A REVIEW OF EDUCATIONAL PROVISION FOR CHILDREN UNABLE TO ATTEND SCHOOL FOR MEDICAL REASONS

BY UNIVERSITY COLLEGE LONDON, INSTITUTE OF EDUCATION

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LIST OF ABBREVIATIONS

CAMHS Child and Adolescent Mental Health Services

CCGs Clinical Commissioning Groups

CHS Children Hospital School

CPD Continuing Professional Development

CQC Care Quality Commission

CYP Children and Young People

CYPMD Children and Young People with Medical Conditions

CYPMH Children and Young People with Mental Health issues

HHE Hospital and Home Education

HHELC Hospital and Home Education Learning Centre

HS Home School

KS3 Key Stage 3

KS4 Key Stage 4

LeHo Learning at Home and in the Hospital

MHFA Mental Health First Aid

NHS National Health Service

PICU Psychiatric Intensive Care Unit

PSHE Personal Social and Health Education

PRUs Pupil Referral Units

SELB Social Emotional Learning Behaviour
INTRODUCTION

SCOPE

This report presents findings from a review of hospital and home education (HHE) services conducted by UCL Institute of Education. Data was gathered from staff from eight HHE services across England between July and October 2017. In addition, the report includes a review of the relevant literature in order to set a wider evidence informed context for the findings. The conclusions are presented as the distillation of the views and perceptions of the teachers that we spoke to, as well as the view of the research team on the implications of the international literature. The research utilises a qualitative research design and as such it provides a particular perspective on the phenomenon being studied. Although we believe it will be highly informative for HHEs in England, it does not purport to provide a simplistic representation of reality, and there may be elements of the report which do not coincide with the perspectives of others working in the field. In particular, we can only report on the responses made by the participants, and where references are made to elements of particular services, there is, unless explicitly stated, no implication that particular elements noted in one service are or are not present in other services. This report is intended for use by the eight services who contributed as participant sites in the research, and it is not intended for general distribution beyond those services.

THE NATIONAL CONTEXT

In 2016 the Office of National Statistics survey of the mental health of children and young people (Natcen, 2016) identified an evident increase in mental health issues for children and young people (CYP) since a previous report in 2004 (Green et al. 2004). The report noted that “mental health illnesses are a leading cause of health-related disabilities in CYP and can have adverse and long-lasting effects” (p. 4) and estimated that 695,000 children in England aged five to sixteen years had a clinically significant mental health illness with the most common being
anxiety, depression, Attention Deficit Hyperactivity Disorder (ADHD) and conduct disorder. Consequently, there has been an increase in hospital admissions rates for mental health issues among children for example, each year self-harm leads 150,000 CYP attending Accident and Emergency (A&E). It is estimated that mental health (MH) affects approximately one in ten children (Department of Health and NHS in England, 2015, 2017). Some of the traits or behaviours that are associated with MH might require the same approach as those caused by other medical conditions, such as autism. Research suggests that there has been an increase in the diagnosis of autism and ADHD in recent years and that around one in 100 children are now diagnosed on the autistic spectrum disorder, compared with one in 2500 in 1996 (Russell et al. 2015). Internationally, it has been reported that up to twenty per cent of adolescents experience clinically recognisable MH difficulties (Belfer 2008), whilst Polanczyck et al. (2015) indicated worldwide prevalence of disorders in CYP at 13.5 per cent.

In the wider societal context, **MH in children and young people is a significant element of NHS expenditure**. In 2013, the Chief Medical Officer for England estimated that once a young client is referred to the Child and Adolescent Mental Health Service (CAMHS) the cost of responding to that one referral will be between £11,030 and £59,130 annually (Department of Health 2013). This is despite the fact there are cost effective early interventions available including non-clinical based therapies (Greig et al. 2016).

Thorley’s (2016) report on behalf of the Institute of Public Policy Research (Education, Mental Health: Supporting secondary schools to play a central role in early intervention mental health services) claimed that schools are facing a “perfect storm”, and emphasised that secondary schools need to be at the heart of early intervention provision. Despite several reports suggesting that early intervention should be a priority there are still 12 % of CYP who live with a MH issue, as illustrated in Figure 1:
The increase of MH illnesses among CYP has led to a plethora of government and third-party reports (CYPMH) including the “Future in Mind: Promoting, protecting and improving our children and young people’s mental health and wellbeing” (NHS 2015) which aims to tackle the promotion, protection and improvement of children and young people’s mental health and well-being.

In January 2017, the Prime Minster announced that CYPMH were a priority in the government’s agenda and set out a range of measures to raise awareness around MH and effective support of CYPMH. In October 2017, the first phase of a government-commissioned review of mental health services for children and young people in England was released (https://www.cqc.org.uk/news/releases/cqc-completes-initial-review-mental-health-services-children-young-people). The report indicated that CYP are facing difficulties and waiting periods of up to eighteen months to access services once they have referred by their General Practitioner.
(GP) or a teacher at their schools. It described how support for mental health can be fragmented and services can vary in quality. The Care and Quality Commission (CQC) “rated 39% (26 services) of specialist community child and adolescent mental health services (CAMHS) as requires improvement and 2% as inadequate against CQC’s ‘responsive’ key question, which looks at whether people access care and treatment in a timely way”. (CQC 2017: 12)

CQC identified the **key challenges for high quality services for CYP**: the complexity of MH issues and how they vary depending on the needs of individual children with different backgrounds, the stages of the illness, funding and resources, collaboration, access to timely care and support, inadequate physical environments that can lead to serious safety issues, staffing and recording and reporting information in an appropriate manner (CQC 2017). It also emphasised that the services around CYPMH are complex as many different services such as schools, CAMHS, local authorities, community organisations inpatient wards and GP practices all play a role in supporting CYPMH. Consequently, the funding comes from different sources (such as NHS, local authorities) and there is a variation in the level of funding, with the report concluding that it is “a system under pressure, leading to long waiting times, appointments being cancelled, and some children being unable to access timely and appropriate help” (CQC 2017, p.9-10). At the same time CYPMH are unable to attend mainstream education, are waiting for a referral and can be “invisible” within this complex system and critical educational time can be been lost.

In May 2017 the joint Health and Education Select Committee published an inquiry into “The Role of Education” (House of Commons Education and Health Committees 2017) and made a number of recommendations, which aimed to inform the Government’s forthcoming Green Paper on CYPMH. These recommendations were:

- Commitment to making Personal, Social and Health Education (PSHE) a compulsory part of the curriculum
- Commitment to whole school approaches
- Senior leadership must embed well-being throughout their provision and culture
• Inclusion of the personal development and well-being criteria in the Ofsted inspection framework
• Training school and college staff in MHFA
• Introduce a structured approach to referrals from education providers to CAMHS
• All schools and colleges to establish partnerships with mental health services
• Schools should include education on social media as part of PSHE.

However, in the whole CQC report of this phase, although home schools are mentioned and how home schools can support CYP with MH issues, there is no mention of the role of HHE as an important service supporting CYP with MH issues which indicated that the emphasis seems to be on the healthcare system only. As one CQC spokesperson said: “[the role of the report is] to identify the strengths and weaknesses of healthcare system to support children and young people’s mental health and help improve understanding of the pathways that they follow and the obstacles that they face”

Additionally, there are many children with chronic illnesses who are hospitalised for long periods of time or spend substantial time in hospitals. One study suggested that approximately 270,000 children each year are living with cancer, with the number steadily increasing in the last two decades as medical improvements help improve long term survival rates (Jemal et al. 2010). Advancement of medical treatments of chronic illnesses means that more and more children are spending time in hospitals, unable to attend mainstream education, thus in need either of education at hospital or home. A study conducted by Bsiri-Moghaddam et al. (2011), on the effects of hospitalisation of CYP found that hospitalisation brings some degree of emotional disturbance to CYP. Especially, prolonged and repeated hospitalisation increased the chance of later problems in life, especially MH related issues. The study suggested that it was important during hospitalisation for children to take an active role as it helps them to reduce their emotional distress during admission. Earlier Coyne’s (2006) research concluded that hospitalised children undergo a lot of stress and experience various fears and anxieties. Both studies, among others (e.g. Gallery 1997, Gabbay et al. 2000, Carney et al. 2003, Nahalla et
al. 2003), suggested that high levels of mental and physical activities during hospitalisation of CYP helps them to cope with the medical conditions that impact on their health (physical or mental).

In another study conducted on the educational services for hospitalised children in Canada (Ratnapalan, Rayer and Crawley 2009), it was found that it is essential when children are hospitalised to ensure that they have access to appropriate education.

“It seems that schooling hospitalized children is either taken for granted or forgotten, or a low priority […]. Even when it does exist, most centers are blissfully unaware of its existence, and the idea of letting the children catch up later seems to prevail. This heightens the idea that being ill is a stalemate situation during which time normality drops by the wayside. In many instances, child life services is the only department that is aware of the teachers’ existence. It appears that on many fronts, the fight for education in hospitals is either forgotten or under attack” (p 436).

Research has shown strong evidence that supporting children to stay connected with education and social activities during hospitalisation reduces difficulties during school re-entry, helps children to cope with their medical illness and manage it in better ways, provides children with a sense of normalcy and helps them to avoid potential MH issues due to their absence from “normal” life in later life, especially for children that have spent long periods of time in hospital (Rechart 2016, Cane 2016, Wade 2016). This has also been acknowledged at policy level nationally and internationally (Leho 2015, UNICEF 2007). In an earlier study in 2000 Gabbey et al. warned that:

“Children who miss schooling for medical reasons can be at double jeopardy - suffering not only of their illness or injury, but also the consequences of educational deprivation […]. As LEAs struggle to provide even mainstream education, services for sick children are often threatened in this and other ways. Authorities may, for example, claim that a reduction in inpatient provision is a reason for closing a school, or severely restricting its resources, rather than switching provision to the increasing number of outpatients unable to attend their normal school. These are probably the most vulnerable pupils within an education authority's responsibility and their
transient circumstances and their parents’ preoccupation with health priorities leaves them without advocates” (p.53)

From a long time now, numerous studies (Kayc 1978, Cock 1981, Wiles, 1987, Bolton 1997, Kearney 2008, Kendall and Taylor 2016, Boles 2017) have called for more research on the education of CYPMC and urged health professionals to lobby on their behalf for access to high quality education when they are hospitalised or unable to attend HS for MC. Throughout the literature review examined in this report, it has been strongly suggested that without education CYPMC are further disadvantaged and they, their families and society could continue to count the financial and social costs for generations. The growing numbers of MH issues among CYP, particularly for behavioural and emotional conditions such as anxiety, depression and conduct disorders is now well known. However, educational services for CYP in hospitals do not seem to have received the same attention despite their important role.

In the UK, as it will be explored more fully later, the education of students with medical needs has been supported by national guidance to local authorities, see:


and to schools, who are legally obliged to meet the education of young people unable to attend a mainstream school, see:


Since the Education Act in 1996 and the DfES Guidance 0732/2001 (Access to Education for Pupils with Medical Needs), all local authorities are obliged by Section 19 to:

“Make arrangements for the provision of suitable education otherwise than at school for those children of compulsory school age who, by reason of illness, exclusion from school or otherwise, may not for any period receive suitable education unless such arrangements are made for them.”
THE REVIEW QUESTIONS

The scope of the review was as follows:

- What outcomes are most important in hospital and home education to the future lives and well-being of children and young people unable to attend school for physical, emotional and mental health reasons?
- What elements of provision and experiences, including organisation, curriculum content, innovations and style of delivery, contribute effectively to these outcomes?
- What models of provision exist which are effective at providing the outcomes identified from points 1 and 2, including provision for transition?

METHODOLOGY

Research Design

In addition to the literature review, twenty one interviews were undertaken with hospital and home education service staff. As well as the project team, an advisory board was formulated and involved in reviewing the project methodology as it was developed and implemented.

Data Collection

The phases and associated activities were:

1) Literature Review (May to July 2017)

A review of the existing academic and policy literature on Hospital School Education services and other provision for children unable to attend school for medical/emotional reasons, and relevant wider literature on children’s mental health and the role of CAMHS in supporting mental health in young people at Tier 4.

2) Interviews with professionals at nine HHE school sites across England (initially June to July and then September to October).
Interview guides were developed and piloted by the project team with the input of the advisory board.

The data were transcribed, and analysed using the Nvivo qualitative data analysis package.

**ETHICS**

This project followed the ethical procedures of UCL Institute of Education. Ethics forms were completed and were approved by the Ethics Committee of UCL Institute of Education. All participants signed ethics forms. A copy of each was kept in UCL and one copy was given to each participant. All the audio recordings were transcribed, and a copy of the transcript was returned to each participant for final approval.

**All participants were informed of and assured of confidentiality, anonymity and the right to withdraw at any point.**
PARTICIPANTS

Table 1 presents the participants that were involved in the project:

**TABLE 1 PARTICIPANTS: HHE SERVICES (N=8)**

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<th>Type of Service</th>
<th>Interviews with</th>
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<td>Service A</td>
<td>On-site hospital school in North of England serving mainly mental health patients. Primary/Middle School and Secondary School. Day patient service for complex mental health needs.</td>
<td>Headteacher, Key Teacher</td>
</tr>
<tr>
<td>Service B</td>
<td>On hospital site Medical PRU in London dealing with: Short stay referrals of children signed off as medically unfit. Typically, children with mental health needs – anxiety and depression. Children from community hospital wards – generally very short stays</td>
<td>Headteacher</td>
</tr>
<tr>
<td>Service C</td>
<td>Home Tuition Service for children aged 5-16 in the midlands. Offers face to face tuition to children who are not in school, mainly for mental health needs including anxiety and school refusal.</td>
<td>Headteacher, Specialist Teacher</td>
</tr>
<tr>
<td>Service D</td>
<td>On-site hospital school service serving general hospital in North of England. CYP have a broad range of conditions. Also provide service for hospital inpatient child and adolescent mental health unit,</td>
<td>Headteacher, Lead Teacher</td>
</tr>
<tr>
<td>Service E</td>
<td>Hospital School Service in south of England covering general hospital and adolescent mental health inpatient unit. The service also has a base learning centre which provides on-site tuition for children who are unable to attend their home school. There is also a home tuition service.</td>
<td>Headteacher and 4 other teachers</td>
</tr>
<tr>
<td>Service G</td>
<td>On-site hospital school serving general hospital in north of England, including range of medical and surgical wards, but also a child and</td>
<td>Headteacher and 3 other teachers and a</td>
</tr>
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adolescent mental health inpatient. There is also a day hospital school service for children who come for day tuition. governor

Service H  A foundation special school in the midlands with a hospital school, service for children mental health problems, and an outreach service to provide education for children as a stepping stone to go back into mainstream. Deputy Head

Note that in order to preserve anonymity, certain identifying characteristics of individual services have been modified in some cases.

LITERATURE REVIEW

INTERNATIONAL DIMENSIONS AND TERMINOLOGY

The United Nations Convention on the Rights of the Child (UNCRC) came into force in the UK in 1992 and since then all policies related to CYP are shaped and influenced by it and is clearly stated in Articles 26 to 29 that every child has the right to education. In particular, it is stated that governments are responsible for making education available to every child and ensure that they provide for “the development of the child’s personality, talents and mental and physical abilities to their fullest potential” (Article 29a, UNCRC 1989). The introduction of the UNCRC has changed the way we think and provide services for CYP and governments have begun to change domestic policies, legislation and evaluate services to ensure that CYP’s rights are protected and promoted. In the UK, as a result of the UNCRC, in the last 25 years there has been a shift towards changing legislation in order to meet the requirements of the UNCRC rights such as the National Childcare Strategy, Quality Protects and Children’s Rights.

However, in 2015/16 in the UK, 10.5% of pupils were identified as persistent absentees in state funded primary, secondary and special schools which means that these CYP have missed 10% cent or more of sessions. Illness was the most common reason for absence in 2015/16, accounting for 57.3% cent of all absence. There was also an increase of 1.6% from 2014/15 in absences for pupils attending referral units totalling a 32.6%, up from 31.5% in 2014/15. The percentage of enrolments in pupil referral units who were persistent absentees was 72.5% in

As the official statistics show there are an increasing number of CYP that are absent from school for a long period of time due to medical absenteeism. International research demonstrates that school absenteeism may affect children’s emotional, social and cognitive well-being negatively and can cause children’s educational development to stagnate which, in turn, may lead to lower levels of academic achievement and not meeting their full potential in life (Gabbay et al. 2000, Shiu 2001, Vance and Eisr 2002, Haggins and Lavin 2015, Boles, et. al., 2017).

Figure 2 visualises the impact of school absenteeism due to medical reasons (physical or mental) for health conditions and educational outcomes (Vanneste et al. 2016).
Absenteeism from school is a serious mental and physical health concern for many children and adolescents. Absenteeism or placement in alternative educational settings, usually for absenteeism, is a key risk factor for suicide attempts, perilous sexual behaviour, teenage pregnancy, violence, unintentional injury, driving under the influence of alcohol, and alcohol, marijuana, tobacco and other substance use (Almeida, Aquino, & de Barros, 2006; Chou, Ho, Chen, & Chen, 2006; Denny, Clark, & Watson, 2003; Grunbaum et al., 2004; Guttmacher, Weitzman, Kapadia, & Weinberg, 2002; Hallfors et al., 2002; Henry & Huizinga, 2007). Long term absenteeism is often associated as well with school dropout, an event that leads to immediate disconnection from school-based health and mental health programmes, economic deprivation and marital, social, and psychiatric problems in adulthood (Kogan, Luo, Murry, & Brody, 2005; Tramontina et al., 2001; US Census Bureau, 2005). Psychiatric conditions related to extensive school absences primarily include anxiety, depressive and disruptive behaviour disorders. As such, school absenteeism remains an important public health issue for mental health professionals, physicians and educators.

Throughout the available literature, medical absenteeism has strong interrelationships with CYP development and low educational level and school dropout (Eames, Shippen and Sharp 2016, Leger 2014, Dixon 2014, Roffey 2016) and there is a strong emphasis on the effective role of education of CYP with medical conditions (e.g. Moss, 2012, Cane 2016, Reichart 2016). However, CYP with medical health needs and conditions have been described as a ‘hitherto hidden, but growing group of pupils’ (Lightfoot, Mukherjee, and Sloper 2001 p. 67.) The reference to hidden relates to a lack of recognition of these young people as a group, with particular support needs, who rely on complex funding arrangements from both health and education government departments. This is perhaps reflected in the relatively sparse international and UK research literature on home and hospital education.

There are a variety of terms used to describe the education of CYP with medical conditions who cannot attend mainstream school such as special school and alternative provision. Others pursue the notion of the ‘irregular school’, a term developed ‘in reaction to the ill-considered and over-used couplet of regular school
or normal school’ (Slee 2011, p.12). This term has been adopted by the “Keeping Connected” context of hospital-based learning in Australia. The Keeping Connected project was funded by an educational institution in Australia that was attached to a hospital school and was a national project to evaluate the education children receive when they are in hospital due to chronic illness (Yates 2010, 2014, Moss 2012).

Across Europe there are several different terms to describe the educational services for CYPMC. In Poland, for example, the term “Special Needs School” is used to describe an educational, tutorial establishment that operates within a hospital system. The School Services Somatic and Psychiatric wards (inpatient and day) of two hospitals in Krakow include the Regional Children's Hospital on Strzelecka Street and the Child and Adolescent Psychiatry Clinic on Kopernika Street. The term “Special Needs School” is used to describe the whole context where school related activities take place. These include the:

“day to day rules and organisation of the school, from the regular lesson times, the lesson plans and the educational programme as well as a clear designations of tasks which particular school workers have to perform, through clear definition of the behaviour promoted as acceptable behaviour and the consequences of such behaviour to the contracts that the pupils enter into with the school and which regulate their duties” (Dziubalska 2017 p8).

In Germany, the term Special Education is also used to describe HHE and recently, for example, there was a movement to create further training in higher education for teachers and pedagogues working with CYPMC. Due to their federal state system, there is no structured national training for hospital teachers. Thus they established the 'Hamburger Institut für Pädagogik' (HiP): Competency in Teaching Young People with Medical Conditions. After much preparatory work with the community of the state representatives of the Verband Sonderpädagogik [Association for Special Education] training was introduced in the form of seminars for teachers and pedagogues in hospital schools (Meister 2017).

Officially in Europe, Home and Hospital Education (HHE) is a term widely used to refer to the learning opportunities that are provided to all children and young people with medical needs (physical or mental) who cannot attend mainstream school. The
term was first introduced by the EU funded project LeHo (Learning at Home and in the Hospital). LeHo was an international 3-year project (Capurso and Dennis 2015a) managed by the Fondazione Politecnico di Milano aiming to research, develop and disseminate effective pedagogical practices and appropriate use of ICT within the hospital school sector. In a key project report (Capurso and Dennis 2015b) the research team noted that:

“The issue of providing education to children and youngsters with medical or psychological needs, which preclude them from accessing mainstream education, is a world-wide problem and every country has its own solution for it.”

Hospital for Pedagogues in Europe (HOPE) is an international organisation that aims to bring together hospital teachers who work with CYPMC. Although they also acknowledge that there is a variety of terms and practices around the education of CYPMC, they do recognise the importance for creating positive environments for CYPMC and the need for education no matter what the illness.

However, a key conclusion from this report is that whilst there is no uniform model or approach that can be defined as best practice, all successful approaches rely on effective collaboration within the multidisciplinary team: patient, parents, doctors, nurses, therapists, educational psychologists, mainstream school and HHE and suggests that all of them need to be considered and to contribute to the process of caring for the needs of the individual child.

THE POLICY CONTEXT

As mentioned earlier in Section 1.3, the right to education for all children has now been recognised nationally and internationally as a fundamental right by UNESCO Universal Declaration of Human Rights 1948 (article 26). Since then this fundamental right has been reinforced by other international conventions and treaties such as UNESCO Convention Against Discrimination, Convention on the Rights of the Child 1989 and the UNESCO Salamanca Resolution of 1994. These conventions have been ratified by many countries, including the UK, and have shaped national
policies and legislations. Moreover, the European Union Charter of Fundamental Rights dating from 2000 (Article 14) emphasises the right for all children’s education. This right has become a legally binding issue for all EU countries since the Lisbon Treaty in December 2009. This right to education is thus now acknowledged at policy level as fundamental for children who cannot attend school due to medical needs (physical or mental).

Many CYP with medical conditions preventing them from attending school received education via Medical Pupil Referral Units (PRUs). Section 100 of the Children and Families Act 2014 places responsibility on maintained school’s governing bodies, proprietors of academies and management committees of PRUs i.e. Medical PRUs, to make appropriate arrangements so pupils at their school with medical conditions are able to be supported and are not educationally disadvantaged. It states that:

“Children and young people with medical conditions are entitled to a full education and have the same rights of admission to school as other children. This means that no child with a medical condition can be denied admission or prevented from taking up a place in school because arrangements for their medical condition have not been made. However, in line with their safeguarding duties, governing bodies should ensure that pupils’ health is not put at unnecessary risk from, for example, infectious diseases. They therefore do not have to accept a child in school at times where it would be detrimental to the health of that child or others to do so”. (Supporting pupils with medical conditions 2014)

The Act goes on to indicate that responsibility for the implementation of the statutory guidance lies with the following:

- governing bodies of maintained schools (excluding maintained nursery schools)
- management committees of PRUs
- proprietors of academies, including alternative provision academies (but not including 16–19 academies).
The guidance not only aims to assist schools, academies and local authorities, but is also extended to other services such as clinical commissioning groups (CCGs), NHS England and other services such as independent schools, charities who have an interest in safeguarding and supporting the well-being of CYP with medical issues, parents/carers, pupils and health service providers. The legislation, in common with policy across Europe, explicitly acknowledges the importance of education of CYP to their emotional and social well-being. It also emphasises the fact that long term absence due to medical reasons affects educational attainment and this can lead to issues with reintegration and concomitant difficulties with interacting with the peer group. Once a child or young person has spent a long time out of school due to medical reasons there are issues with their return thus it is recommended that:

“Reintegration back into school should be properly supported so that children with medical conditions fully engage with learning and do not fall behind when they are unable to attend. Short-term and frequent absences, including those for appointments connected with a pupil’s medical condition (which can often be lengthy), also need to be effectively managed and appropriate support put in place to limit the impact on the child’s educational attainment and emotional and general well-being.”

The second variety of provision for CYP that are unable to attend mainstream schools due to medical conditions (physical or and mental/psychiatric) is provided by Hospital School and Home Education. Currently in UK there are (16) Hospital Schools and approximately 300 Medical Pupil Referral Units (PRUs).

As noted, the education of students with medical needs has been supported by national guidance to local authorities and schools as follows:

Guidance to Local Authorities


Guidance for Schools, who are legally obliged to meet the education of young people unable to attend a mainstream school:
Although HHE is often used as a collective term there are significant differences between provisions in terms of the nature of the CYP they are working with, as well as with structure and organisation. Hospital schools are normally maintained schools. This means they are managed by a governing body or the local authority management board. As such they have a duty to support all CYP who cannot attend school due to medical conditions. Where a CYP is not attending school due to emotional or psychiatric reasons, then the mainstream school is obliged to refer this student to hospital school via a medical practitioner. In cases where a pupil is medically ill and not able to attend mainstream schools, the local authority must provide evidence that appropriate and adequate education is available and the mainstream school has a duty to demonstrate that they are communicating and cooperating with the hospital school so the pupils are not educationally disadvantaged or deprived. Additionally, both hospital and mainstream schools need to work together for the effective reintegration of the pupils back into mainstream school or home school environment. Typically, CYP remain on roll in the mainstream school and their educational outcomes show in the results of that school at the end of Year 11, as well as in the results of the hospital school. Figure 3 illustrates the complexities of HHE showing potential movements of a CYP and the communication channels that might be involved among a variety of services:
FIGURE 3 POTENTIAL MOVEMENTS OF A CYP MD AND SERVICES INVOLVED

Inpatient unit
- Medical Staff
- CAMHS
- Other Services
- Family/Guardians

Home
- Family/Guardians
- Social environment of CYP
- Education Base

Home Education (outpatient)
- CAMHS
- Families/Guardians
- Other services

College, University
Work Place
Throughout the literature there were a variety of examples of practices in hospital and home education described in this section. We do not suggest that these are examples of effective practice, but the aim of presenting these is to demonstrate the different approaches in different countries in terms of their organisation of the education for CYPMC.

**EXAMPLE 1 HHE ALBANIA**

In Albania for children that need to stay in hospital for longer periods of time (more than two weeks), normally are hospitalised in the capital city of, Tirana. During their stay there are teachers, psychologists and social workers available. In 2015 a new project started a portable tablet, donated to sick children especially the ones that were on oncology, were included in the lessons. The tablets were appropriately programmed with teaching apps like the ones used in home schools. The aim was to promote online distance learning. Alongside the introduction of the tablets each child was given their own educational programme. A typical teaching programme is designed around teaching levels. The children access the teaching materials only according to the teaching programme of the school. The purpose of this goes beyond just children carrying on learning when hospitalised, but to ensure they remain connected with their home school so they can still feel a sense of continuity in their lives and also not miss out of their social lives. Most of the lessons are done online (distance learning). The lessons are supported by videos, films, documentaries and other relevant online materials. All this is done according to the home school programme (Trumza 2016).

In this example, the hospital learning of the CYPMC is synchronised with the curriculum of the home school where children are coming from. There is emphasis on distance learning and each child following the same teaching levels as in their home school with the use of technology.

**EXAMPLE 2 HHE IN FINLAND**

“I am principal of Koivikkopuisto school (Koivikkopuiston koulu), a hospital school in the city of Tampere in Finland. As well as the leadership of the school, I teach pupils
from psychiatric wards at Tampere University Hospital. I have a Master’s Degree in Education, studied as a special needs class teacher and primary school teacher and specialise in visual art. I have a specialist qualification in management. According to the Basic Education Act in Finland the sick pupil has the right to education while sick and in hospital.

Our school, Koivikkopuisto school is a hospital school in the city of Tampere and is situated in Tampere University Hospital Campus. The pupils of our school are being treated at Tampere University Hospital in the child psychiatric or paediatric wards (and other wards) or they are outpatient pupils (grade 0-9). The pupils come from different municipalities of the Tampere University Hospital district or occasionally from other parts of the country. The subjects of the comprehensive school taught in the hospital school according to the Finnish curriculum which uses flexible child-centred learning methods.

Cooperation with parents, hospital staff and the pupil’s own schools is at the centre of our work. Our school is involved in the Art Arc (Taidekaari) program in Tampere. It is a municipality cultural programme for the schools of the city of Tampere. By doing art projects, e.g. social circus and visits to and workshops at art exhibitions with psychiatric pupils, or graphic projects with paediatric pupils in our hospital school, we have learnt how pupils can explore their skills and express themselves. Taking part in our art projects motivates all the pupils, builds confidence in shy pupils, helps the restless ones to concentrate and teachers everybody in outdoor education.”

There is a big construction project of the new hospital for the children and adolescent next to our hospital school in Tampere University Hospital Campus. The younger pupils can follow through the windows what is going on in the worksite. The Finnish hospital teachers, principals and school assistants have a national meeting at least once a year. Hospital schools in Finland have development projects and cooperation with Finnish National Board of Education and Ministry of Education and Culture. The Finnish hospital schools are very active in developing future work.” (HOPE 2017; adapted from April; May Newsletter)
In this example, we can see that although there is an emphasis on the curriculum and that the school is linked with external providers to offer other activities to the CYPMC. In the example the role of the arts is emphasised as a key element for CYPMC well-being. Core to all these activities is effective collaboration.

EXAMPLE 3 HHE IN NORWAY

“St. Olav’s University Hospital (Norwegian: St. Olavs Hospital Universitetssykehuset i Trondheim) is the hospital in Trondheim, Norway. It is part of St. Olavs Hospital Trust that operates all the hospitals in Sør-Trøndelag and thus indirectly state owned. It cooperates closely with the Norwegian University of Science and Technology in research and in education of medical doctors.

The university is named after Olaf II of Norway, also known as St. Olav.

The hospital performed 274,441 somatic and 88,692 psychiatric consultations in 2005 with 8,691 employees and a budget of Norwegian Krone 5.1 billion.

Trondheim Heliport, St. Olav’s Hospital (ICAO: ENTR) is a helipad located adjacent to the emergency ward.

The School at St. Olav’s Hospital offers education at primary and secondary level to pupils/students and adults who are patients at the hospital. We are located at the Unit for Children and Youths and at the Unit for Physical Medicine and Rehabilitation. In addition, we provide curriculum education for students at college/high school level at other units at the hospital. We maintain a close relationship with the various units.

The school activities are located within the hospital area in Trondheim. Situated in the central part of Norway, Trondheim is the third largest city in the country. Our school has a headmaster and seven teachers. Most of our pupils/students come from the three counties “Møre og Romsdal”, “Sør-Trøndelag” and “Nord Trøndelag”. The State owns the hospital. However, it is Sør-Trøndelag county which is responsible for the school and the teaching of the youngsters (age 6 – 18) at St. Olav’s Hospital. The county cooperates with the municipality of Trondheim in the running of the school. We give individual tuition/education to children, youths and
adults hospitalized at St. Olav’s Hospital who have rights according to the national law of education (“Opplæringslova”). SKOLEN ST. OLAV’S HOSPITAL AIMS:

We want to provide the pupils/students with a life situation as normal as possible, with focus on confidence, prosperity and life quality. In cooperation with the pupils’/students’ home schools we want to give chronic ill and long-term hospitalized children adapted education, to make it easier for them to return to their home school.” (HOPE 2016, adapted from December 2015 - January 2016 Newsletter)

What makes this example interesting is that they offer education at all levels and also include the adult patient in the school. Again, we can see the emphasis on academic subjects, but the school has created networks and collaborations so they can offer other activities as well.

In all the above examples although there were a variety of practices and it was evident that the format of HHE was focusing on teaching core subjects that are in line with the national curriculum of each country (or guidelines). It was also evident that the mission of the teachers focuses on pupils’ well-being and their social development. Despite the variety of teaching methods and approaches the common characteristics were:

- To provide support for CYPMC not to discontinue engagement with their education
- To provide support with children’s well-being, emotional and social development
- To create normalcy around their lives when they are hospitalised
- To provide support for the re-entry to home school/mainstream school
- To provide core subjects in their curriculum alongside other subjects such as Arts and Music that benefit the CYPMC’s well-being
- To create meaningful and supportive collaborations with parents/guardians and other services
- Networking.

The LeHO project that studied several EU countries practice in HHE (Carpuso and Dennis 2015a, b) found three key formats of education for CYP with medical
conditions. Firstly, HHE are using their own curriculum; secondly, they try to synchronise their own curriculum with the mainstream school’s pedagogy and, thirdly, they are focusing only on providing tuition:

1. “In some hospital schools, children with medical conditions can attend classes following the hospital school’s own curriculum (taking into account the level and kind of education the child normally follows in their mainstream school). The advantages of this system for teachers are that they can use familiar handbooks and that teaching and learning materials will be available that can be adapted to switch between classical and more individual teaching. It offers teachers the flexibly to adapt their teaching/learning support in line with the treatment regimens. Not all subjects will/can be covered by this type of education: Often the child’s concentration and effort are limited by the illness and the treatment, and some practical and technical subjects often require specific equipment that is not available in hospital schools. For this reason, subjects taught in the hospital school often cover only the main core subjects.

2. Hospital schools try to match, as far as possible, the child’s mainstream school pedagogical system. For this approach, they must contact the mainstream school of each child to obtain background information, obtain the necessary teaching and learning materials and follow the mainstream school’s didactical approach. This can take some time and not all mainstream schools are willing and able to respond quickly and comprehensively to the request of the hospital schoolteacher. However, secondary school students will often need such an approach, as their curriculum will contain more elective subjects than elementary school pupils. To help with this, the Hospital Organisation of Pedagogues in Europe (HOPE; http://www.hospitalteachers.eu/) recommends that ill children remain enrolled in their mainstream school during their stay in hospital. Continuity of education and a smooth return to the mainstream school after treatment can be supported in this way.
3. Finally, in some hospital schools, teachers act as tutors that support pupils and students who are working through learning packages (written materials and/or e-learning) provided by educational establishments”.

(adopted by LeHo [2016] Teaching children with medical needs - Home and Hospital Education: A guide to international innovative practices)

Examining several examples and policies in regards of CYPMC across the world (USA, Canada, Australia and Europe) overall, we can classify types of provision as:

**Hospital school:** located in a hospital environment (normally in specialised children’s wards) and teaching can take place either in the wards or on a different physical space for the children that are able to leave the ward.

**Teaching at home:** this is in the format of home tuition. CYP with medical conditions who are staying at home receive limited hours of face to face teaching.

**Asynchronous teaching and learning at home:** this is based on materials that are developed for distance learning and coaching. This is based on commercial packages that do not entirely match the education programmes of schools, but can offer valid and interesting educational activities for CYP with medical conditions.

**Education within mainstream school:** schools have developed their own facilities to accommodate teaching CYP with medical conditions. The CYP are attending classes and follow the curriculum of the mainstream school, but with special or alternative arrangements and additional support.

**Mainstream school in hospital or at home:** this format relies on ICT and CYP with medical conditions to attend classes in mainstream school with the support of digital technology, such as videoconferencing and special software that allows either full or part coverage of the mainstream school day.
EFFECTIVE ORGANISATION AND STRUCTURE

Examining the literature on the role of education and what makes effective HHE practice the following key themes were identified:

- Holistic approach
- Workforce skills and training
- Workforce collaboration
- Collaborative assessment processes.

Each of these themes are discussed in the following sections.

HOLISTIC APPROACH

Examination of the available limited literature nationally and internationally that addresses medical absenteeism of CYPMC suggests a holistic approach at two levels. Firstly, a curriculum that requires an approach which takes a wider spectrum of action/s from promoting emotional resilience and well-being to catering for mental health issues. Secondly, effective communication and collaboration requires a joint approach for the entire school for specialised interventions. It should involve all the relevant services such as CAMHS, psychologists, social workers, local authorities and medical staff (Lavis and Robson 2015, Roffey, Williams, Greig and Kay 2016, Bantley, Hagan and Raff 2016).

In 2015 the ‘Promoting children and young people’s emotional health and well-being: A whole school and college approach’ report was published by Public Health England in conjunction with the Children and Young People’s Mental Health Coalition whose 14 members included charities such as Young Minds and organisations such as the British Psychological Society. The report suggested eight principles that need to be met to achieve the holistic approach to provide support for CYPMH. These principles are illustrated in the following figure:
A central point in the report was that leadership and management are the driving force to create a culture of commitment to addressing social, emotional well-being. This culture of commitment can include:

- improvement plans;
- policies (such as safeguarding, confidentiality and personal, social, health and economic (PSHE) education);
- social, moral, spiritual and cultural (SMSC) education;
- behaviour and rewards practice.
The report puts responsibility on the leadership to collaborate with local mental health commissioners and related services such as GPs and psychologists.

In the recent published report on *Children’s and young people’s mental Health-the role of education* (2017), it was recommended:

“to avoid tokenism, the need for a whole school approach to well-being was advocated. This might involve training of staff, engagement with parents and addressing well-being throughout the curriculum” (p. 6).

It was also suggested that well-being should extend beyond PSHE provision. The inclusion of subjects such as music and the arts should be considered as vital contributors to pupil’s well-being. The report emphasised the role of leadership and argued that well-being should be embedded in the structure and culture of the school.

This is supported by a recent report, *Exploring Mental Health and Well-being: The Role of Arts and Humanities Research*, published by the Arts and Humanities Research Council (AHRC) where it was recommended that:

“Arts and humanities subjects are essential for understanding the complexity and the real-life impact of mental health conditions as they affect both individuals and those around them,” (AHRC 2017, p.5).

Such an approach of course has financial implications as the HHE needs to have available resources to be able to employ teachers with specialism in these subjects.

All recent reports conclude that supporting CYPMH needs to be approached in a holistic way where there is a re-examination on the subjects included in the curriculum. They concur that due to complexity of the issues joint thinking is required, as well as an ethos that promotes support, dialogue and collaboration.

Examining the relevant literature, there was limited research on the holistic approach in HHE. This is the same for research on HHE in general and the available research seems to focus on pedagogy, curriculum and teaching methods rather than on what a holistic approach might mean in HHE. Ratnapala, Rayer and Crawley (2009), in a study evaluating hospitals to assess hospital based services including education,
concluded that that across Canada the educational service available to hospitalised children was not uniform and the information on these services was not easily accessible. They concluded that a more strategic approach is required towards working in an holistic way where partnerships and collaboration are fostered amongst a variety of services and, most importantly, between medical staff and education staff. The review of Children and Young People’s Mental Health Services (2017) focused on systems that support CYPMH and found that the issues are complex and in most cases the services are fragmented preventing a holistic approach.

From the available literature discussed above, we can apply the principles of a holistic approach to the mission of HHE. As mentioned previously, HHE has as an overall purpose to support CYPMC, first and foremost with the right to education, but also to promote CYPMC’s well-being and their whole development (not limited to cognitive development but also emotional, social and moral) to reach their full potential despite their medical conditions.

The nature of HHE is complex, as well as unique to particular school contexts, in the sense that their pupils’ time also belongs to the home school and the duty of the HHE is to communicate with the home school. If adopting an holistic approach, HHE needs to focus on creating a balanced curriculum between academic subjects and activities around well-being and the management of emotions, feelings and social skills. Moreover, they need to communicate with the home school and services such as medical staff and CAMHS as well as involve parents/guardians. The holistic approach requires strategic leadership, clear vision and aims and objectives of the provision as was seen in the examples from Finland and Norway.

WORKFORCE COLLABORATION

Although there is limited research on workforce collaboration, or multi-professional working in HHE, there is a plethora of such research focusing on children’s services. Especially, as a consequence of the introduction of the Every Child Matters policy in 2004 where “joined up work” or “better multi-professional work” among education, health, social work and other related services to support children and young people became a priority. This “better multi-professional working” has been the remedy of
choice and many researchers have addressed the benefits and the challenges of it in education and in children’s services (Fitzgerald and Kay, 2008; Anning et al., 2010; Gasper, 2010, Warmington et al., 2004; Anning, 2005, Anning et al., 2010).

However, all such research concludes that for children’s services and education to function effectively to meet the needs of vulnerable CYP, collaboration is essential (Glenny and Roaf 2008, Siraj-Blatchford, Clarke and Needham 2007, Goodall and Vorhaus, 2011, Wolfe, 2014, Goodall, 2013; Gasper 2017). In an earlier study, Palaiologou (2012) examined the terminology that is used to describe the different terms that are associated with the type of work that requires a number of services such as education, social work, health to be involved and these are:

“*Inter-agency working:* involving more than one agency, working together in a planned and formal manner rather than simply through informal channels of communication;

*Multi-agency working:* joint planning or, possibly, a form of replication, resulting from the lack of a coherent policy;

*Joined-up working:* policy or thinking referring to deliberately conceptualised and coordinated planning that takes account of multiple policies and varying agency practices”

(p. 116).

When multi-agency work became a priority in the government’s agenda in 2004 in children’s services, the NFER (National Foundation for Educational Research) reviewed Effective Interagency Working in services such as education, social work, health (Tomlinson 2003) and suggested the following factors that underline effective partnerships:

- Full strategic and operational commitment to collaboration;
- An awareness of agencies differing aims and values with a commitment to working towards a common goal;
- Involvement of relevant people often including clients and their carers;
• Clear roles and responsibilities for individuals and agencies involved in collaboration;
• Supportive and committed management of staff in partnerships;
• Flexible and innovative funding mechanisms;
• Systems for inter-agency collecting, sharing and analysis of data;
• Joint training, with accreditation where appropriate;
• Strategies to encourage team commitment beyond the personal interests of key individuals;
• Effective and appropriate communication between agencies and professionals;
• A suitable, and sometimes altered, location for the delivery of services.

In a more recent study that examined the formation and sustainability of partnerships in English schools (Palaiologou and Male 2018, Male and Palaiologou 2017) it was found that required elements on the formation of partnerships include first and foremost shared values and beliefs, so all can engage and participate in the creation of the learning environment. However, it was not proposed that families and teachers should hold identical values and expectations, but together set common values and expectations. Equally important was the proximity/nearness of services and frequent face to face meetings so all stakeholders and users can come together physically. Other key elements for effective collaborative work were: willingness, trust, shared responsibility, avoidance of blame culture, avoidance of stereotypic views of people, events, conditions or actions, avoidance of labelling culture, shared aspirations, resilience as the ability to adapt successfully to situation and circumstance, commitment from all parties involved, a sense of altruism, empathy, a culture of inclusion by all stakeholders being considered as valuable and, finally, reciprocity and complementarity of needs (cognitive, social, emotional).

The research literature has strongly emphasised the benefits of workforce collaboration when children’s services are involved. However, there are challenges as well. Atkinson et al. (2001) and Atkinson et al. (2007) examined the collaboration among education, health, social work and other services around the child and demonstrated the following key challenges:
- Complexity in terms of funding and resources, roles and responsibilities, competing priorities, communications among professional and agency cultures and management;
- Conflicting professional and agency cultures, conflicting policies and procedures, finding accommodation, staffing, turn-over of personnel, difficulties in ensuring agency commitment, in particular involving the health sector.

In an earlier study on the services around the child (such as education, health and social work), Mott (2004) concluded that when a number of services are coming together there are enumerating barriers to effective collaboration such as the large number of agencies, disciplines and services involved, different agency perspectives and structures, poor leadership or lack of leadership, lack of shared training and different expectations from within the agency and other services. He also emphasised the fact that core to these barriers is the fact that there is a lack of knowledge and awareness of the benefits of working together.

Extensive research on services involved around the child (Roaf and Lloyd, 1995; Watson et al., 2002; Anning, 2005; Warmington, 2004; Allen, 2003; Anning et al., 2010; Fitzgerald and Kay, 2008; Gasper, 2010; Siraj-Blatchford et al., 2007) has shown that workforce collaboration has its challenges and barriers because professional identities and culture can be divisive. Specifically, education has a different culture compared to social work or health.

As may be seen from the above discussion, there is a wealth of research into effective multi-agency work on services for the child, especially vulnerable children who are at risk of missing out on their education due to abuse, neglect or medical conditions. All conclude that multi-agency work is complex and challenging. The following table attempts to provide a summary of the challenges and success factors of multi-agency working for services for children:
<table>
<thead>
<tr>
<th>Challenges</th>
<th>Successes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agencies’ aims and objectives</td>
<td>Common aims and objectives</td>
</tr>
<tr>
<td>Budgets and finances</td>
<td>Sharing access to funding</td>
</tr>
<tr>
<td>Resources</td>
<td>Sharing access to resources</td>
</tr>
<tr>
<td>Confusion of roles and responsibilities</td>
<td>Understanding roles and responsibilities</td>
</tr>
<tr>
<td>Competing priorities</td>
<td>Leadership drive</td>
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<tr>
<td>Barriers in terms of physical spaces</td>
<td>Proximity of services</td>
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<tr>
<td>Communication</td>
<td>Communication and willingness</td>
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<tr>
<td>Professional and agency cultures</td>
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<tr>
<td>“Barriers” of differences of professional culture and identity</td>
<td>Understanding roles and responsibilities</td>
</tr>
<tr>
<td>Management</td>
<td>Involving the relevant personnel</td>
</tr>
<tr>
<td>Training opportunities</td>
<td>Joint training among all services involved</td>
</tr>
<tr>
<td>Time investment</td>
<td>Allowing time for collaboration</td>
</tr>
</tbody>
</table>

**TABLE 2 CHALLENGES TO AND SUCCESS FACTORS IN MULTI-AGENCY WORK: (ADAPTED FROM PALAIIOLOGOU, 2012: 118).**

Research that has examined workforce collaboration in HHE has found similar challenges and successes. For example, research projects examining HHE such as the Keeping Connected in Australia or LeHo in Europe have clearly noted that for effective HHE communication among all services, professionals and families is important.

The Keeping Connected programme in Australia used knowledge translation as a theoretical framework to examine effective practice in HHE. The concept of knowledge translation is the movement of research into action (Graham et al. 2006).
Knowledge translation theory is gaining a central role in health because it is addressing the problem of “research findings not making their way into practice in a timely fashion, coupled with the current emphasis on evidence-based, cost-effective, and accountable health care”, as Graham et al. (2006, 14) suggest. One aspect of effective communication is sharing information (knowledge) about each CYP with medical needs among all services involved, but as Landry et al (2006:597) stress, “creating, transferring and transforming knowledge from one social or organisational unit to another in a value-creating chain is a complex interactive process that depends on human beings and their context”. Putting this another way, the family, professionals and the child or young person themselves each have an important perspective and set of knowledge, but that as these perspectives vary, unifying this knowledge so that all the actors can make use of it in meeting their needs is not a straightforward process and needs careful consideration, related to the specific local context, to make sure that it happens effectively.

Davison (2009) draws from a review of the literature from 1997 to 2006 to suggest several indicators that could be used to evaluate activities that involve collaboration among different professionals involved in children’s services. There are two main subsets:

1) interactions between professionals that produce knowledge, and
2) applications of professional knowledge.

Leger (2014), in applying Davison’s indicators to HHE, suggests the following themes as evaluating indicators for effective knowledge communication of all different services:
Interactions between stakeholders that influence the production of knowledge

| The context and characteristics of the hospital and school settings |
| How health and education professionals frame the support process |
| Building relationships with young people and their families |
| Communication channels and connections between health and education professionals |
| Decision making process |

Use or application of knowledge

| Knowledge being used to inform decision making in relation to individuals or in relation to policy and practice within systems or institutions |
| Changes in behaviour, awareness, communication or interaction patterns evident among stakeholders |
| Knowledge being used to help create and support interventions |

### TABLE 3 KNOWLEDGE TRANSLATION INDICATORS USED TO ANALYSE HEALTH AND EDUCATION PROFESSIONALLY PRACTICE IN SUPPORTING YOUNG PEOPLE LIVING WITH MEDICAL CONDITIONS

For structures to be effective in HHE, all professionals (such as from health, education, psychology) need to frame the support process and the nature and context of their interactions. This framing is important for the channels of the language and communication to be used. The channels of communication need to be characterised by clarity about the nature and accessibility of support that young people receive to keep them on their education trajectory.
“Application of professional knowledge may present as structures, processes, products, and practices that emerge from these interactions within and across sectors” (Leger 2014, p255).

Thus Leger (2014) argues that it is the process of communication and interaction between professionals, family and the young person that leads to knowledge about what might constitute effective practice, which can then be applied to create better outcomes.

Leger (2014) notes examples of effective structures and organisations that have developed policy and practices to ensure effective communication among all professionals involved in education of CYP with medical conditions. From our research we found that some hospital schools have developed their own comprehensive questionnaires to collect information of the child’s academic pastoral and additional needs from all involved in the multidisciplinary teams. For example, one hospital school service (Service F) in England has developed a system consisting of a Pupil Referral Form, Pupil Passport and Review Materials where they collect information (personal, curriculum, social status and medical) that can be shared among all the team involved with the pupils which leads on to a comprehensive plan and steps for future developments. Another example comes from a mainstream school in England where the SENCO explained that the school policy for pupils with medical needs stated clearly that when necessary and, based on evidence, an individual health care plan will be created and will be essential in cases where “conditions fluctuate or there is a high risk that emergency intervention will be needed”. These individual health care plans include key information and actions required to support pupils with medical conditions, but the emphasis is on the individual pupil and the characteristics and circumstances of the medical condition. A key element of each plan is that it is devised “in partnership between the school, parents and a relevant healthcare professional, e.g. school, specialist or children’s community nurse, who can best advise on the particular needs of the child. Pupils will also be involved when appropriate”. The school’s policy also draws attention to the role of parents in writing the plan, but the responsibility for completing the plan and implemented it rests with the school (SENCO from a HS).
Examining international examples, in Switzerland since 2001 HHE has implemented the International Classification Functioning Disability and Health (ICF) known more commonly as ICF as a classificatory system. ICF is a classification of health and health related domains. ICF takes on board not only indicators related with the individuals’ health, but also examines the environment that the individual lives in as an important element for the individual’s health.

Based on ICF they have developed the School Based Collaborative Education Programme (similar to Individualised Education Programmes in the USA or the Individualised Education System in Canada or England). In this programme, every six months to one year the team around the child (teachers, special needs teachers, therapists, social workers, pupil and parents, sometimes even the principal from the home school or the paediatrician or any other person involved in the daily life of the pupil such after school care people) meet to evaluate the situation and set two common goals for the next period.

All the above examples suggest that it is important for all stakeholders to be involved in setting common goals and aims. Emphasis also needs to be given to listening to the voice of the pupils in the process. This was highlighted by the CQC (Care Quality Committee 2017) as a limited practice as they found that CYPMC and their families are not always involved effectively in designing services and planning care.

The Keeping Connected Project (Dixon 2014) highlighted the following themes:

1) The binary themes of ‘normalcy’ and difference in the lives of these young people – of being the same as everybody else and yet being particularly vulnerable – and the impact of this on the ability of schools to sensitively see, arrange and claim appropriate support needs;

2) The importance of perceiving the young people’s situations as a process, not a checklist, and the implications of this for policies and practices of support;

3) The need for diversity to be ‘seen and heard’. Young people’s needs and wants are not all the same and cannot simply be deduced or interpreted from the condition they have;

4) The need for better communication, advocacy and protection of rights for this group must be recognised and addressed. Better avenues of communication
are required between institutions, families and young people; and greater clarity about rights, entitlements and means of access to support is also sorely needed.” (Hopkins et al. 2014:313);

5) The need for a key person. They found that finding the right person in HS to get the necessary information, especially in secondary HS, is important for the information to be transferred so the education plans for CYPMC are not discontinued, but at the same time challenging. Thus, they proposed that HS and HHE should place emphasis on having key contacts so the information can flow between HS and HHE and vice versa (Dixon 2014).

Finally, a Scottish study Kearney et al. (2016) found that services in Glasgow had formulated a system based on evidence informed by data and worked towards a unifying approach among all agencies involved with CYP with medical conditions. Their approach is based on “co-production” which is “a process of active dialogue and engagement between people who use services and those who provide them” (p.44). The key elements in such a way of working collaboratively were identified as:

- Recognising people as assets, not as problems
- Building on people’s existing skills and resources
- Building supportive social networks
- Valuing working differently
- Facilitating rather than delivering
- Breaking down divisions between services providers and service users.

Although there is research that advocates strategies for teachers (Nabors et al. 2008; Sawyer et al. 2007; Shaw and McCabe 2008; Shiu 2004) and the need for better communication in multi-disciplinary teams that care for CYP with medical conditions (Gagnon et al.2008; Georgiadi and Kourkutas 2010; Henry et al. 2009; Nabors et al. 2008;Notaras et al. 2002; Shiu 2004; Thies and McAlister 2001), there are few studies that examine the conditions and mechanisms that enhance communication at the interface of health and education. Therefore, Niseselle et al. (2011) urge us to reimagine the hospital and, consequently the team around CYP with medical conditions, from traditional health spaces into multidisciplinary spaces for health, development, well-being and learning. Kearney (2008) also conclude that
as school absenteeism and school refusal behaviour continue to represent critical public health problems for educators, health and mental health professionals, a key issue is a general disconnection between sets of professionals who use varying terminology and investigate only specific subsets of youths with problematic absenteeism. It is proposed that for better coordination and synthesis of information on individual CYPMC it is necessary to fully understand and address the complexity of professionals involved. Cross-multi-inter-disciplinary work requires consensus regarding definition, classification, assessment and intervention.

WORKFORCE TRAINING

As mentioned above, for effective collaboration among children’s services, training is required. Research which has examined workforce training in relation to collaborative advantages has concluded that the training in each service and cross service training is essential (Mott 2004; Gleny and Roaf 2008; CQC 2017). Mott (2004) suggests that:

“Safe, effective and compassionate care requires staff and professionals with the right skills, in appropriate numbers, who are supported with training and supervision to provide high-quality care” (p. 18).

Whitmarsh (2007) suggests that:

Tensions exist in multi-agency working. They are often caused by misunderstandings about shared language, shared information and mutual practices relating to them. (p. 87)

Whitmarsh introduces three questions for children’s services as guiding points, based on reflection (What do we know?), clarification (What is the problem?) and consideration (How can the issue be addressed?).

She points out that:

“In a multi-agency team, the code of ethical beliefs and values of the team may be as diverse as those of the general population. Tackling this dilemma requires us to stop thinking in dualistic terms: that is, to halt the dialectic in which something is either true or it is not. Instead, we need to begin thinking
more in terms of ethical behaviour as an interaction can vary according to its context.” (p. 93-94)

For HHE, rigorous consideration of the training of all staff involved will help to develop a common understanding of the problems, common language of communication and reflection on individuals’ and agencies’ expectations and priorities, as well as on the aims and objectives of the multi-agency work.

A number of studies (Roaf and Lloyd, 1995; Watson et al., 2002; Atkinson et al., 2002; Anning, 2005; Warmington, 2004; Allen, 2003; Anning et al., 2010, Fitzgerald and Kay, 2008; Gasper, 2010; Siraj-Blatchford et al., 2007) demonstrate multi-/inter-agency work requires professionals to develop practices with common aims and objectives and a language that is understood by everyone as a means through which they can support the children and families, while attempting to ensure that the best level of practice is achieved. Consequently, training needs to be a joint activity among all the professionals in the services involved.

Glenny and Roaf (2008) examined effective collaborative activities among children’s services and proposed the configuration of local forums in the forms either of hubs or networks or steering groups. They suggest that for these to function effectively regular face to face meetings among all involved need to take place as well as joint training. In their study they found that when the regular core staff are represented in meetings and joint training (such as teachers, general practitioner, health, social worker, psychologist and SEN coordinator), nested systems are formed where communication systems are constructed and established. Finally, Kearney (2008) suggests mental health professionals should be located within schools and aim to offer training to teachers and others involved about strategies and assessment methods for school refusal behaviour.

ASSESSMENT

Due to the nature of HHE, assessment is complex and multi-featured as there are many factors involved such as the MC that lead to HHE, the HS, the current medical situation of CYP and the services involved. There is limited research in the literature on assessment in HHE nationally and internationally. Most of the literature on
assessments of CYPMC focuses medical or psychological assessment, most commonly the ones that educational psychologists are using (e.g. Lauchlan, Resing and Elliot 2011). In the field of educational psychology there is a variety of assessment practices. Some are using the Children’s Global Assessment Scale (SGAS) based on the work of Shaffer et al. (1983), or the Global Assessment of Functioning Scale (GAF) based on the American Psychiatric Association (2000).

Sutton and Herbert (1992) introduced an influential model of assessment ASPIRE to assess in a full way CYPMC. The ASPIRE approach is abbreviated by the following:

**AS** Assessment

**P** Planning

**I** Implementation

**RE** Review and Evaluation

ASPIRE has influenced assessment, not only in the field of educational psychology, but in education as well as it is considered as a collaborative assessment process that requires all involved in CYP. Based on reflective questions on the purpose, context, actions and monitoring ASPIRE requires sharing aims, objectives, information plans and evaluations as a joint process that is a continuum rather than a static process, as is illustrated in the figure below:
The assessment of school absenteeism traditionally involves measuring days or periods of time a child is out of school. Other pertinent variables include child resistance going to school or having to be taken to school by a parent (Egger et al., 2003). Researchers often rely on parent and child reporting as well as school attendance records to monitor absenteeism. When absenteeism is associated with psychiatric conditions or school refusal behaviour, however, assessment becomes broader.

Traditional methods of assessing school refusal behaviour include structured diagnostic interviews, child self-report measures of internalising problems (fear, anxiety, depression, worry, self-efficacy, problematic cognitions) and parent and teacher reports of internalising and externalising problems, e.g. rule-breaking,
aggression, noncompliance, running away from home/school (Hanna, Fischer, & Fluent, 2006; King, Heyne, Tonge, Gullone, & Ollendick, 2001). In addition, parents and children may be encouraged to complete daily logbooks that assess attendance, difficulties preparing for and entering school, level of emotional distress, defiance and other misbehaviours as well as parent and teacher reactions. A full medical examination and reviews of psychiatric, academic, legal and other pertinent records are commonly recommended for this population as well (Heyne, King, Tonge, & Cooper, 2002; Kearney, 2003). Specific questions that family physicians may submit to parents of youths with school refusal behaviour, with other recommendations for assessment, have been presented in the literature (Kearney 2006a, 2008).

There have been developments in the use of measures specific to youths with school refusal behaviour. Of note is the School Refusal Assessment Scale-Revised, a 24-item measure with parent and child versions designed to assess the relative strength of four functions of school refusal behaviour mentioned earlier (avoidance of school-related stimuli that provoke negative affectivity, escape from aversive social and/or evaluative situations, pursuit of attention from significant others, pursuit of tangible reinforcers outside of school). The scale in original and revised form has demonstrated good reliability, validity and utility (Brandibas, Jeunier, Clanet, & Fouraste, 2004; Brandibas, Jeunier, Gaspard, & Fouraste, 2001; Higa, Daleiden, & Chorpita, 2002; Kearney, 2002a, 2002b). The scale has been used successfully to assign prescriptive intervention, or intervention tailored to the individual characteristics of a child with school refusal behaviour.

The School Avoidance Scale and School Refusal Personality Scale has also been recently designed to assess youth dislike of school and desire to leave school. This scale measures obsessive–compulsive, passive–unsocial, and socially introverted behaviour in this population.

Scores on both scales have been linked to depression, a particularly common phenomenon among youths with anxiety-based absenteeism (Honjo et al., 2003). Although these measures represent progress assessing youths with problematic absenteeism, more specific and consensual protocols for evaluating this population to increase comparability across studies are needed (Kearney, 2003).
As can be seen psychological assessments are used in education to shape decisions around curriculum and decisions made by the teachers for the pupil. The most common types of decisions made by educational institutions based on psychological assessments are:

- **Instructional decisions** (teachers determine the pace of their courses, for example to slow down, speed up, continue or discontinue a subject)
- **Grading decisions** (teachers use the psychological results to assign grades to pupils)
- **Diagnostic decisions** (teachers use the results of psychological assessments to understand student’s learning difficulties)
- **Selection decisions** (specialists use results of psychological assessments to make admissions decisions and select individuals for special programmes)
- **Placement decisions** (specialists use psychological assessments to place individuals into the proper level of the course)
- **Counselling and guidance decisions** (specialists use the psychological assessments to help pupils select subjects or careers that match the pupil's strengths and interests)
- **Programme and curriculum decisions** (specialists use psychological assessments to determine the success of the programme or curriculum and determine whether the programme or curriculum should be implemented or dropped)
- **Administrative policy decision** (specialists use the psychological assessment to determine where money should be invested and what programmes should be implemented to improve the achievement scores of a school, for example schools where results and scores are low normally get extra funding to improve their outcomes). (Thorndike et al. 1991, Miller et al. 2013)

In education, when the outcomes are assessed, curriculum targets are often used. However, as it has already been demonstrated HHE, by its complexity, needs to focus on educational outcomes as this is the main purpose of its service, but at the same time needs to consider the medical assessment as well as psychological outcomes for the CYPMC in their care. Due to the limited research on assessment
on HHE, it was decided to undertake a meta-analysis of assessment policies that are published in the websites of twenty HHE in to understand the purposes and processes of assessment. As some of the websites referred to include the external HHE sites were we undertook interviews, we do not list the names of the services.

The website analysis revealed a variety of systems in terms of how records are kept, what is assessed and how it is assessed. Some HHE are basing their assessment on educational outcomes only whereas other HHE services approach assessment in a more collaborative and holistic way.

For example one HHE is using a Personalised Education Plan (PEP) that focuses on holistic objectives. The PEP is divided into three areas:

1) Holistic Objectives that includes academic outcomes as well as items related to personal social and emotional progress of the pupils such as engagement in the classroom transitions to HS, and PHSE.
2) Actions
3) Progress

Detailed records are kept for each child under these three headings for each term.

Similarly, for another service, their assessment policy states clearly the purposes, how a pupil will be assessed, who will be involved and how a pupil will be assessed. In the policy it is clearly indicated what meant as progress for the school and how the MC might impact on a pupil’s progress, thus they approach assessment from all three elements: a pupil’s medical-physical well-being, as well as emotional and educational progress.

In another HHE, their assessment procedures acknowledge the fact that HHEs are unusual settings, thus assessment is different from a typical HS. The assessment includes involvement of the pupils and parents, readiness to learn and engagement in terms of their MC that might prevent them from accessing education.

HHE assessment varies as well from country to country as indicated in the LeHo project reports (Carpuso and Dennis 2015a, 2015b). For example, in the USA they use the principles of the Individualized Education Program (IEP). The individualised
document is accessible to teachers, parents, school administrators, related services and personnel and, where it is considered appropriate, it is shared with the pupil. The purpose of this approach is that all related services can work together to address and improve educational and any other needs of the pupils. To create an effective IEP, parents, teachers, other school staff, and often the student, must come together to look closely at the student’s unique needs. Although emphasis is placed on educational achievements and support for the student there are other elements considered such as the MC and the impact that might have on educational outcomes. A key element for the IEP to be completed fully is the collaboration of all services, parents and pupils.

In Poland although well-being is central in the curriculum, following the principles of social therapy, when it comes to assessment, HHE follows the national curriculum assessment processes and the HHE pupils are expected to sit external examinations as in HS at the end of primary, secondary and final high school.

Analysing assessment policies of the above HHE, key elements central to assessment in HHE are the following:

1. Clear definition /statement of what progress means in HHE
2. Evaluation of pupils’ overall achievements in the content of the HHE (academic, well-being and PHSE). This evaluation is two-fold to assess the pupil initially before lesson starts and to assess the outcomes of the lesson. Prior to the beginning of a lesson/activity an initial assessment takes place for all pupils involving understanding the MC of the pupil at the time (this information can be also obtained by the medical staff or other related services such as educational psychologists especially for the inpatient pupils), a discussion with the parent/s, assessing child’s readiness to learn (feelings such as anxiety, fear, discomfort or feeling created because of the MH issues), negotiation of the lessons and/or activities. Finally, assessment takes place at the end of the lesson/activity based on the CYP’s ability of readiness to learn, the outcomes of the subject or activity that was taught during the lesson activity, on attention focus and feeling of the CYP during the lesson activity.
3. Although there is a variety of assessment and record keeping, the majority of HHE assessment policies have created a synergy between educational outcomes and well-being to plan individualised/personalised plans/instructional plans. Although terminology differs, all these plans are tailored in the needs (medical, emotional academic) and interests of the CYP at the time. For inpatient pupils, or in-home education, these plans can be long term as well as based on the same process as described above. For CYPMC that are considered as regular returners, based on the same processes these plans can be a continuation of the CYP’s current work negotiated with the HS and CYP.

4. Assessments are used to place the CYP on appropriate educational plans.

5. Assessment for CYPMC focuses on how they cope with the school with respect to the academic success but equally how they are coping to manage their MC.

6. Assessment needs to be clear so it can be communicated with the HS if necessary.

7. Involvement of CYP in their assessment as well as their families.

8. Communicate the assessment records with other services that are involved in the CYPMC.

In terms of approaches on how HHE record assessment, a variation of personalised or individualised records are used. These records have different formats in different HHE, but the key items that are included in the records and requiring being completed by the teacher in collaboration with the pupils are:

- Clear Aims and Objectives (these include academic as well as related to the well-being and PHSE outcomes). One service has introduced personalised ward booklets appropriate matched to age groups.
- Pupils self-assessment/evaluation
- Parents information-opportunity to comment
- Current HS information that has been communicated with HHE
- Medical (or other) records (in brief) that might influence the learning conditions /readiness to learn of the CYP
- Action plans with activities
• Evaluation/Reflection of progress at the end of lesson, activity.

A key finding from the meta-analysis of the assessment policies was that in the majority of HHE policies, assessment does not only happen at the end of the lesson, but it is ongoing throughout the lesson as the medical condition might impact on the CYP’s ability to carry on with a lesson or activity.

Examining the assessment policies of HHE across the UK it is clear that the focus of assessment in HHE goes beyond the educational outcomes. It considers the medical conditions of CYP and the impact this might have on educational outcomes and equally importantly assesses children’s well-being and the overall development. Emphasis is placed on the “ability to learn” (Elliot 2003, Jeltova et al. 2007, Sternberg and Grigorenko 2002, Elliot et al. 2010). Assessment is individualised - the purpose of assessment should be to provide information for understanding individual’s holistic well-being, educational, physical, emotional and social needs for planning the learning steps and activities (Resing et al. 2002).

There are variety of approaches to assessment and this report does not aim to present one model as being superior to another. From the literature that was available so far, and the meta-analysis findings on assessment policies, we suggest that HHE needs to tailor an assessment process to fit their context, culture and structural idiosyncratic peculiarities. The conclusion is that in effective HHE, central to the purpose of the assessments collaboration with all involved in CYPMC, assessment should go beyond educational outcomes and include well-being and emotional/psychological outcomes, as well as including clear record keeping that all stakeholders involved are be able to understand and share.

As well, we draw attention to Dixon’s (2014) point that the transmission of information from hospital to HS (and from HS to hospital) is problematic due to lack of effective communication from HS. Also, the assessment is “normally” carried by the parents, but the HS does not have the complete picture of the child’s MC that might impact on the child’s performance before hospitalisation (Dixon 2014).
Many authors have examined the nature of pedagogy and curriculum (Knowles 1980, Rogoff 1990, 1998, Mortimore 1999, Marsh 2004, Bruner 2006a and b, Leach and Moon 2008, Eikeland 2008, Oliviera-Formonshino and Formoshino 2012). On the one hand, the term pedagogy is commonly used to describe dualistic relationships based on teaching learning interactions. However, a body of researchers has examined the term in more depth and suggest that pedagogy goes beyond a simplistic approach of describing such relationships and propose that it is a:

“discipline [that] extends to the consideration of the development of health and bodily fitness, social and moral welfare, ethics and aesthetics, as well as to the institutional forms that serve to facilitate society’s and the individuals’ pedagogic aims” (Marton and Booth, 1997:178)

In that sense:

“Pedagogy must encompass all the complex factors that influence the process of learning and teaching. Our discourse is, therefore, wide ranging. In creating and sustaining pedagogic settings teachers crucially determine both the nature and the quality of learning. Pedagogy is more than the accumulation of techniques and strategies, more than arranging a classroom, formulating questions and developing explanations. It is informed by a view of mind, of learning and learners and the kinds of knowledge and outcomes are valued.” (Leach and Moon, 2008: 6)

Leach and Moon argue that pedagogy is not just focusing on the interactions between teaching and learning, but should be seen as a social process. This has implications in the creation of learning environments as learning cannot be seen as a process that takes place only in the boundaries of a school. It goes beyond the characteristics of traditional teaching and learning activities normally offered in educational settings and is concerned with embracing all the influences that impinge on learning in their social settings. A social view of learning recognises that learning is ongoing in every aspect of our lives and takes the broader view of learners’ trajectories through the world-their sense of self, where they are coming from, where they think they are going and what sort of person they want to be (Leach and Moon, 2008). Earlier, Davies (1994) suggested that pedagogy is related to the ethos that
underpins teaching and learning and this ethos includes “a vision (theory, set of beliefs) about society, human nature, knowledge and production, in relation to educational ends, with terms and rules inserted as to the practical and mundane means of realisation” (Davies, 1994: 26).

Wegner and Eikeland (2008) extended this view and focused their approach to the notion of pedagogy as being conveyed by a broader holistic approach rooted in social complexities. Male and Palaiologou (2015) suggested a re-examination of the definition of the term by proposing that pedagogy is a triangular concept based on the relationships between learners, learning environments and teachers, families and the community.

On the other hand, curriculum is associated with the subjects; learning activities that are taking place during teaching and learning. Marsh (2004) examined the term and concluded that curriculum is concerned with subjects as grammar, reading, logic, rhetoric, mathematics and science. He argues that curriculum should include those subjects that are most useful for living in contemporary society. Latterly, Kelly (2008) argued that curriculum can be used to describe many kinds of programme of teaching instructions.

Elliott (1998) suggests that:

“…a curriculum which organises cultural resources in usable forms for the purposes of enabling pupils to deepen and extend their understanding of the problems and dilemmas of everyday life in society and to make informed and intelligent judgments about how they might be resolved. Such a curriculum will be responsive to pupil’s own thinking and their emerging understandings and insights into human situations. It will therefore be continuously tested, reconstructed and developed by teachers as part of the pedagogical process itself, rather than in advance of it. Hence, the idea of pedagogically driven curriculum change as an innovative experience” (1998: xiii)

Scott (2008) concludes that a curriculum differs from pedagogy in the sense that:

“curriculum refers to a system, as in a national curriculum, an institution, as in the school curriculum, or even to an individual school…. Its four dimensions are: aims or objectives, content or subject matter and this refers to knowledge, skills or
dispositions which are implicit in choice of terms and the way that they are arranged. (2008:19).

To conclude, the literature has argued that pedagogy is related to the philosophy and ethos that underpins the curriculum.

Applying these ideas to pedagogy and curriculum in HHE is relevant as learning environments in HHE are concerned not only with the learners, but their MC, their families and a number of services.

Thus, in the following paragraphs we aim to discuss pedagogy and curriculum in HHE, taking the approach that although these two terms are interlinked, pedagogy is related with the philosophy, ethos and values that underpins the design of the teaching and learning (curriculum).

Research on the nature of pedagogy and curriculum in HHE suggests that it is about “opening of possibilities” (Osberg and Biesta 2010, p604.) in which all students can play their part (Hopkins et al. 2014, p319). Yates (2014) proposes that opportunities “in the curriculum are produced through multiple influences and contingencies and cannot be foreseen in advance” (p. 283). Instead he suggests that education in HHE should evolve around the following themes:

1. The desire for being normal, alongside unpredictable experiences of being vulnerable, accepting the changing dynamic of participants’ identities and their relationship to schooling;
2. Seeing schooling as a process over time and not just an incident at a single point in time.

He also concludes that a clear distinction between pedagogy and curriculum should be made and that “is a need to consider both what is done to particular students and the broader issue of what purposes school serve” (p286). Heterogeneity, and in particular identity and circumstances should be considered, and pedagogy and curriculum in HHE should not be limited only in compensating for what may be missed in mainstream school. On the one hand, mainstream schools take into account policy and institutional functions (pedagogy) to design and implement curriculum and on the other hand the HHE takes into account the ways that are
possible to connect and relate to the pupils, their characteristics and circumstances (via pedagogy) and implement the curriculum. Thus, the pedagogy of HHE will be expected to differ from that in mainstream, just as the curriculum will also not be identical. Consequently, within the literature (Boles et al. 2017, Harris 2009, Hay et al. 2015), there is a strong line of reasoning that HHE cannot be expected simply to reconstruct the curriculum that might have taken place for the CYP in their home school.

Roffey (2011) in examining potential risks factors that can lead some CYP to chronic medical issues, especially mental health issues, promotes the idea of including protective factors in education with emphasis on resilience, positive outlook and a willingness to discuss issues that are located in a child’s environment. These protective factors require supportive relationships “including bonding with pro-social individuals, high expectations with clear and consistent boundaries, opportunities to participate and contribute [the sense of belonging], teaching social and emotional skills such as co-operation, communication skills and problem solving, giving pupils agency, and working collaboratively with families” (p.33).

At a more practical level, Boles et al. (2017), studying the American context of education of pupils with medical conditions and in particular with cancer, propose that children who are medically ill feel loneliness, confusion and suggest that HHE should be “fun” and involve enjoyable activities, provide diversion of medical experiences and opportunities to interact with peers, if this is permitted. They propose creating a curriculum in HHE the following key elements:

1. School should involve fun and enjoyable activities;
2. Group educational formats should be permeable and allow CYP choice in joining the group;
3. Being or feeling a “good student” is important during medical treatment;
4. Attending school during treatment is complicated by illness and treatment thus the curriculum should provide distraction from challenges of therapy or as means of connecting with peers.

These ideas are supported by Dixon’s (2014) earlier study in HHE which found that CYP with medical needs and chronic illnesses want to be considered as “normal”,

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continuing relationships with peers at school. He argues that when a child is ill and hospitalised their lives are public with the “critical” knowledge regarding them being held by health authorities - thus education should ensure their rights to knowledge and ownership of knowledge. He also makes the case for a “curriculum of connection” between young people and the relevant education and related services that involved in CYPMC. He suggests that as both health and education professionals jointly hold the knowledge of CYPMC their needs and wants can be shared by a “curriculum of connection” which will encourage collaboration among the different services and use a common language that is clearly understood by CYPMC.

The LeHo project examined the education contexts for successful learning in HHE and introduced six fundamental factors that can shape an effective pedagogy:

1. **Relationships**: involves all interactions in the learning environment such as cultural artefacts, immediate settings, availability of tools and facilitators, emotional climate in the classroom, teaching practices and technology;

2. **Making sense and constructing knowledge**: learning is acknowledged as a complex process which, for it to be constructed, has to be meaningful, a continuum and stable;

3. **Assuming roles**: acknowledgment that pupils are achieving and acquire new skills and consequently can hold new roles;

4. **Metacognition**: pupils are in a position that they can understand and recognise their own learning and the learning process;

5. **Individualities**: acknowledgement of the different learning strategies and processes. Teachers should create learning environments where the learning process is approached as a phase of listening to and assessing the learner’s own history, desires, aptitudes and culture;

6. **Inter-institutional communication**: all involved in CYP with medical needs should share information about the child and assessment should include academic as well as personal and social developmental abilities.

Others argue that HHE, drawing on ideas of social therapy theory as philosophical underpinnings for their pedagogy, should design curricula that reflect these ideas.
Social therapy theory derives from psychological theories of holistic, dynamic and systematic concepts. The focus of social systems theory is that a person cannot be isolated by his/her biological dimensions and needs to be considered as a social one and, consequently, as a whole. Central to this approach is the idea that a person’s development should be viewed as a constant flow with potentialities and possibilities of change resulting from both development of individuals and the influence of factors from their environment (immediate-micro, a more extended meso and external macro) (Bronfenbrenner 1979, Bronfenbrenner 2005, Jarvis 1998, Giovacco-Johnson 2009). In this context the search for an effective pedagogy in HHE indicates that all involved in a person’s development (social workers, schools and families) should come together to discuss and plan for a holistic approach to the progress of this person and seek common solutions and actions in a culture of mutual respect and understanding. Thus, the curriculum is designed in a collaborative way with all services involved, not only by HHE, and becomes part of the CYPMC treatment, with the pupil being seen as a whole i.e. “pupil-patient”. This approach puts emphasis on pedagogy (ethos, values) and aims to create a collaboration of all services, with the main aim being to create a curriculum that is targeting all aspects of the development of the pupil-patient.

Examining different pedagogical approaches of HHE nationally and internationally reveals a variety of approaches to pedagogy and curriculum. For example, the HHE in Bucharest are using the BODY-SOUL-MIND triangle approach in HHE. They see their role as helping CYPMC to manage medical treatments with psycho-spiritual and educational outcomes (Sînziana and Duțoiu 2017). However, whilst there is variety of perspectives on the pedagogy of HHE when it comes to curriculum, our review indicates there is a commonality in the sense that it is tailored to each pupil. There are many different terms uses such as Individualised or Personalised, but the essence is that learning opportunities offered to each pupil-patient are tailored to their needs.

In regard to the notion of a “therapeutic curriculum” we have not found any literature relating to this, but it is evident from the material we examined for this report that there is a common theme in HHE to pedagogical approaches and curricula practices. HHE should provide a stable, safe “normal” environment as it has a therapeutic
effect in CYPMC (Dixon 2014, Yates 2014, Yates et al. 2010, Boles et al 2017, Hay et al. 2015, Hopkins and Hughes 2015, Jones and MacDougall 2010). No matter which underpinning ideology each HHE chooses to adopt for their pedagogy (i.e. social theory therapy, BODY SOUL MIND), a key similarity among all research examined here was that HHE sets boundaries and reflects elements of their lives before the MC impacted on them to create unstable, uncertain or /and chaotic situations. HHE can become a predicable environment where the pupil-patient can feel safe and “normalcy” is achieved to maintain a relationship and engagement with learning.

Yates et al. (2010) caution those involved in HHE that “a better understanding of the way the desire to be normal and the situation and awareness of being vulnerable are intertwined in the identity and practices of the young people, and that institutional policy and practices can fail by being too focused on only one end of this dynamic” (p.83). Consequently, an equilibrium between education and well-being is required. Similarly, the studies which have focused on MH and school refusal issues (Kearney 2007a and 2007b, Kearney 2008, Kearney and Albano 2006, Reid 2003 a and 2003b, Scott and Friedli 2002, Bowen and Richman 2002) urge that HHE should include a wide range of approaches and systematic interventions where the curriculum is extended to, for example, after-school programmes to meet a child’s educational needs, but also to ensure these programmes are linked directly to other services (such as health, educational psychologists and social work)

In terms of the curriculum that involves the day to day activities and lessons that take place in HHE, the literature suggests that the inclusion of lessons and activities should have fun and joyful elements. Lessons that are humorous, enjoyable, relevant and meaningful to CYPMC will provide learning opportunities that can be engaging and also buffer the stress of hospitalisation (Boles et al. 2017). Other important elements when constructing the curriculum were evolving around the social aspect of the lessons and activities (Hay et al. 2015) and finally the use of digital technologies which will be discussed in more detail in the next section.
THE ROLE OF DIGITAL TECHNOLOGIES IN HHE

Three major research studies - Keeping Connected in Australia, the Bednet project in Belgium and the LeHo project - have emphasised the beneficial role that digital technologies can play in HHE.

A growing body of literature emphasises the role of digital technologies in HHE as a helpful tool for CYP with medical conditions to improve children's literacy, problem-solving skills and overall cognitive abilities, regardless of whether they have been specifically designed for education (e.g. Gee 2003). The Keeping Connected project in Australia examined the use of digital media by children and young people with medical conditions (Corrin, Lockyer, & Bennett 2010) and found that:

- over two-thirds of 14 to 17 year-old young people believed that the Internet played an important role in their life;
- access to a mobile phone was important for 75% of 16 to 17 year-olds (Australian Communications and Media Authority, 2007).

As part of a more effective approach to the provision of education support for children with chronic health conditions the potential to use technologies to connect children with their schools and contribute to a learning culture within a hospital setting are increasingly being realised. However, such potential gains have not yet been fully explored by research and there still appears to be some scepticism around the use of technologies in HHE.

In Australia, The Royal Children's Hospital (RCH) Melbourne, provides in-patient care for approximately 11,000 school-aged children and young people each year, and out-patient care for approximately 30,000. Educational support at the hospital is provided by the RCH Education Institute as part of a multidisciplinary approach to patient healthcare. Teams of teachers and education support staff provide educational support on all hospital wards, including day stay areas. There are designated learning spaces on selected wards, such as the Children's Cancer Centre and the Adolescent Ward (the 'Cool School'). More than 100 netbooks are provided for patient use, distributed across a variety of wards and day stay areas.
Patients are also encouraged to use their own laptops and netbooks (Nisselle, Green, and Scrimshaw 2011).

The Bednet project in Belgium, based on the principles of individualised learning in HHE, is using synchronous internet education (SIE). SIE makes use of the internet to connect CYPMC who are hospitalised with their HS. It is available for preschool children from the age of five and all pupils in primary and secondary education. HHE, families and the HS are equipped and supported with free adequate devices for the period that CYPMC are hospitalised. The Bednet programme supports CYPMC to “attend” lessons from the hospital bed to their HS class. The aim of the programme, supported by the legislation across Belgium, is to prevent CYPMC missing lessons and learning when unable to attend HS. It creates a live connection between CYPMC and the HS classroom teacher and classmates’ CYPMC can see their classmates and the teacher during the lesson through a audio-video link with the help of the internet. The CYPMC can direct the camera in any direction they wish enabling them to “attend” the lesson in their HS and at the same time to participate in any activities that take place in the classrooms. This way CYPMC feel connected with their HS and its social life of the school (https://bednet.be/bednet-english).

The LeHo project examined the role of ICT and how it can be embedded in the curriculum for HHE. The project team, based on their analysis of studies such as Lombaert et al. (2006) and Tielen (2003), proposed that ICT can become a valuable tool in assuring continuity in education. CYP with medical conditions who are unable to attend school and either hospitalised or homebound might not want to continue with attending mainstream school due to lack of social contact with peers (Fels & Weiss, 2001; Searle, Askins & Bleyer, 2003). They also proposed that CYP with medical conditions can follow classes live from home by using educational software and interactive learning (Carpuso and Dennis 2015a, b).
RECOMMENDATIONS FROM THE LITERATURE

- For effective organisation and structure to be achieved a holistic approach is required with joint development of workforce skills and training, coupled with coherent and collaborative assessment. We conclude that an effective holistic approach is one where channels of communication have been established and work effectively. It is also recommended that this holistic ethos needs to be reflected in the curriculum. This, as mentioned above, has implications for resources and staffing. However, a rich curriculum that extends beyond the core academic subjects can be beneficial to CYPMC. Thus, it is proposed that:

1. Multi agency, joined up working is needed to support CYP with medical needs. All services involved require a commitment to systematic method/s and programme/s, with visionary and robust leadership across all services;

2. Joint training is necessary for all staff involved from all services (such as education, health, educational psychologists and social workers) so common terminology, language, aims and objectives are developed. This training needs to be frequent and face to face to promote dialogue and collaboration;

3. For effective structures and organisation of HHE for CYP with medical needs it is important to evaluate the individual child’s medical conditions and needs and have a collaborative educational and health plan where:
   a. there is an individualised plan based on medical conditions;
   b. all members of the team involved around CYP with medical conditions have regular communication;
   c. there is an established common language and frame of reference of how the individualised plan will be implemented and identification of who is responsible for aspects of the plan;
   d. there is a comprehensive systematic way for collecting and sharing information among all teams involved;
- **Co-ordination between medical and educational aspects** is important. The literature has suggested medical absenteeism (especially due to MH) can lead to long-term problems critical for the development of CYP. Thus, medical professionals and other services, as well as educational professionals, should understand the parameters of the impacting issues and factors to develop better and consensual intervention programmes;

- **Listening to and involving CYP and their families.** All services should seek ways to engage CYPMC and their families effectively in designing services and planning educational and care/treatment plans, assessments and be given the opportunity to be part of the routine meetings so they can have their voices heard;

- **Pedagogy and curriculum in HHE** cannot be focused only on education outcomes. The literature revealed that education outcomes are important aspects of well-being and PHSE development of CYPMC. Thus, it is proposed that:
   1. Maintain a distinction between pedagogy and curriculum:
      - **Pedagogy** involves the general ethos, structures, formats and organisation of the education of CYP with medical needs. It should focus on the educational well-being and offer learning opportunities for CYP with medical conditions that cannot attend school;
      - **Curriculum** involves the practical activities involving academic subjects and social, emotional developmental aspects depending on each CYP with circumstances relating to their medical conditions. The curriculum for CYP with medical conditions who cannot attend school should be individualised and promote protective factors such as resilience, agency, social and emotional learning, mental well-being and positive behaviours;
   2. HHE is and should be viewed as **normalcy**, thus it is important where circumstances allow for CYP to be able to interact with peers, to be able to leave the ward (if a CYP is hospitalised) and attend classrooms even when this “distracts” them from medical treatments;
3. Individualised plans that allow for CYP to have a sense of agency in terms of having ownership in activities in the given environment. This can be curriculum directed;

4. Stable and safe HHE services, although they do not seek to replace treatments and therapy, play a crucial adjunct role to the treatment and therapy of CYPMC.

- **In England there is a lack of guidance at policy or legal level in the use of digital technologies for medically ill students** The research studies considered in this report suggest that digital technologies have the potential to play a significant role, particularly from a pedagogical position, and may help students to continue to have a sense of normalcy and feel connected to their sense of identity.
FINDINGS FROM INTERVIEWS

The findings from interviews with staff working in HHE are organised around seven main themes related to the research questions of this report, and are presented in detail in the following sections. In each theme there were several sub-themes that are presented and discussed. The analysis involved coding all the text from the interview data, however in order to ensure confidentiality, specific extracts from interviews are not presented.

These themes were:

1. **Environmental features**
2. **Effective structure and organisation:**
   2.1 The role of leadership
   2.2 Communication and cross agency work
   2.3 Networking
3. **Quality and characteristics of staff**
4. **Pedagogy and curriculum**
5. **Assessment and tracking records**
6. **Safety handling**
7. **Working in an educational base setting for CYP unable to attend HS.**

ENVIRONMENTAL FEATURES

Central to providing support for CYP with medical conditions that prevent them to attend school is the physical space (building) and equipment. The following features seemed to be important and optimum according to the responses, as illustrated in the following figure:
Data revealed that the environmental factors such as the physical space for a “school” is essential. There were two sub-themes in relation to environmental factors. Firstly, the design and quality of the physical space of the school. As can be seen from Figure 6 all participants valued the quality of the space in terms of having access to natural day light, size and areas that CYPMC can leave the bed and “go”
to the school. Equally important it was found that for most of the time when hospitalised CYPMC have lost their privacy. They are in a ward where they share their “bedroom” with many other children, with no opportunities for privacy. Their lives have become less private in the sense that a number of nurses, doctors and visitors are coming at any time and the CYPMC is constantly in a bed in the ward where parents, medical staff, visitors and other patients are constantly present.

It was emphasised by headteachers from three services that it is important for CYPMC to have access to the physical space of the school during the period of holidays as it is offering them the opportunity to have a break from the wards and do some other activities that cannot be done in the ward.

All headteachers raised the issue, which was shared by the parents in the second phase of the project, that during school holidays the CYPMC at the inpatient units might not have anywhere else to go and if the school is closed there is no area or place to “escape from the ward”.

The Headteacher from one service also said that during school holidays the inpatient CYP have access to the school space and other activities such as cooking or gardening. Two other heads said that this very important for the school refusing CYP as they are not “disconnected” with the physical space of the school. This makes it easier for when the school re-opens after the holidays.

In hospital, participants emphasised the need to have a space outside of the wards where the teachers can take CYP who are allowed medically to move out of the ward and be taught in a “classroom”, as this helps them to be “distracted from their medical issues” and feel “normal” again.

The existence of physical space in hospital was considered important to provide a curriculum that promotes “educational well-being” that will impact on supporting with the medical conditions. In particular for CYP with mental health issues that refuse to attend school, or are unable to attend mainstream education, it is important to have a building where it operates like a “mini” mainstream school. However, respondents also emphasised that this school should be flexible and have alternatives areas where CYP can join a group or withdraw from the group. For example, at one service
they used mini workstations built in to the classroom. One teacher at another service noted that for CYP with mental health needs spacing in the classroom could be an important factor and that they ensure that there is enough “personal space” between classroom tables. Also at this service, one of the teachers noted that they use a “quiet zone” which is mixed space in the middle, but with satellite breakout rooms/space around that allow children to be in a room, with the door open obviously, so that for children with anxiety about learning can have more of a sense of control over their environment. One service had also developed an outside space for recreation, whilst another had very nicely developed grounds which were felt to be a positive aspect of the physical space of the site itself.

A teacher at one service noted that there were restrictions on the space available for one to one tuition and that this could impact on the flexibility of the curriculum.

All participants in all case studies of HHE services - except one service – agreed that it is important to have a school-like building as the main focal point. Services that had recently had a significant reduction in available space noted that this had had a significant detrimental impact on their work and that being restricted to working on the wards made it more difficult for them to have a positive impact for CYP. A number of services were actively involved in looking for additional accommodation and negotiating with medical/local authority partners to see how this could be achieved.

The issue of the physical proximity to other services was raised by a teacher in one service who suggested that HHE services, including those for CYP with mental health needs need to be accessible by public transport, so that adolescent service users can use public transport to get there, which they linked to facilitating transition back to mainstream provision.

The headteacher of the same service was in agreement, but cautioned that safety is a key issue when the physical space of the service is in urban areas.

Finally, in terms of how many hours should be offered the majority of the services said that as they are first and foremost a school. They emphasised that the school in
all sites /units (inpatient or home education) should be accessible for all school hours.

**EFFECTIVE STRUCTURE AND ORGANISATION**

Essential aspects that were revealed for effective structures and organisation are presented in the following figure and each theme will be discussed into details in the following sections. The data indicated that there are three key factors for effectively structuring and organising HHE: the role of leadership, communication and cross agency work and networking:
Elements of effective structure and organisation of HHE

Leadership
- Visible
  - Clear vision - mission - aims

Communication
- Staff
- Other services
- Supportive
- Transparency
- Openness

Ethos
- Cross base work and collaboration

Communication/cross agency work
- Regular face to face meetings
- Regular email communication
- Joined up activities

Networking
- Website
- Presence in HS
- Key person/s

FIGURE 7 KEY THEMES OF EFFECTIVE STRUCTURE AND ORGANISATIONS
THE ROLE OF LEADERSHIP

Respondents across the sample indicated that having strong leadership that is visible in all units (in the case of services with multi units) or visible in the school and in the wards (in the case of hospital in the schools) with a clear vision, a clear mission and which promoted an ethos of collaboration was key in ensuring the impact of the service. In all services we studied the visibility of the leaders in all units, in the class and in the wards was an essential element. In some cases, where the distance of the units were more than 30 minutes travelling time, it was suggested that the leader needs to make sure to allow time to make his/her presence visible at all sites.

In regard to the clear vision and mission of HHE all participants from the eight services focused on the following seven themes in terms of overall mission:

1. Education outcomes;
2. Reintegration to HS or college, university or community (work);
3. Well-being;
4. Personalised learning /bespoke teaching (universal responses);
5. Collaboration with HS;
6. Collaboration with other relevant services;
7. Quality of service.

From the interviews with the headteachers or deputy heads it was evident that the vision and mission of the school was first and foremost to be a school and offer a normal environment:

Leadership that creates a supportive ethos and allow opportunities for professional development was also thought to be important. All leaders we interviewed emphasised how important it is for their staff to have support at all levels. This covered not only professional, but also emotional support as they all agreed that teachers deal with challenging situations in HHE at all levels (headteachers from five services) and they said that the support of the staff is included in their policies. One service that deals with complex MH is also offering psychological support to the staff in collaboration with CAMHS which the staff found beneficial.
In regard to communication, analysis of the data indicated that there are two key elements. At leadership level communication is required with the staff and the other services involved such as NHS, CAMHS, HS, social workers and child protection services. Most participants emphasised the role of communication between leadership and staff (as well as among the staff) as illustrated in the quote below. Data revealed that for an effective HHE there is a need for the staff to feel secure and that their headteacher is “stable”, “not looking elsewhere”, “is devoted to the job”, “understand the challenges and the nature of the job”, and “has time to listen”.

At some services, it was noted that staff had opportunities to work across different functions within the service and with different staff groups within the constraints of logistical efficiency. Nevertheless, the sense of being part of a wider team, that went across different elements of a service, was thought to be important by a number of participants across different services.

Linked to this there was a broad unanimity across respondents who expressed a view on the issue in the sample that unified leadership across elements of a service was key in ensuring that these elements of effective leadership outlined above could be brought about effectively. A key element of this was leadership that fostered a sense of the all the services as being part of one “school” and could, therefore, leverage the full range of expertise in the school and lead on developments such as CPD efficiently across all services.

In services with multi-sites and units, it was universally accepted that although the nature of inpatient units /schools differ, it is important to operate as one school both in terms of effective use of financial and staffing resources as well as focusing on the common aim of the provision: education. Moreover, they emphasised that some of the CYMC tend to use more than one unit within the service, so it ensures continuation in terms of transferring assessment records and progress files in a speedy manner. It is worth emphasising that in all of these HHE services the distances between the different units could take up to 30-45 minutes, but they did not see the distance as an obstacle for cross-base work. However, there was also a note of caution in that it is also recognised that there is a need some staff to be located
and be responsible for certain units within the service, with a balance being required between moving staff across the different sites, and emphasised the need for regular face to face meeting across all units within the service and cross-collaboration.

COMMUNICATION- CROSS AGENCY WORK AND NETWORKING

The data gathered for this aspect of the report revealed that liaison and communication, as well as cross agency work in HHE, are multi-faceted, multi-dimensional and multi-purposed as illustrated in Figure 8. To be effective HHE services have to form partnerships with the families/guardians, home schools, other services that they are involved in the treatment of CYPMC and also communicate with the CYMMC themselves, due to their assessment or progress files.

Consistent in all the services we explored was agreement that partnership with parents/guardians, although challenging, is not as challenging as communicating with home schools.
Analysing the data it was found that communication with parents can be challenging especially for CYPMH. However, the majority of the participants agreed that the most
effective forms of communication with the parents/guardians are face to face meetings, letters or emails (depending on the technological skills of the parents), and in some cases, through the school’s website.

**With Home Schools**

Liaison with home schools was seen as a key issue by the participants. The need for this to be both coordinated and properly resourced was noted across the services. A repeated theme was the importance of having a key person responsible for school liaison who would coordinate the process and provide overarching support, although in most cases individual key teachers would also be involved in the process.

The perceived level of quality of communication with home schools across the services was variable, particularly for short stay patients on medical wards. Services often found that the quality depended on the level of engagement by the home school. Most services we met with felt that although, especially in the recent years, HS are aware of mental health issues and the teachers in HS are now more sensitive around these issues there are still challenges in terms of effective liaison.

Some HHE try to do outreach activities in raising awareness of their existence among the HS such as the use of a video on the website of one service explaining how they would like to work with mainstream schools.

Hospital schools seem to encounter many difficulties when trying to communicate with HS. Accessing the CYPMC work and transferring files was a complex and challenging process. Most of the participants agreed that primary schools were easier in terms of communication, as there is only one teacher per class, so telephoning the school makes it easier to get the files and the resources for the child. Secondary schools are more challenging due to the size of the school, the many teachers involved and in some cases it is very difficult to get to the personal tutor of a secondary school pupil, resulting in delays.

One service noted that they had daily access the NHS Bed State Report which allowed them to see, within the limits of its accuracy, who was coming on to the wards that might be making use of the service and thus provided another check on this independent of communication from the medical team.
There was considerable variability across the sample in the confidence that respondents expressed in terms of the quality of liaison and communication with hospital staff. Where this was strong, there seemed to be a link to the HHE service demonstrating what they had to offer to the hospital in a proactive way. For example, in several services, hospital school staff were involved in advising and contributing to medical education, which had contributed to improved communication and liaison between school and hospital.

In terms of effective communication, a number of respondents stressed that this needs to cover a number of levels – day to day with nursing and medical staff, and at strategic level with hospital senior managers.

To conclude, it became evident from the data that for effective communication with the other services, attention is required at three levels:

- leadership-strategic planning
- networking with as many services as possible and available
- fostering the awareness of HHE in the other services.

Finally, mutual respect on both sides is essential as a lack of this can cause breakdowns in communication and create difficulties. The headteacher of one service noted how the lack of understanding of the education context by health staff can make it a difficult relationship at times. For example, there can be a lack of understanding or consideration about the impact on HHE provision that developments in health services will have.
QUALITY AND CHARACTERISTICS OF STAFF

Staffing

- Subject knowledge
- Flexibility
- Ability to work well with others
- Ability to adjust
- Emotional intelligence
- Experience
- Resilience
- Empathy
- Self confidence
- Trustworthy
- Politeness
- Building rapport
- Innovation
- Creativity
- Time management

FIGURE 9 KEY THEMES ON QUALITY AND CHARACTERISTICS OF STAFF
There was near universal agreement among participants that in terms of staff qualities, subject knowledge was the key priority. However, Headteachers emphasised that due to the nature of HHE there is a need to be able to teach other subjects as well as deliver functional skills or enriched curriculum activities.

Apart from subject knowledge, there was a variety of views on what are the priorities when recruiting staff to teaching roles:

- Special School or PRU Experience
- 3-4 Years of Mainstream Experience
- Having dignity and respect for children
- The ability to respond to the individual needs of children
- Understanding of and ability to foster resilience in children
- Resilience as a teacher
- The ability to keep boundaries (between educational and pastoral role)

Most participants agreed that an effective teacher in HHE is the one who can work as a team member and have the ability to adjust the lesson depending on the medical conditions of the CYP, as well as the ability to be flexible, especially in hospital schools as they might start a lesson and then have to stop due to a visit from the medical staff in the ward.

Across the sample, even for secondary phase, although good subject knowledge was seen as a *sine qua non*, experience and expertise as a subject leader was not listed as a key priority for recruitment by any participant. Overall, the sense was that personal qualities, the ability to respond to the individual needs of children, flexibility and the ability to foster "emotional resilience" in children were the key qualities for recruiting staff.
PEDAGOGY AND CURRICULUM

As in the literature review it became evident that a clear distinction between pedagogy and curriculum needs to be made, so we analyse the data in the light of these findings. The following themes emerged from the data:

![Figure 10: Key Themes of Pedagogy and Curriculum](image)

**FIGURE 10 KEY THEMES OF PEDAGOGY AND CURRICULUM**
When asked whether the curriculum plays a therapeutic role, nearly all the participants agreed that it is part of the CYPMC treatment, but it should not be confused with therapy. Especially for CYPMH and school refusals most participants that worked with those CYP emphasised that they need to keep their boundaries as teachers and their role, which was about education and pastoral care.

Interviews indicated that although education in the lives of CYPMC can play a therapeutic role or be part of their treatment, their role is about offering pastoral care and it is about “education for well-being”.

Another theme that emerged from the interviews was the expectations that the school had of pupils, especially the ones with MH. It was agreed, especially among staff the work mainly in HSs, that this depends on the MCs or the MH issues. However three headteachers were clear that: "we do not allow the mental health to prevent their learning". They promoted the idea that they teach the child, and not the condition, and although they take on board the condition they see that these pupils have the same learning potentials as others.

The services in the sample were engaged in a range of service types – hospital schools for medical and mental health patients, home education, and outpatient/base education services - and thus a range of pedagogical and curriculum approaches were reported on. Common emerging themes across the sample included the need to have a clear focus on academic subjects, but at the same time to include time for functional and life skills development depending on the individual child. Additionally, participants agreed on the need for an individualised, “bespoke” curriculum, nevertheless balanced with the need, particularly for CYP with mental health problems, to provide a predictable a curriculum offer across the day. One service noted that for psychiatric inpatients predictability in the curriculum is very important and they use a defined visualised map of the curriculum content that will allow students to see what is expected to happen at any given point in the day.

The need for academic progress was a clear focus, although the extent to which this should be linked in to national or home school assessment frameworks was a point of debate across the sample. Thus, whilst all respondents for where it was relevant reported on the need to support CYP’s progress towards and entry for national
examinations, the broad sense of the data was that this was subordinated to the broader need for CYP to be engaged in the process of education,” being in school”, as a normalising element of their lives.

The teacher at one service noted that they were innovating in the curriculum around online safety and diversity. In terms of the latter they were developing a database of lessons around areas such as Black History and Lesbian, Gay, Bisexual, and Transgender perspectives.

The pattern of curriculum and the need to balance a planned curriculum with personalisation for the child was clearly an issue across all the services. In general, each service had a structured approach for long, medium and short-term planning, but this was intercalated with on the ground flexibility to personalise for individual needs.

Some services were using bespoke databases for tracking pupil progress.

There was a focus across the sample on the “core curriculum” with a particular focus on Maths and English, although a number of senior leader respondents recognised that this was a “pretty dry curriculum” for many children and that the need for broader engagement with arts and creativity as well as life skills such as cooking was also important, although it seemed that often resource restrictions were the main barrier to implementing this in many services.

However, across the sample there were several examples of activities for CYPMC and especially the CYPMH where although they were not part of the academic curriculum and could be considered as extra-curricular activities, the services regarded them as integral part of the school curriculum as they offer functional skills and took, especially the CYPMH, out of their comfort zone in an enjoyable way. To design and deliver these activities there was collaboration between education staff and staff either from health or CAMHS or other services, but mainly for inpatient students with health staff.

This was the consensus among five services that collaborations can be developed for extra curricula activities between educational staff and clinical staff using the space of school, especially for CYPMH.
In terms of the use of digital technology, the respondents in the sample were less sanguine about the potential use than some of the voices on this topic noted in the literature review. There was use of tablets for academic subjects and, in some occasions when the medical condition was allowing it to Skype or face time the HS classes, so the CYPMC to feel that they are part of the class, but these attempts were very limited and sporadic. There were concerns raised about the potential interference of mobile technology with the idea that students were now in a time or space focused on school work and that for some CYP with mental health problems that digital technology can be a way of avoiding interpersonal contact.

One service has purchased an internet connected robot to see if this might help keep children connected with the HS. Within the functions of the robot a child can be present in the class or a class trip without the child being seen or his or her voice can be altered if they do not feel confident to speak directly in the class.
THE OUTCOMES OF HOSPITAL AND HOME EDUCATION

There was debate amongst the services about how exactly this might and should be defined. Nevertheless, there was broad agreement that effective HHE should view education not as therapy, as was shown in the previous section as well, but as focused on the following areas:

1. Normalcy
2. Social, emotional, moral well-being and development
3. Pastoral care
4. General well-being
5. Learning opportunities - we teach the pupils and not the disease
6. Striving for mastery of subjects - continuation of education
7. Functional skills
8. Feeling of belonging

However, there was a view from some services that hospital school services can have a therapeutic effect, but that this is in a sense a "side effect" of their core educational function and their contribution to the "normalcy" of the student experience.

There was a range of views about the extent to which HHELCs had a formal therapeutic role and, although there was clearly no one agreed position on this complex issue, it seemed important for the leadership team and staff to be clear about their position and how this might be translated into pedagogy and curriculum.
Although there were variety of assessment processes, all the services saw assessment as a key process, particularly on admission, and discussions about assessment indicated that children making progress, in both academic, functional, and emotional spheres (albeit with varying emphasis between the three areas) was a key focus for schools. Figure 11 presents a model of how one service conducts an initial assessment for a pupil.

Services discussed the use of database systems and a variety of assessment tools for tracking progress. Some services used standardised test measures as an approach to measuring progress. Assessing a baseline on admission was a clear area of focus for all services. One service used an assessment tool – BKSb – as well as teacher assessment to decide on pathways for Key Stage 4 study. Another service made use of the SIMS package assessment extensions.
It was felt important by a number of services for ‘formal’ assessments to be linked in to regular collaborative team meetings about CYP.

There was, as noted, a measure of debate amongst services as to the importance of a) formal assessment linked to the National Curriculum or in relation to national examinations compared to locally developed measures, and b) assessment focused on academic areas as opposed to creative/arts/functional and emotional development.

As noted, assessment on admission was seen as a key, if not unproblematic, issue across the services. All the services felt that liaison with home schools and the sharing of assessment information when working with students and when they return to their home school was important. One relevant issue noted is the complexity that assessment without levels has added to assessment liaison for services. They also note the importance, again reflected by all the respondents, of liaison in terms of assessment with families.

One service indicated that if a child is with the service for any longer than two weeks, a written academic report, detailing the work that they’ve done and the progress that they’ve made, is sent out to the home school as well. For shorter stays, the child is given their work to take with them back to school to show to their teacher.

SAFETY AND HANDLING

A range of services noted that for CYP with complex or severe mental health needs the use of daily risk assessments, often in collaboration with the medical team, were important in assessing whether children would come out of the ward on to a school site and as to whether education would take place at the bedside or not. However, across the participants, the general pattern was that in nearly all cases education continued to be offered to CYP and what was key was the initial period of engagement, relationship and confidence building.

One service advised that hospital schools should ensure that they are aware of and compliant with the wider hospital policy on safe handling. Another service noted that where an assessment is made to work at the bedside, but there are concerns about
safety and handling, then it was sometimes the case that a psychiatric nurse would accompany the teacher onto the ward. One service noted that they had specific training in place for teaching staff in terms of secure handling and used several training approaches including ‘Team Teach’ (http://www.teamteach.co.uk/). This service also uses a risk assessment approach whereby each CYP is assessed collaboratively with the medical team in the morning, which feeds in to whether they will come down to the school or be seen on the ward.

WORKING IN AN EDUCATIONAL BASE SETTING FOR CYP UNABLE TO ATTEND HS

Several services involved with home education noted the importance of having a base site where teaching and reintegration could take place. Services that were offering such an educational base agreed that these “mini-schools” are important and should include CYP from all conditions such as special needs (e.g. autism), medical conditions (recovery from a medical condition such as cancer or having a chronic medical condition that cannot attend a busy mainstream school) and anxious school refusals. They agreed that these bases need to offer all school hours and it will depend on the condition of each pupil on how many hours they can be in the school.

There were also comments from one service that access to public transport was important both in terms of children reintegrating from home education, but also in terms of reintegration in to school from a base, i.e. in terms of access to college/

All the respondents who were involved in home tuition and reintegration believed having a base where CYP could come for integration was very positive and that this led to opportunities for social integration, normalisation and potentially increased the chances of either more rapid return to mainstream schooling or promoted independence in the context of moving on to college or employment.
Conclusions

The final conclusions are based on the literature review and the empirical data analysed.

1. **Key outcomes of HHE** are education for CYPMC. Education also includes the elements of socialisation and promoting well-being. In HHE normalcy is key. Aspects of effective outcomes are the continuation of the academic progress of the CYPMC, effective re-entry in HS and resilience (especially CYPMH).

2. **Effective organisation and structure:** depends on effective leadership, collaboration, cross agency working and networking. Leadership needs to be stable, visible to all units and other services, strategic with clear vision aims and objectives and needs to establish effective communication channels and mutual respect. Collaboration requires multiple forms of communication such as presence in meetings, as well as collaboration in activities that involve different aspects of the school.

   It was evident from the data, especially from HHEs that operate in multi-service units and that have inpatient and outpatient pupils, that all services related to education for children with medical conditions who cannot attend need to be the responsibility of one body with clear leadership. Our analysis indicates that if all these services are under the same leadership as one organisation or service and operate as one school there are many advantages in terms of sharing information about CYPMC, resources, experiences and avoiding the duplication of certain services. Within this body, structures can allow for different departments depending on the nature of the needs of CYP. An effective structure can be visualised in the following figure:
3. **Key people** as links among departments who are flexible and can move physically in different spaces. Our analysis indicates that there are many benefits if staff are moving across the different units, even in services where the physical locations have travelling distances up to 30-45 minutes. However, these movements need to be balanced and each unit/site needs to have key people who are stable to the unit.

4. **Pedagogy** is about the school ethos that revolves around offering normalcy, focusing on academic subjects as well as educational well-being and networking to offer enriched activities, and has to be seen as an integral part of the therapy or treatment of CYP.

5. **Curriculum:** Although all participants agreed that the curriculum can play a therapeutic role, a clear distinction needs to be made between curriculum and therapy. Using the term therapy for the curriculum might pathologise it as this term is used in medical and psychological disciplines. The curriculum can play an indirect (and important) therapeutic role, but
needs to be seen as distinct from therapy. Several participants express their concerns in the use of the term therapy in the context of the curriculum as pathologising education and especially for CYPMH there is core belief that education should be depathologised as their environment (especially inpatient) is pathologised. The curriculum needs to be personalised, based on academic subjects, but also offer opportunities for well-being and social and emotional development. Outdoors activities and networking with local charities, museums and arts galleries can become excellent places and spaces for gaining functional skills. Such curricula approaches could involve the creation of supportive hubs.

6. **Inclusion of digital technologies:** The use of technologies such as laptops, notebooks, tablets and internet-connected toys can contribute to the learning culture that is created by HHE. Also, social media and networks can keep CYP socialised, connected with the mainstream school peers and gives them the sense of “normalcy”. However, in cases with mental health issues then this needs to be considered in the planning of individual health and educational plans.

7. **Extra curricula activities:** can be offered in collaboration with clinical staff especially such as cooking or small projects around raising money for charity or the production of a play.

8. **Assessment:** varies across HHE. Common characteristics are that assessment has three levels of equal importance: academic, functional skills and PHSE. Assessment records need to clear, consistent and easily understood by others.

9. **Environmental spaces:** It is important that there is a physical space that operates like a school. From the discussion of the findings it was evident that the proximity of physical space with other services is important for effective collaboration. This space needs to have an outdoor area. It is also important to consider if it is possible for the school to provide some form of function during the school holidays. This is important for all CYPMC, especially ones with MH, as it offers them the opportunity to access activities during hospitalisation and moreover to keep a sense of continuity (especially school refusers). It is also important for the schools
(especially for CYPMH or CYPMC that are unable to attend mainstream education) to have access to the school physical space for all hours that they are entitled to, whether they decide or are able to use them or not.

10. **Collaboration within the HHE service**: our analysis shows that multi-service units have built effective teams through regular face to face meetings amongst all staff as one school and collaborative cross unit activities and projects.

11. **Collaboration with parents and others**: effective collaborations require channels of communication and partnerships at multiple levels. These include not only the parents, services involved in the treatment or therapy of the CYPMC, but also local charities, universities and other organisations that might be able to offer their expertise (e.g. arts, museums and galleries). Collaboration requires a clear understanding of each other’s role, mutual respect and every stakeholder needs to be valued for what can offer to the holistic treatment of the CYPMC.

12. **Service level collaboration**: All the services we interviewed try to create collaborations with other services such as nursing staff to offer extra curricula activities to their pupils (especially the inpatient ones). Collaborations can be extended in joint protocols of good practice, meetings for the care and treatment of CYPMC as well as in discharge or re-integration planning, and projects such as charity activities raising awareness for the role of the services around the CYPMC. Mutual respect and collaboration were key elements for effective provision. We found that for effective cross agency work joint training among staff from all services is required.

13. **Qualities and characteristics of staff**: include most importantly good subject knowledge, but also the abilities to be adaptable, flexible, to work with others, to be prepared to teach subjects beyond their own specialism, experience, resilience, clear boundaries of their role and a set of skills such as empathy.

14. **Training and support of staff**: it was evident that training is required at two levels. Firstly, in regards of academic subjects, for example, asking their staff to spend a day in a mainstream school to get in touch with the
mainstream education and its pressure. Secondly, training around issues on MC and MH, safeguarding and collaboration. However, an important finding was that emotional support should be available to staff either through the methods of the school or through collaboration with CAMHS.

15. **The importance of working in a base educational service** for CYP that cannot attend school. These can be children with special needs, such as autism or MC recovering from cancer, and where the HS is not advisable for the condition or anxious school leavers. There is a need for a physical school location for all those CYP who cannot attend school.
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