



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

Future Achievable Potential Models of Child Health Electronic Record Systems to Support Care Delivery

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Future Achievable Potential Models of Child Health Electronic Record Systems to Support Care Delivery

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Introduction

This is the second and last formal deliverable from Work Package 8 of the MOCHA Project, which is responsible for ascertaining how Electronic Records (and by implication other forms of E-Health) can support the optimum models of primary care for children. This deliverable was scheduled to be delivered earlier in the last scientific year of the project. However, it has been produced later for three reasons. First, maternity cover and other personnel changes led to interruptions in the research workforce. Second, though the topic is the support role of e-health to delivery of models of care it was not a deliverable on which other work packages depended, and thus retiming to enable inclusion of additional later material strengthened the content. And finally, strategic productive collaboration with outside research and organisational partners continued up to the penultimate week of the project (see last section) and gives a very exciting conclusion to the work of the deliverable and a clear direction of further travel in the MOCHA theme through what are now partner initiatives.

Backdrop

Child Health Computing - an early innovation

In any healthcare setting the use of health care informatics technologies, configured as e-health, is seen as advantageous to effectiveness and efficiency. Particularly for population-based services, with recipients being dispersed and invisible in their own homes rather than being in healthcare facilities, the benefits might be assumed to be considerable.

Preventive community child health was an early area of innovative deployment of child record computerisation, initially to ensure high uptake of childhood vaccination. It was over 50 years ago, in 1962, that a county council in England created a computer recording and scheduling system, creating records for all of its pre-school children and ensuring that they were actively scheduled for immunisation [1]. Moreover, this system was evaluated, and shown to increase uptake, reduce illness, and be cost-effective [2]. Given the success of this innovation, it steadily cascaded across the UK through individual municipalities, and soon extending also to scheduling and recording of developmental screening as well, with an early example showing total socio-economic equity of uptake [3].

Local innovation also had its disadvantages of variation and fragmentation, and by 1975 a move towards a comprehensive national system, operated locally, was in place and a development strategy agreed. To ensure professional and regional stakeholder ownership, from 1977 the UK had a National Child Health Computing Committee to oversee phased development and at scale piloting [4,5]. The system was ultimately used, in the majority of not all of its functions, in all of Wales, most of England, and much of Scotland.

Negative Fragmentation

Given this early start, it might be expected that there would have built up a strong evidence base and practice in electronic records in child health, and that this would have cascaded to other like-minded countries. However, this far from the case. In the United Kingdom, to conclude this case study, an alignment of the flexing of local autonomy and a political desire to decentralise policy including computer application policy and design, coupled with a political decision to locate as much child preventive care as possible within generic general practice, led to the

freezing then dismantling of the national system and the overseeing national committee. These were decisions based on political and professional persuasions, not on evidence for or against, setting a trend in e-health that largely continues.

E-health and Children – an Aspiration-rich but Evidence-free Zone

As this report will demonstrate, there is no significant evaluation, nor evidence base, to support use of electronic records and scheduling in child health beyond the early British success, and that itself was based in a very different service delivery, societal and computing context. This makes the work of this workstream of MOCHA significant but also large, and it is only just touching on the full subject.

Prior experience, including widespread implementation, seems to have been systematically forgotten. Indeed, one of the very few literature items retrieved is from Wandsworth, London in 2013, reporting a pilot study in 2011 [6]. This instigated a reminder system to parents of immunisations due, with health visitor involvement being triggered for repeated failures. This exactly replicates the process of the early [1] and [4,5] schemes of some 40 years earlier, yet is presented as a new initiative. Apart from one American-led literature review in 2000 [7], none of the practical papers cited by the Wandsworth study is more than four years old. The Wandsworth study is based on use of individual primary care proprietary EHR systems, and the computing aspects are not mentioned. It does cite National Institute for Clinical Excellence (NICE) guidance, and this too [8] only refers to the recall processes, with background computing being an implied given. Moreover, while this NICE guidance refers to the lack of evidence other than from the USA on the effects on immunisation uptake rates of call and reminder systems, and identifies the need for further research, there is again no reference to the need for research or cost-benefit analysis of computer use. A 2011 systematic review cited by the Wandsworth study into justification for their initiative reports 22 studies in developed countries of the benefits of reminder or recall systems for childhood immunisation – 19 are USA based, one Australian, and two in Wales (using reminder letters) [9]. Thus there is a worrying paucity of European research published, and no reporting in the literature of initiatives implemented. There is total lack of institutional memory at nation level, or use of either literature or grey material. Moreover, and more importantly for this document, there is no mention of EHRs or computing. E-health research is nobody's responsibility; e-health implementation is based on aspiration rather than evidence-based policy [10], and this applies not least in child health computing.

The expectation and aspiration that EHR systems will improve healthcare effectiveness and efficiency is long-standing and widespread. From an early UK policy advisory report in the UK stating (but not citing supporting evidence) that: *“Screening and surveillance of children, as well as immunisation, require a level of administration and coordination which cannot be undertaken effectively without a computer-based system.”* [11 (para 8.12)] through to the modern European State of Health in the EU: Companion Report 2017 view that *“More holistic, person-centred health data will have an enormous potential for improving the quality of care and the performance of health systems across the EU.”* [12, page 9] There is a constant aspiration for computerisation of records, without supporting evidence. Thus there is a risk of there being self-believing truth in this regard in line with the quotation attributed to psychologist and philosopher William James (1842-1910) that *“There is nothing ... that it cannot be believed as truth if repeated often enough.”*

Words of caution have however been offered. In the USA, the respected Agency for Healthcare Research and Quality said in 2006: *“Although the use of electronic health records (EHRs) is limited in healthcare, there is a renewed conviction by the government, provider groups, and healthcare purchasers that widespread adoption is critical to the delivery of consistent, high-quality care. However, EHR implementation, without other important changes in the way healthcare services are provided, is unlikely to improve quality.”* [13]. Similarly, but more recently and in Europe, the European Commission’s eHealth Action Plan 2012-2020 has realistically identified one of seven barriers to deployment of eHealth as being *“limited large-scale evidence of the cost-effectiveness of eHealth tools and services”* [14 (page 5)].

However, in the somewhat different child health setting in the USA, Miller and Tucker have calculated that a 10% increase in the proportion of obstetric departments using EHRs reduced neonatal mortality by 3%, and if EHR-linked electronic monitoring systems are also included then the reduction in neonatal mortality was 7.3% [15]. This effect is strongest in higher risk patient population groups. The authors calculated the cost per life saved of the E-health functionality was \$531,000. While the details of some aspects can be questioned, and the USA at the time of the study (up to 2006) had a low obstetric hospital EHR uptake and a high neonatal mortality (behind all but three of the EU countries at that time), the key point is that the health outcome benefits of a defined E-health initiative were calculated and the cost of the benefits computed. Thus policy makers could assess the likely health gain from an e-health investment and prioritise it against other spending options, while the e-health sector can demonstrate objectively the likely beneficial outcomes of an application. This is a worryingly rare process, seemingly absent from Europe, and indeed this cited paper is rather hidden in a Political Economy journal and is not discoverable through PubMed.

So the e-health sector is not seeking to quantify or verify its benefits. At the same time e-health policy is perforce being developed without an evidence base. This is an unsatisfactory situation, jeopardising optimal healthcare delivery and optimal use of resources.

A Child-free Policy Arena

The final backdrop challenge to this report is that in Europe and in many countries e-Health is one of those not infrequent policy areas which omit any significant consideration of children. The European Commission’s e-Health action plan [14] has no mention of children; the Companion Report to the 2017 State of Health in the EU country series only mentions children in terms of obesity and nutrition [12]. Deliverable D8.1 in August 2016 [16] showed the large number of countries which did not have mention of children’s e-health needs in their national e-health strategy, and this finding has also been published [17]. That analysis did also show the potential, in that some countries highlighted major initiatives planned or in hand to harness e-health in children’s services. So at both national and European level, e-health for children is only weakly and patchily addressed.

E-Health Support for Children in Practice

An important baseline for assessing current and potential E-Health support to children’s primary care is the extent of use currently. The MOCHA project undertook a study through its country agents, and Figure 1 shows the extent of e-health use in the study countries. These results triangulate well with the results of a slightly earlier study for a smaller set of countries and using a different methodology [18].



Figure 1: Use of EHRs in delivery of primary care for children

Child-orientated Basis of Design

When asked whether these were specifically child-orientated systems, or adult based systems, only Croatia reported the application of an electronic record system specifically designed for children. In Italy, family paediatricians use software designed specifically for children’s records, while general practitioners have generic systems with inclusion of child health items. In the Czech Republic there are “customized” systems used for all types of ambulatory specialists, however some systems specifically produced for children’s general practitioners are on the market.

Currently, the German healthcare system is in a process of change concerning e-health, as different advances are planned including a new eHealth law. Those changes are yet not widely implemented in clinical practice.

Iceland applies both generic and child specific systems. Interestingly, the Icelandic child specific system consists of two components, a preventive child health service for younger children aged 0 - 5 years and another EHR for children 6 – 15 years of age in compulsory schools. Apart from that, there are other systems in place in the private sector.

In Lithuania, there are mostly systems for registration of consultation. EHR systems are applied in the tertiary sector of care. Big university hospitals use EHR systems, but this is limited to the actual time spent in hospital. EHR systems are not yet common in primary care, where there may only be some scattered EHR platforms in individual clinics.

In the Netherlands, preventive child health care is provided by separate organisations which have their EHR system specifically designed for this type of care, i.e. immunizations, growth monitoring, etc. Other primary care for children is provided by GPs, who have the same EHR for adults and children, but this is mostly organised per family.

The rest of Europe presents a rather scattered picture with most countries have a mix of systems of designed primarily on adults

Given the types of primary care organisation and funding operating in each country, it was felt important to ascertain whether EHR systems were being used primarily for health care deliver, or primarily for claiming fees. Figure 2 shows the answer.

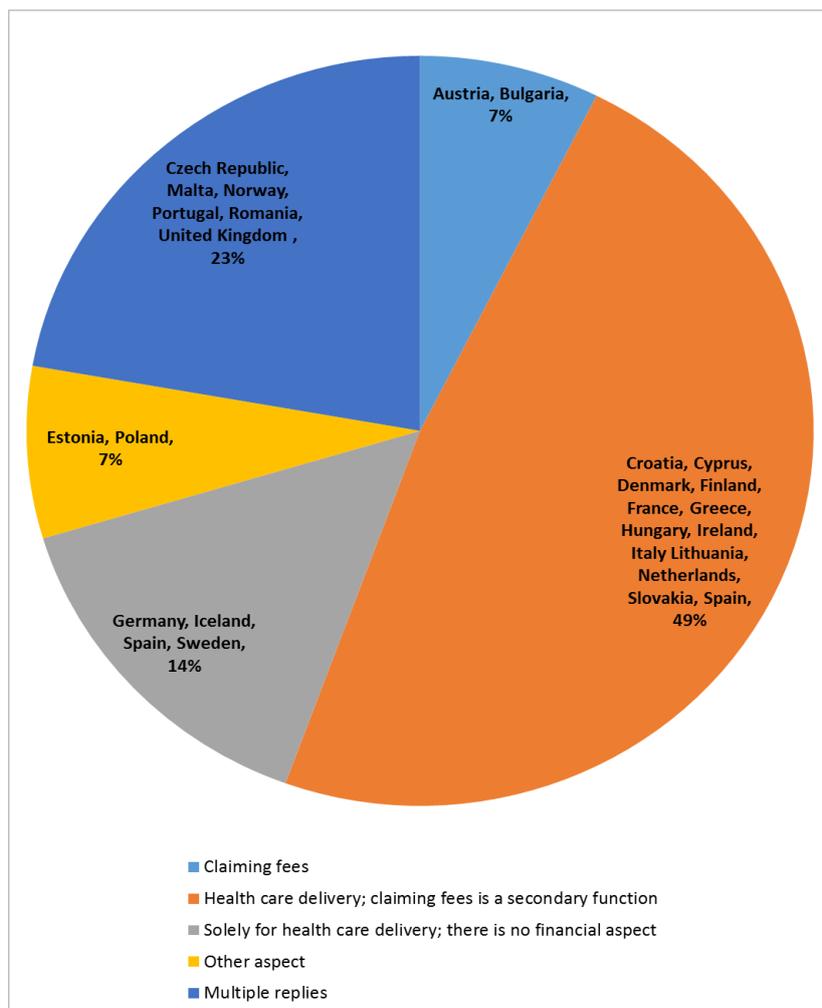


Figure 2: Primary Purpose of EHR systems in Child Primary Care

Additional Research and Knowledge Uses

Though the primary purpose of EHRs is to enable better and more coordinated care delivery, the availability of the data in anonymised form is a valuable research and planning tool. Figure 3 shows the extent of downloading to anonymised research databases. The literature also shows this is a major beneficial by-product of EHRs, though experience elsewhere within MOCHA has identified how difficult it is to initiate such research.

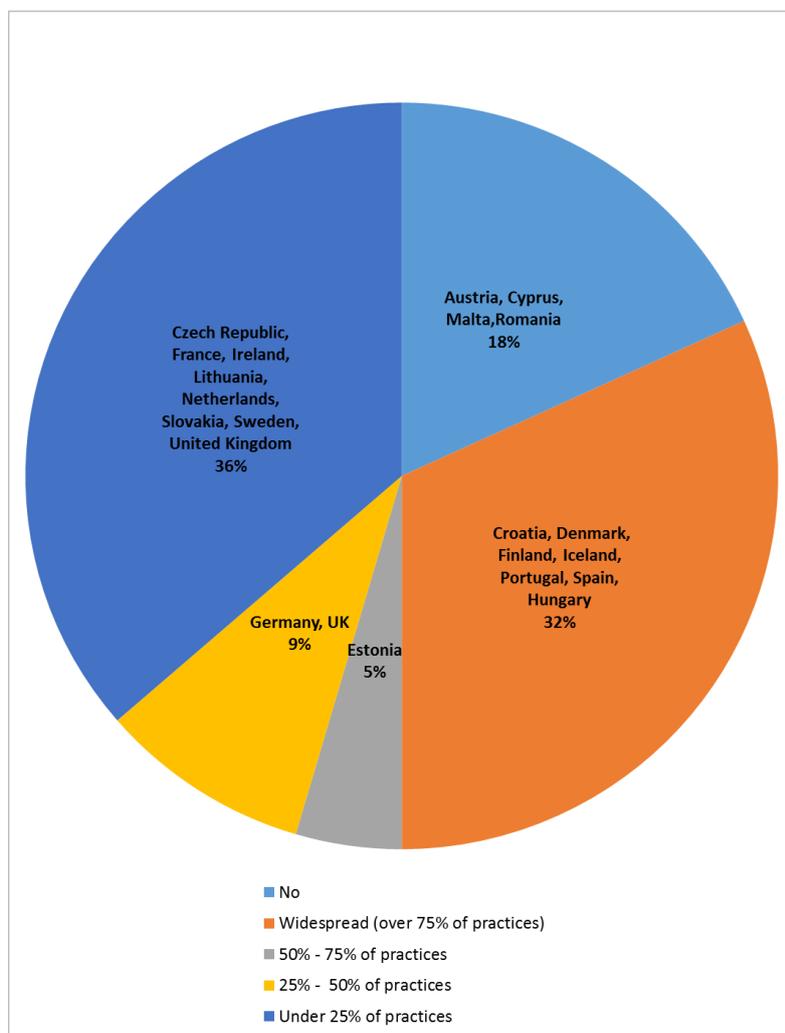


Figure 3. Countries downloading Primary Care EHR data to anonymised primary care data repositories

Child Public Health Systems

Distinct from EHR systems, many countries have case based child public health record systems. Figure 4 shows the countries involved, and the functionality.

Figure 4: Geographic Spread of Child Public Health Electronic Systems



We also ascertained whether the child public health systems were merely passively recording data, or whether they pro-actively schedule appointment or identify those running late. Figure 5 gives this analysis.

Figure 5: Functionality of Child Public Health Electronic Systems

System Directly Schedules Appointments	System advises Provider of Children Overdue	Passive Record
Czech Republic Denmark Estonia Iceland Spain UK (Northern Ireland and Scotland) (SA)	Czech Republic Denmark Estonia Hungary (SA) Iceland Ireland (SA) Italy Norway Romania Spain UK (England) (SA)	Croatia (SA) Finland Malta (SA) UK (Wales)
All use a form of automated data exchange unless marked Stand Alone (SA)		

Standard Data Standards and Sets

The study also sought to ascertain the extent and nature of use of data standards, and of standard data sets for specific child health functions. The mixed and heterogeneous replies received suggested that most countries still do not fully understand the issues at operational level, and this has further strengthened our appreciation of the task which ought to be undertaken in Europe to introduce then apply appropriate standards.

Systematised Data Sharing

A key purpose of electronic records is to enable controlled sharing of key data to enable smooth continuity of care, and minimise duplicate history taking and recording. Explicit enquiries were made about this, and Figure 6 shows the flows reported.

Figure 6. Overview on organisational linkages for electronic record data sharing

	Hospitals	Home / community care providers	Social care	Schools	Any other agency (mainly registries local systems funding)
Austria					
Bulgaria					✓
Croatia					
Cyprus					
Czech Republic	✓				✓
Denmark					
Estonia	✓			✓	✓
Finland	✓	✓	✓	✓	✓
France			✓		
Germany					
Greece					
Hungary					✓
Iceland	✓			✓	✓
Ireland	✓				✓
Italy	✓	✓			✓
Latvia					
Lithuania					
Malta					
Netherlands	✓				
Norway	✓				✓
Poland					
Portugal	✓				
Romania	✓			✓	✓
Slovakia					
Spain	✓				
Sweden	✓				✓
United Kingdom					
Total	12	2	2	4	11

Meanwhile, Figure 7 shows the type of data exchanged.

Figure 7. Overview of data types exchanged with electronic record data sharing

Country	No Reported Data Exchange	Data Set Exchange or Messaging					
		Data on Newborns	Data on Hospital Discharge	Home visiting nurses	Immun.	Preventive or routine exams	Possible maltreatment
Austria	✓						
Bulgaria	✓						
Croatia					✓		
Cyprus	✓						
Czech Republic	✓						
Denmark		✓	✓	✓	✓	✓	
Estonia		✓	✓	✓	✓	✓	
Finland	✓						
France	✓						
Germany	✓						
Greece	✓						
Hungary		✓					
Iceland		✓	✓		✓		
Ireland		✓		✓	✓		
Italy	✓						
Latvia	✓						
Lithuania	✓						
Malta	✓						
Netherl'ds		✓	✓	✓	✓	✓	✓
Norway					✓		
Poland	✓						
Portugal		✓	✓	✓	✓	✓	✓
Romania	✓						
Slovakia	✓						
Spain		✓	✓				
Sweden							
UK	✓						
Total	16	8	6	5	8	4	2

It is clear from these tables that potential for seamless, coordinated and integrated care is far from being supported electronically.

Collaboration with ECDC

While MOCHA is a research project, the European Centre for Disease Control was in parallel addressing similar lines in its quest to promote all-age immunisation records to be held in Immunisation Information Systems (IISs). They have produced a Technical Brief [19], and have studied similar key issues to MOCHA. A detailed report cross-mapping ECDC results and MOCHA results has been undertaken, and has shown strong triangulation on issues such as Unique Record Identifier nature and issue. Figure 8 shows the respective results regarding IISs and Child Public Health Systems.

Figure 8. Mapping of IIS and Child Public Health Systems

	IIS	Child Public Health System
	ECDC	MOCHA
Austria	Yes	No

Belgium *	Yes	No data
Bulgaria	Yes	Yes
Croatia	No	Yes
Cyprus	No	No
Czech Republic	No	Yes
Denmark	Yes	Yes
Estonia	No	Yes
Finland	Yes	Yes
France	Yes	No
Germany	Yes	No
Greece	Yes	No
Hungary	Yes	Yes
Iceland	Yes	Yes
Ireland	Yes	Yes
Italy	No data	Yes
Latvia	Yes	No
Lithuania	No data	No
Luxembourg	No	No data
Malta	Yes	Yes
Netherlands	Yes	Yes
Norway	Yes	Yes
Poland	No data	No
Portugal **	Yes	Yes
Romania	Yes	Yes
Slovakia	Yes	Yes
Slovenia	No	No data
Spain ***	Yes	Yes
Sweden	Yes	Yes
UK ****	Yes	Yes
Total countries replied	27	27
Yes replies, and as (%) of question respondents	Yes 20 (74%)	Yes 19 (70%)

Key to colours

IIS present but no Child Public Health System	Child Public Health System present but no IIS
Neither present	Both present (may not be same system)

Child and Parental Access to the Record

For adults it is now considered as good practice for patients to be able to see their electronic health records, so as to facilitate accuracy and co-ownership of health. However, many places in Europe are reluctant to give children co-involvement until they are 18 years old, or in some cases 16 years.

It is also seen as good policy for adolescents to be able to consult a health practitioner without parental involvement, and if the parent can access the child's record then confidentiality is lost. We therefore enquired on two reciprocal items. Figure 9 shows the position regarding persons under 18 having access to their own health record.

Figure 9. Policy on Children’s Access to their Own Health Records

Country	Yes	Yes, but only for certain age groups (please give details)	Only if the parent agrees (Please add any comments e.g. if this only happens in certain cases such as referring to contraception)	No
Austria		✓		
Cyprus				✓
Czech Republic			✓	
Estonia		✓	✓	
Germany		✓		
Iceland	✓			
Italy			✓	
Latvia	✓			
Lithuania		✓		
Norway		✓		
Portugal			✓	
Sweden	N/A	N/A	N/A	N/A
Total numbers	2	5	4	1

Figure 10 shows how a child’s wish to block parental access is handled.

Figure 10. Can a Child Block Parental Access?

Country	Yes	Yes, but only for certain age groups (please give details)	Only if the parent agrees (Please add any comments e.g. if this only happens in certain cases such as referring to contraception)	No
Austria		✓		
Cyprus				✓
Czech Republic				✓
Estonia	✓			
Germany		✓		

Iceland		✓	✓	
Italy			✓	
Latvia				✓
Lithuania				✓
Norway		✓		
Portugal		✓		
Sweden		✓		
Total numbers	1	6	2	4

The view of MOCHA is that there are some very fundamental issues involved here, and that the whole subject of child autonomy needs further stakeholder discussion. This is not a technological issue, but technology does change the potential problems and benefits.

Home Based (Parent Held) Records

Home based records for new-born children exist in many countries, and are seen by many as a good way of boosting uptake of immunisation; others see them as much more valuable when they cover all key issues on a child’s health. However, in the modern idiom it is clearly desirable for the data items to be the same as for other health records, and to minimise the amount of data capture. Therefore, in collaboration with the European Regional Office of the WHO, MOCHA started by ascertaining the current situation in the 30 study countries. A special report was produced and is available [20], detailing what countries are involved, what age groups, whether children moving after birth are included, and who issues the record.

To give an introduction to the subject, and to identify the potential interaction with electronic records, Figure 11 shows the type of data by country.

Figure 11- Types of Content of Home Based Records

	Birth and postnatal data	Allergies and other alerts	Height and weight measurements	Immunisation	Developmental checks	Long term conditions	Prescribed medication	Urgent referral plans for long term conditions	Plan of care and services	Other
<i>Austria</i>	✓	✓	✓	✓	✓	✓				✓
<i>Bulgaria</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<i>Croatia</i>	✓	✓	✓	✓	✓	✓	✓			
<i>Cyprus</i>	✓	✓	✓	✓	✓	✓	✓			
<i>Czech Republic</i>	✓	✓	✓	✓	✓					✓
<i>Denmark</i>	✓	✓	✓	✓	✓					
<i>Estonia</i>	✓			✓						
<i>France</i>	✓	✓	✓	✓	✓	✓	✓			✓
<i>Germany</i>	✓	✓	✓	✓	✓	✓				✓
<i>Greece</i>	✓	✓	✓	✓	✓	✓	✓			✓
<i>Hungary</i>	✓	✓	✓	✓	✓	✓	✓			✓
<i>Iceland</i>	✓	✓	✓	✓	✓	✓	✓			
<i>Ireland*</i>	✓	✓	✓		✓	✓				✓
<i>Italy</i>	✓	✓	✓	✓	✓	✓				✓
<i>Luxembourg</i>	✓	✓	✓	✓	✓	✓	✓			
<i>Malta</i>	✓	✓	✓	✓	✓	✓				
<i>Netherlands</i>	✓	✓	✓	✓	✓	✓	✓	✓		
<i>Poland</i>	✓	✓	✓	✓	✓	✓				✓
<i>Portugal</i>	✓	✓	✓	✓	✓	✓		✓		✓
<i>Romania</i>	✓			✓						
<i>Spain</i>	✓	✓	✓	✓	✓	✓	✓		✓	✓
<i>UK</i>	✓	✓	✓	✓	✓	✓				

Apart from their being another child health record, which needs to be as close in data content as formal records, there is one other interest in the e-health context. Some countries, such as Finland and Hungary, are in process with electronic records systems to enable parental and child data subjects access to their data, through a portal, In other countries apps are appearing, mimicking formal home based records, but there is no formal assessment yet of any new market entrant and whether they meet optimum requirements. This topic therefore needs picking up and harmonising with future e-health support to children’s records and services.

Finally, in due course countries may need to consider whether to provide portal access, or sponsor an official app, that has the same function as the paper Home Based Record. This is not directly a MOCHA issue, but an example of how MOCHA is interfacing with other modern issues and providing hitherto unavailable empirical evidence.

Apps, Web Sites and Telephone Lines

These are a new form of e-health, and one which MOCHA has looked at in some depth. Already one publication has resulted from study of this area [21]

Overall, the MOCHA study found the following planned consumer e-health activities for or regarding children, as shown in Figure 12.

	<u>Apps</u>	<u>Websites</u>	<u>Health advice line</u>	<u>Helplines</u>
Austria		◆	◆	◆
Bulgaria				
Croatia				
Cyprus				
Czech Republic		◆		◆
Denmark		◆	◆	◆
Estonia	◆	◆	◆	◆
Finland			◆	◆
Germany	◆	◆	◆	◆

Greece		◆		
Iceland			◆	◆
Ireland	◆	◆		
Italy				
Latvia		◆	◆	
Lithuania				
Netherlands			◆	
Norway			◆	◆
Poland		◆		
Portugal		◆		
Romania		◆	◆	
Spain		◆		
Sweden		◆		
United Kingdom	◆	◆	◆	◆

Figure 12. App and Web Site Accreditation Help and Advice Line Provision

Apps

A very modern form of health advice and interaction is via smartphone apps. While these can be innovative and helpful, they can also be unscientific or even malicious, and they can surreptitiously gather user data. There has been some discussion within the European Commission as to whether to seek to create standards. MOCHA studied how many countries already had safeguards in place, and found that was only in five countries and some of these were not particularly robust (Figure 13):

Figure 13. MOCHA countries with Apps accreditation process reported

Country	Accreditation process reported
Estonia	Child Helpline Service app
Germany	Unofficial, internal regulation

Portugal	No specific details given
Slovenia	Slovenian Institute of Quality and Metrology (SIQ) certifies apps as any other medical equipment
Spain	Processes vary across autonomous regions
United Kingdom	MHRA, National Information Board

Web Sites

There are numerous web sites that children can access regarding health matters, whether or not designed for children. It is also known that many web sites can be malicious, and others ineffectual or containing poor advice, but few countries have developed means of validating and protecting children against poor or dangerous web sites. Enquiries of the MOCHA countries identified seven with processes in place, as in Figure 14.

Figure 14. MOCHA countries with website accreditation process in place

Country	Accreditation process reported
Austria	HON code
Croatia	No specific details given
Estonia	No specific details given
France	HON code
Germany	HON code
Portugal	Institutional websites, accredited by providers
Spain	HON code, MedCIRCLE...
United Kingdom	The Information Standard

The HON Code refers to a generic initiative run by the Health on the Net Foundation (<https://www.hon.ch/en/>).

Help Lines and Advice Lines

These are another new service at the edge of e-health. It is modern ICTs which provide the means of providing either type of service, but at present most of the service is provided by

skilled human beings. However, in due course technologies will enable telephone menus, voice recognition and interrogation, and other ways in which the technology will help drive the service. This would then appear to become an Artificial Intelligence (AI) service.

Newly Initiated External Collaboration

The very positive note on which this report ends as MOCHA concludes is active engagement with Standards bodies and projects. Engagement with the HL7 Foundation led to a recognition of common interest with its Trillium II project, charged with developing an international Patient Summary, The desire of MOCHA to see good e-health standards fitted well with Trillium II's interest to make patient summaries relevant. Initially immunisation was seen as the fruitful field, given the need to harmonise many European initiatives including the proposed European Vaccination Card, its conceptual link with Home Based Records and ECDC's own desire to see furtherance of information standards. In turn other MOCHA interests have been seen as ideal for standard patient summaries, including the work on the coordination of response to need forge complex care cases.

To start, a workshop was held as part of the Medical Informatics European conference in Gothenburg in April 2018, taking use cases and emergency room record needs to scope out the nature of future work. That led into design of a workshop held in the CEN offices in Brussels in September 2018, with the following objectives:

1. To identify the actors, processes and data involved in childhood immunisation:
 - a. Scheduling, immunisation programs, and delivery
 - b. Recording
 - c. Displaying- supply of summary
2. To identify the areas of need for standards
3. To identify current progress and unmet needs
4. To contextualise within holistic child health records
5. To relate to other European initiatives

The attendance was by invitation but mould breaking, including DGs Health and CNECT, WHO, immunization system managers or high officials from five Member States , as well as Trillium and MOCHA partners. This meeting started to identify study and consultation areas needing to be addressed and agreed to take these points to a stakeholder meeting in November 2018.

The November meeting was hosted by the World Health Organization Regional Office for European, Copenhagen, and participants included professional bodies, ECDC and SNOMED. A firm plan was framed, to take up individual issues through consultation clusters, workshops, or seeking funding for small research and consultation projects. This, if successful, will very much fuel the development of a suite of agreed standards at CEN TC251, SNOMED, HL7 and Trillium ii. It has also put senior actors in different constituencies of health practice, data science, standards, and health policy into collaborative work mode.

Summary and Conclusion

Work Package 8 has had an interesting and important challenge, somewhat to one side of the main MOCHA thrust of looking at models of service delivery, but strongly linked to it through

examining the role of modern e-health as an enabler, and identifying how e-health itself could use a fusion of evidence base and vision to enable child-centric ways of working.

This report is an overview of a range of areas tackled, all of which have deeper material already published. But above all, though, its great success has been to stimulate creation of a dynamic body of child-focused work through commitment to teamwork across the European e-health community.

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