



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

Work Package 8

Description and Analysis of current child health electronic record keeping across Europe

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Description and Analysis of current child health electronic record keeping across Europe

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Introduction and Context

This Deliverable is the current version of the report on the state of adoption of electronic health records for children in Europe. However, as the work undertaken by Work Package 8 on The Role of Electronic Records and Data to Support Safe and Efficient Models has been planned in logical stages, and the obtaining of field information from each of the 30 EU and EEA countries through the MOCHA country agents has had to be slotted into the overall planned schedule of work for those agents, this is an necessarily interim report, in recognition of the fast changing policy landscape in Europe. The Work Package has so far benefitted from two rounds of enquiries through Country Agents, the results of which are included in this report, but the third key enquiry, as to the current practical state of provision (as distinct from policy commitments) is scheduled for later in 2016, with completion of analysis anticipated for the end of the year.

In addressing the question of the current state of electronic records in supporting primary care for children, the Work Package team has worked sequentially on the following steps:

- i. Literature review, of a range of databases to cover medical, health and computing literature (this work is ongoing)
- ii. Description of the use of unique identifiers to link electronic (and paper) records for children across care providers from the time of birth
- iii. Review of current national e-Health policies, whether they include due reference to children's health records and their specific requirements
- iv. Description of the current situation on the ground with regard to electronic records and e-Health support for children in primary care, and linking with primary care.
- v. Evaluation of the impact of these applications on practice and the delivery of quality coordinated care.

The deliverable focuses on:

Part 1: The current situation with regard to Unique Record Identifiers in 30 countries

Part 2: The focus on children's needs as identified in national e-Health strategies.

Part 3: A forwards in assessing the current level of e-Health activity regarding children's services and to address the question of impact of e-Health activity and delivery of primary care for children.

Part 1: The situation with regard to Unique Identifiers in Child Primary Care in 30 European Countries

Introduction

Work Package 8 aims to identify to what extent current electronic record keeping supports child primary care in Europe, and optimal achievable patterns for the future. The use of unique record identifiers (URI) is a key instrument in this regard. A URI is a nationally organised alphanumeric (or numeric) number allocated to each citizen, including children at or near the time of birth, to link their health records, and related health activity. It may be a national citizen ID and used in health, or it may be specific for health only. It is national, in that it follows the child if he/she moves within country. However, key events relevant to a child's health and care occur at birth and immediately afterwards, in more than one location, and thus means of record linkage should apply from birth onwards. This poses a logistical challenge which not all countries achieve, yet failure to link from birth is likely to result in sub-optimal record keeping, and possibly sub-optimal care. The aim of this study was therefore to investigate the variation in the generation, use and application of URI for newborn children in the countries of Europe, and possible factors hindering implementation.

Methods

The data collection on unique record identifiers for new-born children was carried out between 14th October and 11th November 2015. The questionnaire was designed as a semi structured survey instrument, and asked whether the country had a specific unique record identifier for children, when this was issued, the structure of the number and what type of records it linked (e.g. was it also a unique citizen identifier for all services). The study also enquired whether the identifier, if it existed, was issued to the parents or to the health system. The questionnaire also asked about whether there were on-going plans or policy debates on strengthening children's record linkage (Appendix 1., p. 60). Data for Denmark and Slovenia is awaited, and will be added as soon as received. The attached spreadsheet provides an overview of all responses received.

Summary of URI Usage in Europe

As shown in figure 1 (p.7), responses were received from 28 countries. The majority of European countries use a number mechanism to link child health records. Eight of these issue the URI right at birth, the other counties at a later stage. In 9 European countries health-specific URI are applied and in 14 more general citizen numbers are used for health record linkage. These 23 countries use URI for all records, electronic as well as paper records. Five countries - Austria, Germany, Ireland, Latvia and Slovakia currently do not link child health records. These countries differ, however, in the extent to which there are plans for URI implementation. Whereas in Austria, Germany and Ireland there are concrete plans and a set timescale for implementation of a URI including for children, their possible implementation is under debate in Latvia. Slovakia has a number mechanism in place but currently does not use it for record linkage.

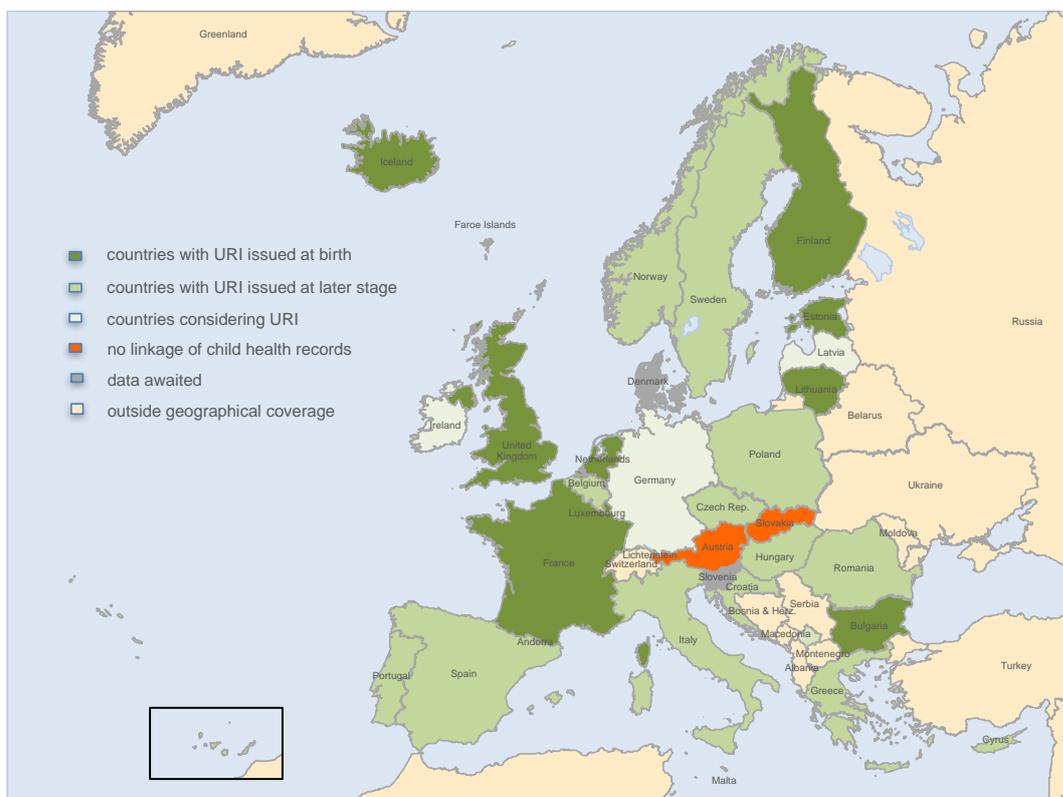


Figure 1: Overview on countries using URI to link child health record

European countries differ regarding the type of identifier used, details contained in the URI, the actual issuing process and application of the identifiers.

Summary of URI Function and Issuing Process

The format of the URI, the issuing process, and the patterns of application of the identifier to service records vary across Europe.

What type of URI is issued?

There is considerable variety as to how URI or national identifiers are used in the context of child health record linkage, as shown below:

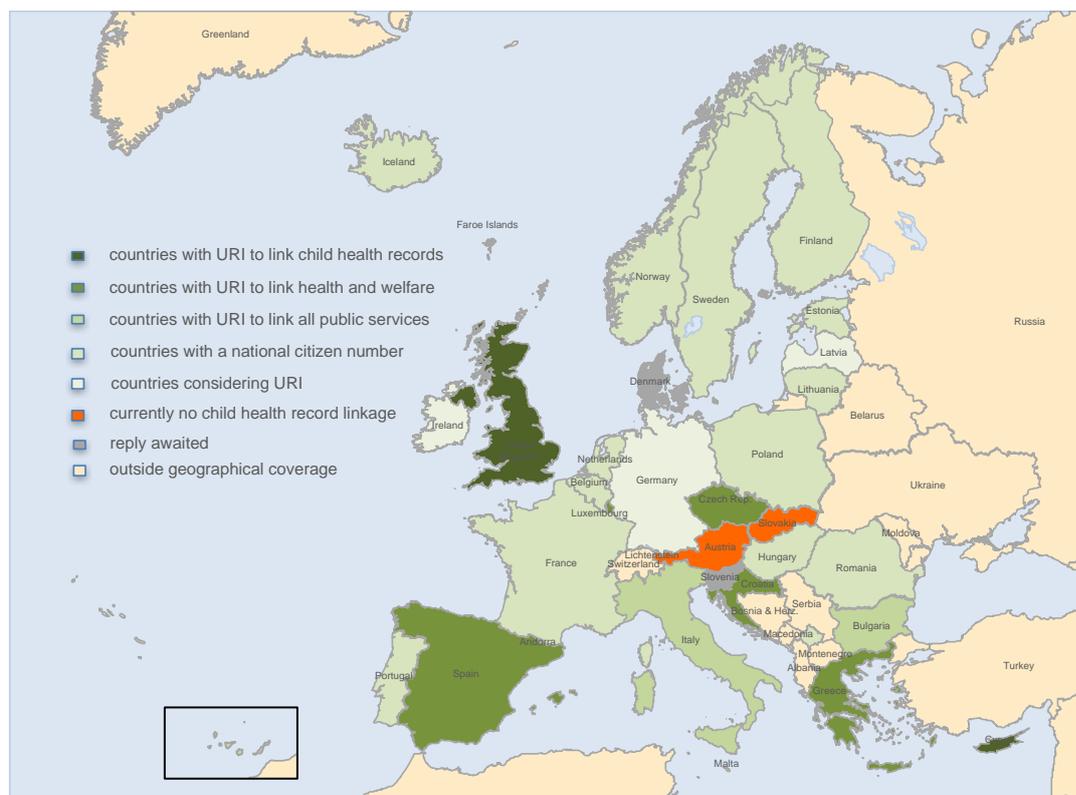


Figure 2: Overview Type of URI

The national citizen number in Iceland is probably one of the most widely applied identifiers as it is used in all contacts of the child with health and welfare services, in schools and even for video renting services.

In Croatia, the health insurance number applies to healthcare services covered by the national health insurance (Croatian national insurance fund).

The Italian fiscal code is also used in the health system. It is additionally used by all public services, such as the registry service, the tax service, the library service and as the citizen ID. The linkage to full personal health records is, however, work in progress.

The national citizen number in Malta applies to all public and most private services. In Luxembourg, the use of unique identifiers is not limited to health and welfare and extends to public services. In France, the national citizen number is devoted to social protection, which is a very extensive domain in the country. The use of the identifier is, however, limited and strictly regulated and is in the responsibility of “la commission nationale informatique et liberté”.

Besides health and social care services, the Hungarian social security number is also applied in labour administration – including unemployment benefit- and detention records, as well as military administration.

In the Czech Republic the so-called “Birth Number” is issued by the Ministry of Interior and is applied to health records, health and welfare, but not necessarily to all public services.

The number issuing process in Slovakia follows a similar pattern as in the Czech Republic. A child is registered under the mother’s name and number and upon presentation of the birth

certificate by the parents to the council administration between 8 to 15 days after birth. This Birth Number is a personal identifier but it is not used for record linkage.

In Portugal, the unique identifier is called “Unique Card” and is a national citizen number, which is used to link health records.

The unique identifier to link children’s health records in Poland is PESEL. Currently in Poland it is used to identify the patient within particular settings, however there are attempts (within the project/system P1) which will lead to an improved exchange of information about the patients among providers with respect to the patient’s right to privacy. Patients will have to agree to data exchange.

The Cypriot system distinguishes between the sectors of health care provision. The ID of the child is mainly applied to health records related to the secondary and tertiary sector of health care and only in the public sector.

Besides differences regarding the application of unique identifiers in health systems, health and welfare and public services, there are also differences at subnational level. England, Scotland and Wales use similar systems where unique identifiers are issued as 10 number digits at birth. A similar system is also used in Northern Ireland with each one of the four using the same format but with non-overlapping number blocks thus preventing the issue of the same number by more than one system.

When is the URI issued?

The point in time when a unique identifier is issued is a highly relevant indicator for the quality of available child health data. As birth is a crucially important event and any medical procedures may have a significant health impact on the baby’s/ child’s future, there is a risk of data discontinuity and incomplete electronic (or paper) health records if the unique identifier is issued at a later point and not directly at birth.

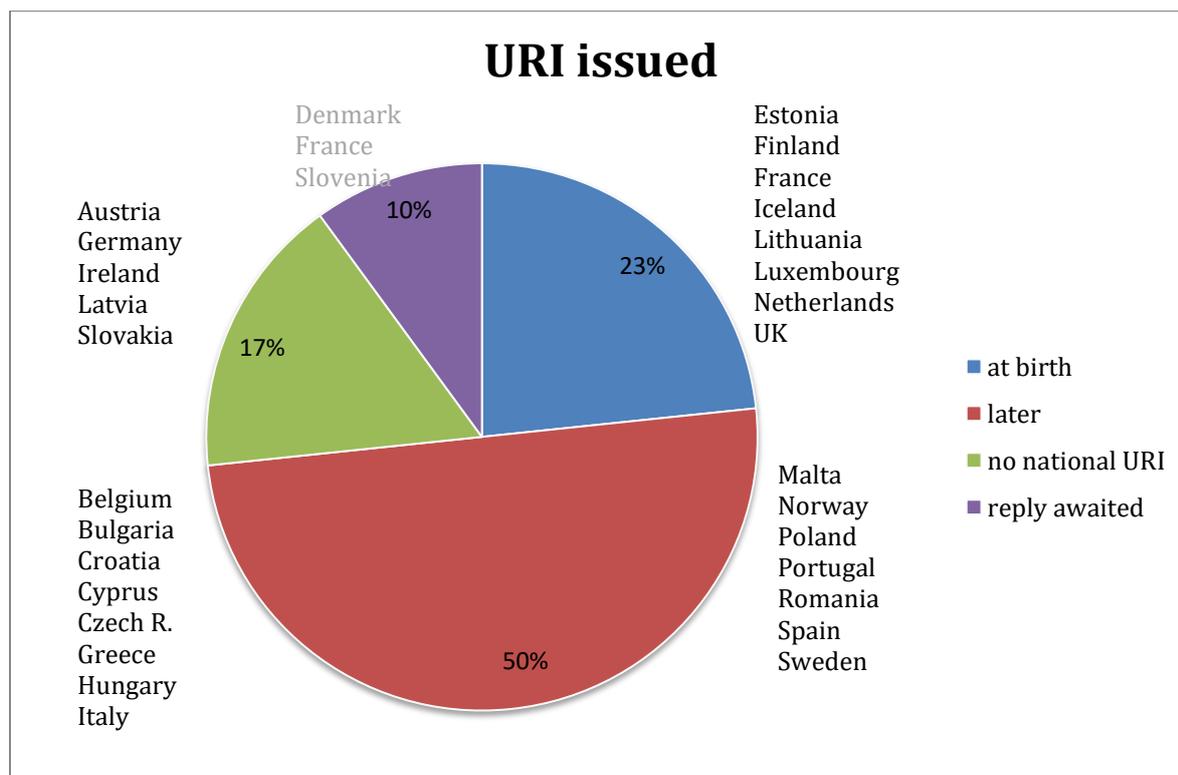


Figure 3: Overview on when the URI is issued

In this initial study it was not ascertained how, and how effectively, data about the delivery and the immediate postnatal period of the child are linked to ongoing health records in those 15 countries where the URI is not available from the beginning of the child’s life.

Who is the URI issued to?

None of the countries issues the identifier only to the health system, which means in all countries with a URI there is awareness, if not full involvement, of parents. Thirteen countries issue the URI to both health system and parents simultaneously, while ten countries issue it to the parents or child, giving them a key role in ensuring linkage. Whether this is a hindering or supportive factor as regards healthcare access or health record linkage if parents cannot or do not want to provide the URI has not been included in this study.

The assumption that the type of number would have an effect on who the identifier is issued to, holds true, in that for those countries where the URI is restricted to health, or health and welfare, linkage it is likely to be issued to both the health system and the parents simultaneously (6 out of 7 such countries). By contrast, where it is a national identifier or citizen number, only 6 out of 14 such countries issue it to the health system directly.

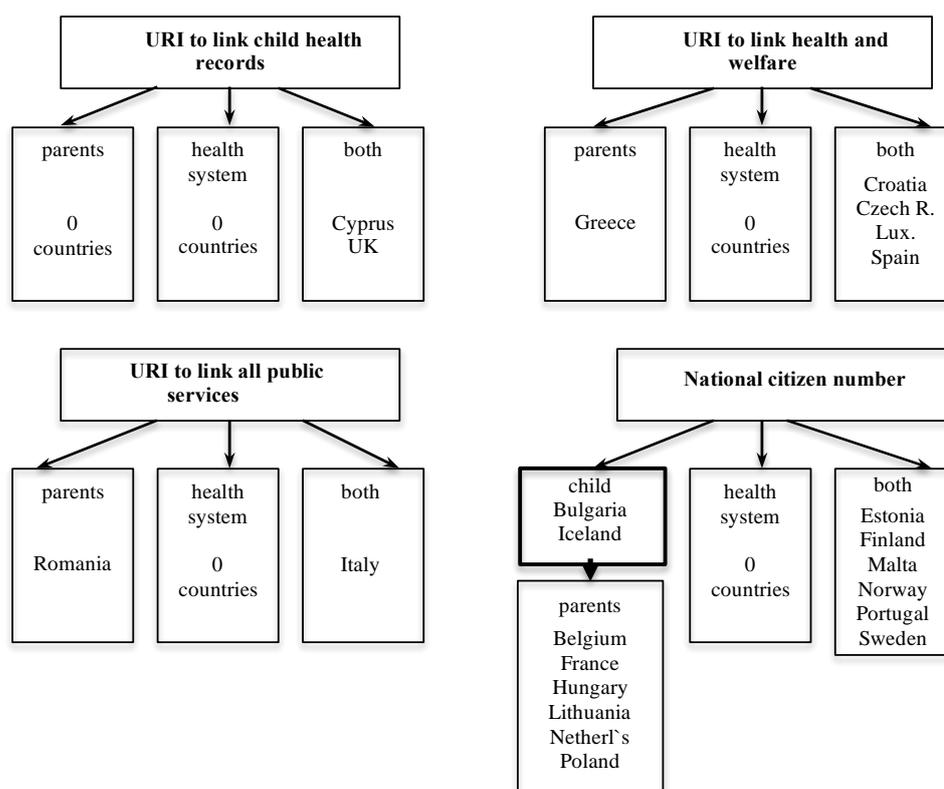


Figure 4: Overview on national issuing process and URI function

The Bulgarian and Icelandic policies are exceptional in this respect as the unique identifiers are issued to the new-born child directly. Although this at first sight seems unusual as a child will for their first years need adult representation, upon reflection it is a progressive statement that adults are agents for the child, not controllers of the child's health data. In most situations, parents will act as agents for the child. However, in special cases where parents are physically or mentally not able to fulfil their responsibilities, or the child moves with family restructuring, the Bulgarian and Icelandic systems hold the advantage that the child will be able to pass on the record identifier without seeking permission, or if an infant the appointed person covering parental responsibility will be able to ensure continuity.

The legal basis for URI and Identifier issue?

The national URI issuing processes differ as regards the actual procedure, as shown in Table 1. In 18 countries the URI is issued by civil process and in the remaining 10 countries it is by the health system or other process and details regarding the issuing process are awaited.

Table 1: Overview on URI issuing process

	URI issued by civil process	response awaited	currently no URI	countries considering URI
countries	Belgium	Denmark	Austria	Germany
	Bulgaria	Estonia	Slovakia	Ireland
	Croatia	Latvia		Lithuania
	Cyprus	The Netherlands		
	Czech R.	Slovenia		
	Finland	Sweden		
	France	UK		
	Greece			
	Hungary			
	Iceland			
	Italy			
	Luxembourg			
	Malta			
	Norway			
	Poland			
	Portugal			
	Romania			
	Spain			
total	18	7	2	3

What information is contained within URI number structure?

The amount of personal detail embedded within the URI itself varies significantly among countries. This exemplifies a dilemma between ensuring the highest accuracy in URI use and therefore accuracy of records, and data protection and privacy issues.

On the one hand the amount and detail of identifying data contained in the URI may potentially add to accuracy of data linkage. This is particularly so in cases where individuals share certain personal characteristics such as gender and family name in cases of father and son sharing the same name, where for example the year of birth can be the deciding data item facilitating identification and more precise health record linkage. Balanced against this, inclusion in the URI of personal information such as date of birth (thus identifying age) may be considered a breach of confidentiality when the child becomes an adult, and in data protection terms could be considered unnecessary for the purpose of identification of a record. Inclusion of gender may have record linkage accuracy benefits, but will be difficult and potentially discriminatory for persons with gender identification difficulties including gender reassignment. The extent to which this balance between underpinning accuracy and emphasising privacy is put into practice varies greatly among countries, as any inclusion of personal data will have to be balanced against the consideration of data protection and privacy concerns. This leads to great variety regarding whether the year, month or date of birth, location, place of birth or gender embedded within the number structure.

The year of birth is the information included in the majority of countries. Thirteen countries, i.e. Belgium, Bulgaria, the Czech Republic, Estonia, Finland, France, Iceland, Italy, Lithuania, Luxembourg, Poland, Romanian and Sweden also include the month and/ or the date of birth.

Only 5 countries, Croatia, Cyprus, Hungary, the Netherlands and the UK issue a totally anonymous number devoid of all readable data items.

Table 2: Information contained in URI

URI item contained	Number of responses
Year of birth	18
Month and date of birth	13
Gender	10
Location	4
Family linkage	2
First name and surname	1
Civil status	1

Bulgaria, France, Spain and Portugal include information on location of birth.

The Czech URI is a ten digit number that can be divided by eleven, thus providing a safeguard against mis-recording. The first two digits represent the last two digits of the year of birth and the following two digits the month of birth (in the case of females these two digits are increased by 50), the next two digits the day of birth. The birth number is issued by the Ministry of Interior.

In Malta, the last two digits of the identifier indicate the year of birth for persons born in Malta. The first four digits indicate the order of registration for that particular year.

Beside the date of birth, the identifiers in Bulgaria, the Czech Republic, Estonia, Finland, France, Italy, Lithuania, Poland, Romania and Sweden contain information on gender. In Bulgaria, France and Italy also the place of birth is included. The Italian identifier additionally contains the person's surname and first name.

The URI for each child in Romania also contains the civil status, whether the child is a citizen, an immigrant or a foreigner, the gender of the child (coded odd for male and even for female). The last number is a result of a procedure based on the computation of all the previous numbers.

Not issuing at birth puts the risk of data discontinuity. Some countries are aware of this and have an interim solution. In Hungary for example, newborns up to 6-8 weeks, the time they usually get this number, have their mother's social security number, with the first number changed to 8. This results, however, in doubling efforts of URI issuing processes as after that time the child will need his or her own URI.

In Slovakia, the child is registered 8 to 15 days after birth under the name and number of the mother. Upon presentation of the birth certificate at the council administration department by the parents, the unique child Birth Number is issued. It is an identifier containing the day, month, year of birth. The last four letters assign for the region of birth. If a child is a girl 50 is added to the month digit to differentiate between genders. The Birth Number is used by health and social insurances as an identifier but it does not link any health or social information except permanent address and status (e. g. child, single, married).

In Croatia, currently at child delivery, the child is linked to the mother's health insurance number. This will change as the Croatian E-newborn project becomes widely adopted, when the

child will be issued a health insurance number at delivery, which will then be used for hospital records independently of the mother. The project is currently in its pilot phase with almost half of hospitals with maternity wards involved.

Portugal and Spain include family linkage in the child's URI, all other countries do not. In Norway, the central registration system at the "Folkeregisteret", the central Norwegian agency for information on identification of individuals, links the child's URI to the mother's and father's identifiers. This has, however, no clinical relevance as information on family medical history and possible effects on the child's health can not be readily accessed at the point of care.

In Finland, it is possible to change the identifier. This can happen in few cases, when the date of birth has been coded incorrectly (for older generations or for recent migrants), if the gender is legally changed for inter- or transgendered persons, or the identifier has been used in fraud. All these require a legal process. The Central Population Register keeps the link between the old and the new URI, which is released to public services if needed but not to other parties.

Challenges of Health Record Linkage

Challenges for the linkage of health records may arise from various sources. Besides technical, legal or political issues, the characteristics of special child population groups may result in particular health care needs and thus also in special requirements regarding data linkage.

In Norway, the current paper based URI issuing process takes up to four weeks. During that time between birth and until the identifier is available, the hospitals issue their own unique identifiers. The problem arises when very sick children are moved between hospitals for treatment and each hospital issues their unique identifier for the newborn. Hence, there is an ongoing process to improve the situation. As of December 1st, 2015, a pilot project was started, which includes that a batch of reports on newly born babies are sent electronically to the central registration authority, the "Folkeregisteret" twice per day. The "Folkeregisteret" can then submit the identifier to the hospitals and the parents. This is expected to be the future system of registration of newborns in Norway.

Besides old-fashioned paper-based systems, another challenge may be the institutional structure within countries. There may be a single national institution that holds the data linkage monopoly and thus the responsibility for data protection, as in Hungary where the social security number is universally used on all levels of healthcare, including paediatrics. The vast majority of primary care settings, hospitals and specialists' offices with EHR software can easily search for patient data, sometimes also the social security number is applied for that purpose. However, currently only the National Health Insurance has the possibility to look at all levels of healthcare delivered - i.e. there is almost no interface for primary care physicians to follow their patients digitally (some labs provide this service for extra charges).

A similar situation appears in Romania, where each hospital or primary care provider uses the URI upon the provision of healthcare services. The National Insurance System then uses this number to sum up all services. The individual service provider, however, cannot gain access to services of other providers, thus the National Insurance System is in the full picture but individual providers are not.

Both the Romanian and the Hungarian systems lead to clinically irrelevant linkage of health data. The institutions that are in a position to link health records are not involved in actual health care and do not feed back relevant data. Consequently, vital information is locked into different silos endangering effectiveness of primary care provision to newborn babies. The situation in Hungary and Romania are examples for where countries are struggling with record linkage.

A remarkable step forward is taken in Croatia in this regard. Within the frame of a pilot project, the health insurance and public administration are brought together to test the issuing of the number electronically at birth. To care for effectiveness this is even supported by a change in law and will be evaluated before roll out nationally.

The Use of multiple identifiers

The majority of countries use URI as primary identifiers when searching for patient data across providers. Iceland is among the countries that use the same URI for all services, be it public or private healthcare or day-care services. In eleven countries unique identifiers are applied for hospital record linkage and in 5, the Czech Republic, Estonia, Italy, the Netherlands and Sweden, URI are used as primary identifiers by primary care providers (see attached excel file).

Table 3: URI as primary identifiers

URI	Number of responses
as primary identifier	20
as primary identifier in hospitals only	11
as primary identifier in primary care only	5

Fourteen countries exclusively use URI as the primary identifier and nine countries mentioned they use other identifiers beside the URI as the primary identifier in hospitals and primary care settings.

Table 4: URI used exclusively

	URI used exclusively	URI used beside other individual identifiers	response awaited	currently no URI	countries considering URI
countries	Belgium Bulgaria Croatia Cyprus Estonia Finland Iceland Lithuania Luxembourg Malta Poland Romania Spain Sweden	Czech R. France Greece Hungary Italy Netherlands Norway Portugal UK	Denmark Slovenia	Austria Slovakia	Germany Ireland Latvia
total	14	9	2	2	3

The establishment of primary identifiers may be desired as in the UK, where increasingly there is an expectation on all healthcare providers to use the National Health Service number even if additional organisation specific identification systems are used.

The URI is fast becoming the primary identifier in Greece. However, each insured person also has a registry number from their insurance agency which in this case depends on the parent's employment. Although Greek hospitals still register patients with an internal patient record number, the unique national social security number called AMKA is currently the only number used for electronic prescriptions and referrals for any testing or procedures.

In Bulgaria, the assigned identifier is used also in primary health care. Moreover, it allows that upon hospitalisation each hospital can check the patient's insurance status. For children up to 18 years of age the state covers the health insurance disregarding the status of their parents. This means that the identifier is just used to confirm that at the time of potential hospitalisation they are under 18 years of age.

Health Record Linkage – A perspective from the public and private sector of health care

The structure of national health care systems may have an influence on the application of URI for the linkage of child health records. National health care systems differ largely among European countries (see Overview on national health care systems in appendix 2, p. 61), with national health models financed through general tax revenues in Denmark, Ireland and the United Kingdom on the one end of the continuum and employment-tax based models in Austria, Belgium, France, Germany, Luxembourg and the Netherlands on the other. In contrast to those publicly funded models, there are private health insurance models, which are characterised by employer-based or individual purchase of health services.

In most countries private health insurance exists to offer additional coverage either for persons not included in public health insurance or for additional services excluded from public health insurance (1-4). Only in France and Slovenia did private insurance exceeded 10% of health expenditures in 2012. In the other European countries, private insurances generally represented a small share of all healthcare expenditure(3).

The deciding factor on whether a unique identifier will be applied in child primary care in Croatia is whether a health service was provided by the public or private sector of health care. The Croatian health insurance number is used as the primary record identifier. Currently at child delivery, the child is linked to the mother's health insurance number. This will change as the E-newborn project becomes widely adopted, when the child will be issued a health insurance number at delivery, which will then be used for hospital records independently of the mother. Private hospitals (there currently is only one private maternity ward) may be an exception, as their expenses are not covered by the Croatian health insurance fund and thus do not need to register children using the health insurance number as the identifier. There are no barriers to personal identification and the purposeful linkage of health records in private health care.

In Cyprus, the URI is used as the primary record identifier only in public hospitals. The public and the private sector do not interlink. In Malta, however, the public and the private healthcare sectors do use the same URI. However, there is no single electronic health system for both sectors but a patient interface called MyHealth where certain data from the public health services are available. Parents may opt to authorise the doctor of their choice to gain access to

their children’s health records from birth onwards. Interestingly, does the current system not permit parents or guardians to access their children’s electronic health data online through My Health. The reason ist hat there is presently no online database that provides readily available verification of the identity of adults and guardians of a child. Children above the age of fourteen can apply for an electronic identity and access their own health records through the MyHealth system.

Linking health records of migrant children

The URI issuing process for migrant children is a special case in this regard - equally important but arguably more challenging. As they are not necessarily born in the country of residence but migrate in at a later stage, they are particularly vulnerable to data fragmentation. There is a risk that national health care organisation models do not adequately picture their health status and needs due to various political, cultural and language barriers. In Estonia, the URI issuing process for migrant children is linked to the issuing process of the residence permission. How URI for migrant children are issued in other countries was not focused in this study and needs more investigation.

National Plans and Debates on URI in Countries that currently do not link Child Health Records

Despite the fact that Austria, Germany, Ireland, Latvia and Slovakia currently do not link child health records, there is awareness of the benefits of the implementation of URI to a varying degree. National strategies and approaches differ but there are ongoing processes. Most initiatives focus patients and do not differentiate age groups.

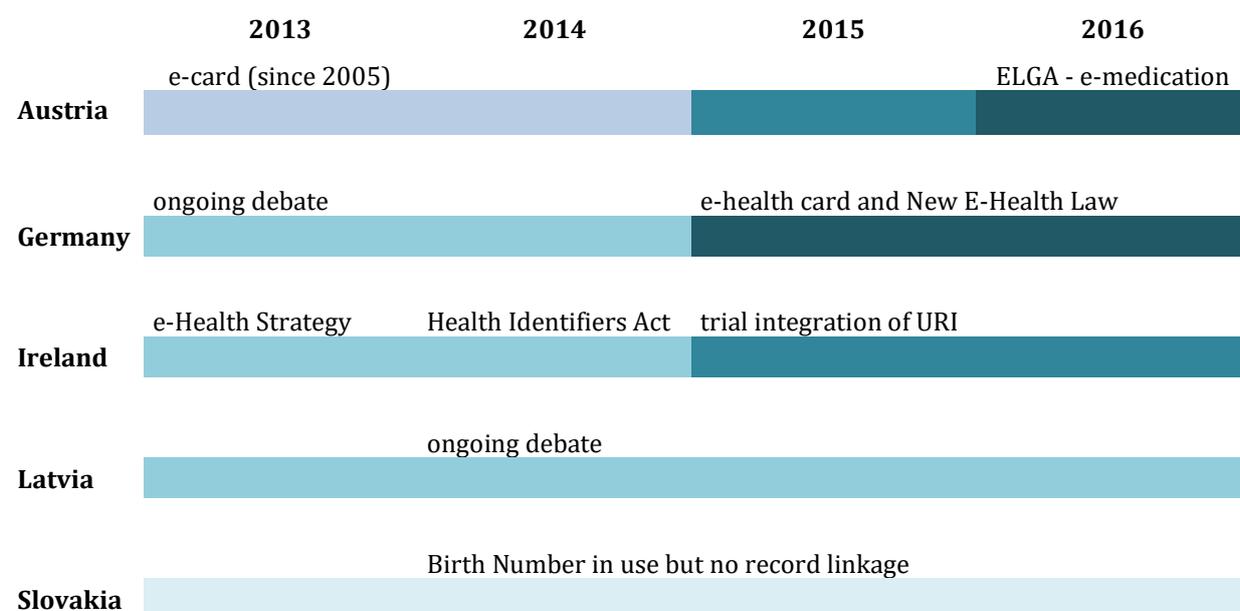


Figure 5: Overview on national plans and debates on URI in currently non-linking countries

Austria

The e-card was introduced nationwide at the end of 2005. It contains primarily relevant administrative data and health insurance data. The e-card is the basis for the so-called Electronic Health Record (Elektronische Gesundheitsakte, ELGA), which was introduced by the Austrian Ministry of Health, to allow access to all health and medication related patient data with the aim to improve transfer of health data and consequently health care. The patient is empowered to decide which detail is available to whom. Since 2014 citizens have been empowered to decide whether they wanted to join ELGA and the detail available to the individual health professional. A pilot phase started in 2015 and in 2016 the ELGA e-medication started in defined areas in Austria. It remains unclear whether parents act as advocates for their children and if so up to what age.

Germany

Data protection concerns have been a major obstacle to the linkage of child health records in Germany. Children are insured through their parents. Regarding record linkage two milestones have been achieved in recent years. With the introduction of the electronic health card in 2015, a first step has been taken to provide relevant administrative patient data, such as name, date of birth and address as well as information about the health insurance to the treating health professional for statutorily insured patients. For persons aged 15 and older a photo is included on the card to avoid fraud. The New E-Health Law is gradually implemented between 2016 and 2018 to provide for safe exchange of patient data. Data security concerns have been taken into account in as far as decoding patient data will only be possible with the patient's health card and the Health Profession Card of the treating professional. Patients decide, which medical data may be stored on their electronic health card and who is allowed to access these data. Additionally the patient will have to enter a code to grant access to health related data. Emergency data, such as information on allergies and relevant pre-existing conditions will be accessible without the code.

Ireland

Currently there are plans to introduce a URI for the population of Ireland. The Health Service Executive (HSE) is the body responsible for the provision of publicly funded health and social services for the population of Ireland. In 2013, the HSE launched an eHealth Strategy for Ireland, a key component of which is the Health Identifiers (HIDs) Programme. This programme will involve the assignment of a URI to individual service users of Health and Social Care Services in Ireland, the development of a single national register of URI, and a technical infrastructure to support the register, as well as the development of registers for Health Service Provider Identifiers (Practitioners and Organisations).

In July 2014, the Irish Health Identifiers Act was enacted to provide the legislative framework for the HIDs Programme. The URI Dataset (but not the identifier itself) will not contain any health specific information but will include personal details such as name, date and place of birth, sex, addresss and nationality.

Two other drivers which are contributing to the debate on the unique identifiers in children's healthcare in Ireland are:

a) The planned build of a new National Children's Hospital (due to open in 2020) which will combine the three existing children's hospitals in the state into one service, and which is being designed as a digital hospital.

b) Model of Care for Paediatrics and Neonatology which will see the development of a hub and spoke model of care with patients moving between the new hospital and the regional services.

In 2016, a public consultation on Privacy Impact Assessment for the URI was conducted in Ireland. The resulting report proposes that parental requests on behalf of children are made jointly or require proof of legal guardianship.

Latvia

For Latvia current national debates on e-health are reported. Medical records are based on a personal code, which is crucial for data linkage. Challenges are, however, bound to the legislative framework for data collection and data linkage that has resulted in differing database structures and each institution using their individual URI. Individual health care providers follow their own data-processing requirements and safety conditions and use their own URI, which has added to the multitude of available data formats.

Slovakia

Slovakia is struggling with responsibilities, resources and the right approach to tackle the challenges of e-health record linkage. Stakeholders have signalled openness for discussion, which may bring forward the issue and will possibly start national debates.

Conclusion

Based on a variety of historic and traditional factors, and the lack of a common vision or standard, there continues to be significant variation in achieving the essential quality enablement of good child health delivery through linkage of early health records.

Some broad patterns emerge:

- 23 countries out of 28 reporting have a public service identifier or a national citizen number used for this purpose; these include the Nordic countries, 2 of the Baltic States, and Italy, Portugal and Romania.
- 5 countries have a specific identifier to link health and welfare records, and 2 (including the UK) a similar identifier restricted only to health records.
- 5 countries – Austria, Germany, Slovakia, Latvia and Ireland have no health record identifier, but of these Austria, Germany and Ireland have specific implementation plans that are either theoretically prepared or in the process of implementation. Latvia is currently debating the issue, leaving only Slovakia with no current practical intentions.
- In 8 of the countries the number is given to the parents, in 2 it is given to the child, while in 13 it is issued concurrently to the health system and the parents; no country fails to give it to the parents or child at all.
- In only 8 of the 23 countries with an identifier is it issued at the time of birth
- 3 countries out of 28 reporting differentiated between the application of URI regarding public and private health insurance; these include Croatia, Cyprus and Malta.

The focus has been on children born in that country because this is a particular issue and affects the great majority of children. We have not at this point considered children moving into a country, including asylum seekers and refugees but also children moving for planned family or economic reasons. While continuity of health is important for all children, the transfer of prime records and the linkage within the new country of residence is therefore not addressed in this report.

The safety and efficiency of child primary care, as well as convenience for parents, are at stake, balanced by the need for confidentiality and consumer choice. While five countries still do not have a unique identifier to enable safe linkage of children's health records, only two countries appear prepared to perpetuate impeded record linkage among health professionals which in turn may affect the ability to provide safe and timely health care to the child. With regards to non linkage between private and public services as well as health and non health providers, there is a real risk that parents can move between sectors and potential child safeguarding issues can be successfully "hidden" from child health professionals.

Fourteen countries have been identified as issuing the unique identifier for record linkage a while after the birth. Follow-up study is needed as to whether there are effective means in these countries of ensuring rapid linkage ahead of the number issue for children requiring immediate treatment, or retrospectively upon issuing of the number.

Part 2: The situation with regard to children's needs as identified in national e-Health strategies

Introduction

In May 2012, the Estonian President Toomas Hendrik Ilves, Chair of the independent high-level European Commission's e-Health Task Force said: *We know that in healthcare we lag at least 10 years behind virtually every other area in the implementation of IT solutions. We know from a wide range of other services that information technology applications can radically revolutionise and improve the way we do things*" (5).

The e-Health Task Force identified 5 levers for change to adapt to current challenges of healthcare in Europe. It stressed that the principle that individuals are owners and controllers of their own health data, with the right to make decisions over access to the data and to be informed about how it will be used. This principle has also been laid out in EU law and European jurisprudence. In national health systems, however, it is rarely fully implemented (5). The core issue for the Models of Child Health Appraised (MOCHA) study is to ascertain how this principle can be put into practice for children and adolescents.

The National e-Health and Information Principal Committee has described e-health as a means to ensure "the right health information is provided to the right person at the right place and time in a secure, electronic form for the purpose of optimising the quality and efficiency of health care delivery"(6). The WHO definition on e-health adds to this that in its broadest sense e-health aims to improve the information flow by electronic means to support the delivery of health care and the management of the health system (7).

In child health the issues are even more important for a number of reasons. Infants and young children cannot speak for themselves, give their own history, or supply past health information, so an up-to-date health record is vital. This is even more essential where parents may not know the full details (such as clinical factors at birth), are themselves stressed or confused, or in those cases where for whatever reason the parents neglect their child's best interests. In these cases, as Rigby has previously indicated, the record acts as the child's advocate (8). Electronic health records give a modern effective way of ensuring that the accurate, timely data is available at the point of clinical contact, or when ensuring that all preventive services (including immunisation) have reached a child. However, not only is the pattern of implementation of e-health very varied across Europe, in many cases systems are designed and implemented to a generic model based on adults' needs, without awareness of the particular issues of child e-health records – ranging from the need to link records even before the child has a formal name or civil citizen status, through to the child-specific data items which are important to record such as accurate preventive care (screening and immunisation), growth and developmental status.

The need for a national strategy

E-health is a complex field, which at the same time should be harmonised and compatible between installations and applications. A strategy to direct multi-agent investment is necessary to ensure orderly and efficient progress, focussed on clear health benefit objectives. In order to ascertain the currency of national policies, the WHO holds for each country a depository on e-health policies and claims that this be a collection of current national e-health strategies. This repository stood as at 2010 until June 2016, when many of the entries were updated (9). The attached schedule shows what the WHO holds for the individual countries including the link to the policy document attributed to each country (Table 9, p. 54). This report provides a locally informed overview whether these policies are up-to-date and whether children have been considered in the national e-health strategies.

In 2012 the WHO and the International Telecommunications Union (ITU) published a national e-Health Strategy Toolkit to offer support to those countries developing an e-health vision and strategy as well as for those where there is a necessity to revitalise available strategies (10). According to WHO and ITU, national strategies should be based on national health priorities, available and potential resources, and a current e-health environment, which in theory is justified. In practice, however, a considerable number of countries are struggling with meeting these requirements.

This study will provide an insight to what extent European countries have defined the health needs of children and adolescents as a priority in their national strategies and to what extent modern ICT solutions have been considered as possible means for the implementation of these strategic goals.

Methods

In February 2016, in order to see how well children and child e-health were supported in national policies, the MOCHA project carried out an analysis of available national e-health strategies as contained in the WHO depository (<http://www.who.int/goe/policies/countries/en/>, (access dates 8 and 9/02/16). At the time 6 out of 30 national e-health strategies were readily available in English with a working link, for 16 countries the documents were available in the countries' own languages only and for eight countries the document was not accessible at all either because a false link was provided or the document was not available at the link provided (see Table 9, p. 54).

To investigate whether children and e-health are considered in national e-health strategies, data were gathered between 21 March and 29 April 2016 through the MOCHA country agent network, thus ensuring local analysis in national languages. The questionnaire was designed as a semi structured survey instrument and asked whether the e-health strategy available in the WHO depository was the only current document for each country, and whether it was the only one (Appendix 1, p. 43). MOCHA country agents were provided the WHO link for their country's e-health strategy as in the WHO depository. They were asked to list any other relevant e-health document and summarise the content of each document regarding e-health and children.

Summary of findings on national e-Health strategies

Replies were initially received from 24 countries. Ten out of 24 countries replied that the e-health strategy contained in the WHO depository (as of April 2016) was the latest. Sixteen said that beside the documents contained in the WHO depository there were other national

strategies. Only ten countries, i. e. Cyprus, Germany, Hungary, Ireland, Latvia, Lithuania, Norway, Poland, Portugal and Spain, mentioned that their countries' e-health strategy contained considerations on children and adolescents. Fourteen countries replied that their national e-health strategy did not consider children and adolescents. Data for 6 countries are still outstanding. Details are given below.

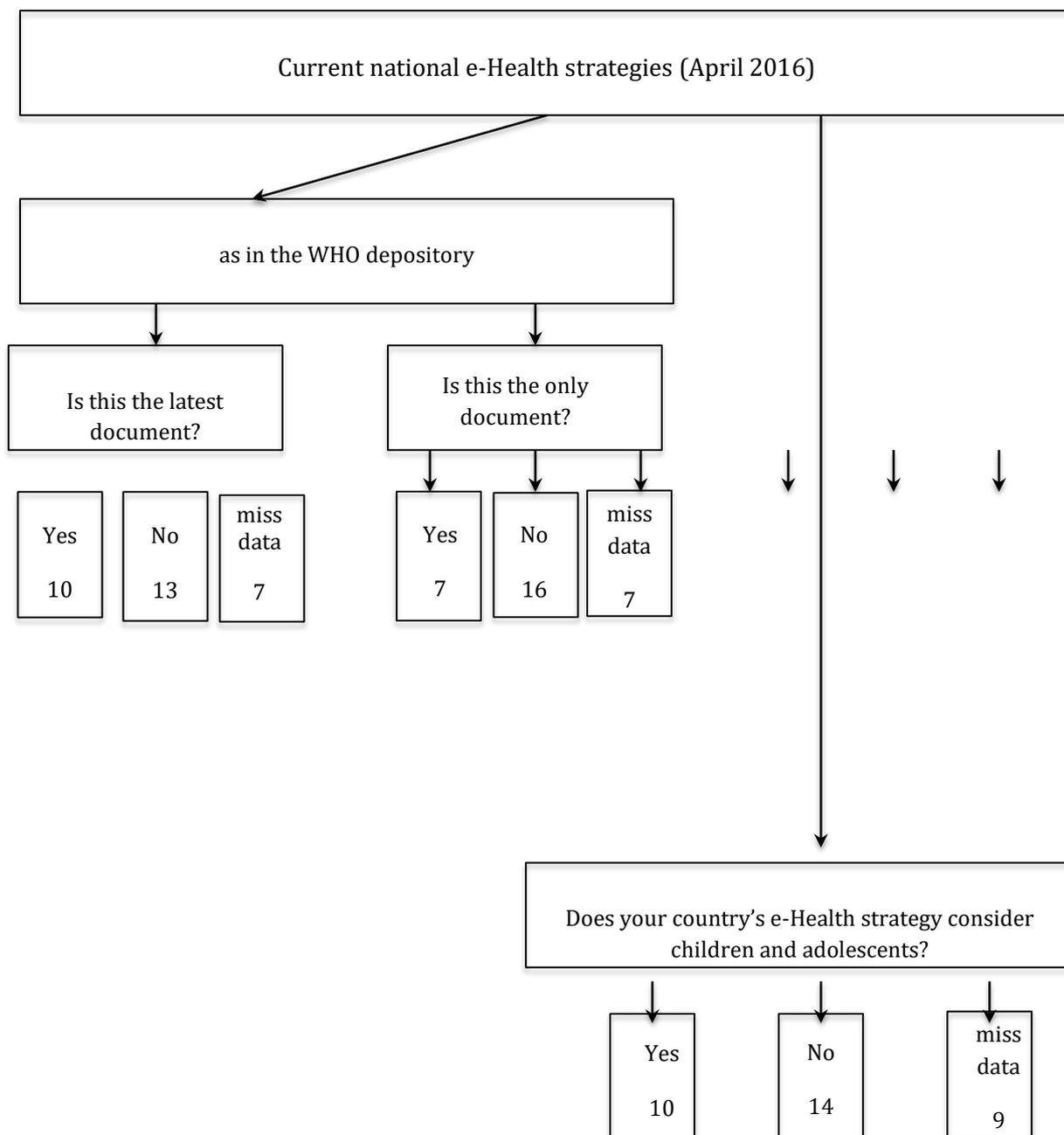


Figure 6: Overview national e-health strategies

Table 5: Overview on document currency and context (April 2016)¹

* WHO update since June 2016

Is the WHO document the latest?		Is the WHO document the only document?	
Yes	No	Yes	No
Cyprus* Finland* Hungary Italy Latvia Lithuania Portugal* Slovakia Spain* Sweden	Austria* Belgium* Croatia Czech Republic* Estonia Germany Greece* Iceland* Ireland* Malta Norway Poland* Romania	Finland* Hungary Italy Latvia Romania Slovakia Sweden	Austria* Belgium* Croatia Cyprus* Czech Republic* Estonia Germany Greece* Iceland* Ireland* Lithuania Malta Norway Poland* Portugal* Spain*
10	13	7	16

¹ Independent of the analysis in this report, the WHO has updated the depository on national e-health strategies since June 2016. Because field work had been completed in May 2016, it has not yet been possible to update. Table 9 (p. 54) contains indications which national e-health strategies have been updated in the WHO depository since June 2016. Further analysis will be carried out for the next edition of this report.

Children and Adolescents in Current e-Health Strategies in Europe

Only ten of 24 countries mention children and adolescents in their national e-health strategy documents, ranging from mere reflections of data protection concerns to comprehensive approaches covering a broad variety of potential areas for the improvement of child primary care through information and communication technology. Whether this is due to insufficient prioritisation of child healthcare, a lack of appreciation of ICT solutions in the healthcare context or a lack of resources to sufficiently address challenges bound to a possible implementation can not be answered at this stage. It is, however, astonishing how little strategic thought is currently spent on the potential of ICT approaches to make child health care safe and efficient. Current strategic considerations predominantly focus on single niches of child healthcare and are bound to a local or regional context. Clear descriptions of current child health needs, definitions of goals for improvement in child health care, stakeholders to be involved and aligned ICT measures as means of improvement are largely missing.

Figure 2 provides an overview on countries considering children and adolescents in national e-health strategies and those that do not independent from the actual implementation status of the strategies. This is based on the content analysis of national strategy documents and the MOCHA country agents evaluation on whether children and adolescents were considered in theory. In cases where national e-health strategies do not refer to the needs and vulnerability of children and adolescents, this has been considered as such as this is seen as a necessary prerequisite to make child and adolescent health care safe and efficient.

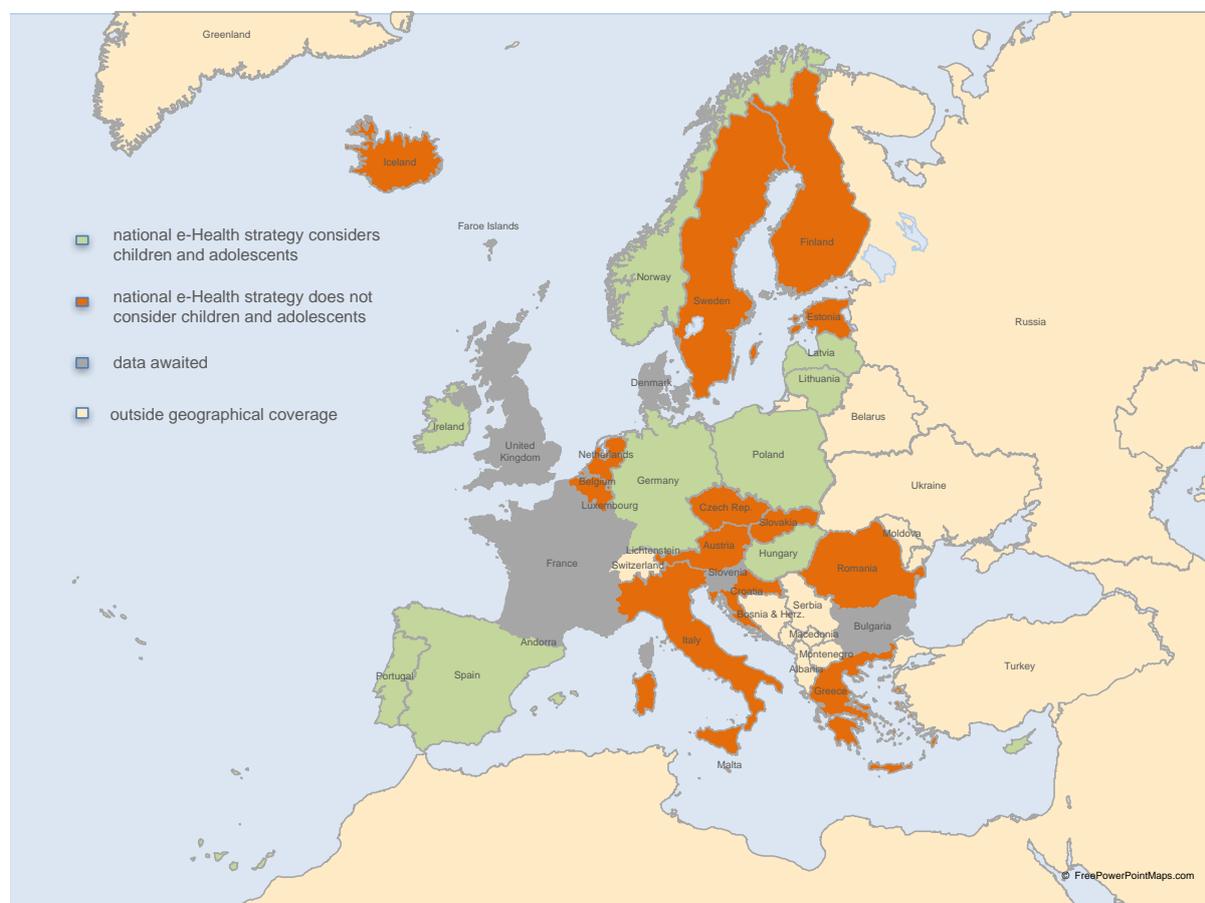


Figure 7: Overview on consideration of children and adolescents in national e-Health strategies in Europe

The WHO and ITU developed a context framework that allows grouping national e-health actions as to whether they are early adoptions of e-health, developing and building up or scale up and mainstreaming of e-health approaches (10).

Findings from the MOCHA country agent survey on the consideration of children and adolescents in national e-health strategies have been grouped into the strategy context grid for national e-health strategies as proposed by the WHO and ITU.

The majority of initiatives either mark early adoption or experimentation with e-health solutions. Some have evolved to a stage where more comprehensive e-solutions to child health care are taken. None of the strategies reported pictures an e-health mainstreaming approach at national level.

Table 6: Context for national e-health strategies

Context	Country	Example Focus	Example Actions
I. Experimentation and early adoption	Hungary	Improve vaccination coverage	Intention to set up cloud based vaccination registry
	Latvia	Establish core service	“My newborn children data”
	Lithuania	Make the case for e-health	Definition of strategic e-health goal - improvement of maternal and child health
	Norway	Establish legal foundations for e-health in child health care	2012 Personal Data Act
	Poland	Make the case for e-health	Medical training courses for children and adolescents in schools
	Portugal	Strengthen exchange of health data among network hospitals in the oporto region	Oporto project
II. Developing and building up	Cyprus	Strengthen and link core systems	Regional Health Network
	Germany	Establish a core digital service	Introduction of the electronic health card
	Ireland	Establish a core digital service	Maternal & Newborn Clinical Management System
	Spain	Strengthen and link core system	Annual evaluation of pediatric primary care services
III. Scale up and	none of the reporting countries		

mainstreaming

Individual national approaches differ as to where countries set strategic priorities on children and e-health. Cyprus, Germany, Hungary, Iceland, Ireland, Latvia, Lithuania, Norway, Poland, Portugal and Spain consider ICT solutions in their national strategy documents in relation to child health care.

Children and Adolescents in national e-Health strategies

Cyprus

Existing strategies include pediatric patients and pediatric wards in all provinces in Cyprus. The Ministry of Health defined the creation of Regional Health Networks (RHN) to exchange information in real time between all hospitals, Health Centers, regional clinics and private doctors. The RHN will enable healthcare providers to have access to the right information, any time necessary for better and higher quality medical care.

Germany

The two recent government initiatives, the new e-health law and the e-health initiative for the facilitation of telemedicine applications in Germany, focus on data protection and the establishment of a safe digital infrastructure. The recently adapted law for safe digital communication and applications in health care (E-Health Law, adapted in 2015) contains a timetable for the introduction of a digital infrastructure that meets highest security standards and the introduction of useful applications on the electronic health card. Upon agreement of the insured encrypted sensitive medical data may be saved on the card beginning 2018. This is planned for emergency data (e.g. allergies or previous illnesses), electronic medication plans, electronic doctors' letters and patient files (to submit data by patients themselves, e.g. data of wearables or physical activity trackers, patient diary including blood glucose measurement). Children are issued an electronic health card. This card does not have to display the photo of the insured child if he/ she is younger than 15 years. Apart from that children's needs are not given any deeper thought.

Hungary

In the only official strategy document available for Hungary, which was released in 2004, the then ruling Hungarian government had the intention to set up a cloud-based vaccination registry, which would provide epidemiological data on mandatory and/ or voluntary vaccination coverage of children. In cases of skin injury, it was planned to deliver data on the last anti-tetanus shot. The registry would send reminders to parents and primary caretakers when a vaccination was due. This strategy remained a draft and did not reach the implementation stage. Since 2004, Hungary has not taken any new efforts on e-health and children. The document as in the WHO directory is the most current but out-of-date.

Ireland

Ireland is among the countries following a comprehensive approach in their e-health strategy. The most recent document is the Knowledge and Information Strategy of 2015, which builds on the e-Health Strategy for Ireland listed in the WHO inventory. In the former children and adolescents were not considered, in the latter, however, child and adolescent health has been

considered in far more detail as the national e-Health programme set up with ten priority areas, nine of which either directly or indirectly relevant for children and adolescents (11).

The core planned activity was the opening of the new National Children's Hospital, which was to combine three paediatric hospitals with the goal to be the first digital hospital in the country. The opening of the National Children's Hospital is now six years overdue and still at the planning stage, delayed due to a series of political, practical and planning issues.

The implementation of electronic health records has been identified as a cornerstone of Ireland's e-Health strategy. The aim is the aggregation of patient data into one national record with access rights for health and social care professionals as well as patients, carers and care users. The project on the implementation of electronic health records commenced in 2016 at four maternity hospitals with the goal to involve the remaining 15 hospitals thereafter in a phased approach.

The Irish strategy also set out the establishment of a Maternal and Newborn Clinical Management System, which is intended to be an electronic health record for all women and babies in maternity services in Ireland as to provide relevant health data at the point of care.

The Health Service Executive (HSE), which is the agency responsible for the provision of publicly funded health and social care in Ireland, has engaged extensively with e-health industry vendors to gain insight into the capabilities of electronic health record solutions internationally. This led to the development of an eHealth Blueprint which maps the current structures in Ireland onto the core components of an electronic health record (<http://www.ehealthireland.ie/Library/Image-Library/EHR%20Architecture.png>). Arising from this work, a business case for a national electronic health record was developed and is currently awaiting approval from the Department of Health. The programme recognises that to ensure patients receive seamless care, it is essential to enable the integration and accessibility of patient data across the continuum of care within all sectors of the health service.

Latvia

Latvia has four e-services in place, one directly relevant for child health (authenticated with ibank, electronic signature). An e-service on new-born health data is offered, which allows parents to access their children's health records.

Lithuania

The country defined the improvement of maternal and child health care as an explicit goal within the Lithuanian e-health system development programme 2015 – 2025. The document names clear responsibilities and credits the Lithuanian Ministry of Health in charge of the electronic health system. Potential funds are named and precise numbers of initiatives are stipulated – none implemented so far. Peculiarities in child and adolescent health care are neglected and children and adolescents are treated the same as adults in the national strategy documents.

Norway

The Norwegian Directorate of e-Health (NDE) was established on January 1st, 2016, and is a sub-ordinate institution of our Ministry of Health and Care Services. The Norwegian Directorate of e-Health will implement the national policy on e-Health, establish the requisite standards, and administrate the use of e-Health methodology nation-wide. So far there is only one strategic

document that considers children and adolescents, i. e. the report of the Privacy Commission. It pinpoints that special legislation is needed to protect children against unsolicited publication of personal data on the internet. The Personal Data Act was revised in 2012 to amongst other strengthen children's rights in this area. This act is currently implemented and a new e-health strategy is currently developed.

Poland

In Poland, what first appears as limiting the valuable and various ICT solutions for health care, turns out to be an innovative approach to health promotion in the school setting implemented in a national strategy document. Health Promotion in Schools is a well established concept. Poland adds the e-health component to it as the Polish strategy document (as in the WHO directory) postulates the implementation of medical training courses for children and adolescents. It aims to communicate and promote basic health issues as a novel approach to health promotion. As part of the online medical training will be possible to propagate the action "Health Promoting School" (aimed at mobilizing schools to prepare and implement programs that promote healthy lifestyles). Health promoting schools apart from the intellectual knowledge should also develop habits of taking care of the children's physical condition and health by facilitating access to information, including the Internet. The best solutions should be promoted in the central portal of health.

Portugal

Portugal seems to be concerned with data protection issues. Strategy documents deal with the question of how to handle data of minors. With the Oporto pediatric urgency service a regional initiative has been put into practice to provide for the exchange of most relevant clinical and administrative data among the hospitals in the network. The data gathered are also available for multi-centre clinical research studies. The efforts are, however, at the moment limited to acutely ill children and adolescents in the Oporto region. No information is available as to whether this project is envisioned to be developed into a more comprehensive approach to also cover long term conditions, vaccination information, e- referrals, further care services or whether it is planned to also be transferred to other regions or expanded nationally.

Spain

The Spanish National Quality Plan has resulted in a number of actions and programmes in pediatric care services. Child and adolescent primary care services are annually and electronically evaluated both in terms of services coverage and quality. The unique electronic medical record is transferrable between all care levels and serves as the basis for the evaluations. Data protection of children and adolescents is practically implemented in that the electronic health card for children and adolescents contains sparse details such as the name and social security number.

Missing consideration of Children and Adolescents in national e-Health Strategies

Belgium and Italy state that their national strategy documents do not consider children and adolescents. The same is true for the countries and national strategies briefly outlined below. It is remarkable that despite the fact that national strategic goals are of clear relevance to child and adolescent health care, the needs of children and adolescents are omitted.

Austria

The Austrian health care system facilitates access to health data via the Electronic Health Record (ELGA). The system will be open and available to all insured patients as well as health care providers on a voluntary basis. Beginning 2016, the ELGA function “e-findings” (medical findings) will be gradually implemented in its roll-out version. With ELGA the right of the patients is effectively guaranteed to decide which of their health data will be provided to which health care facility or health service provider. Patients have to contradict a full or partial participation in ELGA, if they wish so.

Exceptions are only allowed with respect to medication data or where externally created health data is made available and accessible via ELGA, which will be adopted into the own patient-related documentation (medical history). For this system of making available decentralized present health data an own information security management system will be implemented (12).

Children and adolescents are not explicitly mentioned.

Croatia

Although Croatian strategy documents deal with child health and e-health, strategies handle both topics separately, denying the potential e-health measures would have to make child health care safe and more effective.

Czech Republic

In the strategy documents of the Czech Republic children and adolescents are not mentioned. The overview document 2020 Health Action Plan no 11: Computerization of health from 2015 mentions the “Association of general practitioners for children and adolescents” as involved stakeholders. Although the association also occurs as one of the bodies that created the strategy, no child or adolescent specific contents is visible in the document.

Greece

In 2015, the Greek Ministry of Health announced the constitution/formation of the “National e-Health Board”. During the “e-Health Forum 2015”, the General Secretary of Public Health provided information about this new e-health policy, which is currently being implemented. The e-health policy names responsibilities of government bodies at national and European level. Relevant initiatives are currently planned for the whole population including children – specialized services for children are not mentioned.

Estonia

The Estonian e-Health Strategic Development 2020 Plan is currently in the implementation phase (until 2020). The strategy is based on the assumption that the creation of e-Health is a prerequisite for the achievement of the substantial health goals, the health of children and adolescents is, however, not considered.

Finland

The Finish strategy is thoroughly laid out. The main objective is to support the renewal of the social welfare and health care sector and the active role of citizens in maintaining their own well-being by improving information management and increasing the provision of online services. Means to achieve these goals are carefully defined. It is noteworthy that children and adolescent are not mentioned in the strategy.

Iceland

The National e-Health Strategy 2016-2020 is an over-all policy regarding the development of electronic health records in Iceland. This includes interconnection of health data from primary healthcare and hospitals into a seamless process. This includes children as well as adults. Further it addresses the issue of VERA – a system that allows patients to look at their own data in electronic health records. This would give parents access to their children’s data. This is a new strategy that is being implemented.

Apart from that, however, in Iceland, the needs of children and adolescents are not given any particular attention in e-health strategy documents. Nevertheless, it is known from other sources that Iceland has initiatives in child e-Health. For instance, there is one document in English that describes electronic health record for children 0-5 years of age, and school health record for children 6-15 years of age (13).

Malta

The current e-health strategy is part of the National Health Systems Strategy, which was published in 2014 and is currently being implemented. There is no specific mention of e-health and children. However, the proposed suite of actions ranging from further development of “my health electronic record” through to e-prescriptions as well as improving health ICT literacy are intended to cover the whole population and will therefore also include medical records and prescriptions for children.

The Netherlands

The Dutch Ministry of Public Health published a progress report on e-health and care improvement in 2015 stating a series of action points but no consideration of children and adolescents. The same is true for the other strategy document, the letter on information and communication technology in health care of 2014, in which the need for more self-management in health care by the use of e-health is stated. No information is given how this can come true for children and adolescents.

Slovakia

The country has been struggling with constant political changes and shifts in the prioritisation of e-health. This has resulted in a hold up of the implementation of e-health strategies, such as the implementation of the national healthcare information system agreed in 2013. Apart from this considerably time lag, the current situation leaves children and adolescents unnoticed in official e-health strategy documents. Strategies that may be of relevance for younger age groups have not yet been released for publication. According to first hand information provided to the MOCHA project, future strategic priorities may focus the prevention and diagnosis of child cancer, prevention of sexually transmitted diseases and HIV and the prevention, screening and diagnosis of multi-resistant bacteria in pediatric units. These have, however, not yet been approved or published.

Sweden

The Swedish strategy does not consider children or child health care at all and focuses on general infrastructure of electronic documentation and system creation to allow electronic communication among caregivers and easy data collection for quality evaluation instead. One important piece in this strategy is putting demands on software producers create software that enables communication with other software for electronic records. At the moment, this strategy

is being implemented at a comparatively slow pace. Swedish health care is run by 21 independent county councils and they all have their own strategies and the right to choose their own software for electronic records. This lack of national coordination has been, and still is a general obstacle for implementation of the new strategy. Still, there has been an overall improvement in the possibilities of using electronic records for collecting quality information on the basis of this strategy.

Romania

The National Health Strategy 2014-2020 plans for measures to create the national integrated information system of public health. This strategy document contains detailed guidelines for the development of an integrated e-health system in Romania, but does not contain any specific goals regarding e-health for children. For adults there is an electronic health insurance card system. For children there is no such system. This seems to be due to the fact that the Ministry of Health covers all costs and that the insurance system is not involved, as up to the age of 18 all health services are free in Romania. In the part of the National Strategy that discusses the need of the electronic prescriptions, the e-case/file management, and the inter-operability of the services, there is no mention about health care for children.

Ad hoc Initiatives on Child Health Care outside National Strategies

As is seen in the introduction the net version of this document seeks to capture a full range of child based e-health initiatives in individual countries. As explained, this part of the study has not yet commenced and is scheduled for the later part of 2016 but already our interaction with country agents and other sources has shown that several countries have introduced important initiatives. The ones already identified are outlined briefly below but it should be understood that at this stage this is not a comprehensive list but rather an introduction to the material we try to capture in the next few months.

Table 7: Overview on Ad-hoc initiatives

	Country	Ad hoc initiative
1.	Croatia	1.1) eNewborn project aim: linkage of hospitals, the National Insurance Fund (providing health insurance ID), public administration offices, national birth registry at the National Institute of Public Health, primary health care and other relevant actors. Medical records on delivery and postnatal care are being directly used for vital statistics and quality of care assessment. Next scale-up phase will include data exchange with primary healthcare providers supporting continuity of care provided by nurse-at-home visitors and family physicians. After a positive pilot phase, national adoption and deploy is expected.

2.	Hungary	<p>2.1) E-health project called ‘Nemzeti Egészségügyi Informatikai (e-Health) Rendszer’ aim: ensure development of efficient and high standard healthcare via virtual communicating methods. Communication between state and private healthcare institutions, medical universities and colleges, IT partners involved in healthcare and the citizens, themselves was targeted.</p> <p>2.2) ‘Egészségügyi Elektronikus Szolgáltatási Tér’ (EESzT: Electronic health service domain) aims: (1) easy data processing and publication considering privacy issues, (2) data exchange in between involved stakeholders, (3) creation of a fully harmonized regulatory framework.</p>
3.	Iceland	3.1) establishment of parent’s access to their child’s/ children’s personal electronic health records
4.	Norway	<p>4.1) establishment of the Norwegian Directorate of e-Health on January 1st, 2016, a sub-ordinate institution of the Norwegian Ministry of Health and Care Services responsibilities:</p> <ol style="list-style-type: none"> 1. National steering and coordination of e-Health through close cooperation with regional health authorities, local authorities, technical organisations, and other interested parties. 2. Develop and administer digital solutions that will improve and simplify our health and care sector.
5.	Poland	<p>5.1) Act on the information system in the health care aim: creation of an automatic, continuous, immediate mechanism for information transfer of medical events from service providers to the “System of Medical Information” (SMI) (System Informacji Medycznej – SIM). The system is planned to be fully operational from 1.01.2018.</p>
6.	Slovakia	6.1) in 2015 4 hospitals started to use a "project hospital" DRG system, (Children’s teaching Hospital in Bratislava, University Akad. Derer’s Hospital in Bratislava and Faculty Hospital in Malacky, DFNSP in Banská Bystrica – Children’s Teaching Hospital) an e-health app which was implemented in 3 hospitals. Beginning 2018 this app is to be used in all hospitals in Slovakia.
7.	Sweden	7.1) A general problem has been that the electronic records for preventive child health care has not been given due attention in the software for primary care records. Software has often been chosen on other quality parameters that are more important for GPs. Since 2015, however, a new version of one of the three most popular softwares has produced a pretty good child health care module which has been introduced in quite a substantial proportion of the country.

Conclusion

Ten MOCHA countries consider children and adolescents in their national health strategies, six of which ranging in a stage of early adoption of e-health solutions to child health care. This underpins how little strategic thought is spent on child health interest and the ICT solutions for more effective and safer child health care.

The appropriate development of electronic health records and e-health services for children is severely compromised if only 50% of reporting countries have any mention of the particular needs of children and adolescents. Where the safety and effectiveness of child health care are at stake, mere considerations of e-health solutions fitting the needs of the adult population will not lead to improvements in child health care. The findings of this report present the lack of attention devoted to children and adolescents in the context of e-health.

Part 3 The Current Level of e-Health Activity and its Impact regarding Children's Health Services

Current e-Health Activity

As with the other work within MOCHA, the strength of the evidence presented is that it is obtained from informed participants in each of the 30 countries. By agreement their work is paced, and each Work Package has topics for them to investigate. Having received two opportunities so far, resulting in the topics reported in Parts 1 and 2, Work Package 8 has had to wait in turn for its next opportunity, which is scheduled for September 2016.

In this next round, Country Agents will be asked the extent of eHealth activities in their country. The exact wording has not yet been finalised through the internal QA process involving members of the External Advisory Board, but it is anticipated that the focus will be separately on electronic records in primary care; specified child health components in generic primary care electronic record systems; child-specific electronic records or linkages in public health including immunisation and screening; and eHealth support such as secure electronic messaging and prescriptions available to support child health delivery.

It is also important to report a recently published study by the European Academy of Paediatrics Research in Ambulatory Setting Network (EAPRASnet), surveying child primary care practitioners in 10 countries (14). The results of this publication, and any other similar literature, will be put alongside the Country Agent findings in this next phase of work. Though this survey was based on one pattern of primary healthcare provision for children, in the next phase of work the possibility will be explored of external collaboration to consider the possibility of whether any similar survey which could be applied Europe-wide. MOCHA is not resourced or authorised to conduct its own survey work, but would be interested in collaborating with those who are.

Impact of E-Health on Child Primary Care Delivery

The core issue, however, is not the availability of eHealth systems, including Electronic Health Records, for children, but their impact on care delivery. Important initial innovative work is being undertaken on this topic by OECD, and within Europe by the Finnish National Institute for Health and Welfare (THL), commissioned by the Nordic Council of Ministers and linked with the OECD work. The metrics on the effect on children's services are likely to be different, including for example record linkage at birth, and immunisation uptake facilitated by public health records. Work Package 8 of the MOCHA Project will seek to explore, and if possible instigate, joint work with these bodies to examine the differential impact of eHealth in support of child health in Europe.

School Health Record Systems, Adolescent Health Services and Record Linkage

Electronic Health Records for school children raise a number of important issues. There are records of health interventions in school; illness and accident within school; notification to schools of health needs of individual children; and controlled messaging and linkage (with consent) between schools and mainstream primary health care providers. Work Package 8 will liaise with Work Package 3, which leads on School Health and Adolescent Health, to see how

best to cover these issues jointly. In turn, there is planned collaboration between MOCHA (lead by WP 3) and the WHO on school health innovation.

There are also arguments for direct access primary health services for adolescents, which will be examined by WP 3. Such services raise tensions in the field of records and record linkage, between stand-alone privacy and good record linkage for safe care, and this Work Package will collaborate with those discussions which will be at a later stage of the MOCHA Project.

Conclusion

This report presents the results of the first two aspects of the state of adoption of electronic health records for children in Europe, namely policy commitment and record linkage identifiers, and identifies the next work in hand. It is intended to produce a second version in spring 2017, when the study of available applications is completed. A further update, towards the end of the project in 2018, is also envisaged.

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Table 8: Overview on national e-Health strategy documents that consider children and adolescents

	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
1.	Austria	E-HEALTH in Austria http://www.bmg.gv.at/home/Schwerpunkte/E_Health_Elga/E_Health_in_Oesterreich/		X			X		X	
2.	Belgium	2.1) Actieplan eGezondheid 2013-2018 (NL), versie 2013 Plan action eSante 2013-2018 (Fr), version 2013		X	n.a.		X			
		2.2) Actieplan eGezondheid 2013-2018 (NL), versie 2015 (http://www.plan-eGezondheid.be) Plan action eSante 2013-2018 (Fr), version 2015 (http://www.plan-esante.be)		X	n.a.		X			
3.	Bulgaria									

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
4.	Croatia	<p>4.1) National Health Strategy 2012 -2020 https://zdravlje.gov.hr/UserDocsImages/dokumenti/Programi,%20projekti%20i%20strategije/National%20Health%20Care%20Strategy%202012-2020.pdf)</p> <p>4.2) National e-Health Development Strategy https://zdravlje.gov.hr/UserDocsImages/dokumenti/Programi,%20projekti%20i%20strategije/Strate%C5%A1ki-plan_razvoja_eZdravlja.pdf</p> <p>4.3) National Public Health Development Strategy</p>	X		4.1) focus areas: vulnerable groups and health equity, children in primary care practice, breast feeding promotion, family violence prevention, children injuries and suicide prevention, psychosocial support to child patients in oncology departments, body over-weight prevention, Roma population national programme		X			
				X			X			
			X				X			

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	<p>Croatia (continued)</p>	<p>(including Health Information) https://zdravlje.gov.hr/UserDocsImages/dokumenti/Programi.%20projekti%20%20strategije/Strateski plan razvoja Javnog zdravstva 2013 2015 final.pdf</p> <p>4.4) National Program for rare Diseases https://zdravlje.gov.hr/UserDocsImages//Programi%20%20projekti%20-%20Ostali%20programi//NACIONALNI-PROGRAM-ZA-RIJETKE-BOLESTI-2015-</p> <p>4.5) Breast-feeding Promotion National Programme https://zdravlje.gov.hr/UserDocsImages//Programi%20%20projekti%20-%20Ostali%20programi//Program%20za%20za%C5%A1titu%20i%20promicanje%20dojenja%202015-2016..pdf</p> <p>4.6) Vision Impairment Early Detection Program</p>	<p>X</p> <p>X</p>		<p>4.3) topics covered: systematic research covering child health care needs and interventions, systematic empowerment of educational sector staff in primary prevention, preventive examinations of childrens revision, physical activity promotion among children, anti-tobacco and anit-alcohol campaigns among children, obesity prevention, dental health promotion, mental health disorder prevention</p>	<p>X</p> <p>X</p>				
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	Croatia (continued)	<p>https://zdravlje.gov.hr/UserDocsImages//Programi%20i%20projekti%20-%20Ostali%20programi//Program%20za%20za%C5%A1titu%20i%20promicanje%20dojenja%202015-2016..pdf</p> <p>4.7) further national strategies, plans and programmes</p> <p>https://zdravlje.gov.hr/nacionalne-strategije/1522</p> <p>https://zdravlje.gov.hr/ostali-programi/1524</p>	X				X			
			X				X			
5.	Cyprus	<p>5.1) e-Health strategy and implementation activities in Cyprus</p> <p>5.2) Cyprus Digital strategy</p>	X		<p>5.1) Creation of Regional Health Networks</p> <p>5.2) Implementation of Integrated Health Care Information System, drug management system, physicians access to patients' electronic health records</p>		X			
							X			

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
6.	The Czech Republic	6.1) Soustava cílů a opatření Národní strategie elektronického zdravotnictví s popisy cílů - The system of goals and measures of the National Strategy e-Health 6.2) 2020 Health Action Plan no. 11: Computerization of health from year 2015		X			X		X	
				X	6.2) Association of general practitioners for children and adolescents involved in creation of the document					
7.	Denmark	outstanding reply								
8.	Estonia	Estonian e-Health Strategic Development 2020 Plan (http://sm.ee/sites/default/files/content-editors/eesmargid_ja_tegevused/Eesti_e_tervise_strateegia/e-tervise_strateegia_2020.pdf)		X			X			
9.	Finland	e-Health Roadmap – Finland (http://www.julkari.fi/bitstream/handle/10024/129709/URN_ISBN_978-952-302-563-9.pdf?sequence=1)		X		X		X		
10.	France	outstanding reply								

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
11.	Germany	<p>11.1) E-Health-Initiative for the Facilitation of Telemedicine Applications in Germany http://www.bmg.bund.de/themen/krankenversicherung/e-health-initiative-und-telemedizin/e-health-initiative.html https://www.bundesgesundheitsministerium.de/fileadmin/dateien/Pressemitteilungen/2015/2015_04/151203-45_PM_E-Health-Gesetz.pdf</p> <p>11.2) The New e-Health Law https://www.bundesgesundheitsministerium.de/fileadmin/dateien/Pressemitteilungen/2015/2015_02/150527_PM_17_E-Health_Gesetz.pdf http://www.bgbl.de/xaver/bgbl/start.xav?startbk=Bundesanzeiger_BGBl&jumpTo=bgbl115s2408.pdf#_bgbl_%2F%2F*%5B%40attr_id%3D%27bgbl115s2408.pdf%27%5D_1472114744174)</p>	X		11.1/2: Children are issued an electronic health card and that this card does not have to display the photo of the insured child if he/ she is younger than 15 years. Apart from that children's needs are not given any deeper thought.		X			
			X				X			

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
12.	Greece	National e-Health Board		X			X			
13.	Hungary	<p>13.1) Hungarian Information Society Strategy, Health and Social Services (http://www.who.int/goe/policies/countries/hun/en/)</p> <p>13.2) Nemzeti Egészségügyi Informatikai (e-Health) Rendszer' (National e-Health System)</p> <p>13.3) 'Egészségügyi Elektronikus Szolgáltatási Tér' (EESzT: Electronic health service domain)</p>	X	X	<p>13.1) Hungarian Information Society Strategy' (HISS) to set up cloud-based vaccination registry (not implemented)</p> <p>set up of new electronic digital culture in preparation</p>	X		X		

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
14.	Iceland	<p>14.1) National e-Health Strategy 2016-2020 http://www.landlaeknir.is/servlet/file/store93/item28955/National_eHealth_Strategies_January_2016_final.pdf</p> <p>14.2) Icelandic Government Policy on the Information Society 2008 – 2012</p> <p>14.3) National e-Health Strategy 2016-2020</p>	X	X	14.3) VERA allows patients access to personal/ children`s electronic health records		X			

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
15.	Ireland	<p>15.1) Knowledge and Information Strategy (Health Services Executive 2015) http://www.ehealthireland.ie/Knowledge-Information-Plan/Knowledge-and-Information-Plan.pdf)</p> <p>15.2) <i>e-Health Strategy for Ireland</i> (Health Services Executive 2013) http://health.gov.ie/wp-content/uploads/2014/03/Ireland_eHealth_Strategy.pdf)</p>	X	X	<p>15.2) set up of nine priority programmes within national e-Health programme: access to electronic health records, e-referral solutions, National Children’s Hospital (NCH – digital hospital), primary care IT, Cancer Care e-Health Programme, Individual Health Identifier Act 2014, e-pharmacy programme, Maternal and Newborn Clinical Management System, National Medical Laboratory Information System (MedLIS)</p>		X			

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
16.	Italy	The National e-Health Information Strategy (http://www.salute.gov.it/imgs/C_17_pubblicazioni_1653_a_llegato.pdf)		X		X				
17.	Latvia	17.1) Pamatnostādnes „e-Veselība Latvijā” (informatīvā daļa) http://www.who.int/goe/policies/countries/lva/en/ 17.2) Centralized e-health solution	X		17.1) Access to care records via state e-services' portal, i. e. "My newborn children data", "My state paid healthcare services", "My general practitioner", "My data within the diabetes mellitus patients' register". 17.2) e-referrals and e-booking, e-prescriptions and electronic health records as well as e-health porta	X		X		

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
18.	Lithuania	18.1) Lithuanian E-health system development programme 2015 - 2025 18.2) Health system law of Republic of Lithuania	X		18.1) programme goal 6.2.3. improve maternal and child health care		X			
			X			X				
19.	Lux									
20.	Malta	The current e-health strategy is part of the National Health Systems Strategy (2014) (http://health.gov.mt/en/Pages/National-Strategies/NHS.aspx)								
21.	The Netherlands	21.1) Progress report e-health and care improvement of the Dutch ministry of Public Health, 2015 21.2) Information and communication technology in health care		X	21.2) It should be noted that as part of the new funding scheme for general practitioners , e - health is explicitly recognized as a performance indicator		X			
				X			X			

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
22.	Norway	<p>22.1) Governmental White Paper No. 9 (2012–2013) One Citizen – One record</p> <p>22.2) Meld. St. 11 Personvern – Utsikter og utfordringer</p> <p>22.3) Nasjonal handlingsplan for e-helse (2014-16)</p>	X	X	22.2) The Personal Data Act was revised in 2012 to amongst other strengthen children's rights in this area.		X			

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
23.	Poland	<p>23.1) Directions of the informatisation „e-health Poland” for years 2010-2015 (Kierunki informatyzacji „e-Zdrowie Polska” na lata 2010-2015) (http://www.who.int/goe/policies/poland_ehealth2010_2015.pdf?ua=1)</p> <p>23.2) Policy paper for health care for years 2014-2020 (http://www.mz.gov.pl/wp-content/uploads/2015/08/Policy-Paper-dla-ochrony-zdrowia-na-lata-2014-2020-przyjety-przez-KE.pdf)</p> <p>23.3) Act on the information system in the health care (6.12.2011, last amendment 12.27.2015)</p>	X		<p>23.1) Introduction to school education online medical training</p> <p>23.2) project “Electronic Platform for Collection, Analysis and Sharing of Digital Resources on Medical Events”, project “Electronic Platform for Collection, Analysis and Sharing of Digital Resources on Medical Events”.</p>	X		X		<p>Medical training online for children and youth, Introduction to school education online medical training should bring tangible benefits in the future</p>

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	Country	Current national e-Health strategy (link)	Consideration of children and adolescents		How?	Is the latest national strategy the same as in the WHO depository (April 2016)		Consideration of children and adolescents		How?
			Yes	No		Yes	No	Yes	No	
24.	Portugal	24.1) RSE – Registo de Saúde Electrónico (http://www.acss.min-saude.pt/Portals/0/RSER1_Estado_da_Arte_V3.pdf) 24.2) Plano Estratégico. Modelo de execução da estratégia	X		24.1) information on how to handle data of minors 24.2) Oporto pediatric urgency (PIP) – is a regional data repository to allow health professionals timely access to health data of acutely ill children and adolescents		X	X		Oporto pediatric urgency (PIP) – is a regional data repository to allow health professionals timely access to health data of acutely ill children and adolescents
25.	Romania	National Strategy of Health 2014-2020 (http://ms.gov.ro/upload/Anexa%201%20-%20Strategia%20Nationala%20de%20Sanatate%202014-2020.pdf) and		X			X			

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	Romania (continued)	Annex of the National Strategy of Health 2014-2020 (http://www.ms.gov.ro/upload/Anexa%202020-%20Plan%20de%20actiuni)					X			
26.	Slovakia	26.1) e-Health platform is "Injury on holiday house in day of public holiday 26.2) e-Health - new dimension of health care 26.3) e-Health - Relations between Needs and Applications			e-Health applications implemented in 3 hospitals (Children's teaching Hospital in Bratislava, University Akad, Derer's Hospital in Bratislava and Faculty Hospital in Malacky).		X X X			
27.	Slovenia	outstanding reply								
28.	Spain	28.1) Situation of e-health in the Spanish national health system. 2012 http://www.ontsi.red.es/ontsi/sites/default/files/1_48_0_0_0_14022012.pdf 28.2) Users of e-health in Spain http://www.ontsi.red.es/ontsi/sites/default/files/los_ciudadanos_ante_la_e-sanidad.pdf 28.3) The e-health: Strategic priority for the national health system http://www.redaccionmedica.com/contenido/images/E_Sal		X X X			X X X	X		

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	Spain (continued)	ud.pdf 28.4) Plan de Calidad para el Sistema Nacional de Salud (PCSNS) Estrategias #1, 2	X		28.4) child health problems are addressed	X				
29.	Sweden	outstanding reply								
30.	United Kingdom	outstanding reply								

Table 9: WHO E-Health Observatory Identified Policy Documents for MOCHA Countries (April 2016)

(*WHO depository updated since April 2016)

	Country	Title of the Document	WHO published source (April 2016)	MOCHA WP 8 comment
1.	Austria*	Entwurf für eine österreichische e-Health Strategie	http://www.who.int/goe/policies/countries/aut/en/	document not found
2.	Belgium*	Loi du 21 août 2008 relative à l'institution et à l'organisation de la plate-forme e-Health	http://www.who.int/goe/policies/countries/bel/en/	document in French
3.	Bulgaria	Strategy for Implementation of Electronic Healthcare in Bulgaria	http://www.who.int/goe/policies/countries/bgr_ehealth.pdf?ua=1	working link
4.	Croatia	NACIONALNA STRATEGIJA RAZVOJA ZDRAVSTVA 2012.-2020	http://www.hrt.hr/fileadmin/video/49._-1.pdf	document in Croatian
5.	Cyprus*	ΕΘΝΙΚΟ ΣΤΡΑΤΗΓΙΚΟ ΠΛΑΙΣΙΟ ΑΝΑΦΟΡΑΣ	http://www.who.int/goe/policies/countries/cyp/en/	document not found

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	Country	Title of the Document	WHO published source	MOCHA WP 8 comment
6.	Czech Republic*	NÁRODNÍ PLÁN ROZVOJE e-HEALTH	http://www.who.int/goe/policies/countries/cze/en/index.html	document in Czech
7.	Denmark*	National Strategy for the Digitalization of the Danish Health Care Services 2008 - 2012	http://www.who.int/goe/policies/countries/dnk/enhttps	document not found
8.	Estonia	Eesti infoühiskonna arengukava 2013	http://www.who.int/goe/policies/countries/est/en/	document in Estonian
9.	Finland*	e-Health Roadmap - Finland	http://www.who.int/goe/policies/countries/fin/en/	document not found
10.	France*	National strategy for the deployment of telemedicine	http://www.who.int/goe/policies/countries/fra/en/	document not found
11.	Germany	The German e-Health Strategy	http://www.who.int/goe/policies/countries/deu/en/	document not found
12.	Greece*	Προγραμματική Περίοδος 2007 – 2013	http://www.who.int/goe/policies/countries/grc/en/	document in Greece

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	Country	Title of the Document	WHO published source	MOCHA WP 8 comment
13.	Hungary	Hungarian Information Society Strategy, Health and Social Services	http://www.who.int/goe/policies/countries/hun/en/	working link
14.	Iceland*	Icelandic Government Policy on the Information Society 2008 – 2012	http://eng.forsaetisraduneyti.is/media/utgefidefni/Iceland_the_eNation.pdf	working link
15.	Ireland*	Health Information - A National Strategy	http://www.who.int/goe/policies/countries/irl/en/ ; http://www.drugsandalcohol.ie/5862/1/DOHC_health_information_strategy.pdf	document not found
16.	Italy	The National e-Health Information Strategy	http://www.salute.gov.it/imgs/C_17_pubblicazioni_1653_allegato.pdf	working link
17.	Latvia	Pamatnostādnes „e-Veselība Latvijā” (informatīvā daļa)	http://www.who.int/goe/policies/countries/lva/en/	document in Latvian

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	Country	Title of the Document	WHO published source	MOCHA WP 8 comment
18.	Lithuania	DĖL LIETUVOS E. SVEIKATOS 2007–2015 METŲ PLĖTROS STRATEGIJOS PATVIRTINIMO	http://www.who.int/goe/policies/countries/ltu/en/	document in Lithuanian
19.	Luxembourg	PLAN D'ACTION ESANTÉ DU LUXEMBOURG	http://www.sante.public.lu/fr/systeme-sante/programme-esante/esante_plan_actions_detail_006007004_00600926.pdf	document in French
20.	Malta	The National ICT Strategy for Malta 2008-2010	http://unpan1.un.org/intradoc/groups/public/documents/UNPAN/UNPAN00343500.pdf	working link
21.	Netherlands*	Nationale Implementatie Agenda (NIA) e-Health	http://www.who.int/goe/policies/countries/nld/en/	document in Dutch
22.	Norway	Samspill 2.00 Nasjonal strategi for elektronisk samhandling i helse- og omsorgssektoren 2008 – 2013	http://www.who.int/goe/policies/countries/nor/en/	document in Norwegia

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	Country	Title of the Document	WHO published source	MOCHA WP 8 comment
23.	Poland*	Kierunki informatyzacji „e-Zdrowie Polska” na lata 2010-2015	http://www.who.int/goe/policies/countries/pol/en/	document in Polish
24.	Portugal*	Plano Estratégico	http://www.who.int/goe/policies/countries/prt/en/	document in Portuguese
25.	Romania	Strategia de e-Sănătate a Ministerului Sănătății	http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&ved=00CCAQFjAA&url=http%3A%2F%2Fwww.ms.gov.ro%2Fdocumente%2F256_588_Anexa%20strategie%20e-sanatate.doc&ei=KrFIUL_XFYbk00QGPzIH4Aw&usg=AFQjCNHhC9t5i0aSMaFxi_wJ3MtiDjgJLA&sig2=xSnqPuSi	document in Romanian
26.	Slovenia	e-Zdravje 2010 - Strategija informatizacije slovenskega zdravstvenega sistema 2005-2010	http://uploadi.www.ris.org/editor/1130093500670snutekeZdravje200100-001.pdf	document in Slovenian

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	Country	Title of the Document	WHO published source	MOCHA WP 8 comment
27.	Slovakia	Strategické ciele e-Health - kľúčový nástroj informatizácie verejnej správy v oblasti zdravotníctva na Slovensku	http://www.ezdravotnictvo.sk/Program-eHealth/Strategicke-dokumenty/Strategicke-ciele-eHealth/Stranky/default.aspx	document in Slovakian
28.	Spain*	Plan de Calidad para el Sistema Nacional de Salud	http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/pdf/pncalid/PlanCalidad200100.pdf	document in Spanish
29.	Sweden	Nationell eHälsa-strategin för tillgänglig och säker information inom vård och omsorg	no link provided	document not found
30.	United Kingdom	The power of information: Putting all of us in control of the health and care information we need	http://www.who.int/goe/policies/countries/gbr/en/	working link

Appendix 1

WP 8 questionnaire, round 1



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

COUNTRY AGENT QUESTION: ROUND 1 - 14.10.15

MOCHA WP8

Does your country have a unique identifier* to link children's health records?

If **Yes**, please also add:

- a) Does the structure of the identifier contain information such as year of birth, location, family linkage?
- b) Does it apply only to health records; to health and welfare; to all public services; or is it a national citizen number?
- c) When is it issued – at birth linked to delivery; by a civil process; or other (please describe)
- d) Is it issued to the parents, to the health system, or both
- e) Does it apply to all records; paper ones only; or electronic ones only?
- f) Is it the primary record identifier, or does each hospital / primary care provider have their own identifier, with this number being used as the link when searching for data across providers?

If **No**, are there any plans for this; is there any national debate or policy against such an identifier?

* A unique identifier is a nationally organised alpha-numeric (or numeric) number allocated to each citizen, including children at or near the time of birth, to link their health records, and possibly their appointments. It may be a national citizen ID and used in health, or it may be specific for health only. It is national, in that it follows the child if he/she moves.



Please send your answers to Denise Alexander by 11.11.15

Appendix 2

Overview on Models of Child Primary Care in MOCHA countries

Country	MOCHA Country Agent's Description of type of primary care	MOCHA Classification of Child Primary Care Type
Austria	GP and paediatrician	Mixed
Belgium	Family doctor or 1 st line paediatrician	Mixed
Bulgaria	GP for those with health insurance. Pre 2000 was mandatory to have a community paediatrician for children up to 18; this generation now retiring and GPs only have 9 weeks paediatrics training.	General Practitioner
Croatia	Primary care doctor / paediatrician	Paediatrician
Cyprus	Private paediatrician or public funded GP who will refer to hospital Paediatrician if necessary	Mixed
Czech Republic	"registering paediatrician" accessed via triage nurse	Paediatrician
Denmark	-	General Practitioner
Estonia	GP	General Practitioner
Finland	GP (mainly work in public health care centres)	General Practitioner
France	Family physician or GP who is either a Paediatrician or a GP	Mixed
Germany	Paediatrician and GP	Mixed
Greece	GP or Paediatrician chosen from insurance co list Usually paediatrician up to 18 years old.	Paediatrician
Hungary	-	Mixed
Iceland	One family doctor from a health care centre or private paediatrician	Mixed
Ireland	GP	General Practitioner



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Italy	0-14 have paediatrician or GP if none locally. Max 800 children per paediatrician	Paediatrician
Latvia	GP / family doctor or a paediatrician	Mixed
Lithuania	Family doctor or paediatrician	Mixed
Luxembourg	Family doctor. Paediatrician up to the age of 2 years.	Mixed
Malta	Family doctor (private) or walk in community health centre	General Practitioner
Netherlands	GP (Triaged by nurse)	General Practitioner
Norway	GP	General Practitioner
Poland	GP or Paediatrician chosen from insurance company list	Mixed
Portugal	GP (80%) or private paediatrician	General Practitioner
Romania	Family doctor	General Practitioner
Slovakia	-	Paediatrician
Slovenia	-	Paediatrician
Spain	Family doctor in health care centre or a paediatrician	Mixed
Sweden	Child health care nurse up to age 6; school health nurse afterwards. GP/Paediatricians in hospital contacted by nurse	Mixed
United Kingdom	GP as a named accountable professional	General Practitioner



Appendix 3

WP 8 questionnaire, round 4



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

COUNTRY AGENT QUESTION: ROUND 4 – 21.3.16

MOCHA WP8: Use of electronic records to enable safe and efficient models

Response from: ...
Country Agent: ...
Contact Details: ...

The WHO holds for each country a depository on e-health policies. The attached schedule shows what the WHO holds for your country including the policy document attributed to your country.

1.) Is this the latest document on your country's e-health policy? Please state "Yes" or "No".

Comment:

2.) Is this the only document? Please state "Yes" or "No".

Comment:

3.) If **No** (in 1. and/ or 2.), what other documents are there? Please list.

.....
.....

4.) Please can you examine the current policy documents and identify in no more than 2 pages



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for each what it says about e-health and children. Please indicate the source document for each summary. Can you indicate the implementation status of each document (e.g. draft, currently implemented, implementation completed)?

.....

Thank you for completing this questionnaire! In case there are any questions, please do not hesitate to get in touch. Please send your answers to Denise Alexander by **29th April 2016**.

Please see next page for the World Health Organisation Policy documents for your country.



World Health Organisation E-Health Observatory Identified Policy Documents for MOCHA Countries

Country	Title of the document	WHO published source	WHO summary of content	MOCHA WP 8 comment
