



## Principles for provision of integrated complex care for children across the acute–community interface in Europe

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For more on the MOCHA project see <http://www.childhealthservicesmodels.eu>

This Viewpoint presents and discusses the development of the first core principles and standards for effective, personalised care of children living with complex care needs in Europe. These principles and standards emerged from an analysis of data gathered on several areas, including the integration of care for the child at the acute–community interface, the referral–discharge interface, the social care interface, nursing preparedness for practice, and experiences of the child and family. The three main principles, underpinned by a child-centric approach, are access to care, co-creation of care, and effective integrated governance. Collectively, the principles and standards offer a means to benchmark existing services for children living with complex care needs, to influence policy in relation to service delivery for these children, and to provide a suite of indicators with which to assess future service developments in this area.

### Introduction

The aim of this work stream within the Models of Child Health Project Appraised (MOCHA) project is to support the delivery of optimum care at the acute–community interface for children living with complex care needs, through the development of principles and standards for effective personalised care of these children and their families. Funded by the European Commission under the Horizon 2020 programme, MOCHA is the first systematic study and appraisal of the different systems of primary care for children in 30 countries in the EU and European Economic Area (EEA) and of how these systems address the needs of children and young people and their families.

Care delivery at the acute–community interface refers to care provided to children who frequently require both primary and acute care services because of multiple care needs. Optimum care generally refers to the delivery of safe and effective care, guided by standards of care based on evidence of best practice. So far, comprehensive standards of care for this group of children that can be widely used to enhance care across Europe have been absent. Following on from earlier work within the MOCHA project and our Health Policy paper,<sup>1</sup> we present the first published set of principles and standards for care of children living with complex care needs in the EU and EEA. The development of these principles and standards is informed by the findings presented in the Health Policy paper,<sup>1</sup> as well as by wider complementary data gathered across the project for complex care in the following areas: the referral–discharge interface,<sup>2</sup> the social care interface,<sup>3</sup> nursing preparedness for practice,<sup>4</sup> and experiences of the child and family<sup>5</sup> (figure 1).

This work and its findings are timely, especially considering that the concept of a complex care team is not yet an established entity in most countries in this region. We are, therefore, mindful that our findings must have meaning in diverse cultural, sociopolitical, and legal contexts. This Viewpoint presents the data gathered and

synthesised by our large team of multidisciplinary researchers, and sets out principles and standards of care that emerged collectively from our findings, supported by practical exemplars of good practice from across the EU and EEA. The final suite of principles and standards encompasses issues that cross the period from infancy to adolescence, comprising a reference document for policy makers and health and social care professionals to support optimal practice in the care of children living with complex care needs.

### Core principles and standards for effective and personalised care of children living with complex care needs

From the 30 countries surveyed using the MOCHA project methods,<sup>1,5</sup> we received detailed responses on the referral–discharge interface (21 countries [70%]),

#### Key messages

- The integration of health and social care services is generally found to be insufficient across the EU and European Economic Area (EEA) for children living with complex care needs
- There is confusion over points of accessing care, and no defined system for documenting care at the acute–community interface
- As part of the Models of Child Health Appraised (MOCHA) project, we established core principles and standards for the effective, personalised care of children living with complex care needs, based on evidence of what works well and of identified deficits from countries across the EU and EEA
- These three main principles, underpinned by a child-centric approach, are access to care, co-creation of care with parents or guardians, and effective integrated governance
- When applying these principles, each child's needs, stage of development, and age, as well as the context of the wider socioeconomic, family, legal, and health systems, need to be taken into consideration

management of children living with complex care needs (23 [77%]), social care interface (26 [87%]), and nurses' preparedness for practice (24 [80%]). Additionally, we interviewed 20 children living with complex care needs and 24 parents of other such children in the Czech Republic, Germany, the Netherlands, Spain, and the UK to explore the experiences of the child and the family. Considering the variety of needs across a child's life, no one-size-fits-all approach exists when it comes to facilitating optimum care for the diverse and complex needs of these children. However, our research indicates that there are core principles that, when applied, can enhance the quality of care delivery for any individual child living with complex care needs and can support their parents as their primary caregivers. These principles are in line with the MOCHA project's adoption of a child-centric philosophy. The core principles derived from the thematic analysis are access to care, co-creation of care, and effective integrated governance (figure 2).

The principles and standards are drawn from examples of practice in the 30 countries studied to ensure feasibility, and are validated through the case studies supplied by country agents and through consensus validation by clinical and academic researchers (panel 1). Exemplars are provided in support of the standards, drawn from our substantial reports in these areas delivered to the EU Commission in 2017.<sup>1-5</sup> The full suite of principles and standards, with supporting data, are presented in the appendix.

### Principle 1: access to care

The principle of access to care is defined as equitable availability of consistently high-quality, prompt, and accessible services to meet the needs and improve the health of all groups within the population. The 17 standards of care under this core principle reflect key access issues that repeatedly emerged as facilitators of optimum access to care (panel 2), ranging from identification of specific clinical points of access, to access to support structures to enhance continuity of care. A central aspect is that the child has access to age-specific and developmentally appropriate care.

Specific clinical points of access to care included 24-h access, 7 days a week, to non-urgent specialist care in the community, and direct access to and discharge from a paediatric emergency department or a paediatric intensive care unit. Almost two-thirds of all respondent countries have a process in place that facilitates direct access to and discharge from a paediatric intensive care unit for children assisted with long-term ventilation.<sup>8</sup> The need for non-urgent specialist care emerged in relation to the predominant absence of physicians in the community who could care for a child with complex care needs if they required care for a minor illness. While a parent might request a visit from a physician if they have concerns about an otherwise well child during the night, parents of children with complex care needs are challenged by the

fact that they do not have such an option when they have (albeit minor) concerns about their child.

Other key issues included access to palliative care and respite care services. Although nearly two-thirds of countries reported that paediatric palliative care services are available when required for children assisted with long-term ventilation, the absence of respite care services for children living with complex care needs was repeatedly documented as a major concern.<sup>8</sup>

Access to a community pharmacy service that can specifically support the families of children with complex care needs was identified as an important and increasingly common standard of care, with both Estonia and Portugal highlighting the benefit of this service provision in their countries.<sup>2</sup> In particular, as part of the primary care team, the pharmacists would be aware of the child's background and thereby offer more individualised care.

The infrastructure requirements to support access to care are also reflected in this principle, with specific standards referring to the need for electronic health records and the need for a transport service that is fit for purpose to accommodate any assistive technology that a child might require.

### Principle 2: co-creation of care

Co-creation of care refers to professional support that equips the child and family, in partnership with the [See Online for appendix](#)

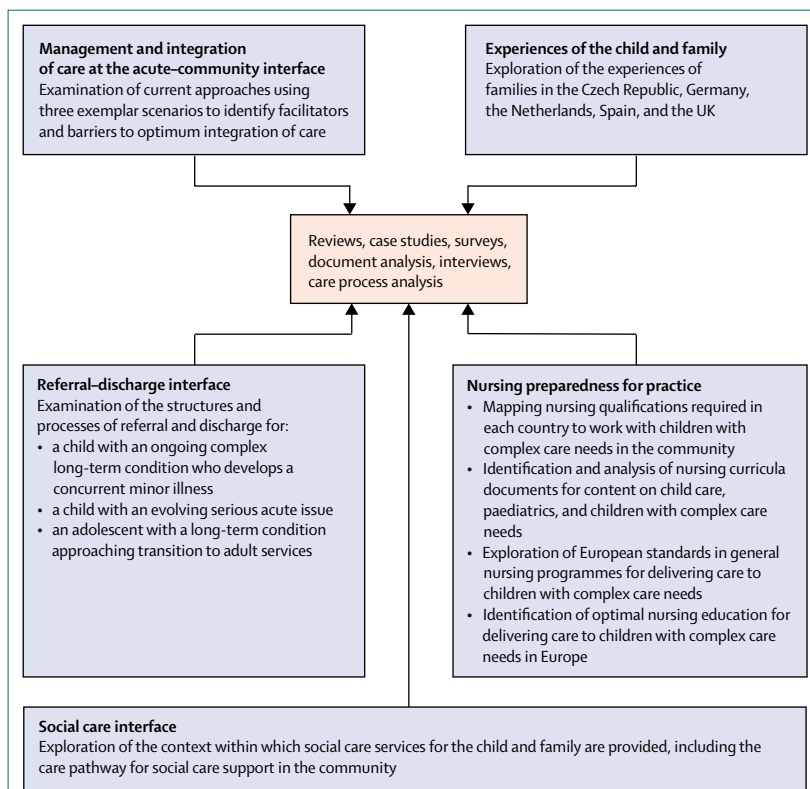


Figure 1: Complementary areas of complex care needs explored in the Models of Child Health Project Appraised (MOCHA) project

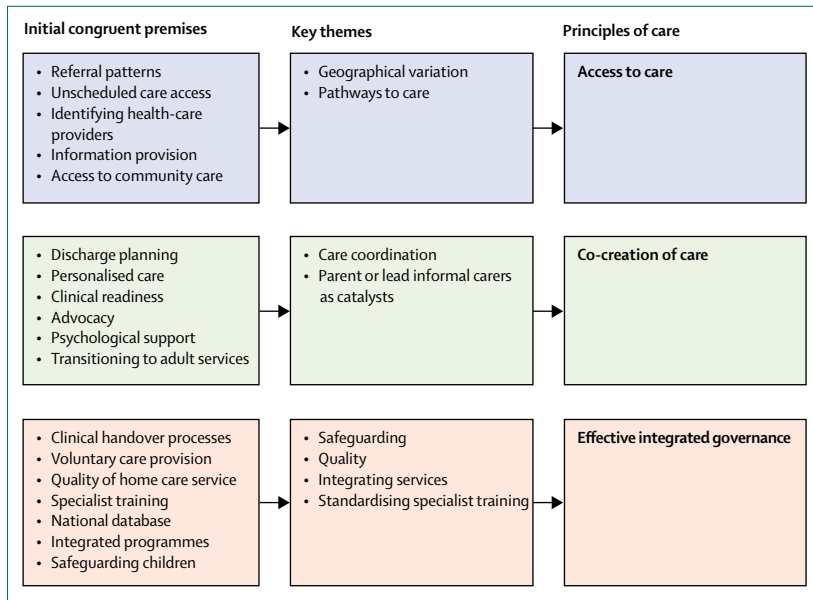


Figure 2: Development of principles of care

### Panel 1: Development of principles and standards of care

We focused on two key issues in the rigorous integration of data: to show how each area was linked, and to identify how there would be meaningful integration of the various data gathered.<sup>6,7</sup> This approach is essential to produce thorough integration that is greater than the sum of the individual components of the research. Two workshops were held (November, 2016, and September, 2017) with the aim of exploring in detail the potential themes emerging from each of the areas of work, and to identify the core facilitators of optimum integration of care at the acute–community interface. The workshops were attended by researchers on the complex care work stream and by the principal investigator, the co-principal investigator, and the research coordinator of the MOCHA project. The systematic approach to thematic analysis included identification of all the lowest-order premises evident across all the findings, followed by organisation of these premises into categories of key themes that emerged from the collective data, and then into principles of care that encapsulated these key themes.

The first step of each workshop was to map out the key highlights from each of the main areas explored. We then developed several iterations of an integration matrix whereby we examined the data from each area for congruence and dissonance, taking into account observations from the clinical and academic experts from each area and their research teams. Patterns and explanations of patterns in findings across each area of data were thus identified. From these workshops, core principles and standards for care of children living with complex care needs emerged.

Given the breadth and depth of data gathered across this programme of research, it was important to return to the gathered data to verify the findings of our integration of the data, to ensure the findings were supported by exemplars of good practice, as provided through self-reports of the country agents in the participating countries. Country agents were given the opportunity to read through each report of data analysis to verify their responses before the submission of our reports to the EU Commission; and the research team returned to the raw data to verify each standard that emerged from our collective analysis. The findings were then subject to examination by the external advisory board of MOCHA for ratification, and were submitted to the EU Commission in November, 2017.

health-care professional, to design, create, deliver, and evaluate health and social care-related support that is responsive to their own needs. Specifically, this principle focuses on key junctures in care delivery: transitioning to home and transitioning to adult services.

The standards under this principle refer to the co-creation of clinical care plans and the clinical support services that are required to facilitate child-centric care coordination (panel 3). These standards include a partnership approach to prepare the family to be clinically ready to care for the child at home, in a gradual manner, and the development of a plan of care for the incremental transition to adult services. Within these processes, the key roles of the discharge coordinator and care coordinator are identified as key support structures necessary for smooth transitions, and the evaluation of care delivery, through the exploration of the experiences of the child and family, is highlighted as an essential element of a responsive care service.

### Principle 3: effective integrated governance

Effective integrated governance refers to the governance necessary to enhance accountability within and across partner sectors to support the provision of integrated, equitable, accessible, and responsive cross-sectoral care to children with complex care needs. The issue of effective governance was repeatedly highlighted as a concern given the increase in the number of children with complex care needs and the struggle of many health services to cope with such needs. Several issues were raised pertaining to educational needs for health and social care professionals and the need for standardised expectations of the quality of care delivery in the home (panel 4). There were also some questions regarding the rapid growth of non-governmental organisations to fill the gap left by state health-care providers and wider services, including social care, education, and housing. These standards support the need to have established systems to identify all care providers and to standardise care delivery to a child in the home. The need for more community health and social care services is supported, with reference to the need for a school health system to support the child living with complex care needs, and the need for specific safeguarding training pertaining to children with communication difficulties for health and social care staff.

### Discussion

As identified in our Health Policy paper,<sup>1</sup> children with complex care needs and their families face great challenges in obtaining responsive, coordinated, sensitive, and personalised services to meet their care needs. In turn, health and social care services struggle to deliver high-quality care that meets these needs. The result is often poor health outcomes.<sup>9,10</sup> Our collective findings show that the integration of health and social care services is generally insufficient, with wide variation in access to, and governance of, care for these children. Extensive challenges remain, including communication of the

**Panel 2: Access to care**

- Children have access to age-specific and developmentally appropriate care
- A pathway for 24-h access, 7 days a week, to non-urgent specialist care in the community is in place
- Where possible, children are cared for by the same doctor and nurse on each consultation
- Community complex care centres are established where there is a substantial population of children with complex care needs, and where the specialist expertise exists to support the child and their family
- Technical support is available in the community to assist parents caring for a child who is technology-dependent (eg, requiring mechanical ventilation, intravenous nutrition or medication, or respiratory or nutritional support)
- Electronic health records are used to support communication and continuity of care across the acute–community interface
- Children and families have access to community pharmacists
- A child living with complex care needs receives ongoing preventive care screening and developmental checks
- All screening results are disseminated to all health services caring for the child and are communicated to the child's parent or guardian
- Families have access to a transportation service that can enable the child, and their assistive technology devices, to attend daily activities and health and social care visits
- All information provided to families is linguistically appropriate
- All information provided to families is culturally appropriate
- When a child living with complex care needs has a medical crisis, there is direct access to, and discharge from, a paediatric emergency department or a paediatric intensive care unit
- Children have timely assessment for, and access to, rehabilitation services
- Paediatric palliative care services are available to the child and family when required
- Children have timely access to respite care services.
- Children have access to diagnostic tests in primary care that enable prevention and early detection of health concerns

needs of the child and their family at the acute–community interface; confusion over points of accessing care; and no defined system for documenting care in a manner accessible for the family and the multidisciplinary team at the acute–community interface.

The challenges we have described in the context of the EU and EEA in relation to access to care are supported in the 2014 Standards for Systems of Care for Children and Youth with Special Health Care Needs,<sup>11</sup> developed for

**Panel 3: Co-creation of care**

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

the health-care system in the USA, and in the 2017 version of this document.<sup>12</sup> Our findings on access to care are also supported by previous studies, which identified that parents are substantially challenged when becoming the primary caregivers for a child with complex care needs and have difficulty accessing the care needed for their child.<sup>13–15</sup> These challenges include difficulties in establishing funding arrangements,<sup>16</sup> with a considerable risk of deepening health inequalities.

In contrast to US standards,<sup>11,12</sup> our identified set of core principles showed a strong need for focus on the co-creation of care and for enhanced effective governance. This difference might be due to the fact that the MOCHA project reflects findings from a multinational and multi-health-system perspective, and therefore genericises at a higher level than do the US standards.

Co-creation of care emerged as an important principle at both the case level and the policy level in our project. At the case level, our findings indicate the need to

**Panel 4: Effective integrated governance**

- Primary care providers have access to specialist support when caring for a child living with complex care needs
- Specialist advanced nurse practice roles are developed in the community for the care of children living with complex care needs
- Standardised systems are in place for the assessment of the child in the community, including those with deteriorating health
- Standardised processes are in place for the clinical handover of the child to and from acute care services
- All health and social care providers who care for a child living with complex care needs are systematically identified
- All voluntary agencies who care for children living with complex care needs are systematically identified
- A system is in place to govern all care delivery to the child in the home
- Specialist training is provided for primary care providers caring for children living with complex care needs and their families
- Appropriate education is provided for all social care staff caring for children living with complex care needs
- There is a retention policy for skilled health-care staff who care for children living with complex care needs
- A national database of children living with complex care needs as well as relevant services is in place
- Quality assurance mechanisms are in place for service providers caring for children living with complex care needs
- Cross-border initiatives are in place if no specialist centre exists nationally for children living with complex care needs
- National integrated care programmes are in place to support care delivery at the acute–community interface
- There is a school health system to support the child living with complex care needs
- Appropriate training is given to school teachers and education support staff when a child is living with complex care needs
- There is special reference to promoting the welfare of children with disabilities within wider child protection legislation
- Safeguarding training for children with communication difficulties is provided for all health and social care staff

facilitate parents or other lead informal carers to do what they can, supported by health and social care professionals. At the policy level, there is a need to work together with stakeholders to attain the services required, while being mindful to ensure that stakeholders are representative of the children and their families. This finding supports some innovative advances in approaches to co-creation of care that have contributed to improving outcomes and governance of health and social care services in this context.<sup>17–22</sup> More widely, the establishment of the role of a discharge coordinator has been found to be extremely beneficial in facilitating the co-creation of care with parents as their child leaves acute care services; ongoing support for families provided by care coordinators in the community has been found to reduce parents' stress and enhance their trust in the health service.<sup>23,24</sup> Evidence also shows that co-creating care can improve the wellbeing and job satisfaction of health-care professionals.<sup>25</sup>

Challenges in the governance of care were collectively identified in our findings. This issue was repeatedly highlighted by concern that the level of education offered for nurses across Europe varies considerably, and that specialist or postgraduate nurse training for children's nurses is not standardised. The issue of governance also emerged repeatedly with regard to the growing number of non-governmental organisations that have developed to fill the gap to care for children with complex care needs when local health systems cannot meet demand. This focus on governance is supported in the literature<sup>26</sup> and aligns with wider work on governance in primary care in the MOCHA project.

To address the issue of governance of care for children with complex care needs, direction at the policy level is needed, with agreement on the criteria for competent care delivery, and clarity in the organisation of services for children with complex care needs and their families. Regulation of the training and education of health and social care staff caring for these children, as well as regulation of voluntary care services, is also urgently needed.

The MOCHA principles of care discussed in this Viewpoint are underpinned by a child-centric approach to the delivery of care to children with complex care needs. The application of these principles and standards is expected to be influenced by each individual child's needs, stage of development, and age, in the context of the wider socioeconomic, family, legal, and health systems, which were previously identified as key constituents in the delivery of care to this group.<sup>27</sup> The MOCHA principles and standards therefore fit well with the three domains of influence on child health set out by the US National Research Council and Institute of Medicine:<sup>28</sup> health conditions, functioning, and health potential. These domains are dynamic and affected by time, stage of development, and age of the child, and can be challenged by complex interactions in the biology, behaviour, and social and physical environments of the child.

The MOCHA principles and standards also articulate well with the evolution of the lifecourse health development model,<sup>29</sup> in which a key tenet is that health is an emergent set of developmental capacities and develops over the lifespan. Our work emphasises the value of this tenet through the need for ongoing developmental issues to be assessed, managed, and integrated into the overall care plan for a child with complex care needs. The MOCHA principles also align with the lifecourse health development model in highlighting the issue of non-linearity in the care and management of children—ie, we do not prescribe care for specific ages, acknowledging that transitions and readiness for care are individual and contextualised for each child and family.

The issues of time and dynamism are constant features in child health models and are supported in our MOCHA



principles and standards. We acknowledge the small window of opportunity in a child's life to address key issues of care that can have a positive or negative effect on subsequent adaptation and coping by a child living with complex care needs, as well as their family. This need for timeliness in care transcends the principles and standards developed, encompassing the initial need for a timely transition to home, the ongoing importance of timely assessment of needs, the timely identification of any deterioration, and the timely management of care to support transitions to end-of-life care.

These collective findings are likely to influence the development of new classification systems for children with complex care needs, and challenge traditional schemas that are dominated by disease systems. The multidisciplinary approach to the development of these principles of care highlights the fact that no single profession has the prerequisite knowledge to effect progress in this area. We therefore expect that the cross-disciplinary nature of this work will positively affect the likelihood of health and social care providers using these principles to enhance the planning and development of integrated care, and capturing these principles in the onward development of their datasets on children living with complex care needs.

## Conclusion

The rising prevalence of complex health conditions among children presents great challenges for the delivery of effective, responsive care. Before the initiation of the MOCHA project, there was a substantial knowledge gap about the management of care of these children at the acute–community care interface, a crucial juncture in care delivery. This project has explored the issues in detail and from numerous perspectives, and we have thereby identified and presented the first set of core principles and standards for the care for these children in the EU and EEA. Our findings encompass a breadth of issues, from infancy to adolescence, and provide health and social care professionals with a reference document to support optimal practice and policy. These principles and standards offer a means to benchmark existing services for children living with complex care needs, to influence policy in relation to service delivery for these children, and to provide a suite of indicators with which to assess future service developments in this area.

## Contributors

MBr was work stream lead and, together with MPO'S, PL, and JB, collected and analysed data on the management and integration of care. IW, SL, and R-MS collected and analysed data on the referral–discharge interface. AW and RM collected and analysed data on the social care interface. AC, EMO, and PL collected and analysed data on nursing preparedness for practice. MA collected and analysed data on the experiences of children and families. DL, FP, and OT completed the business process analysis. MBl, MR, DA, and CH provided direction and context on the approaches taken, in line with the wider project aims. All authors listed were involved in the development of the MOCHA principles and standards of care, and all authors were involved in drafting and reviewing the manuscript as submitted.

## Declaration of interests

We declare no competing interests.

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