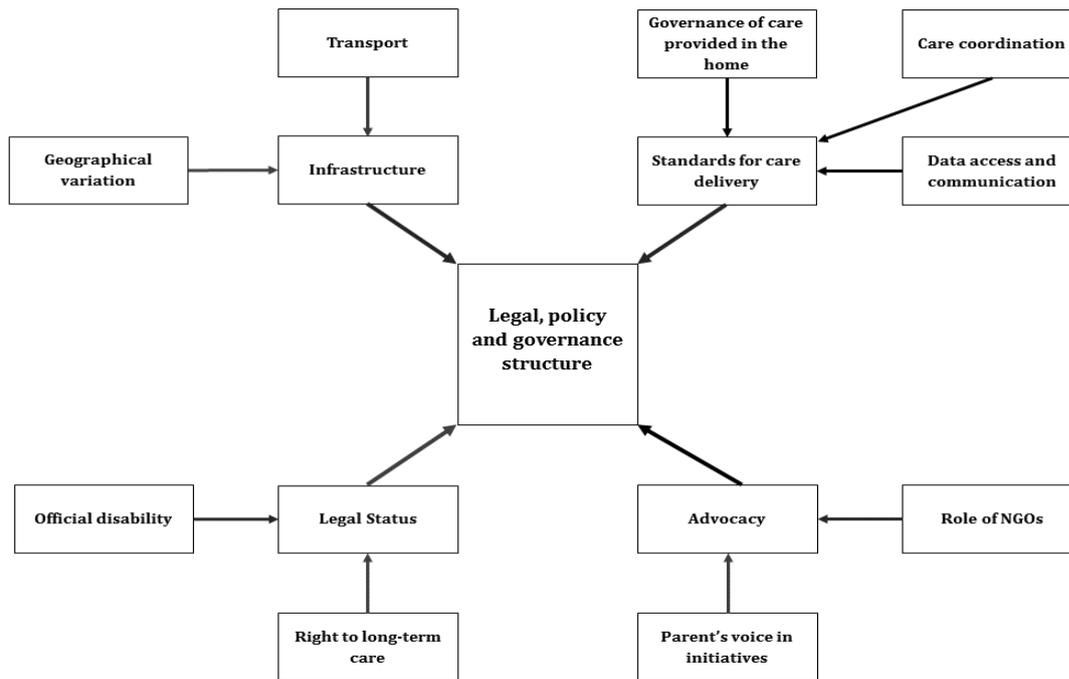


Figure 3.21 Emergence of global theme legal, policy and governance structures

3.5 Summary of optimum integration of care at the acute community interface for a child on LTV

- Tailored education programmes to support clinical readiness of parents to become primary care givers.
- Phased step-down plan where parents increase input into clinical care prior to discharge to home.
- Pathways for access to specialist care including access to a PICU and PED 24/7, access to a physician 24/7 and a pathway for accessing respite care.
- Complex care centres which serve as a 'one-stop-shop' for health and social care services.
- Addressing geographical variability in ability to access community care when a child in on LTV.
- Enhanced governance of care delivery in the home.
- Enhanced education of nursing and care staff to care for children on LTV.
- National standards for the care of children on LTV.
- Establishment of national registry of children on LTV.
- Shared documentation to enhance care coordination and integration.
- Official disability status.
- Ongoing NGO advocacy role.

Chapter 4

Management of a Child with Intractable Epilepsy at the Acute Community Interface

4.1 Introduction

This chapter reports on the findings on the standards and processes in place to manage the care of a child with intractable epilepsy at the acute community interface. A total of 25 surveys were returned from a possible 30 countries (83.3%). The respondent of one country provided a narrative account of the care of children with intractable epilepsy focusing on the care provided in response to disability severity. The response provided by this country was not included in the descriptive analysis of the categorical data. The results of this analysis, therefore, pertain to 24 (80.0%) countries.

4.2 Structures and processes of care in place for a child with intractable epilepsy

The structures and processes in place to manage the care of a child with intractable epilepsy were explored under six domains of the adapted *Standards for Systems of Care for Children and Youth with Special Health Care Needs*: screening, assessment and referral; access to care; care coordination; community-based services and supports; family-professional partnerships and quality assurance.

4.2.1 Screening, assessment and referral

Half of all respondents indicated that there is national and/or regional guidance to support local primary care centres in their country with the care of children with intractable epilepsy (50.0%, $n=12$) (Figure 4.1). In addition, over half of the respondents indicated that their countries have specific mechanisms (policies and procedures/policies or procedures alone), which support preventative screening, developmental assessment and referral of children with intractable epilepsy (54.2%, $n=13$) (Figure 4.2). Furthermore, over one-third (45.9%, $n=11$) of respondents indicated that there are specific mechanisms (policies and procedures/policies or procedures alone) in their country regarding documentation and communication of preventative screening, developmental assessment results, and referrals to all service providers who are engaged in the care of children with intractable epilepsy (Figure 4.3). A similar proportion of respondents indicated that there is a documented mechanism or mechanisms in place in their country, which supports the communication of preventative screening, developmental assessment results and referrals to the parents/guardians of these children (Figure 4.4).



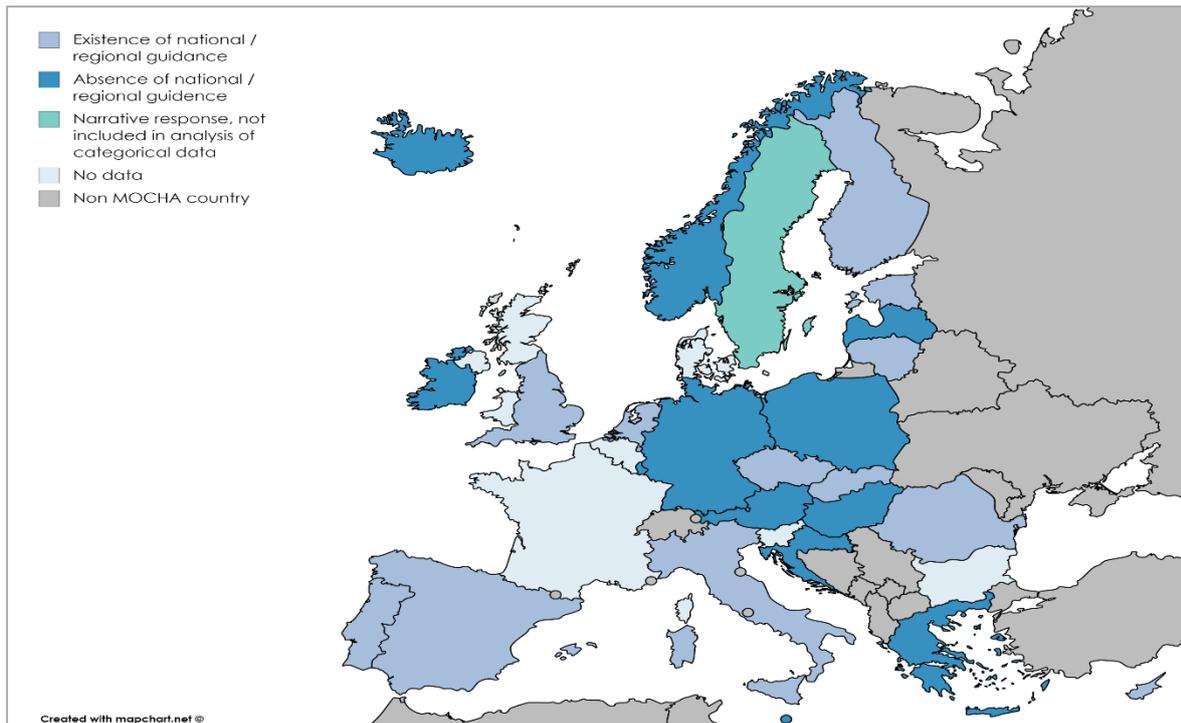


Figure 4.1 Countries with/without national or regional guidance to assist local primary care centres with the care of children with intractable epilepsy

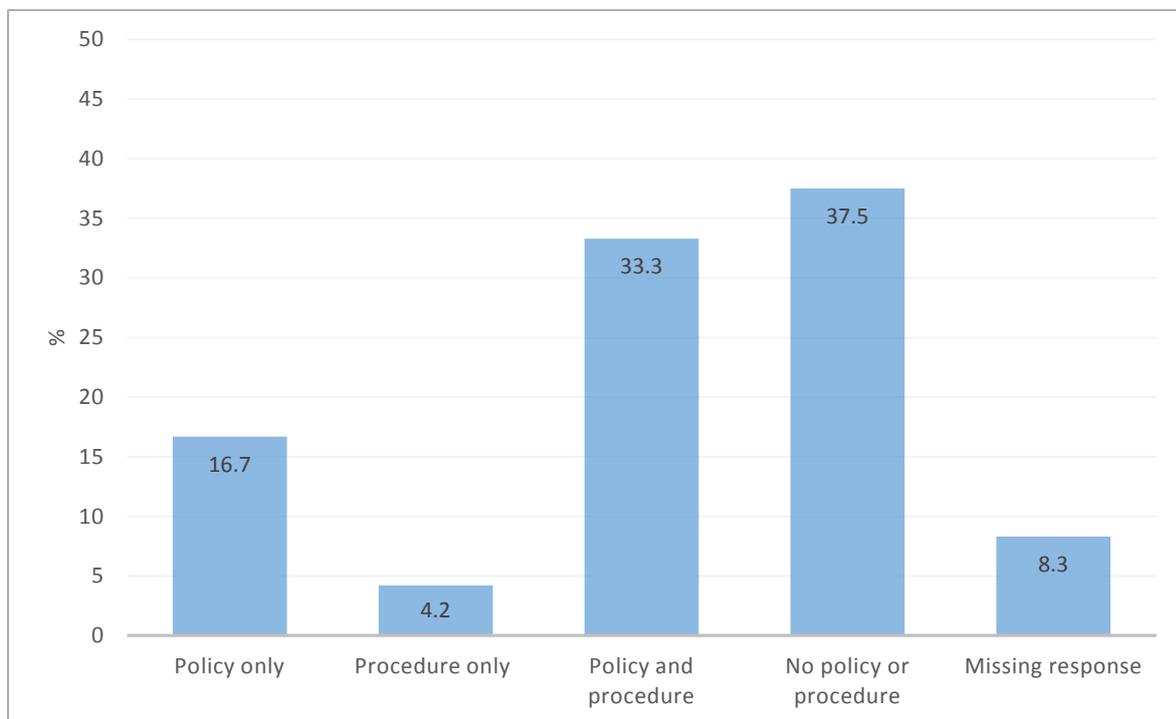


Figure 4.2 Proportion of countries with policies and/or procedures in place, which support preventative care screenings and developmental checks for children with intractable epilepsy

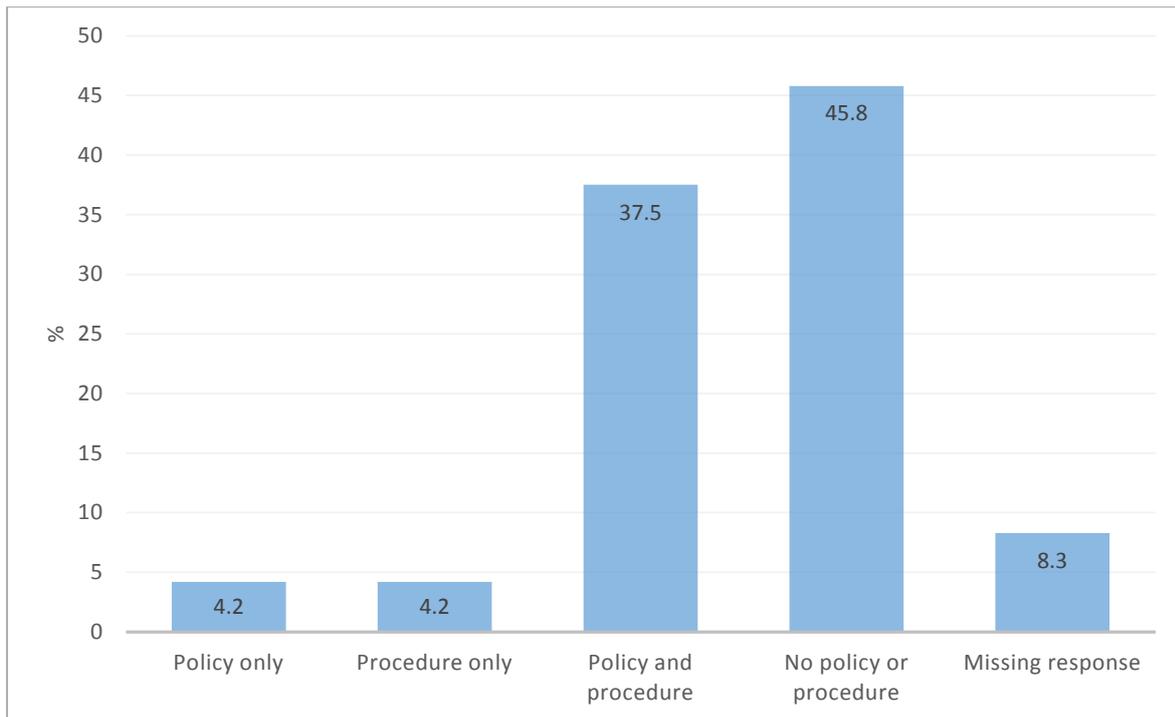


Figure 4.3 Proportion of countries with policies and/or procedures in place to document and communicate the results of screening or developmental checks for children with intractable epilepsy to all care services

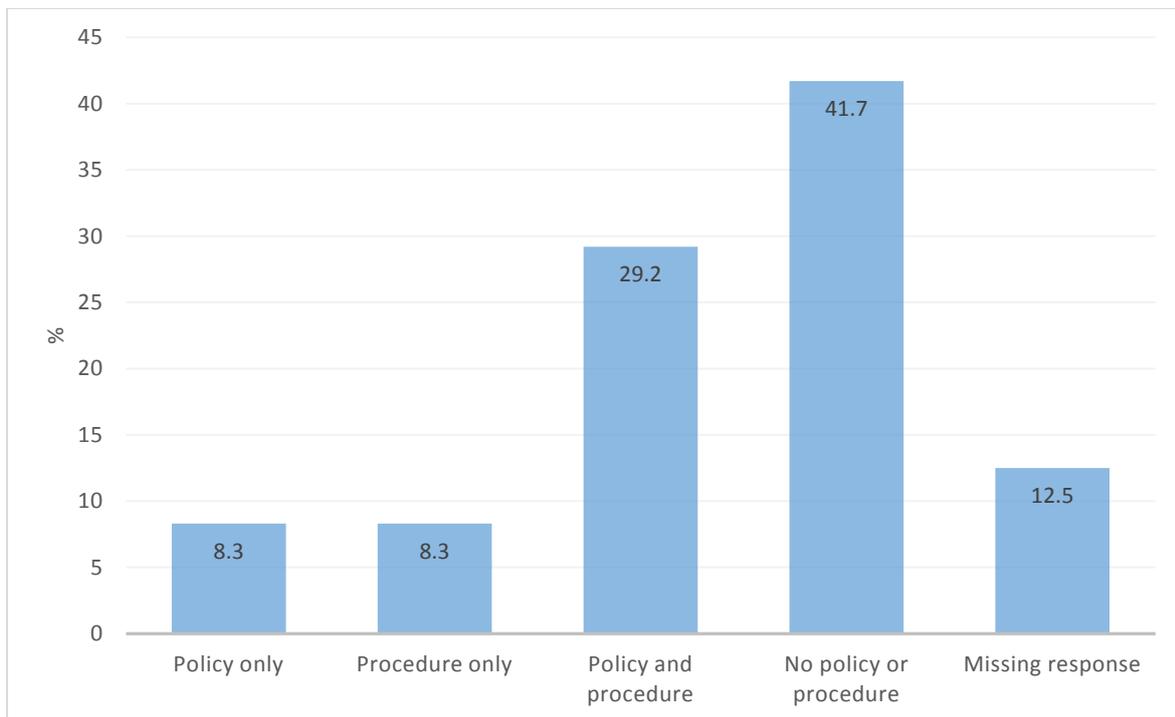


Figure 4.4 Proportion of countries with policies and/or procedures in place to document and communicate the results of screening or developmental checks to the parents/guardians of children with intractable epilepsy

4.2.2 Access to care

Half of participating countries have a system in place that can identify all of the healthcare providers who care for children with intractable epilepsy (50.0%, $n = 12$) (Figure 4.5). The transport of children with intractable epilepsy to accommodate regular daily activities and/or healthcare appointments is facilitated in four (16.7%) countries by their parents/guardians, without any additional support from the State or healthcare provider. The State provides some assistance to parents/guardians with the daily transport requirements of their children in seven (29.2%) countries. Some families of children with intractable epilepsy facilitate their child's transport requirements with varying levels of support from both the State and healthcare providers (26.1%, $n = 7$) (Figure 4.6).

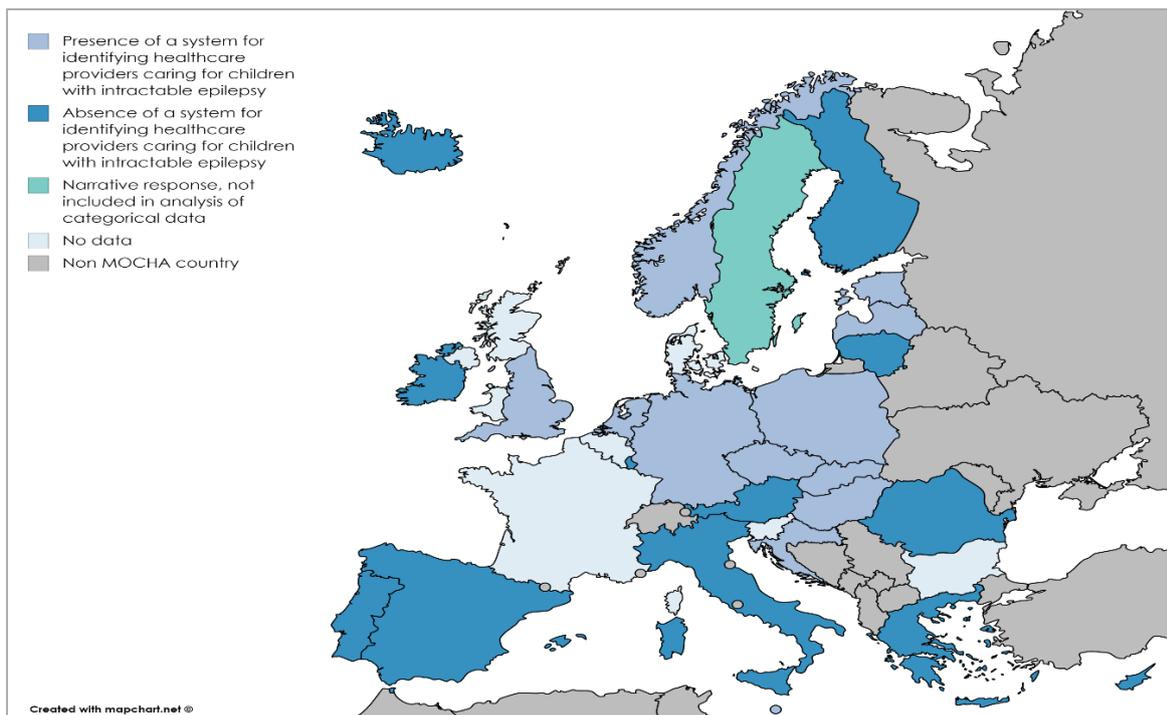


Figure 4.5 Countries with/without systems in place to identify all healthcare providers caring for children with intractable epilepsy

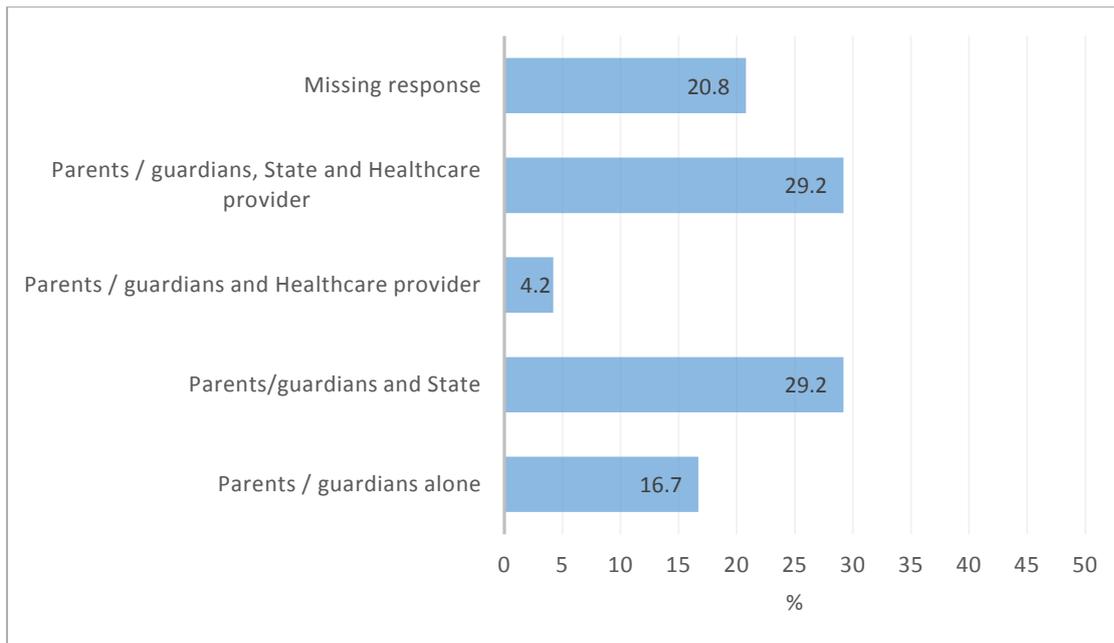


Figure 4.6 Proportional responsibility for the provision of transport to accommodate the daily activities and healthcare visits of children with intractable epilepsy

Over half of the respondents indicated that there are no policies or procedures in place to support the provision of linguistically appropriate (54.2%, $n=13$) and culturally appropriate (58.3%, $n=14$) information to the families of children with intractable epilepsy in their countries (Figure 4.7).

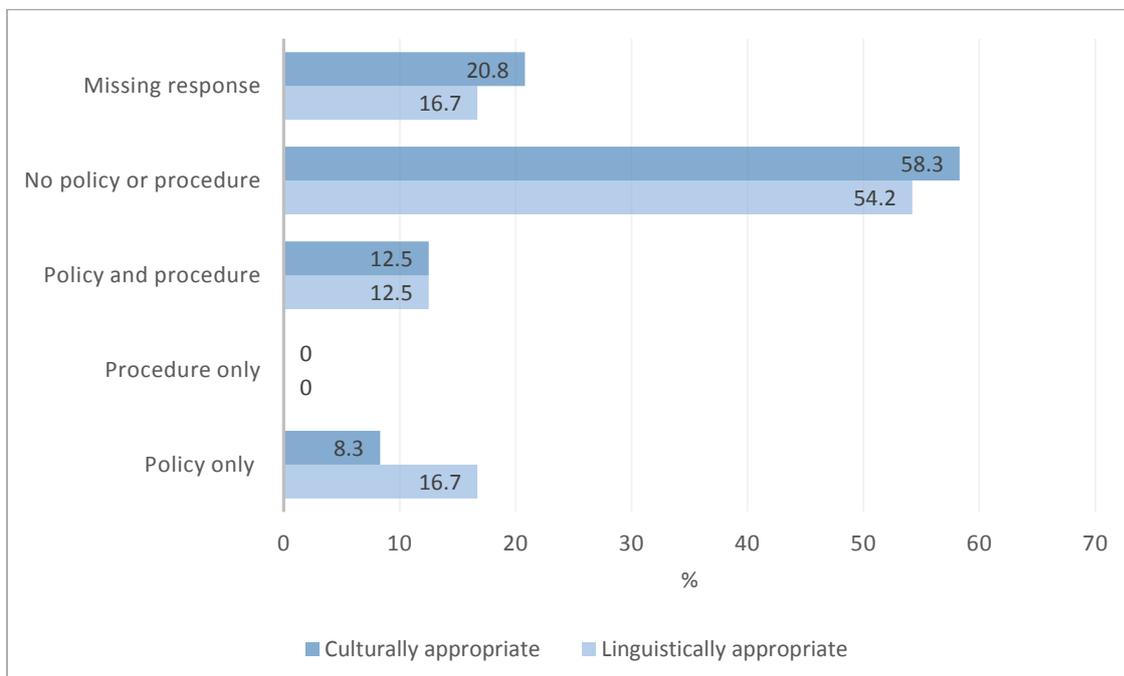


Figure 4.7 Proportion of countries with policies and/or procedure that support the provision of linguistically appropriate and/or culturally appropriate information to the families of children with intractable epilepsy

4.2.3 Care coordination

Over half of respondents (54.1%, $n=12$) indicated that there are mechanisms (policies and procedures/policies or procedures alone) in their country, which support the coordination of care for children with intractable epilepsy (Figure 4.8). A similar proportion of respondents reported that members of the healthcare team are involved in the development of personalised care plans for children with intractable epilepsy (Figure 4.9). In addition, three-quarters of respondents reported that parents/guardians (75.0%, $n=18$) are involved in the development of their children's care plans.

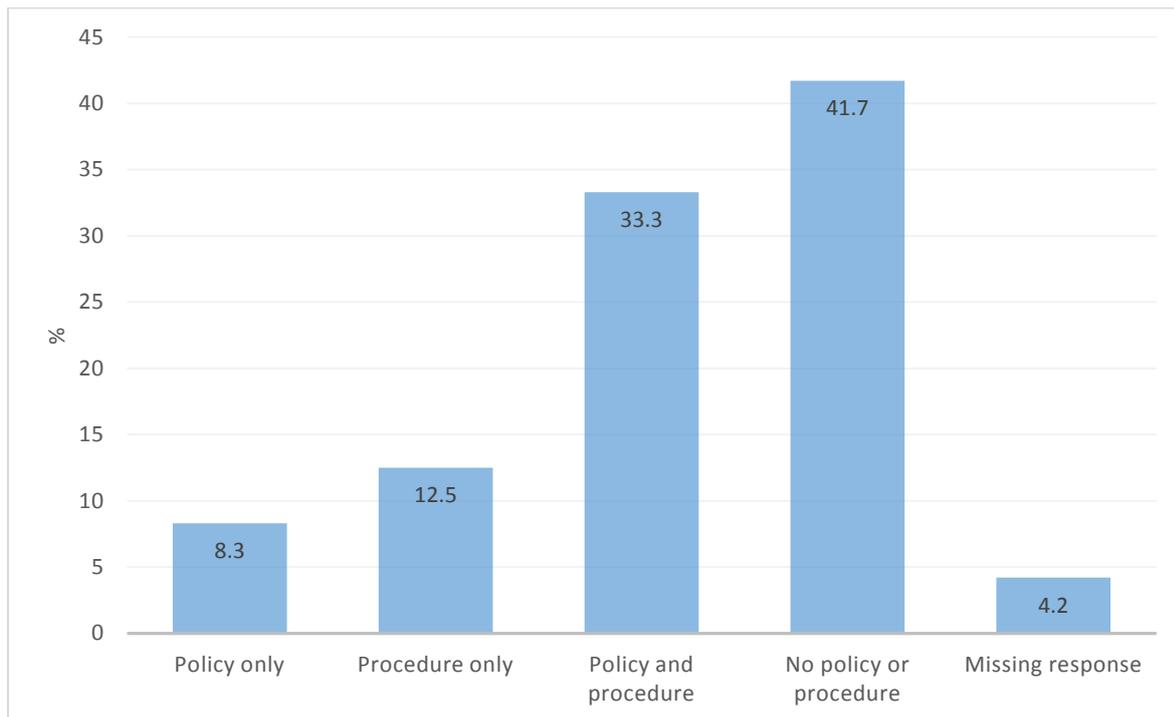


Figure 4.8 Proportion of countries with policies and/or procedures in place promoting care coordination for children with intractable epilepsy

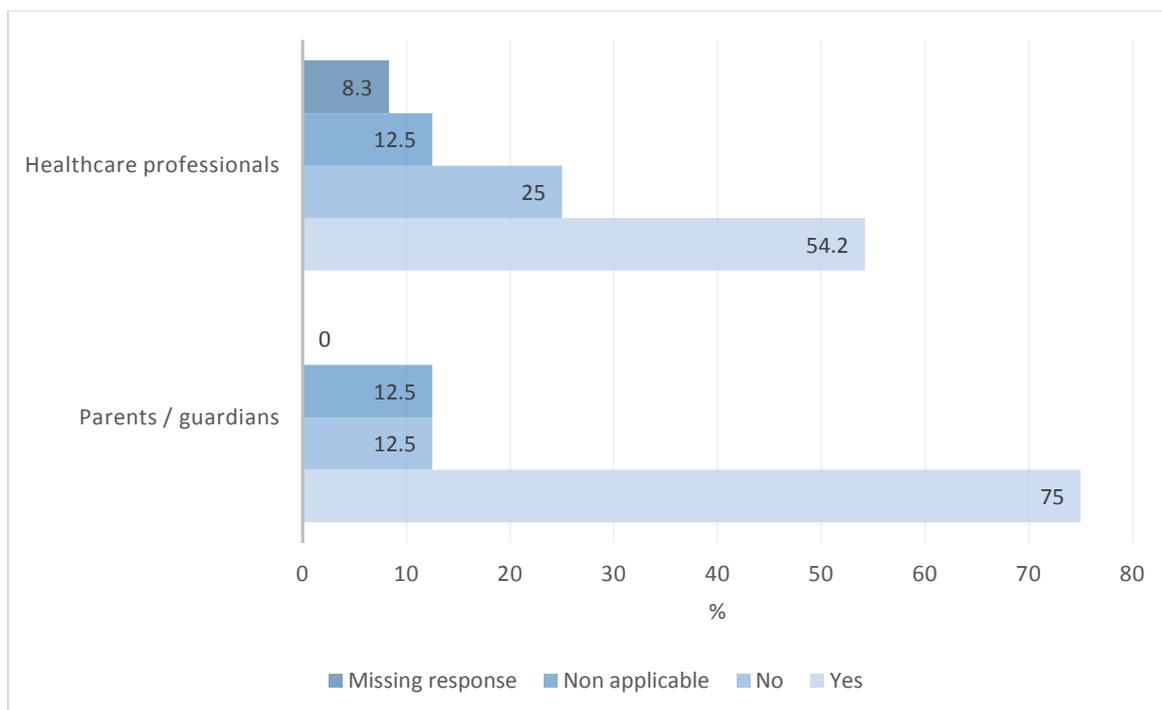


Figure 4.9 Individuals consulted regarding the development of a personalised care plan for a child with intractable epilepsy

Developmental assessments are included in the personalised care plan for a child with intractable epilepsy in the majority of countries (75.0%, $n = 18$) (Figure 4.10). Mental health, vision and hearing assessments are included in the personalised care plan for these children in over two-thirds of the countries (70.8%, $n=17$), while oral health assessments are included in just over a half of countries (54.2%, $n=13$) (Figure 4.10). The respondents from three countries (12.5%) reported that written personalised care plans are not developed for children with intractable epilepsy. The respondent from one country (4.4%) indicated that although there is no national care plan for children with intractable epilepsy, they may receive such assessments through care plans that are implemented at a local level.

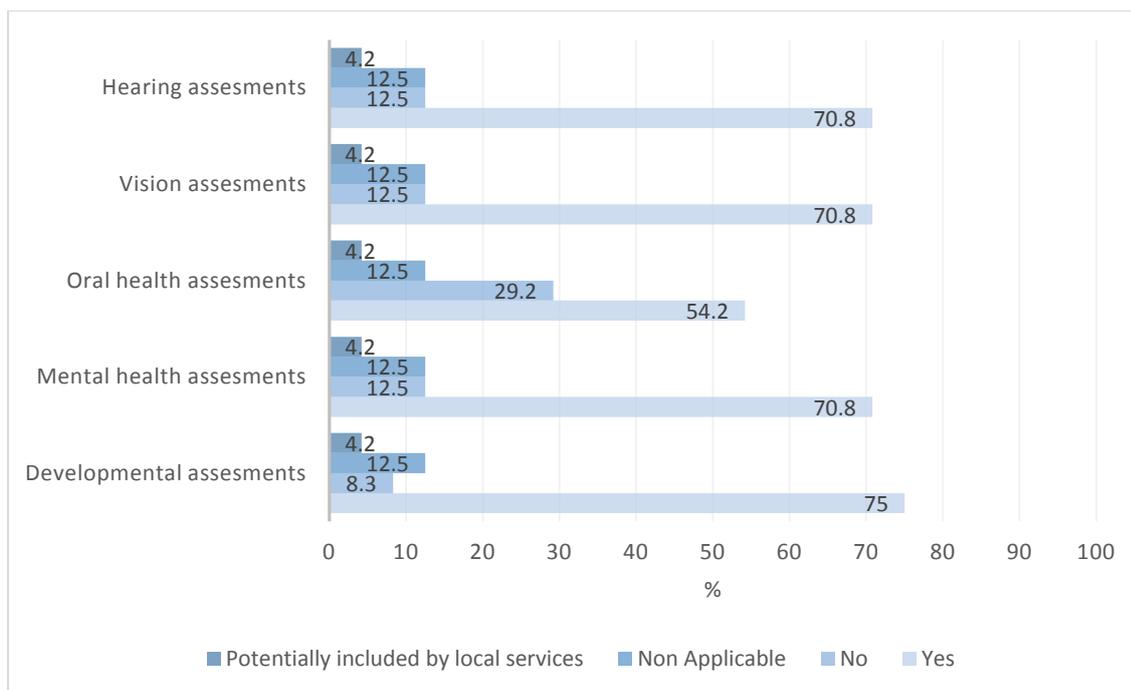


Figure 4.10 Types of health assessments included in the personalised care plan for children with intractable epilepsy in participating countries

4.2.4 Community-based services and supports

The analysis indicates that family advocacy groups are involved in making recommendations to home and community-based epilepsy services in the majority of participating countries (70.8%, $n = 17$) (Figure 4.11). Furthermore, the results of the analysis shows that the parents/guardians and siblings of children with intractable epilepsy have access to psychological support in the majority (87.5%, $n=21$) of participating countries (Figure 4.12).

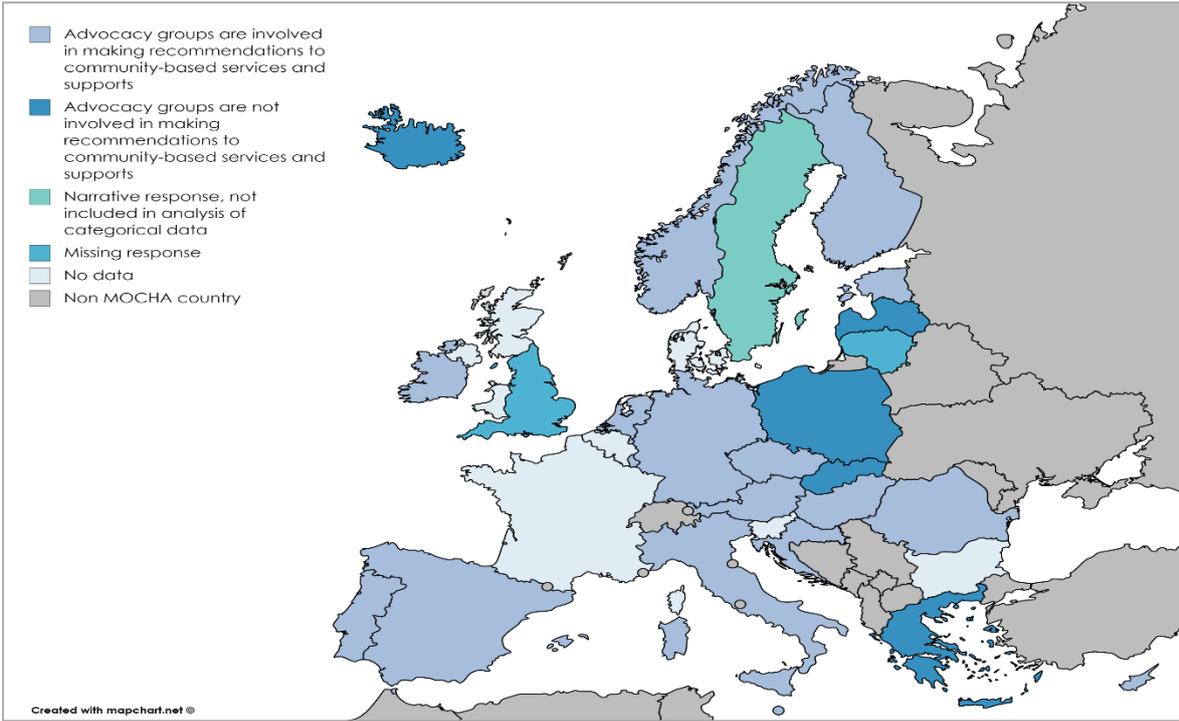


Figure 4.11 The involvement of family advocacy groups in making recommendations to home and community based services for children with intractable epilepsy

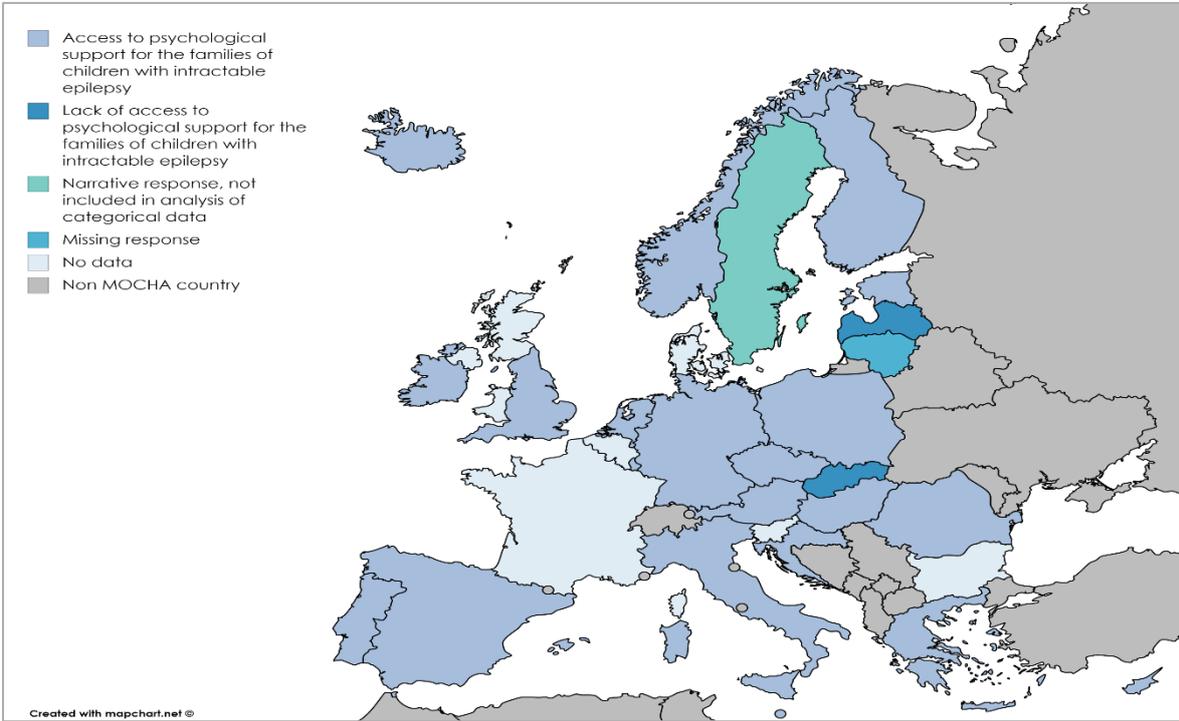


Figure 4.12 Access to psychological support from professionals with paediatric expertise for parents/guardians and siblings of children with intractable epilepsy

4.2.5 Family-professional partnerships

Parents and guardians of children with intractable epilepsy are invited to participate in the development of policies and procedures affecting their children in over half of participating countries (58.3%, $n=14$) (Figure 4.13). The respondents from ten countries (41.7%) reported that the views of parents and guardians of children with intractable epilepsy are included in national quality improvement initiatives in their respective countries (Figure 4.14).

Respondents from nine (37.5%) countries indicated that the parents and guardians of these children are involved in the review of information regarding epilepsy to ensure that it is culturally appropriate and linguistically appropriate (Figure 4.15).

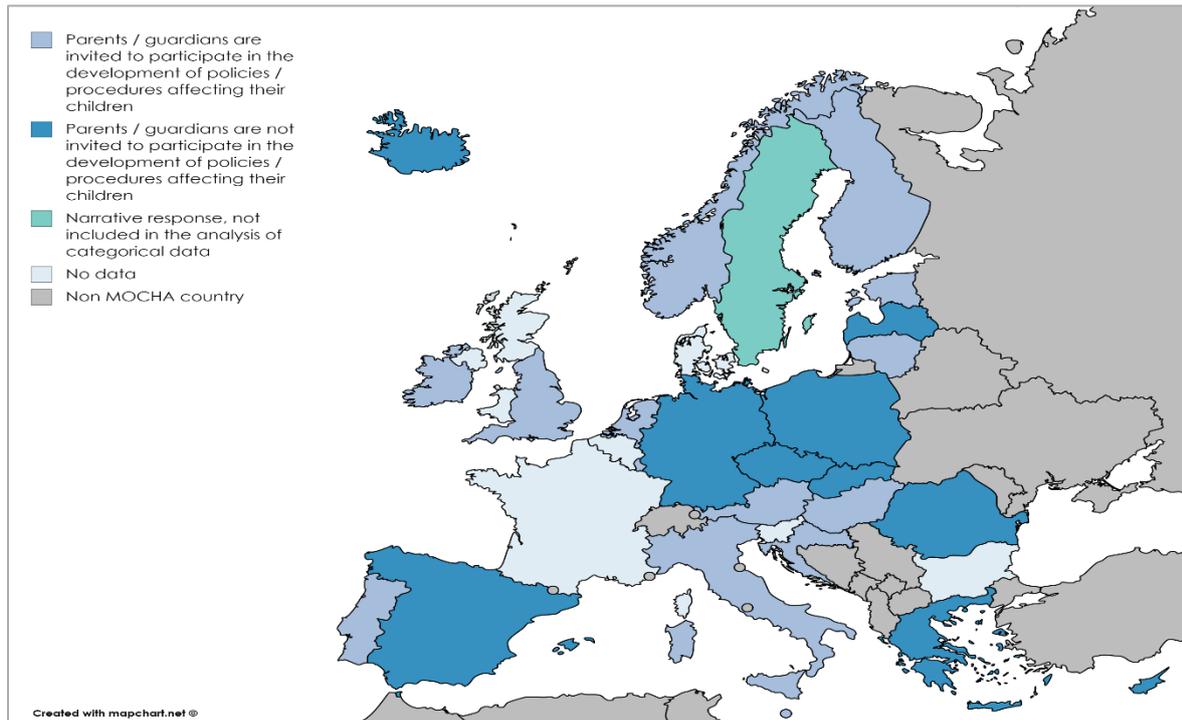


Figure 4.13 The inclusion of parents/guardians of children with intractable epilepsy in the development of policies and procedures affecting their children

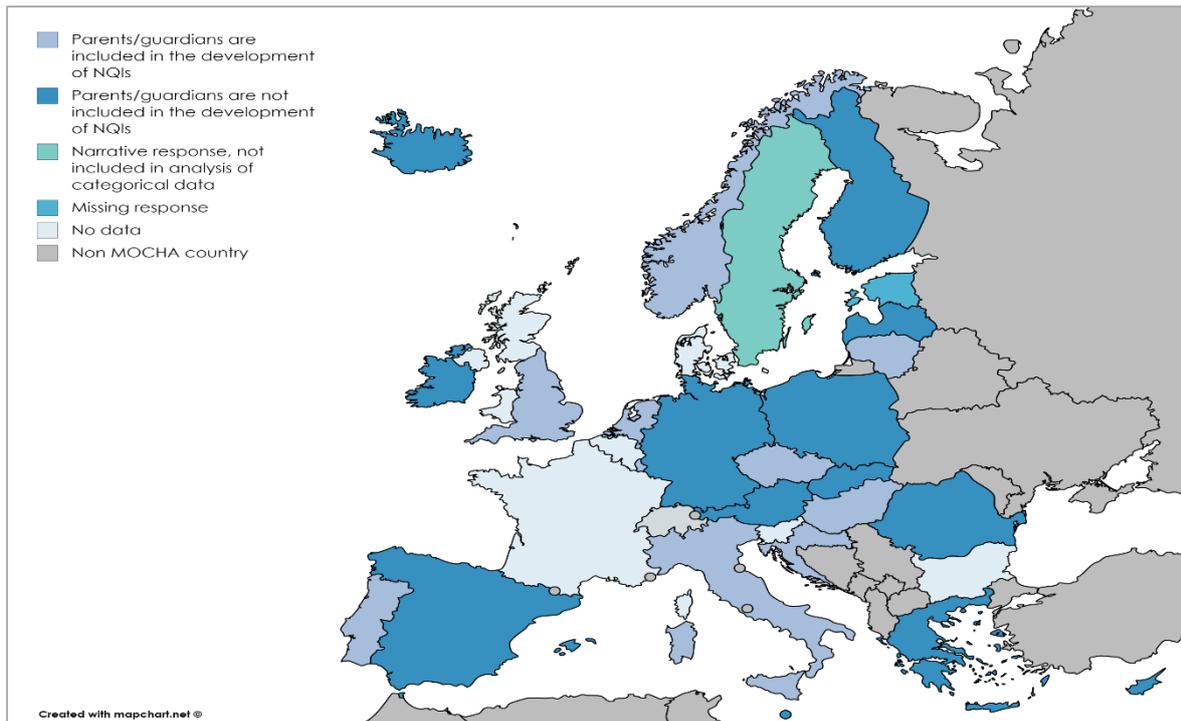


Figure 4.14 The inclusion of parental and guardian opinion in national quality improvement initiatives related to the care of children with intractable epilepsy

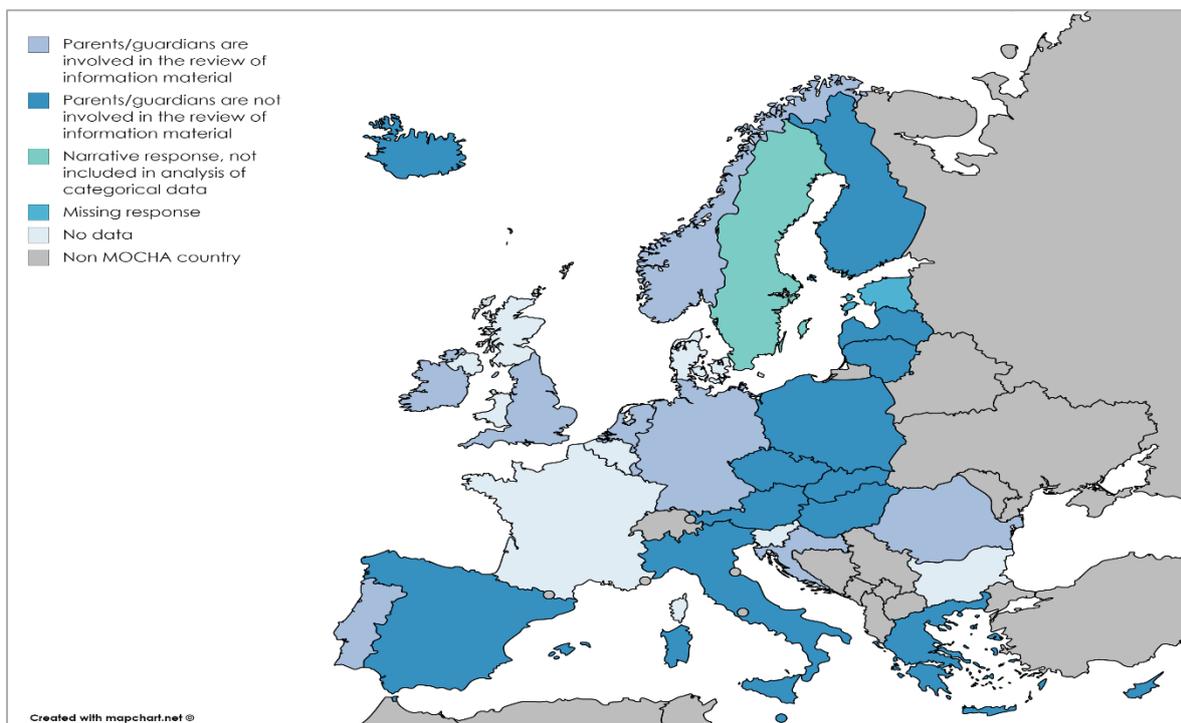


Figure 4.15 The inclusion of parents and guardians of children with intractable epilepsy in the review of information material

4.2.6 Quality assurance

Over one-third of respondents (37.5%, $n = 9$) indicated that their country has policies and procedures in place to support quality assurance for service providers of children with intractable epilepsy. The respondents from a further two countries (8.3%) indicated that their countries had policies relating to quality assurance but that they do not have procedures in place to support this (Figure 4.16). The majority of countries do not currently collect data on the experience of care from the perspective of the parents/guardians (75.0%, $n=18$) or siblings (91.7%, $n=22$) of children with intractable epilepsy (Figure 4.17).

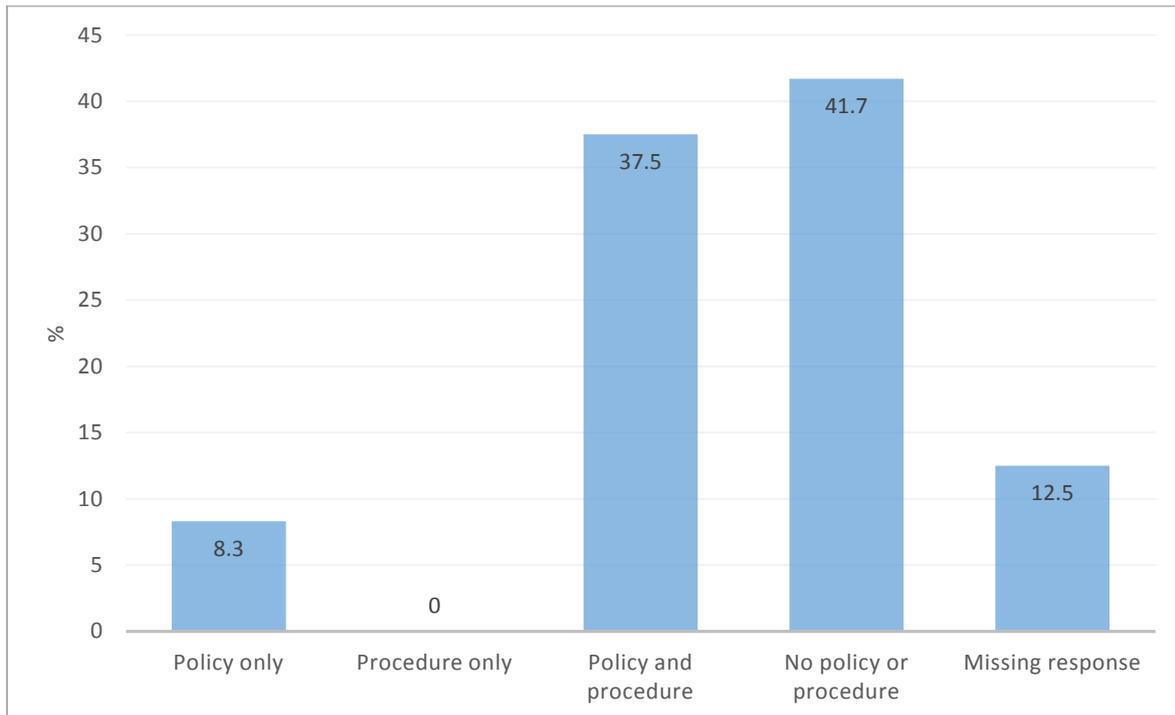


Figure 4.16 Participating countries with/without quality assurance policies and /or procedures for service providers caring for children with intractable epilepsy

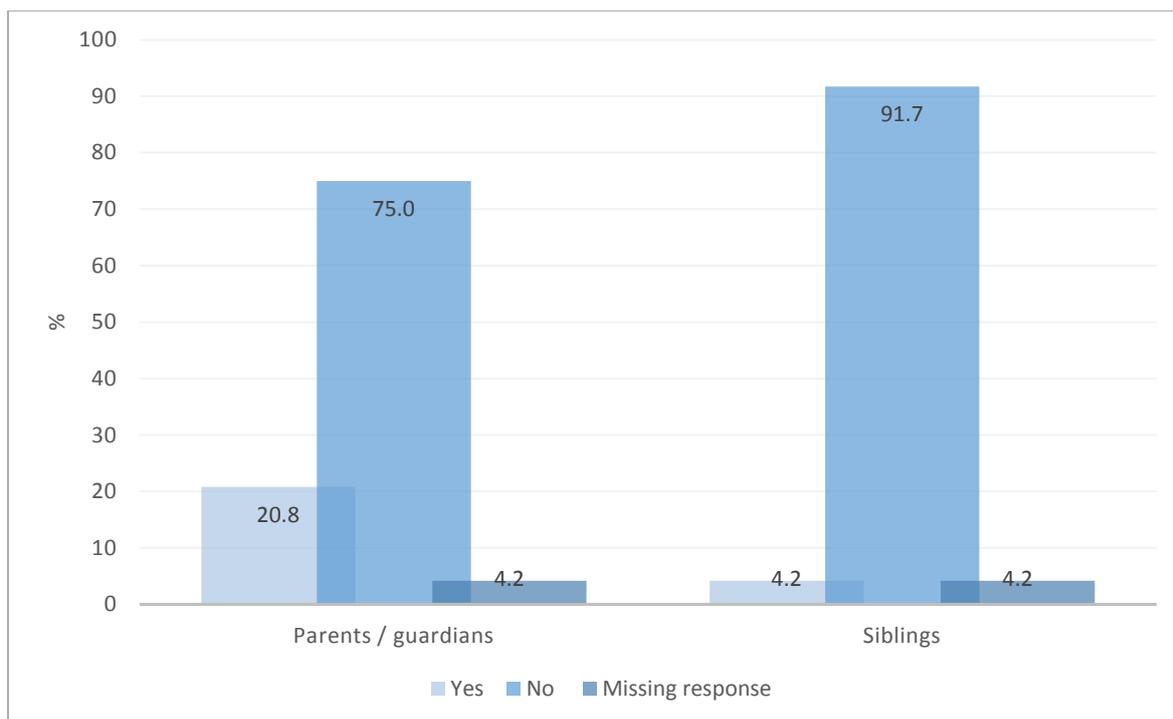


Figure 4.17 Proportion of participating countries that collect data on the care experience of children with intractable epilepsy from the perspective of their parents/guardians and siblings

4.3 Summary of key results in the management of care of a child with intractable epilepsy

- There are limited mechanisms in place to support preventative care screening and developmental checks, and to communicate the results of such screening.
- Few countries have a system in place to identify all of the healthcare providers who care for children with intractable epilepsy.
- There is widely reported involvement of family advocacy groups in the development of care plans and in the provision of recommendations to community-based services.
- There are limited mechanisms in place to support care coordination.
- There is widely reported availability of psychological support for parents/guardians and siblings of children with intractable epilepsy.
- The majority of countries do not collect data on the experience of care from the perspective of the parents/guardians or siblings of children with intractable epilepsy.

4.4 Identification of facilitators and barriers of the optimum integration of care at the primary and secondary care interface for children with intractable epilepsy

A number of countries provided additional text data in the commentary boxes at the end of each section of the survey. Three Global Themes (GTs) emerged from this data: ‘transitions in care’,



‘communication’ and ‘care coordination’. Similar to the data from TBI and LTV, the nature of each GT is such that it has an interdependency on each of the other GTs and knowledge on the topic is therefore cumulative.

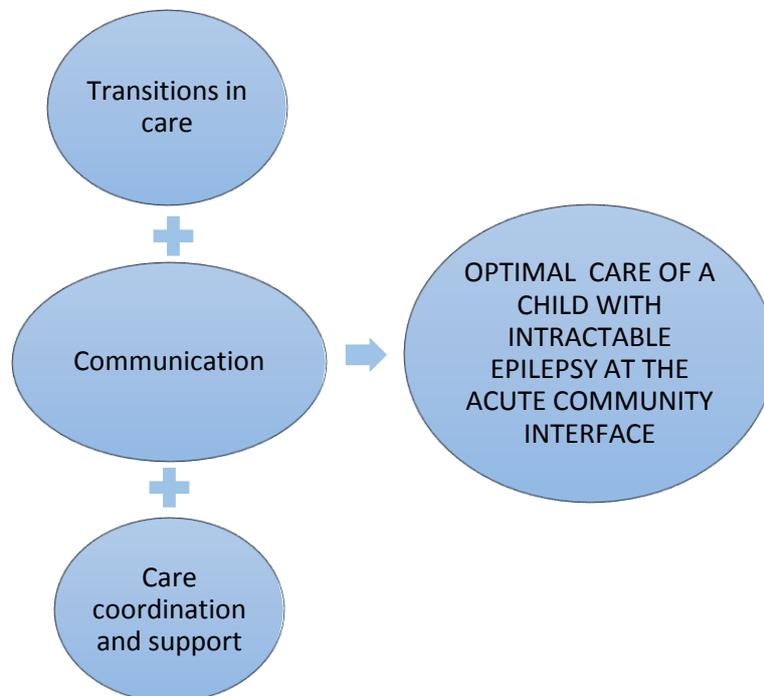


Figure 4.18 Global themes for intractable epilepsy in context

4.4.1 Transitions in care

The GT ‘transitions in care’ describes issues of screening, assessment and access to care. Many countries reported that a child such as Lara would be referred initially to a specialist centre for assessment and in some countries (dependent on size), care would be managed there in its entirety:

The majority of the children are referred to Makarios Hospital and the follow up is undertaken by the paediatric neurologist. Rarely the child might be admitted in another hospital... (Cyprus)

Across the respondents, only a small number indicated any evidence of a strategic and systemic network to co-ordinate care although where reported, this did seem dependent on access to local paediatric neurology services and dependent on personal and professional relationships:

Children with complex and intractable epilepsy usually receive continuous (dispensary) care in one of the four specialized Departments of Pediatric Neurology. There is a national consensus and collaboration of these centers, but the local centre is responsible for the final decision stream-lined to the local/regional existing healthcare environment. (Czech Republic)

In some countries primary care appeared to take a lead in referral and assessment procedures:



Primary health care (family) physicians take care and monitor children with chronic diseases (including epilepsy) and his/her compliance to medicine. If the child needs specialized care, the family physician can refer the child to a paediatric neurologist at a regional [hospital] of the family's choice (Estonia)

However, for most countries, the divide between centres of excellence, often based in the capital city, and local service provision led to fragmentation in policies and procedures, poor evidence of protocols for early identification of epilepsy in high-risk populations and management of co-morbidities. Very few countries were able to identify policies and procedures which specifically focused on epilepsy management. It is noted that in some cases, there was a balance between the referral process based on the actual diagnosis of epilepsy and the extent to which this resulted in disability which meant that care was managed through a disability service:

Health care professionals admit that in our country there is a deficiency of comprehensive system of care for children with a variety of health problems and disabilities, which would provide constant monitoring of their needs and would evaluate their physical and emotional development. Therefore, it is recommended that parents would first have identified the level of disability of their children, which gives rise to certain allowances and entitlements, and support from non-governmental organizations (Poland)

An important factor here is that for some, care was based on need rather than diagnosis:

...it is likely that children such as Lara would be linked in with community based disability services which may initiate and provide ongoing assessment and screening. As part of the national programme, progressing Disability Services for Children and Young People, many community based services are being reconfigured into Children's Disability Network Teams in order to provide integrated care based on needs rather than diagnosis (Ireland)

In the Swedish system the care would be determined primarily by Lara's severe disability and not her epilepsy (Sweden)

One good example, which largely reflects the experience of many countries in terms of screening, access and referral was offered by Romania:

Children are being sent by the general practitioner, from emergency rooms or by pediatrician. After they get the diagnosis of epilepsy they are periodically monitored by the specialist at a local medical service or from a tertiary center; a visit schedule is convened with parents in order to have periodical evaluations by the clinician; depending on the clinical evaluation, there are further investigations: EEG, neuro-psychological tests, blood tests, imagery, and eventual other clinical investigations/ examinations (Romania)

Some countries reported good levels of access to care, with appropriate referral patterns to specialist services where needed. There was evidence of parental choice in terms of where to access services:

In the majority of cases there is a culture of good professional collegial collaboration horizontally and vertically in the Czech healthcare system. Hand-overs do not have a rigid structure, but since most of the documentation is handled by information systems, information flow is generally assured (Czech Republic).



It was noted that where adult services had developed systems, there was an increased likelihood of a better child-focused service.

The National Clinical Care Programme for Epilepsy is focused on the provision of care for adults with epilepsy. Respondents to this questionnaire agreed that the Programme has also positively influenced paediatric epilepsy service delivery by supporting the development of Advanced Nurse Practitioner posts in Children's Epilepsy, providing a model of integrated...streamlined care and the development of SOPs, which are adult focused but which nevertheless give some guidance on the management of children with epilepsy (Ireland).

However, geographical and rural isolation, limiting access and proximity to service was also noted, not necessarily related to economic status of the country:

Geographical challenges, huge distances to nearest hospital in some areas. (approx. driving distance from Oslo to Nordkapp is 2000km) (Norway)

Sometimes it is problematic for families who live in the countryside and far from regional hospitals. In acute cases the local doctors can seek help from the ambulance, including air transport (helicopter) (Estonia)

Some countries had specific policies and services to manage the migrant status of Lara and her family, however, this was variable and healthcare policy in this regard was not always evidenced in legislation.

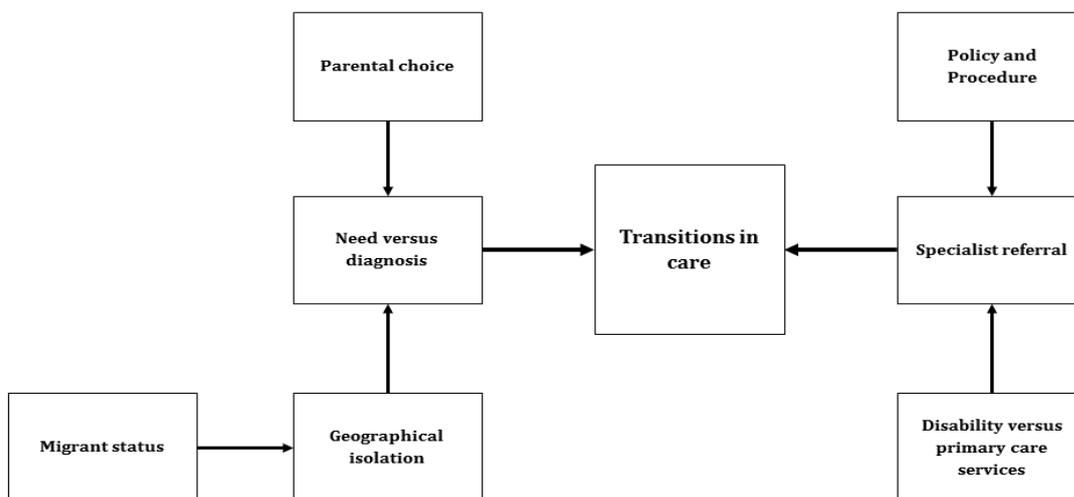


Figure 4.19 Emergence of Global Theme ‘Transitions in care’

4.4.2 Communication

Issues of communication focused particularly on the use of technology to enhance clinical and family communication, a system of quality assurance. The potential of technology to support engagement was noted but its value appeared limited:

There is one website for German speaking countries (Germany, Switzerland, Austria) which offers information, some standards... a list of links e.g. guidelines, but they are expired, not revised, and not really used in daily medical routine.... not useful, because too many different forms and causes for epilepsy (Austria)

Following on from this, a number of countries reported the value of access to electronic health records as a tool to supporting referral and assessment but also in better access to care:

All health care providers should use digital records and a summary of each visit should be sent to the central digital health records system (e-Health system - Tervise infossüsteem) where the next care providers and parents can get an overview of services performed in the past as well as a plan for the future. (Estonia)

...the new Hungarian eHealth initiatives, promised to be arriving in 2017 would implement some suggestions from [the] early development EU project, such as 2-way communication in digital domain. Thus, clinical paediatricians, such as neurologists looking after Lara, would have – if needed – prompt access to recent and former screening results, too (Hungary).

This was not always the case:

Better cooperation is required among pediatric neurologists and pediatricians involved in the treatment of Lara since there is no electronic health record which could facilitate prompt access to her medical information (Cyprus).

The evidence for robust quality assurance systems was dichotomous.

There are no quality care framework and performance measures (Cyprus).

All of the specialized care centers listed previously have national accreditation (usually ISO) requiring written procedures for all processes provided (Czech Republic).

Where there was evidence of robust national systems, quality assurance appeared to be part of the structure which governed epilepsy care. Often, good QA reflected teamwork and positive elements of communication horizontally and vertically. Where national programmes exist, even if adult-focused, there were positive impacts on child-orientated services. A core issue was the need to ensure that health care for people with epilepsy is evidence-based, population-based and patient-centred.



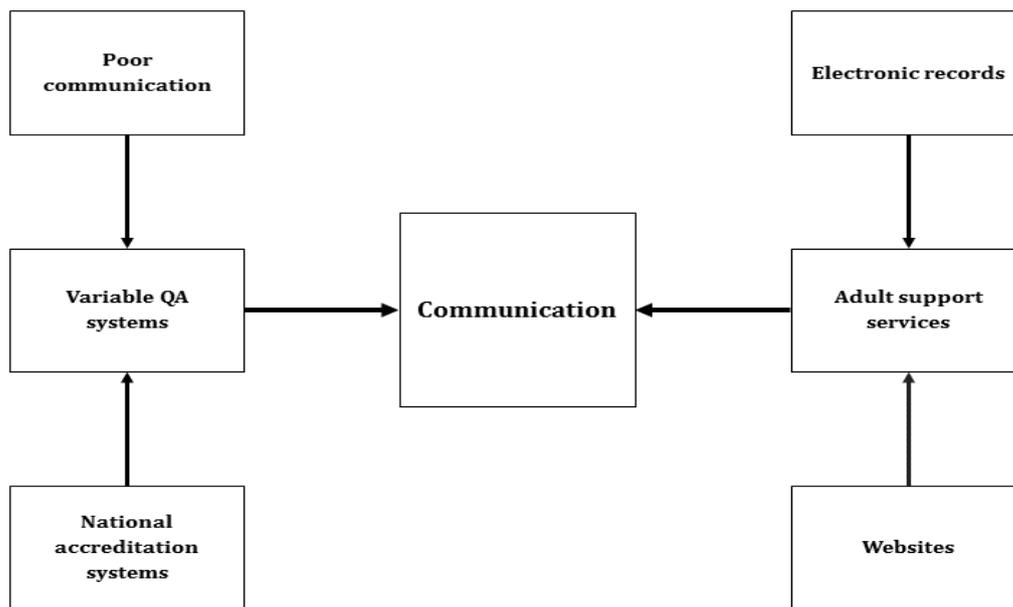


Figure 4.20 Emergence of Global Theme ‘Communication’

4.4.3 Care Coordination and support

The GT of care coordination and support describes the areas of community based services and supports, family and professional partnerships and of course, care coordination. Overall, there was a sense that coordination was poor and teamwork opportunities limited. Although a number of countries reported evidence of multidisciplinary engagement in care coordination and delivery, the emphasis and importance of liaison between paediatricians and neurologists with some level of nursing support was evident:

The care of epilepsy is in the public sector, and central hospitals or university central hospitals, and a child neurologist, an experienced pediatrician or specialist in intellectual disabilities is in charge of the care. The care is done in collaboration with primary health care sector (Finland).

The epilepsy per se is handled by a different hospital based care in a pediatric clinic, where there is a special nurse who is available for advice on a daily basis for all children with epilepsy. Through her the child is also attended by a pediatric neurologist who is responsible for the pharmaceutical treatment and any etiologic investigation (Sweden)

The need for specific roles, especially nursing in link roles and at advance practice levels was reported in the data:

...lessons learned in caring for children with complex health problems e.g. LTV /TBI, the link [age] nurse is an example of good practice aimed at improving referrals and co-ordination between all professionals involved (Spain).

Recent developments have included the development of Advance Nurse Practitioner posts in Children's Epilepsy which respondents unanimously agreed was a significant positive move to enhance access to services (Ireland).

Gaps were also noted:

Epilepsy always is treated as necessary, but the resources for additional therapies like environmental therapy, physiotherapy or psychotherapy is not adequate or sufficient – There is evidence, that 70.000 children don't receive the therapy they need (Austria)

Despite the aspiration for parental involvement, access to parents was often logistically different because of the burden of care-giving and lack of available time to engage in service development initiatives as a service user. Clinicians, especially neurologists were highly valued by parents and other professionals:

According to a parents' satisfaction study in TCH neurologists are highly valued (with satisfaction with care and loyalty of 97-95%) (Estonia).

Where services were limited, the role of the parent was paramount in care management and co-ordination of services:

There is no policies and / or procedures in place to ensure that a child with epilepsy receives ongoing preventative care screening and developmental checks in our country for sure which means that the quality child care in the case of such children as Lara depends primarily on the activity of parents (Poland).

This only served to fragment relationships further:

Often parents' don't understand what to do, and sometimes they get lost – there is no system to make them visible (Austria).

A number of countries reported parents as being both the catalyst of and holding responsibility for the care coordination of their child often with limited engagement from the healthcare system:

When a child with epilepsy is admitted in the hospital the only way for the pediatrician in charge to retrieve medical information for the child is from parents! In many times it is almost impossible to get in contact with his/her pediatric neurologist and the information given from the parents may be misleading. (Cyprus)

The role of the voluntary sector in providing primary care services was described in many countries sometimes without evidence of sustainability. Sometimes, these were described as self-help groups, NGO's, parent-led lobby groups and or others:

Epilepsy Ireland has developed an app for people with epilepsy and parents of children with epilepsy, which, amongst other features, will allow people to track and monitor seizure activity and will help people to identify seizure triggers (Ireland)

There are few NGOs (Caritas, and others) who developed home services for children as Lara, but most of the responsibilities fall to parents (Romania)



The lack of individualised written care planning was also recorded and though variable across the countries (and more evident where an electronic healthcare record existed), there was evidence of the risk of poor and fragmented coordination of services, with different and sometimes multiple agencies involved:

In Austria a personalised written care plan coordinating the different therapies does not exist. Each health provider makes appointments with the parents. Communication or coordination between providers is not a paid service (Austria)

There are no protocols at national level to assist /provide guidance for the care of children with intractable epilepsy in PHC services except in Servicio Andaluz de Salud (Spain).

Many of the challenges of poor communication, lack of coordination, and education and training opportunities for professional staff were equally raised. The need for skills training and supports for school staff was noted. Some countries had excellent examples of community-based support services, including camps for children and siblings as a source of therapeutic recreation. There was evidence that community-based services were limited in some countries but where available, were often of a high standard, including 'walk-in' clinics. That said, the limited opportunity for parent support groups in the community was also noted. Where they existed, they were seen to provide strong support to parents and clinical services, albeit that they have to take a greater level of engagement in the actual delivery of service:

In Hungary there is not a particular family advocacy group for children similar to Lara, but there is an EPI-club...this is not real family advocacy group, but a place to get together for families, siblings, nurses and neurologists. On these twice a year occasions personnel deals with children and siblings separately, while parents can discuss special problems (Hungary)

The Finnish Epilepsy Association (FEA) promotes equality and good care for people with epilepsy and to support them to achieve a world without prejudice...The FEA is the national umbrella organization for the 24 local affiliates in Finland. There are about 300 volunteers in the association and the affiliates. Furthermore the FEA has 2000 donors who support economically the activities of the FEA (Finland).



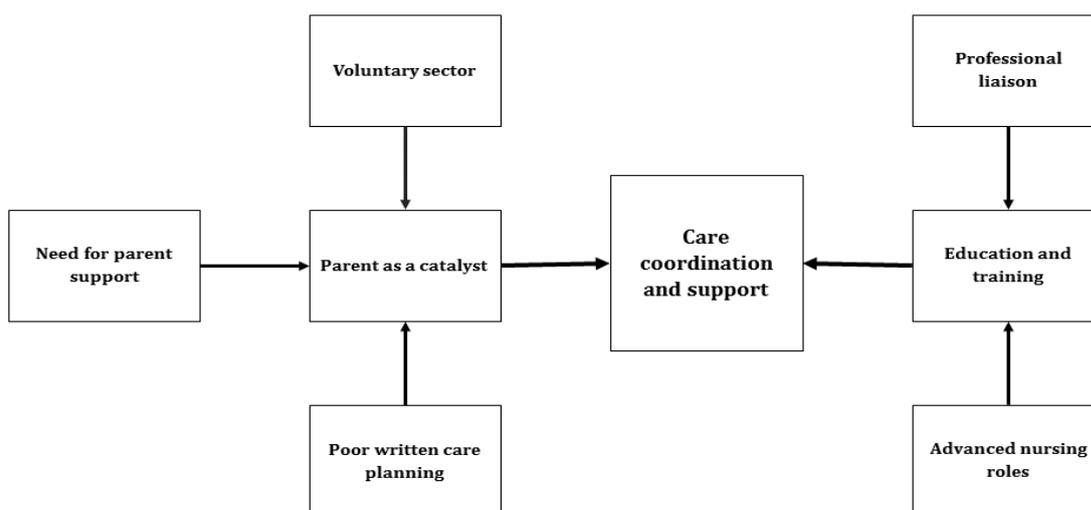


Figure 4.21 Emergence of the Global Theme 'Care coordination and support'

4.5 Summary of optimum integration of care at the acute community interface for a child with intractable epilepsy

- Good personal and professional relationships.
- Access to a range of clinical diagnostic tests.
- Learning from adult-focused policy development.
- Addressing geographical variability in ability to access community care.
- Enhanced IT support.
- High impact QA measure.
- Enhanced education of healthcare professionals and the general public.
- Community support groups.
- Greater support for parents in care coordination.
- Establishment of greater link roles and advanced nursing practice.
- Enhancing individualised care planning.
- Ongoing voluntary sector support.

Chapter 5

Discussion and Conclusions

5.1 Introduction

The aim of our work in this section of the MOCHA project was to provide an account of the current approach to the management of care of children with complex healthcare needs in 30 European countries. To do this we identified ‘in-principle’ complex health issues that would be representative of population trends across childhood, we explored the structures and processes of care in place for children and their families, and we identified facilitators of optimum integration of care at the acute community interface. This chapter begins by discussing key themes that emerged from the findings. This is followed by consideration of limitations of the study and detail of the next steps of our work.

5.2 Key themes emerging on integration of care for children with complex care needs

The adapted version of the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* was a useful tool to explore the structures and processes in place pertaining to the management of care of children at the acute community interface. When we mapped the findings from the survey across all three exemplars we found limited similarity in the direction of the findings (Table 5.1).

Table 5.1 Mapping key findings of structures and processes across exemplar conditions

	Traumatic Brain Injury (TBI)	Long Term Ventilation (LTV)	Intractable Epilepsy (IE)
Screening and referral		Limited mechanisms to support preventative screening assessment and referral	Limited mechanisms to support preventative screening assessment and referral
Access to care	No systems to identify healthcare providers	Mechanisms in place to identify healthcare providers	Few countries have mechanisms in place to identify all healthcare providers
Access to care	Limited support for linguistically and culturally appropriate information.	Limited support for linguistically and culturally appropriate information.	



Care coordination	Limited inclusion of the young person in the planning of their care.	Consultation in development of personalised plans.	
Family-professional partnerships	Limited engagement of family advocacy groups	Limited engagement of family advocacy groups.	Widely reported involvement of family advocacy groups.
Community-based services	Availability of psychological support	Availability of psychological support	Availability of psychological support
Quality assurance		Majority of countries do not collect data on the experience of care from the perspective of the parents/guardians or siblings.	Majority of countries do not collect data on the experience of care from the perspective of the parents/guardians or siblings.

We then examined the themes that emerged from the qualitative data, for congruence in the facilitators of optimum integration of care for a child with complex healthcare needs. We again found limited congruence in the findings between three exemplar conditions (Figure 5.1).



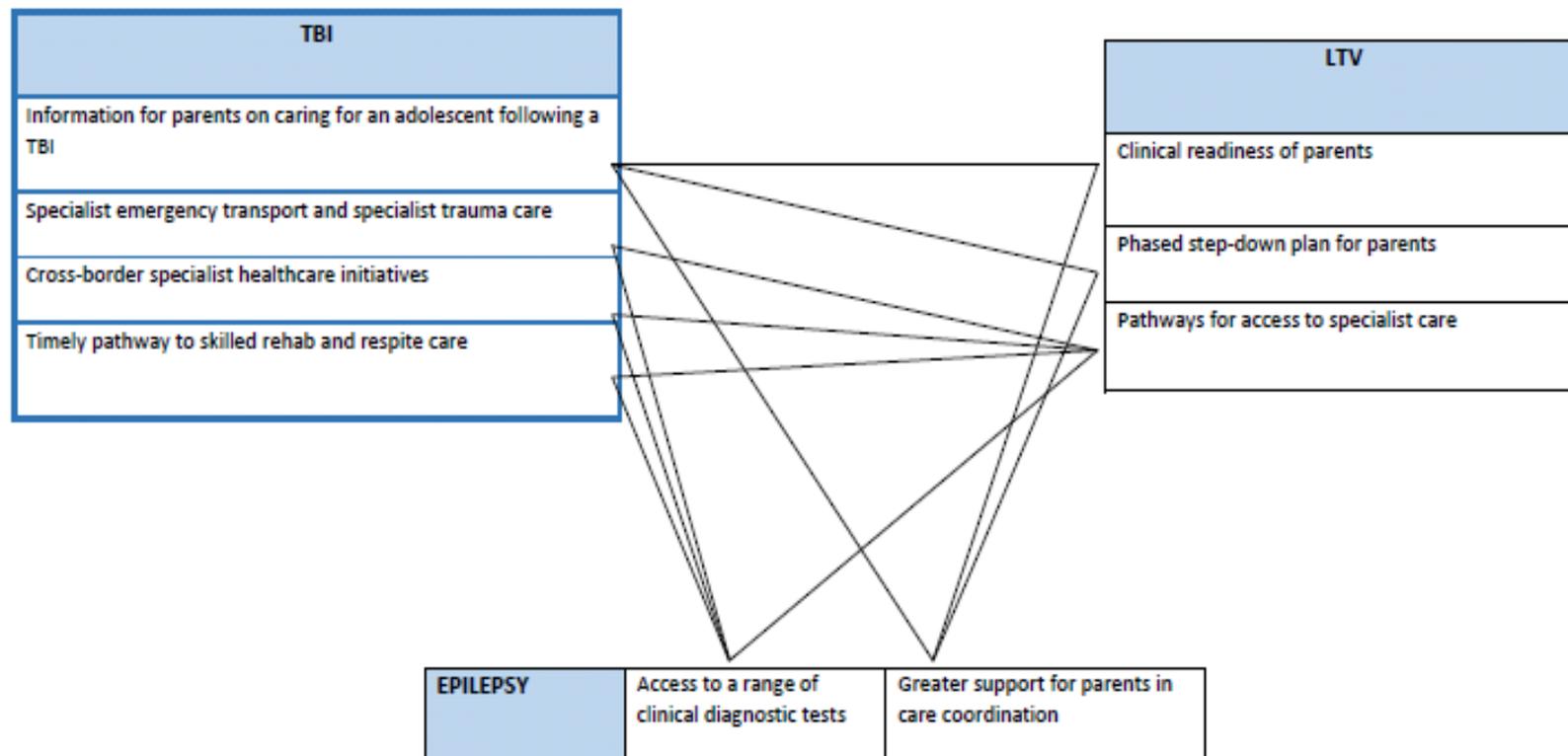


Figure 5.1 Mapping key findings from thematic analysis across exemplars

—congruence between all three exemplar conditions



Some similar issues emerged including parents as catalysts of optimum integration of care and pathways to specialist care. While the two areas identified could be proposed as overarching themes in the management of a child with complex healthcare needs, we would suggest that it is too early to argue for this and instead we would 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. While the links across themes seem to be somewhat obvious, the variance in how they emerged in each area suggest that the specific care needs of each cohort of these children are determined by 1) the dynamic of the specific complex care need and 2) the advancement of understanding of the needs of these children and adolescents.

5.2.1 Parent as catalyst

When reading through the qualitative data returned by the CAs there was a continuous reference to the fact that many of the issues for both the adolescent with TBI and the child on LTV had yet to be addressed due to the small numbers of these children. In the case of LTV there was acknowledgement that many countries were only beginning to appreciate the health service demands that optimum care for this group of children and their families would entail. While there was an appreciation of the needs of an adolescent with a TBI there were concerns that structures to address the needs of the family, to enable them to care for the child at home, were generally deficient. For both cohorts (TBI and LTV) the issues for parents as catalysts for care were predominantly centred on their challenges as they became the primary caregiver of their child with complex healthcare needs. This was not a predominant issue for parents of a child with intractable Epilepsy. The conversation was not about the required resourcefulness of the parents as catalysts in negotiating care at the point of transitioning to home. It was more about the parent as catalysts for care coordination in the ongoing care of the child as they transitioned in and out of a variety of multi-disciplinary services. This suggests that the dynamic nature of the specific complex healthcare needs and the advancement of understanding of these needs may explain why various groups of children with complex healthcare needs, and their families, will have variance in their required facilitators for optimum integration of care.

The need to explore and understand the experiences of those living with complex needs, and of their experience of the integration of healthcare services, is important to identify specific ways that integration of care can be enhanced in meaningful ways for these children and their families. For example, parents have reported a need for an enhanced seamless services, have raised concerns about geographical equity in accessing care, and issues regarding the burden on them to govern care delivery in their own home (26-28). However, our findings show that the majority of countries do not collect data on the experience of care from the perspective of parents or siblings. This would be important going forward to further enhance understanding of the specific needs of each child and family in the context of their specific complex healthcare needs.

5.2.2 Pathways to specialist care

By their very nature, children with complex care needs and their families place great challenges on healthcare 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.



It could be argued that an obvious solution is to increase community based care. However, we found that facilitators of optimum care for children on LTV and adolescents post TBI included direct pathways to EDs and PICUs. This is supported by a study in the US of children with conditions where effective community care is thought to prevent hospital admission, which found that children with complex care needs comprised 40% of all children admitted through the ED (5). In contrast a key facilitator of care for children with intractable Epilepsy is advanced nursing positions in the community. This reflects recent research supporting the value of these roles in the continuity of care (29), however, there may be a potential challenge in terms of how such roles might be operationalized, particularly in smaller countries with a dispersed population of children with intractable Epilepsy.

5.2.3 Summary

When considering the particular focus of the key themes for each exemplar condition it is reasonable to suggest that complex healthcare needs that are more ‘established’ and which are anecdotally known to have a larger population, have specific facilitators of optimum care at the acute community interface that may not reflect those of all children with complex healthcare needs (Figure 5.2). This is important in understanding that one size will not fit all in the future planning for healthcare provision in the acute serves, 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.

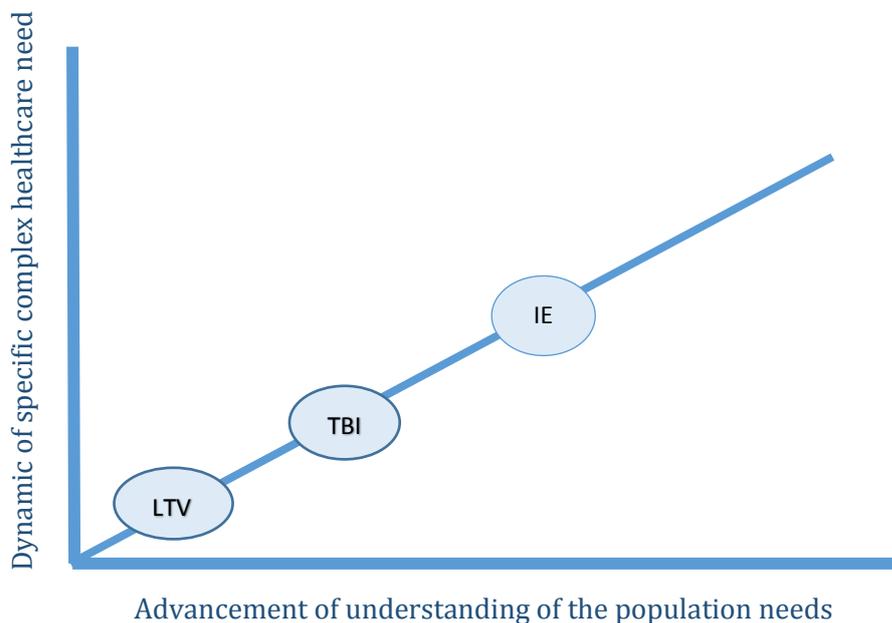


Figure 5.2 Potential determinants of specific care needs of each group of children and their families

However, this conversation is really only beginning. We therefore deliberately sought to understand the socio-cultural context of the responses given by the CAs and the final part of the survey, the *Complex Care European Survey of Change* was adapted from a specific Eurobarometer Survey (15), to provide a socio-cultural context for the findings. The results of this will be presented and discussed in the final report from Work Package 2 in November this year, where the integration of care of children with complex care needs at the acute/community/primary interface is considered within the wider milieu of health care policy, as well as social and cultural factors.

5.3 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. 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 opinions. 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 (19, 30). It has also been suggested that visual representation of a scenario would be better retained by the participants and could capture more of the nuances of real life. However, the type of scenario required for this study would have been quite difficult to depict visually. In the development of the vignettes we therefore identified 'in-principle' exemplar complex problems and 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.

5.4 Conclusion

The growing trajectory of children with complex care needs 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 section of the MOCHA project has begun to address this knowledge deficit by mapping out for the first time the structures and processes in place across the EU/EEA to support the management of the care of these children. It has also identified a comprehensive list of facilitators of optimum integration of care for children with complex care needs at the acute community interface. Although, some commonalities exist across the findings from the three exemplar conditions, it is clear that there are individual critical junctures in care delivery that will demand care provisions 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. Our next report will, therefore, consider the socio-cultural context of our findings so as to identify feasible and relevant implications for care delivery across such a diverse group of member states. This work is ongoing and will be



presented and discussed in the final report from Work Package 2 in November 2017. This will present the future vision of the care of children with complex care needs, situated within the context of key European and international research and policy documents. It will draw on all of the constituents of the Work Package.



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Appendix 1 Glossary of Terms¹

TERM(S)	PROPOSED DEFINITION
ACQUIRED DISORDER	A condition that is not inherited or present at birth, but developed later in life most commonly as a result of injury or infection.
ACUTE CARE	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”
BUSINESS MODEL	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.
BUSINESS PROCESS	A collection of activities designed to produce a specific output for a particular customer or market.
CARE COORDINATION	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
CARE PATHWAY	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: (i) An explicit statement of the goals and key elements of care based on evidence, best practice, and patients’ expectations and their characteristics; (ii) the facilitation of the communication among the team members and with patients and families; (iii) the coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, patients and their relatives;

¹ For references please see the MOCHA website: <http://www.childhealthservicemodels.eu/topics/work-package-2/>



	(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.
CHILD	A child refers to anyone under the age of 18 years old.
CHILD PROTECTION / SAFEGUARDING	Child protection/ safe guarding refers to methods aimed at preventing and responding to violence, exploitation and abuse of children.
CHRONIC ILLNESS	Long term condition that can be treated but not cured
CLASS DIAGRAM	A diagram that shows a collection of declarative (static) model elements, such as classes, types, and their contents and relationships.
CLINICAL CARE	<p>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 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"> • delegated medical treatment and observation • – symptom management • – wound care • – surveillance and referrals/follow up for acute and critical illnesses • – tube feeding, etc.
CLINICAL PATHWAY	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.
COMPLEX CLINICAL CARE NEEDS	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 & 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.
COMPLEX HEALTH STATUS REQUIRING SOCIAL CARE	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' (Mechant, Leferve, Jones, & Luckock, 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.
COMPLEX SOCIAL-HEALTH STATUS	This refers to the situation where a family's socio-economic circumstances may exacerbate a child's complex health condition due to poverty, financial strain and other adverse family factors. In this instance parents require additional family support (beyond those outlined above) to ensure a better standard of living for their children with complex health needs. Children with complex needs who are at risk of abuse or neglect and in contact with child protection services are also included in this category.
COLLABORATION DIAGRAM	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
COMPONENT DIAGRAM	A diagram that shows the organizations and dependencies among components.
COMMUNITY CARE	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'
CONGENITAL MALFORMATION	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
CONTINUITY OF CARE	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.
COMMUNITY-BASED NURSING	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,



	<p>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 outside the hospital. Major activities include case management, patient education, individual and family advocacy, and an interdisciplinary approach (Zotti, Brown, Stotts, 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.</p>
<p>COMMUNITY HEALTH NURSING</p>	<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. 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.</p>
<p>COMMUNITY NURSES KNOWLEDGE AND SKILLS REQUIRED</p>	<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.</p>
<p>COMPETENCIES OF NURSES WORKING IN THE COMMUNITY HEALTH-CARE</p>	<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 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</p>



	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.
CONTACT	Healthcare activity period during which a subject of care interacts, directly or indirectly, with one or more healthcare professionals
ENDURING MENTAL HEALTH NEEDS	Enduring mental health needs in the context of this task refers to children with a mental health condition that threatens or hinders an age-appropriate mental health development, that requires input from a range of health and social care professionals, and from which long-term mental health problems and/or disabilities may be expected.
EPISODE OF CARE	Time interval during which healthcare activities are performed to address one health issue and as identified and labelled by one healthcare professional
FAMILY MEDICINE (FM) OR PRIMARY CARE TEAMS	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, dietitians, 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.
FOSTER CARE	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
GENERAL PRACTICE	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”.
HEALTH CARE	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"> • day-to-day basic medical care for common ailments • health assessment and outreach/case finding • 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. • immunization for vaccine-preventable diseases for all age groups including pregnant women and children • medication management for persons with chronic and stable illnesses • – disease investigations • chronic disease management • health education • health counselling/family counselling • interventions for family planning and birth spacing, etc.
HEALTH CARE ACTIVITY	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
HEALTH CARE ACTIVITY PERIOD	Continuous period of time during which healthcare activities are performed for a subject of care
HEALTH CARE ACTOR	Organization or person participating in healthcare
HEALTH CARE PROFESSIONAL	Healthcare personnel having a healthcare professional entitlement recognized in a given jurisdiction
HEALTH CARE PROVIDER	Healthcare actor participating in the direct provision of healthcare
HEALTH CARE ORGANISATION	Organisation whose healthcare personnel participate in the direct provision of healthcare
HEALTH CARE THIRD PARTY	Healthcare actor other than a healthcare provider or the subject of care



HEALTH ISSUE	Issue related to the health of a subject of care, as identified and labelled by a specific healthcare actor
INITIAL CONTACT	Contact that establishes a clinical process
INTEGRATED CARE	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
INTERACTION DIAGRAM	A generic term that applies to several types of diagrams that emphasize object interactions. These include collaboration diagrams and sequence diagrams.
MODEL	A system of assumptions, concepts and relationships between them allowing to describe (model) in an approximate way a specific aspect of reality.
MODELLING LANGUAGE	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.
NON-CONTACT PERIOD	Healthcare activity period without the involvement of the subject of care
NURSING	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.
OBJECT DIAGRAM	A diagram that encompasses objects and their relationships at a point in time. An object diagram may be considered a special case of a class diagram or a collaboration diagram. See: <i>class diagram, collaboration diagram</i> .
PRIMARY HEALTH CARE	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
PRIMARY HEALTH CARE	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.



PROCESS	A set of interrelated activities, which transform inputs into outputs.
PUBLIC HEALTH NURSING	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 & Standards of Practice 2</i> and the Quad Council of Public Health Nursing Organizations' <i>Core Competencies for Public Health Nurses</i> .
PUBLIC HEALTH NURSING EDUCATION	The baccalaureate degree in nursing (BSN) is recommended for entry-level public health nurses. ²⁶ <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. ²⁷ The graduate is prepared to conduct community assessments and apply the principles of epidemiology among other competencies.
RESIDENTIAL / INSTITUTIONALISED CARE	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.
RESPIRE CARE	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.
SCENARIO	<ul style="list-style-type: none"> • A projected course of action, events or situations leading to specified result. • An ordered sequence of interactions between specified entities (e.g. a system and an actor). • In UML: an execution trace of a use case.



	<ul style="list-style-type: none"> • 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. See: <i>interaction</i>.
SELF-CARE PERIOD	Healthcare activity period where prescribed self-care is performed
SEQUENCE DIAGRAM	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> .
SOCIAL CARE	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 Commission, 2011; World Health Organization, 2004). Social care needs arise when an individual's well-being, ability to live independently, or safety is compromised.
SOCIAL CARE	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.
SOCIAL WORK	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”.
STORYBOARD	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. [HL7]
STAKEHOLDER	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).
STATECHART DIAGRAM	A diagram that shows a state machine.
SUBJECT OF CARE	Person seeking to receive, receiving, or having received healthcare
TRIGGER EVENT	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. [HL7]
USE CASE DIAGRAM	A diagram that shows the relationships among actors and use cases within a system.
UNIFIED MODELLING LANGUAGE	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.
UNIVERSAL SOCIAL SERVICES	Universal social services: Within in this task, ‘social care services’ do not refer to universal social services designed to meet the needs of the general population (e.g. universal preschool). It is acknowledged however that individuals in contact with specialised services also interact with general social services such as social protection (i.e. cash benefits), education services, and primary health care.

Appendix 2 Acknowledgements of Contributions

Traumatic Brain Injury

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Mechtler	Axel	Dr	Trauma surgeon. Kepler Universitätsklinikum – Med Campus III. Trauma Unit	Austria
Mechtler	Reli	Dr	Head of Department of Health System Research, University of Linz	Austria
Mitsakos	Anastasios	Dr	Medical officer in the Hellenic Navy, currently working in the Naval Hospital of Athens	Greece
Nicholson	Alf	Prof	Joint Clinical Lead, National Clinical Programme for Paediatrics and Neonatology, Health Service Executive	Ireland
O'Loughlin	Anne	Ms	Acting Programme Manager, Paediatric Family-Centred Rehabilitation services National Rehabilitation Hospital, Rochestown Avenue, Dun Laoghaire Co. Dublin	Ireland
Paraicz	Eva	Dr	Paediatrician, Paediatric neurologist, musculoskeletal rehabilitation specialist. Head of Pediatric	Hungary



			Rehabilitation Department, Bethesda Children Hospital, Budapest	
Pavic-Simetin	Ivana	Dr		Croatia
Polo Parada	Ana	Ms	Unidad de Calidad. Hospital Infantil Universitario Niño Jesús. Madrid	Spain
Potyka	Stefan	Mr	Office of the State Government of Upper Austria, Department of Health (Landesgesundheitsfonds)	Austria
Reijneveld	Menno (S.A)	Prof		Netherlands
Rogers	Magdalen	Ms	NAI Development Manager, Neurological Alliance of Ireland, Coleraine House Coleraine St. Dublin 7	Ireland
Santos	Teresa	Ms		Portugal
Soler	Doriette	Dr	Consultant Paediatrician with an interest in Neurology	Malta
Stables	Richard	Mr	Information & Support Manager, Headway Ireland, Blackhall Green, Off Blackhall Place, Dublin 7	Ireland
Suditu	Stefan Cosmin	Dr	Specialist surgeon in neurosurgery. The National Institute for Neurology and Neurovascular	Romania
Suurorg	Lagle	Dr	Paediatrician, Head of Department for Quality Assurance, Tallinn Children's Hospital	Estonia
Thórarinsdóttir	Brynja K.	Dr	Specialist in Paediatrics and Neuropediatrics, Children's Hospital Landspítali University Hospital, 101 Reykjavík, Iceland	Iceland
Toader	Corneliu	Prof	Manager, The National Institute for Neurology and Neurovascular Diseases, Bucharest	Romania
Turner	Grace	Ms	Senior Programme Manager, Integrated Care Programme for Children, Health Service Executive	Ireland
van der Willik	Jorieke	Ms		Netherlands
Varandas	Luis	Dr		Portugal
Virela	Daniel	Dr		Portugal
Zviedre	Astra	Dr	Paediatric Surgeon, Department of Pediatric Surgery, University Children's Hospital, Riga, Latvia	Latvia

Long-term ventilation

Surname	Name	Title	Position and/or affiliation (if given)	Country
Albajara	Luis A.	Dr	Hospital Universitario Infantil La Paz Madrid	Spain
Albi Rodríguez	M ^a Salomé	Dr	Hospital Infantil 12 de Octubre Hospital Madrid	Spain
Baka	Agoritsa	Dr	Paediatric Emergency Medicine, Hellenic Centre for Disease Control and Prevention	Greece



Bandeira	Teresa	Dr		Portugal
Barríos	M ^a Isabel	Dr	Hospital Universitario La Paz Madrid	Spain
Benjak	Tomislav	Dr		Croatia
Bignamini	Elisabetta	Dr	Director of Pneumology Unit - Regina Margherita Hospital (City Health and Science) - Turin	Italy
Biliuviene	Jurgita	Dr	Paediatric intensive care specialist, Children's Hospital, Affiliate of Vilnius University Hospital Santariskiu Klinikos	Lithuania
Bourek	Jan	Dr	Dept. of Pediatrics, Regional Hospital Znojmo, MUDr. Jana Janského 11, 669 02 Znojmo, Czech Republic	Czech Republic
Brito	Cristiana	Ms		Portugal
Cazzaroli	Clizia	Dr	Respiratory Physiotherapist, Borgo Trento Hospital, Verona	Italy
Chwalková	Ivana	Ms	Jesenius-Center for Lifelong Learning of the Faculty of Medicine, University of Ostrava, Dvořákova 7, 701 03 Ostrava, Czech Republic	Czech Republic
Coelho	Mario	Dr		Portugal
Colt	Catalina Elena	Dr	Pediatric Specialist, Pediatric Clinic Cluj Napoca, Iuliu Hațieganu University of Medicine and Pharmacy, Cluj-Napoca	Romania
Costa	Rui	Dr		Portugal
Csaba	Lódi	Dr	Head of Department of Intensive Therapy, Semmelweis University, 1 st Department of Paediatrics	Hungary
Cvachovec	Karel	Prof	Head of the Clinic of Anaesthesiology and ICM, 2nd. Faculty of Medicine, Charles University in Prague and Motol University Hospital, V Úvalu 84, 150 06 Praha 5, Czech Republic	Czech Republic
de Weerd	Willemien	Dr	Paediatrician/ Paediatric intensivist. Centre for ventilation at home in Groningen	Netherlands
Dilber do Céu	Daniel	Dr		Croatia
Machado	Maria	Dr		Portugal
Drábková	Jarmila	Dr	Clinic of Anaesthesiology and ICM, 2nd. Faculty of Medicine, Charles University in Prague and Motol University Hospital, V Úvalu 84, 150 06 Praha 5, Czech Republic	Czech Republic
Felix	Miguel	Dr		Portugal
Ferenczi	Cristina	Ms	Parent Association Raul-Serban	Romania
Fraser	James	Mr	Consultant Paediatric Intensive Care Bristol Royal Hospital for Children	England
Fülesdy	Béla	Prof	Head of Department of Anaesthesiology and Intensive Therapy, Debrecen University, Medical and Health Centre	Hungary
García Teresa	M ^a Angeles	Dr	Hospital Infantil Universitario Niño Jesús Madrid	Spain



Gaspar	Tania	Dr		Portugal
Gaspar de Matos	Margarida	Dr		Portugal
Gawlik	Piotr	Dr	Mechanical long term ventilation unit, Bydgoszcz	Poland
Grubauer	Christophe	Mr	Verein Heimbeatmung (Club Home ventilation)	Austria
Guillaume	Iouri	Mr		Belgium
Holzmann	Karl	Dr	Coordination and Competence Team	Austria
Hornath	Franz	Dr	Kepler Universitätsklinikum – Med Campus IV	Austria
Huber	Gudrun	Dr	Kepler Universitätsklinikum – Med Campus IV	Austria
Józwińska	Emilia	Dr	Anaesthetist, Bydgoszcz	Poland
Kovács	Julianna	Dr	Primary care paediatrician, Head of Division of primary paediatric care, College of Health Professions	Hungary
Liszkay	Gábor	Dr	Department of Anaesthesiology and Intensive Therapy, Bethesda Children Hospital, Budapest	Hungary
Luna Paredes	M ^a Carmen	Dr	Hospital Infantil 12 de Octubre Madrid	Spain
Marques	Adilson	Dr		Portugal
Mechtler	Reli	Dr	Head of the Department of Health System Research, University of Linz	Austria
Mičudová	Erna	Ms	Deputy Director of the Unit for Paramedical Care, University Hospital Brno, Jihlavská 340/20, 625 00 Brno-Bohunice, Czech Republic	Czech Republic
Militaru	Mihai	Prof	Emergency Hospital for Children, Cluj, Cluj County, Romania	Romania
Moleiro	Pascoal	Dr		Portugal
Montes	David	Dr	Hospital of Fuenlabrada Comunidad de Madrid	Spain
Paiva	Mario	Dr		Portugal
Pavic-Simetin	Ivana	Dr		Croatia
Potyka	Stefan	Mr	Office of the State Government of Upper Austria, Department of Health (Landesgesundheitsfonds)	Austria
Roth	Maria	Prof	Social Work Department	Romania
Salvesen	Randi	Ms	Head nurse of PILU and LTMV-team St. Olavs Hospital, Trondheim, Norway	Norway
Schmitt	Klaus	Prof	Board of Department of Paediatrics and Adolescent Medicine, Kepler Universitätsklinikum – Med Campus IV	Austria
Šesták	Jakub	Mr		Czech Republic
Siahanidou	Soultana	Prof	Assistant Professor of Paediatrics and Neonatology, University of Athens, Director NICU, Agia Sofia Paediatric Hospital of Athens	Greece



Sigurjónsdóttir	Bára	Ms	Clinical nurse specialist in pediatric nursing. Director of Leidarljós, Support centre for families of children with chronic diseases.	Iceland
Sigurjónsdóttir	Gudrún	Ms	Deputy Director General. Ministry of Welfare	Iceland
Streitová	Dana	Dr	Jesenius-Center for Lifelong Learning of the Faculty of Medicine, University of Ostrava, Dvořákova 7, 701 03 Ostrava, Czech Republic	Czech Republic
Suurorg	Lagle	Dr	Paediatrician, Head of Department for Quality Assurance, Tallinn Children's Hospital	Estonia
Teresa Thorkelsson	Santos Thordur	Ms Dr	Director Neonatal Intensive Care Unit. Children's Hospital Iceland	Portugal Iceland
van Overmeire van Popta	Bart Janet	Prof Ms	Nurse Specialist. Centre for ventilation at home in Groningen	Belgium Netherlands
Varandas Virela Wallace	Luis Daniel Rachel	Dr Dr Ms	Discharge Coordinator, Our Lady's Children's Hospital Crumlin, Dublin	Portugal Portugal Ireland
Wójtowicz	Paweł	Mr	The Chief of the MATIO Foundation, Kraków	Poland
Zoubkova	Renáta	Dr	Jesenius-Center for Lifelong Learning of the Faculty of Medicine, University of Ostrava, Dvořákova 7, 701 03 Ostrava, Czech Republic	Czech Republic
Zviedre	Astra	Dr	Paediatric Surgeon, Department of Pediatric Surgery, University Children's Hospital, Riga, Latvia	Latvia

Intractable Epilepsy

Surname	Name	Title	Position and/or affiliation (if given)	Country
Afonso	Isabel	Ms	Community health nurse	Portugal
Antunes	Maria Teresa	Ms	Nurse	Portugal
Baumgartner	Manuela	Dr	Ambulanz für Entwicklungsneurologie und Neuropädiatrie. Krankenhaus der Barmherzigen Schwestern Linz	Austria
Brandstetter	Friedrich	Dr	Wiener Sozialdienste - Förderung & Begleitung GmbH Zentrum für Entwicklungsförderung	Austria
Colt	Catalina Elena	Dr	Pediatric Specialist I Pediatric Clinic Cluj Napoca, Iuliu Hațieganu University of Medicine and Pharmacy, Cluj-Napoca	Romania



Connelly	Ann	Ms	Advanced Nurse Practitioner, Neurology Service, National Children's Hospital at Tallaght Hospital, Dublin	Ireland
Crampton	Wendy	Ms	Director of Services, Epilepsy Ireland 249 Crumlin Road, Dublin 12	Ireland
Crowley	Suzanne	Ms	Advanced Nurse Practitioner, Temple Street University Children's Hospital, Temple Street, Dublin	Ireland
Denecke	Jonas	Dr	Specialist in children's and youth, senior physician. University Medical Center Hamburg-Eppendorf, Germany	Germany
do Céu Machado	Maria	Dr		Portugal
Dunkley	Colin	Dr		United Kingdom
Dunne	Geraldine	Ms	National Information Officer, Epilepsy Ireland 249 Crumlin Road, Dublin 12	Ireland
Fernandes	Ricardo	Dr		Portugal
Fogarasi	András	Prof	MRE Bethesda Children Hospital, Budapest	Hungary
Gaspar de Matos	Margarida	Dr		Portugal
Gasper	Tania	Dr		Portugal
Gerstner	Thorsten A	Dr	Senior physician, Neuropediatrician, Paediatric department Sørlandet sykehus HF 4809 Arendal, Norway	Norway
Griffin	Grainne	Ms	Advanced Nurse Practitioner Candidate Neurology Service, Our Lady's Children's Hospital Crumlin, Dublin	Ireland
Hauser	Erwin	Dr	Landeskrankenhaus Baden-Mödling Abteilung für Kinder-und Jugendheilkunde	Austria
Kalavska	Andrea	Assoc. Prof	Deputy of Ministry of Health, Ministry of Health, Bratislava, Slovakia	Slovakia
Keegan	Maria	Ms	Clinical Nurse Specialist, Neurology Service, Our Lady's Children's Hospital Crumlin, Dublin	Ireland
Marques	Adilson	Dr		Portugal
Mroczek	Aleksandra	Ms	Lublin's Association of People with Epilepsy and Their Friends	Poland
Murphey	Peter	Mr	CEO Epilepsy Ireland, 249 Crumlin Road, Dublin 12	Ireland
Neves	Ana Margarida	Dr		Portugal
Odete	Lemos e Sousa	Ms	Nurse	Portugal



Owen	Yvonne	Ms	Epilepsy Transition Nurse Coordinator, Temple Street University Children's Hospital, Temple Street, Dublin	Ireland
Payerova	Jarmila	Dr	Head physician at children neurology dept. Children's Teaching Hospital, Limbova 1, Bratislava Slovakia	Slovakia
Peersen	Henrik	Mr	General secretary of the Norwegian Epilepsy Organisation	Norway
Pless	Elisabeth	Ms	zertifizierte Epilepsiefachberaterin / Geschäftsführerin Epilepsie und Arbeit gemeinnützige Beratungs und Entwicklungs GmbH	Austria
Reiter-Fink	Edith	Dr	St. Anna Kinderkrankenhaus – MedUniWien Neuro-Ambulanz St. Anna Tertiärzentrum und neuropädiatrie- Ambulanz MUW	Austria
Rodrigues	Ana Paula	Ms	Child health nurse	Portugal
Roth	Maria	Prof	Babes-Bolyai University, Social Work Department	Romania
Ruiz-Falcó	Maria Luz	Dr	Hospital Infantil Universitario Niño Jesús Madrid	Spain
Santos	Teresa	Ms		Portugal
Santos	Tiago	Dr		Portugal
Soler	Doriette	Dr	Consultant Paediatric Neurologist	Malta
Strautmanis	Jurgis	Dr	Paediatric neurologist, Head of Latvian Paediatric neurologist's society and Latvian League against epilepsy	Latvia
Suurorg	Lagle	Dr	Paediatrician, Head of Department for Quality Assurance Tallinn Children's Hospital	Estonia
Sykora	Pavel	Assoc. Prof	Chief of the Department of Children Neurology and National Children Neurology Center, Children's Teaching Hospital, Limbova 1, Bratislava, Slovakia	Slovakia
Thórarinsdóttir	Brynja K.	Dr	Child neurologist. The Children's hospital Reykjavik	Iceland
Varandas	Luis	Dr		Portugal
Vinagre	Graça	Ms		Portugal
Vintan	Mihaela- Adela	Dr	'Iuliu Hatieganu' University of Medicine and Pharmacy, Faculty of Medicine, Department of Neuroscience, Neurology and Pediatric Neurology 400012, Cluj- Napoca, Romania	Romania
Virela	Daniel	Dr		Portugal



Appendix 3: MOCHA Country Agent Question – Long-term Ventilation



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

WP2: Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care

Task 2: Complex Care Survey (enduring physical health issues)

Dear Colleague,

The research team on Task 2 of WP2 MOCHA are to provide a reliable and comprehensive analysis of the current approach to managing the care of children with complex care needs at the acute/community/primary interface. This is to generate an evidence base of clear and accessible information concerning current provision of care. We are seeking your feedback on a number of specific scenarios where a child has an enduring and complex health condition. In this case, we are looking at **Long Term Ventilation**.

To answer these questions, the WP team suggest that you should seek to find **someone who understands the medical complexity outlined in the scenario, and who is directly involved in the discharge process of this child from hospital to home**. This person could be hospital based, for example a discharge coordinator, respiratory consultant or specialist airway nurse, or similar healthcare professional who is community based.

To answer the questions about family engagement, you should ideally seek the views of a patient advocacy group. Please answer as many questions as you can, giving examples or elaborating if you would like.

At the end of the survey we ask that you to provide us with the names and contact details of all those who provided feedback, so that we may acknowledge their contribution in our final report.



Case Scenario - Long Term Ventilation

Long Term Ventilation (LTV): refers to the provision of prolonged ventilatory support to a child who has either isolated failure of the respiratory system or respiratory failure occurring as a component of chronic critical illness (Nelson *et al.* 2010).

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 (Widdas *et al.* 2013). 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 mum and dad. He lives 120kms from the main children's hospital and 40kms from his nearest regional hospital which has a small paediatric unit.



SECTION 1: SYSTEMS OF CARE FOR CHILDREN WITH COMPLEX HEALTH NEEDS

This section of the survey includes questions on the care of a child on long-term ventilation in your country, adapted from the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (AMCHP and Lucile Packard Foundation, 2014). Please complete each section **guided by the scenario provided of Max and his family.**



SCREENING, ASSESSMENT, AND REFERRAL

In my country, there are policies and/or procedures in place to assure that a child on LTV receives ongoing preventative care screening and developmental checks

Policies

Yes

No

If yes, please provide reference(s) for the policy or policies.

If yes, who starts this process?

Procedures

Yes

No

If yes, please provide reference(s) for the procedure or procedures

If yes, who starts this process?



<p><i>If there are policies and/or procedures in place to ensure that a child on LTV receives ongoing preventative care screening and developmental checks,</i></p> <p>(a) please list the type of examinations provided</p>			
<p>(b) please name the healthcare providers that conduct these examinations</p>			
<p>In my country, there are policies and/or procedures in place to document and communicate the results of such screening to</p> <p>(a) all care services (general practitioners/ primary care</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p> <p><i>If no please list who, if anyone, receives this information in your country</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>



<p>physicians/ paediatrician, community nurses, school, secondary care etc.) caring for the child</p>			
	<p>Procedures</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure or procedures</i></p> <p><i>If no please list who, if anyone, receives this information in your country</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>
<p>(b) to the child's parent(s) / guardian(s).</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>



	No <input type="checkbox"/>		
	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>	<i>If yes, who is in charge of the communication process?</i>
Have you any further comments in relation to the screening, assessment, and referral of children on LTI in your country?			



ACCESS TO CARE		
There is a system in place in my country to identify all of the healthcare providers who care for children on LTV.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who is in charge of this?</i>
Please provide a list of the statutory healthcare providers caring for children on LTV in your country (For example Children's hospitals etc.).		
Please provide a list of the voluntary healthcare providers caring for children on LTV in your country (For example respite services etc.).		



<p>Please list the professions responsible, in your country, for providing general healthcare services to children on LTV in the community after they have been discharged from an acute hospital setting (For example general practitioner / primary care physician, paediatrician, community nurse etc.)</p>	
<p>The transportation service to accommodate daily activities and routine healthcare visits for children on LTV in my country is provided by</p> <p>(a) the child's parent(s) / guardian(s) with support from the state</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>



<p>(b) the child's parent(s) / guardian(s) without support from the state</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>(c) the healthcare provider</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>In my country, there are policies and / procedures in place to ensure that all information provided to families of children on LTV is linguistically appropriate.</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>
	<p>Procedures</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure or procedures</i></p>



In my country, there are policies and / procedures in place to assure that all information provided to families of children on LTV is culturally appropriate.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>
	Procedure Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
Have you any further comments in relation to the accessibility of care for children on LTV in your country?		
CARE COORDINATION		
<i>In my country,</i>		
	Policies	<i>If yes, please provide reference(s) for the policy or policies.</i>



<p>...there are policies and/ or procedures promoting access to care coordination for the child on LTV.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
	<p>Procedures</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure or procedures</i></p>
<p>...the written personalised plan of care for a child on LTV is developed in consultation with</p> <p>(a) the child's parent(s) / guardian(s)</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who starts it?</i></p>
		<p><i>If yes, who is in charge?</i></p>



(b) members of the healthcare team	Yes <input type="checkbox"/>	<i>If yes, who starts it?</i>
	No <input type="checkbox"/>	<i>If yes, who is in charge?</i>
...the personalised written care plan for physical care integrates the following ; (a) developmental assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(b) mental health	Yes <input type="checkbox"/> <input type="checkbox"/>	



	No
(c) oral health	Yes <input type="checkbox"/> No <input type="checkbox"/>
(d) vision health	Yes <input type="checkbox"/> No <input type="checkbox"/>
(e) hearing assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>
... large Children's hospital(s) have a discharge planning coordinator who is responsible for organising the transition of a child on LTV from the acute hospital setting to the child's home or another community based setting	Yes <input type="checkbox"/> No <input type="checkbox"/>



When a child, such as Max, requires acute care in a medical crisis, is there a process in your country that facilitates direct access to, and discharge from, a PICU?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i> Comments
Have you any further comments in relation to the coordination of care for children on LTV in your country?		
COMMUNITY-BASED SERVICES AND SUPPORT		
<i>In my country,</i>		
...family advocacy groups are involved in making recommendations to home and community-based services.	Yes <input type="checkbox"/>	



	No <input type="checkbox"/>		
... there are policies for paediatric palliative and end of life care	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>	<i>If yes, who starts the process of transition to palliative or end of life care</i>
... the parent(s)/guardian(s) and siblings of children on LTV have access to psychological support from professionals with paediatric expertise	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who starts this process?</i>	
Have you any further comments in about the community based services and supports for children on LTV in your country?			
FAMILY PROFESSIONAL PARTNERSHIP			



In my country,		
<p>...parent(s) / guardian(s) of children on LTV are invited to participate in the development of policies and procedures affecting children on LTV</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>...parent(s) / guardian(s) are included in national quality improvement initiatives for children on LTV.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>...parent(s) / guardian(s) are involved in the review of patient and family information material on LTV for the public, to ensure cultural and linguistic competency.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>Have you any further comments in about family professional partnerships relating to the care of children on LTV in your country?</p>		



QUALITY ASSURANCE		
<i>In my country,</i>		
...there are quality assurance policies and/or procedures for service providers caring for children on LTV.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>
	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
...data is collected on the experience of care for children on LTV from the perspective of	Yes <input type="checkbox"/>	<i>If yes, who undertakes the collection and analysis of these data?</i>



(a) the parent(s) / guardian(s)	No <input type="checkbox"/>	
(b) the siblings	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who undertake the collection and analysis of these data?</i>
Have you any further comments about ensuring that children on LTV in your country receive quality care?		



Appendix 4: MOCHA Country Agent Questions – Traumatic Brain Injury



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

WP2: Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care

Task 2: Complex Care Survey (enduring physical health issues): Traumatic Brain Injury

Dear Colleague,

The research team on Task 2 of WP2 MOCHA are to provide a reliable and comprehensive analysis of the current approach to managing the care of children with complex care needs at the acute/community/primary interface. This is to generate an evidence base of clear and accessible information concerning current provision of care. We are seeking your feedback on a number of specific scenarios where a child has an enduring and complex health condition. In this case, we are looking at **Traumatic Brain Injury**.

To answer these questions, the WP team suggest that you should seek to find **someone who understands the medical complexity outlined in the scenario, and who is directly involved in the discharge process of this child from hospital to home**. This person could be hospital based, for example a discharge coordinator, neurology consultant or specialist neurology nurse, they could be based in a rehabilitation centre that works with teenagers with traumatic brain injury, or they could be a community based healthcare professional who works with this population.

Please answer as many questions as you can, giving examples or elaborating if you would like.



Case Scenario – Traumatic Brian Injury

Traumatic Brian Injury (TBI): an alteration in brain function, or other evidence of brain pathology, caused by an external force (Menon et al. 2010).

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.

SECTION 1: SYSTEMS OF CARE FOR CHILDREN WITH COMPLEX HEALTH NEEDS

This section of the survey includes statements and questions on the care of an adolescent with a TBI in your country, adapted from the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (AMCHP and Lucile Packard Foundation, 2014). **Guided by the scenario of the Luke, an adolescent with a TBI** please complete each section.



ACCESS TO CARE		
There is a system in place in my country to identify all of the healthcare providers who care for adolescents with TBI.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who is in charge of this?</i>
Please provide a list of the type of the statutory healthcare providers caring for adolescents with TBI in your country (For example Children's hospitals, adult hospitals, rehabilitation services etc.).		
Are there voluntary agencies who provide care and support for such children in your country?		
Please provide a list the voluntary healthcare providers caring for adolescents with TBI in your country (with web references if possible)		
Please list the professionals responsible, in your country, for providing general healthcare services to adolescents with TBI in the community after they have been discharged from an acute hospital or inpatient rehabilitation setting (For example general practitioner / primary care physician, paediatrician, community nurse etc.)		



<p>The transportation service to accommodate daily activities and routine healthcare visits for adolescents with TBI in my country is provided by</p> <p>(d) the adolescent's parent(s) / guardian(s) with support from the state</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>(e) the adolescent's parent(s) / guardian(s) without support from the state</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>(f) the healthcare provider</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>In my country, there are policies and/or procedures in place to ensure that all information provided to adolescents with TBI and their families is linguistically appropriate.</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>
	<p>Procedures</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure or procedures</i></p>
<p>In my country, there are policies and/or procedures in place to ensure that all information provided to adolescents with TBI and their families is culturally appropriate.</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>



	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
Have you any further comments in relation to the accessibility of care for adolescents with TBI in your country?		
CARE COORDINATION		
<i>In my country,</i>		
...there are policies and/ or procedures promoting access to care coordination for the adolescent with TBI.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>
	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>



<p>Is there an agreed written plan usually produced? If so, the written personalised plan of care for an adolescent with TBI is developed in consultation with</p> <p>(c) the adolescent (where cognition allows)</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who starts it?</i></p> <hr/> <p><i>If yes, who is in charge?</i></p>
<p>(d) the adolescent's parents/guardians</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who starts it?</i></p> <hr/> <p><i>If yes, who is in charge?</i></p>
<p>(e) members of the healthcare team</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who starts it?</i></p>



		<i>If yes, who is in charge?</i>
...the personalised written care plan for physical care integrates the following; (f) developmental assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(g) mental health	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(h) oral health	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(i) vision health	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(j) hearing assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>	



<p>...hospital(s) have a discharge planning coordinator who is responsible for organising the transition of an adolescent with TBI from the acute hospital setting to the adolescent's home or rehabilitation centre.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>		
<p>Have you any further comments in relation to the coordination of care for adolescents with TBI in your country?</p>			
<p>COMMUNITY-BASED SERVICES AND SUPPORT</p>			
<p><i>In my country,</i></p>			
<p>... TBI family advocacy groups are involved in making recommendations to the acute hospitals, rehabilitation, home and community-based services.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>		
<p>... the adolescent with a TBI has access to psychological support from professionals with expertise in paediatric/adolescent health</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who starts this process?</i></p>	<p>Is the support specifically catered for adolescents?</p>
<p>...the parent(s)/guardian(s) and siblings of adolescents with TBI have access to psychological support from professionals</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who starts this process?</i></p>	



Have you any further comments about the community based services and supports for adolescents with TBI in your country?		
FAMILY PROFESSIONAL PARTNERSHIPS		
<i>In my country,</i>		
...adolescents with TBI (where cognition allows) are invited to participate in the development of policies and procedures affecting them.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
...parent(s) / guardian(s) are invited to participate in the development of policies and procedures affecting adolescents with a TBI	Yes <input type="checkbox"/> No <input type="checkbox"/>	
...parent(s) / guardian(s) are included in national quality improvement initiatives for adolescents with a TBI.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
...parent(s) / guardian(s) are involved in the review of patient and family information material on TBI for the public, to assure cultural and linguistic competency.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Have you any further comments about family professional partnerships relating to		



<p>the care of adolescents with TBI in your country?</p>			
<p>TRANSITIONING TO ADULTHOOD</p>			
<p><i>In my country,</i></p>			
<p>... there policies and/or procedures, which provide guidance for the preparation of adolescents with TBI and their families for the transition of care from paediatric to adult healthcare services</p>	<p>Policies Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>	
	<p>Procedures Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure or procedures.</i></p>	
<p>... a plan of care is prepared with the adult healthcare services before the adolescent with a TBI is transferred from paediatric services</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p><i>If yes, when does this planning start?</i></p>	<p><i>If yes, who starts this process?</i></p>



<p>... data is collected on the experience of transitioning from paediatric to adult services from the perspective of</p> <p>(a) the adolescent with a TBI (where cognition allows)</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who undertake the collection and analysis of these data?</i></p>
<p>(b) the parent(s) / guardian(s) of adolescents with a TBI</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who undertake the collection and analysis of these data?</i></p>
<p>Have you any further comments about the transition from paediatric to adult health and community services for adolescents with a TBI in your country?</p>		
<p>QUALITY ASSURANCE</p>		
<p><i>In my country,</i></p>		
<p>...there are quality assurance policies and/or procedures for service providers caring for adolescents with a TBI.</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>
	<p>Procedures</p> <p>Yes <input type="checkbox"/></p> <p><input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure or procedures</i></p>



	No	
<p>...data is collected on the overall experience of care for adolescents with a TBI from the perspective of</p> <p>(a) the adolescent (where cognition allows)</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<i>If yes, who undertakes the collection and analysis of these data?</i>
<p>(b) the parent(s) / guardian(s)</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<i>If yes, who undertakes the collection and analysis of these data?</i>
<p>Have you any further comments about ensuring that adolescents with a TBI in your country receive quality care?</p>		



Appendix 5: MOCHA Country Agent Question – Intractable Epilepsy



Models of Child Health Appraised (A Study of Primary Healthcare in 30 European countries)

WP2: Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care **Task 2: Complex Care Survey (enduring physical health issues). Round 5** **Country Agent Questions – Intractable Epilepsy**

Dear Colleague,

The research team on Task 2 of WP2 MOCHA are to provide a reliable and comprehensive analysis of the current approach to managing the care of children with complex care needs at the acute/community/primary interface. This is to generate an evidence base of clear and accessible information concerning current provision of care. We are seeking your feedback on a number of specific scenarios where a child has an enduring and complex health condition. This is the third and final questionnaire in this series of questions. In this case, we are looking at **Intractable Epilepsy**.

To answer these questions, the WP team suggest that you should seek to find **someone who understands the medical complexity outlined in the scenario, and who is directly involved in the care of this type of child**. This person could be hospital based, for example a clinical nurse specialist in epilepsy, neurology consultant, or similar healthcare professional who is community based.

To answer the questions about family engagement, you should ideally seek the views of a patient advocacy group.

At the end of the survey we ask that you to provide us with the names and contact details of all those who provided feedback, so that we may acknowledge their contribution in our final report.



Case Scenario – Intractable Epilepsy

Intractable epilepsy: failure of at least two tolerated and appropriately chosen and used anti-epileptic drugs, where pseudoresistance, due to incorrect diagnosis, inappropriate medication or inappropriate dosage is ruled out (Kwan *et al.* 2010, Kwan *et al.* 2011, Laxera *et al.* 2014).

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.



SECTION 1: SYSTEMS OF CARE FOR CHILDREN WITH COMPLEX HEALTH NEEDS

This section of the survey includes statements and questions on the care of a child with intractable epilepsy in your country, adapted from the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (AMCHP and Lucile Packard Foundation, 2014). **Guided by the scenario of Lara, the child with intractable epilepsy**, please complete each section with as much information as you can.



SCREENING, ASSESSMENT, AND REFERRAL			
Is there national or regional guidance to assist local primary care centres in the care of a child with intractable epilepsy? Or does the local centre make its own decisions about the care of each individual child?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>Please give further details</i>	
In my country, there are policies and / or procedures in place to ensure that a child with epilepsy receives ongoing preventative care screening and developmental checks	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>	<i>If yes, who starts this process?</i>
	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>	<i>If yes, who starts this process?</i>
<i>If there are policies and / or procedures in place to assure that a child such as Lara receives ongoing preventative care screening and developmental checks,</i> (c) please list the type of examinations provided			



(d) please name the healthcare providers that conduct these examinations			
<p>In my country, there are policies and/or procedures in place to document and communicate the results of such screening to</p> <p>(c) all care services (general practitioner / primary care physician / paediatrician, community nurses, school, secondary care etc.) involved in caring for the child</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>
	<p>Procedures</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure or procedures</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>
(d) the child's parent(s) / guardian(s).	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>



	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>	<i>If yes, who is in charge of the communication process?</i>
Have you any further comments in relation to the screening, assessment, and referral of children with epilepsy, such as Lara, in your country?			
ACCESS TO CARE			
There is a system in place in my country to identify all of the healthcare providers who care for children like Lara.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who is in charge of this?</i>	
Please provide a list of the statutory healthcare providers caring for children with intractable epilepsy in your country (For example Children's hospitals etc.).			
Please provide a list of the voluntary healthcare providers caring for children			



with intractable epilepsy in your country (For example respite services etc.).		
Please list the professionals responsible, in your country, for providing general healthcare services to children with intractable epilepsy in the community (For example general practitioner / primary care physician, paediatrician, community nurse etc.)		
The transportation service to accommodate daily activities and routine healthcare visits for children with epilepsy who require wheelchairs in my country is provided by (g) The child's parent(s) / guardian(s) with support from the state.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(h) The child's parent(s) / guardian(s) without any support from the state.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(i) The healthcare provider.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
In my country, there are policies and / procedures in place to assure that all	Policies Yes <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies</i>



information provided to families of children with epilepsy is linguistically appropriate.	No <input type="checkbox"/>	If yes, please provide reference(s) for the procedure or procedures
	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	
In my country, there are policies and / procedures in place to assure that all information provided to families of children with epilepsy is culturally appropriate.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	If yes, please provide reference(s) for the policy or policies
	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	
Have you any further comments in relation to the accessibility of care for children with epilepsy in your country?		
CARE COORDINATION		



<i>In my country,</i>		
...there are policies and/ or procedures promoting access to care coordination for a child such as Lara.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>
	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
...the written personalised plan of care for a child with epilepsy, such as Lara, is developed in consultation with (f) the child's parent(s) / guardian(s)	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who starts it?</i>
		<i>If yes, who is in charge?</i>
(g) members of the healthcare team	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who starts it?</i>



		<i>If yes, who is in charge?</i>
...the personalised written care plan for physical care integrates the following ; (k) developmental assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(l) mental health	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(m) oral health	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(n) vision health	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(o) hearing assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>	



<p>Have you any further comments in relation to the coordination of care for children with epilepsy in your country?</p>		
<p>COMMUNITY-BASED SERVICES AND SUPPORT</p>		
<p><i>In my country,</i></p>		
<p>...family advocacy groups are involved in making recommendations to home and community-based services who care for children such as Lara.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>...the parent(s)/guardian(s) and siblings of children such as Lara have access to psychological support from professionals with paediatric expertise.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who starts this process?</i></p>
<p>Have you any further comments about the community based services and supports for children with epilepsy in your country?</p>		



FAMILY PROFESSIONAL PARTNERSHIPS		
<i>In my country,</i>		
...parent(s) / guardian(s) of children such as Lara are invited to participate in the development of policies and procedures affecting their child.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
...parent(s) / guardian(s) are included in national quality improvement initiatives for children such as Lara.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
...parent(s) / guardian(s) are involved in the review of patient and family information material on epilepsy for the public, to assure cultural and linguistic competency.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Have you any further comments about family professional partnerships relating to the care of children with epilepsy such as Lara in your country?		
QUALITY ASSURANCE		
<i>In my country,</i>		
...there are quality assurance policies and/or procedures for service providers caring for children such as Lara.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>



	Procedures Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
...data is collected on the experience of care for children like Lara from the perspective of (c) the parent(s) / guardian(s)	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who undertakes the collection and analysis of these data?</i>
(b) the siblings	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who undertake the collection and analysis of these data</i>
Have you any further comments about ensuring that children like Lara in your country receive quality care?		

