Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

Work Package 8: Home Based Records

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Home Based Records

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List of abbreviations

Apps	Mobile applications
ED	Emergency Department
EEA	European Economic Area
EU	European Union
G-BA	Gemeinsamer-Bundesausschuss
GP	General Practitioner
IIS	Immunisation Information System
J1	Health examination for 12-14-year olds in Germany
J2	Health examination for 16-17-year olds in Germany
MOCHA	Models of Child Health Appraised
PMI	Local maternal and child health services in France
RIVM	National Institute for Public Health in the Netherlands
TIS	Health Information System in Estonia
U10	Health examination for 7-8-year olds in Germany
U11	Health examination for 9-10-year olds in Germany
VNs	Visiting Nurses

1. Introduction

A home-based record system is present in many countries and has been portrayed as an effective tool for child health. The record promotes parent and healthcare professional collaborations for a comprehensive understanding of the child's health and development at different life stages and enables co-production of the child's health. Usage of home-based records (initially often known as 'parent held records') has been present in some countries for more than 25 years [1-3].

A home-based record is a record of a child's growth, development and utilisation of public health/preventive health services [4]. The record is traditionally a paper booklet but could also be on a digital platform; some European countries are now implementing 'Citizen Patient Portals' for personal health records. In the record, a health professional records key information about the child but in some cases, the parent(s) and other professionals also make entries. Home-based records are normally issued at birth and held by the parents.

Literature shows that home-based records can be useful for both parents and healthcare professionals [5-7]. Therefore, this study aimed to find out more about the existence and use of such records within the thirty countries of the European Union (EU) and European Economic Area (EEA), and how they fit into delivery of services and adjustment to the digital age. This was done though the Models of Child Health Appraised (MOCHA) Project [8]. This Horizon 2020 funded project has been running from 2015 to 2018 and is tasked with appraising models of primary care for children. Assessment of the existence and use of home-based records is one supportive objective of MOCHA.

2. Methodology

To investigate the existence and use of home-based records, and how they assist service delivery, a semi-structured survey design was used to collect data. Data collection occurred from March 2018 until present, where 27 responses have been collected. A key methodological feature of the MOCHA project is the retention of a local expert in each study country (Country Agent), who collects data using local sources. Questions asked of Country Agents first pass through internal and external scientific scrutiny to confirm their rationale, relevance, and clarity. In this study the WHO Regional Office for Europe was involved in that process.

The questionnaire firstly determined in which countries home based records exist. In this study, a home-based record was defined as "a record, traditionally a paper booklet, but possibly on a digital platform, in which a health professional records key information about the child including administration of routine preventive services, growth data and development data; in some cases, the parent(s) and also other professionals can also make entries. The home-based records are normally issued at birth and held by the parents".

For those who have home based records, details on: the age range covered; when the record is issued; and how the record is administered to the parent, were requested. Additionally, the procedure for issuing records to children moving into the country was queried. The questionnaire considered record issuing methods, record design, the data items included, and whether the parent can enter data themselves. Furthermore, official use of the record, coverage throughout the country, level of utilisation of the record, digitalisation, systematic data sharing, health promotion activity through records, and parent involvement in record design/use were also investigated. Finally, the questionnaire sought to determine whether there were other unofficial equivalents to home-based records.

Results were collected and analysed through descriptive statistics.

3. Results

3.1 The presence of home-based records in MOCHA countries

Twenty-seven responses were collected for this questionnaire.

Results showed that of the 27 respondent countries, twenty-two countries described the presence of a home-based record or a parent-held record system, in all or part of the country. Five countries: Finland, Latvia, Lithuania, Norway and Slovenia reported not having home-based records (Figure 1).

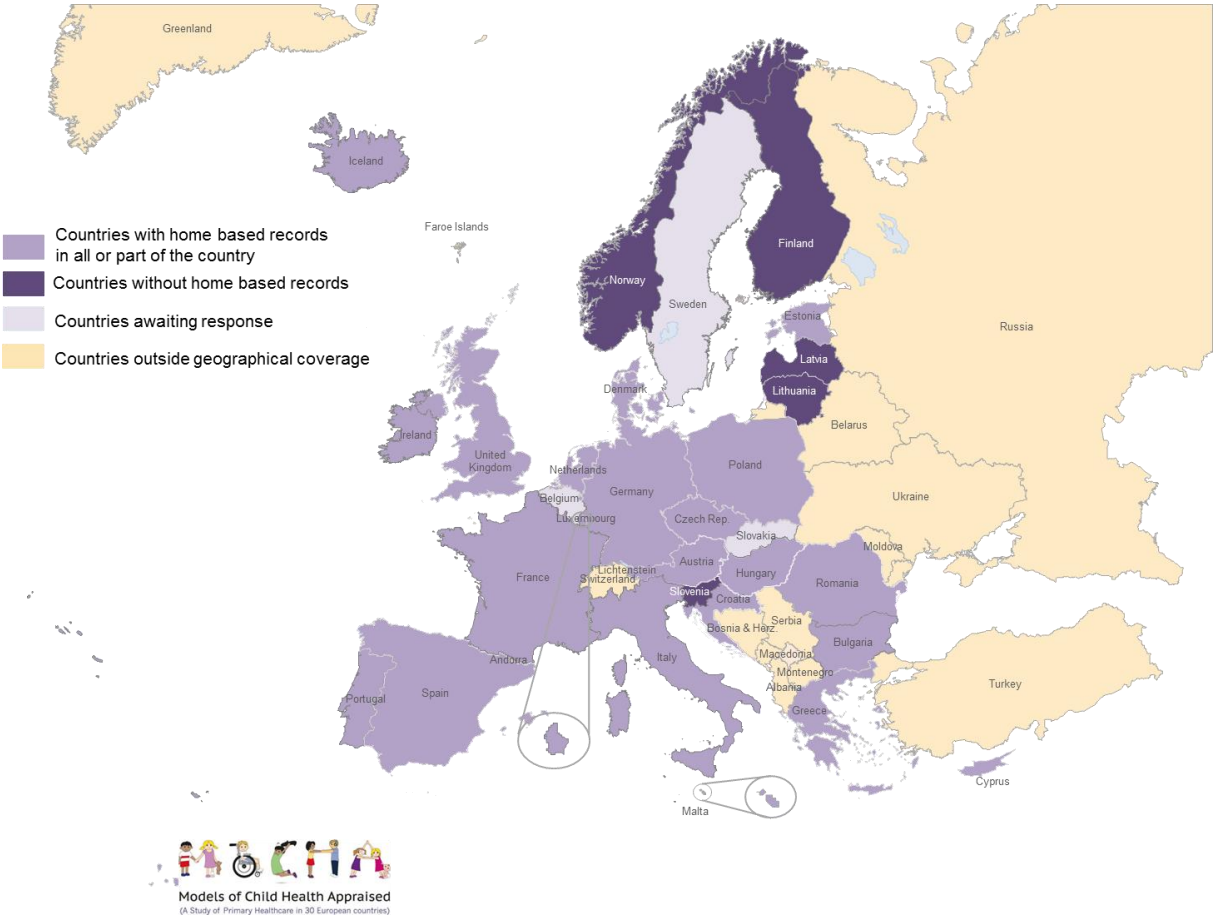

Figure 1: Countries with and without home-based records

3.2 Age range coverage of home-based records

The age range coverage was also covered by the survey. Countries were asked what age range the home-based record covered: 0-5 years, 0-10 years, 0-18 years or other age groups (Figure 2).

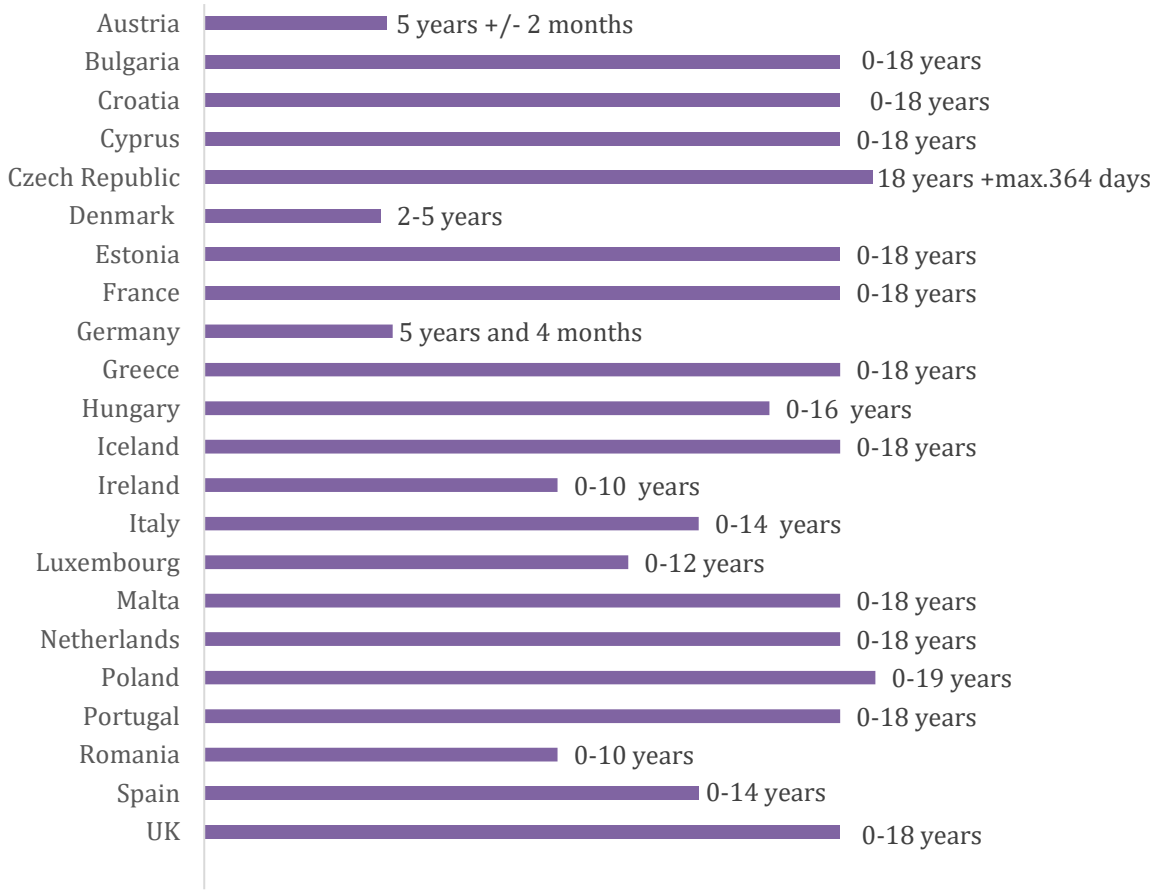

Figure 2: The age range coverage of home-based records

Of the 22 countries reporting home-based records, eleven countries hold home-based records for children from ages 0-18 years. Eight countries, Austria, Czech Republic, Germany, Hungary, Italy, Luxembourg, Poland, and Spain reported holding home-based records for other age groups than those specified in the survey.

In **Austria**, examinations from birth until the 58th/62nd month of life are recorded in the mother-child record, or the 'Mutter-Kind-Pass'. Additionally, five examinations of the mother when she is pregnant are also recorded in the record.

In the **Czech Republic**, the record covers children aged 0-18 years and then up to a maximum of 364 days after, i.e. before their 19th birthday.

In **Denmark**, each of the 98 municipalities decides to what extent the parent-held record system is used. The record, 'Barnets Bog' or 'The Child's Book' is either given to parents as a paper booklet or as an electronic version, depending on the municipality. The Child's Book covers children aged from 2-5 years, unless the electronic version is used. These electronic versions incorporate other

data, for example linking school health journals and so in this case, the Child Book age coverage is until the age of 15 years.

In **Estonia**, information in the immunisation booklet is recorded by the health provider. Additionally, this information is also recorded in the Health Information System (TIS) and an immunisation passport. The immunisation passport is issued by a healthcare provider upon birth in the maternity ward to family members. The healthcare provider may record details in the passport and then must immediately return it to the family.

In **Germany**, the yellow booklet or the 'Untersuchungsheft' covers children for the first 64 months of life, covering nine examinations, U1-U9. However, later in life there are other examinations that can be added to the yellow booklet. Examinations for 7-8-year olds (U10) and 9-10-year olds (U11) are voluntary and are only covered by certain health insurance companies. There are two additional preventive check-ups that are in place for teenagers, at the ages of 12-14 years (J1) and 16-17 years (J2). The former is covered by health insurance but is voluntary, however the latter is only covered by some health insurance companies and is also voluntary. All of these examinations are recorded in the home-based record.

3.3 Age of issuance of home-based record

Countries were asked when the home-based record was issued: pre-birth, at birth, in the first month of life or after a specific diagnosis/health problem. Of the 22 countries reporting home-based records, four reported issuances pre-birth, 16 at birth, and four in the first month of life. Four countries (Bulgaria, Germany, Italy (6 regions) and Romania) deliver records at two separate time points. (Figure 3).

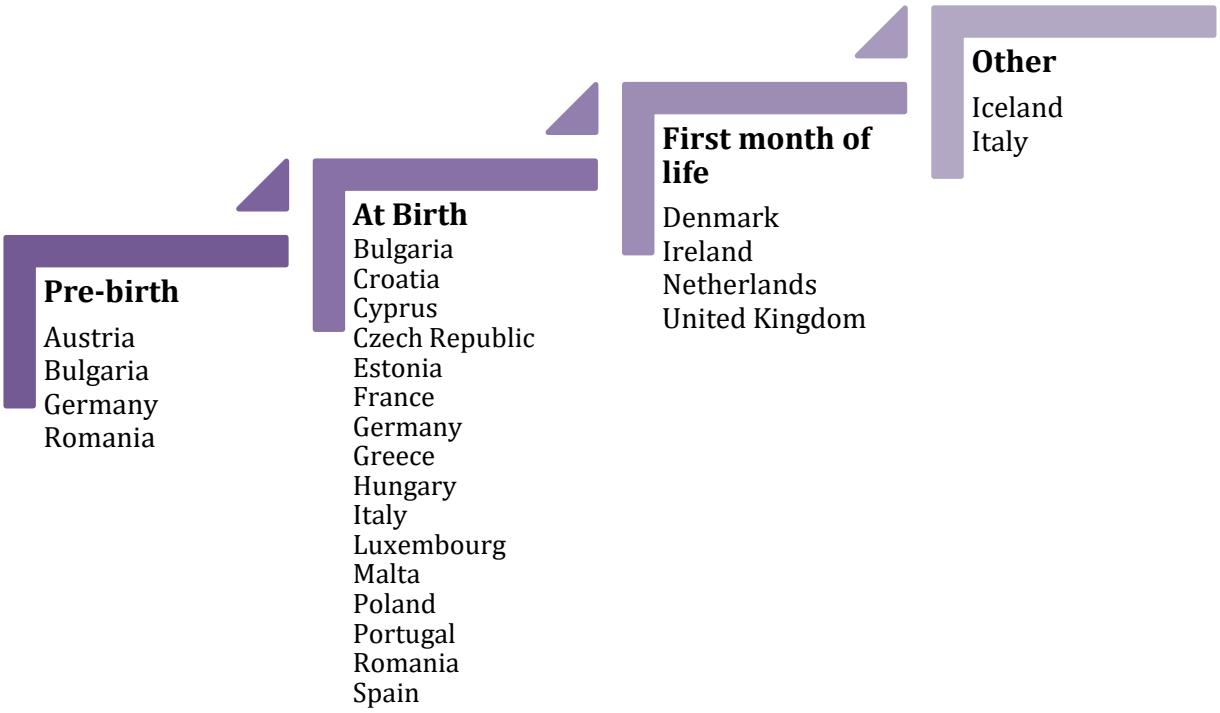

Figure 3: The age at which home-based are issued

In **Austria**, the record issued pre-birth includes data from the 16th week of pregnancy and onwards.

Similarly, **Germany** issues the 'Mutterpass', a maternity record, to all pregnant women in a paper form. A doctor or midwife records results from clinical examinations of both the mother and the child. Results recorded for the mother include medical history, laboratory tests, vaccination information, results of check-ups, and ultrasound results. In the same record, the first examinations of the child after birth are also recorded. The second record in **Germany** is the 'Untersuchungsheft', or the yellow booklet. It is issued specifically for early detection of diseases that may harm or affect normal mental and physical development of the child. It includes medical measures that should be carried out for early detection of health issues.

In **Iceland**, the home-based record is issued at first contact with a preventive child health nurse, when they come for a home visit. The first regular preventive visit starts at 6 weeks of age or at the time of the first vaccination.

In **Italy**, the age of issuance varies according to region. In Campania, Emilia-Romagna and Veneto the record is issued at birth, whereas in Puglia it is issued at the time of enrolment in the National Health Service, usually a few days or weeks after birth.

In **Romania**, the pregnant woman booklet is issued pre-birth and the vaccination booklet is issued at birth.

3.4 Method of record delivery to parents

The questionnaire also enquired how the home-based record was given to parents. The question asked whether the record was included in a discharge pack from the maternity service at birth, given at clinic attendance, sent by post, or through another medium.

Of the 22 countries reporting home-based records, thirteen countries reported the home-based record being included in the discharge pack at birth, four countries reported the home-based record being given at clinic attendance, and eight countries reported other methods of delivery. Three countries (Czech Republic, Italy and Spain) reported two methods of delivery in their country (Figure 4).

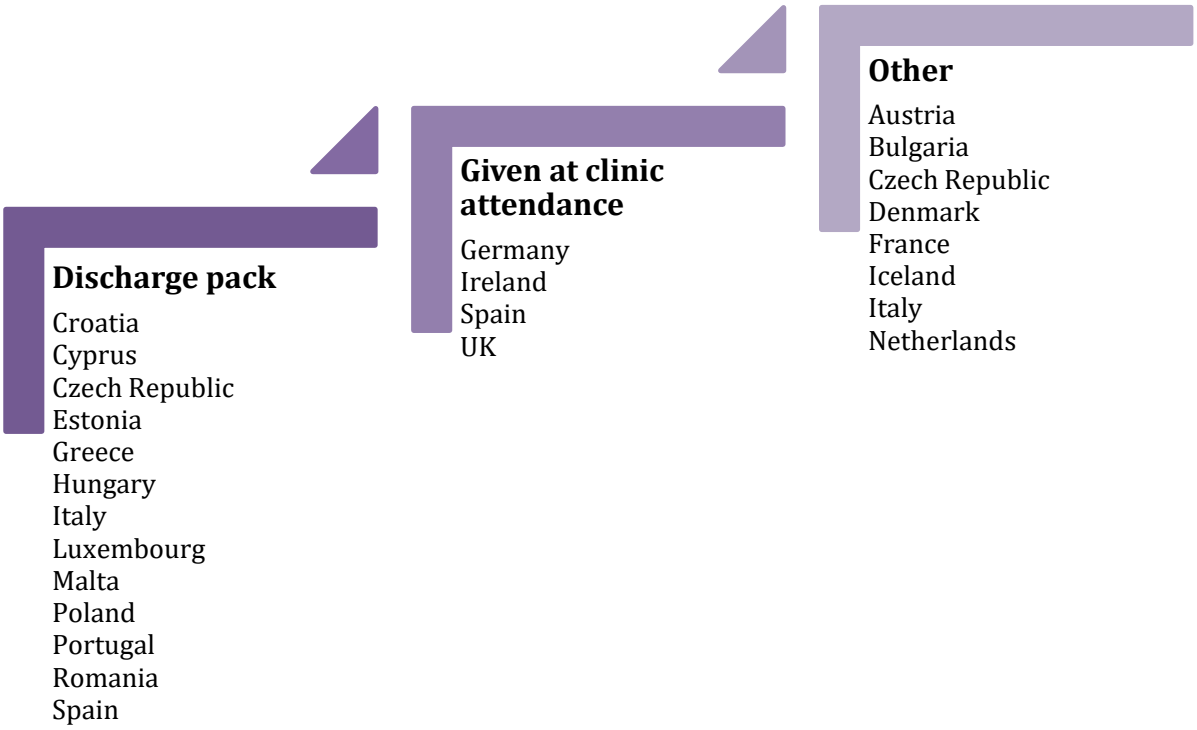

Figure 4: Overview of method of record delivery to parents

In **Estonia,** parents are given the 'Child's Health Journal' or 'lapse tervisepäevik' in the maternity ward upon the birth of their child. Though this record is available as a home-based record, data recording is not mandatory and therefore many parents opt out of using the booklet. Otherwise an immunisation record is also issued. It was reported that an e-immunisation passport was implemented in 2017 to give a full overview of a patient's vaccination history. Previously a paper copy was used and therefore guidance was also given on renewing the immunisation passport, if it is lost.

In **Germany**, the yellow booklet is given on the first examination of the child, which is immediately after birth. This record is handed to the parents by a doctor or midwife.

Every child born in **Hungary** is issued with a record upon discharge from the maternity ward. Perinatal data is handwritten by a medical professional; however, the data is less detailed than the discharge document, due to space limitations in the record. If the record is ever misplaced, an official document produced by visiting nurses (VNs) is available. However, the document only contains details of compulsory vaccination, anthropometry, and screening data.

3.4.1 Countries who reported having another method of home-based record delivery to parents

In **Austria**, the home-based record is usually given to the mother on her first check by the gynaecologist. However, many other options are also available. The record may be given to the parent by their GP, the District Health Offices, a specialised Outpatient clinic of a Health Insurance Institution, or in counselling centres for pregnant women.

In **Bulgaria**, when the child visits the GP for their first visit, they receive a 'Personal Path-Prophylactic Card'. This is a small book in which the GP enters information about the result of each appointment, anthropometric investigations, and vaccinations given. This personal healthcare card must be kept with the parents, not the GP.

Answers from the **Czech Republic** indicated the record is included in the discharge pack at birth but also via another method. The other record refers to a health and vaccination record of the child/adolescent, which can be downloaded from the website of the National Institute of Public Health, where separate versions exist for boys and girls. However, it is also reported that the record is normally 99.99% included in the discharge pack from maternity service at birth.

In **Denmark** the Child's Book is given to parents on the first visit from the health visitor. Depending on what municipality the family resides in, a paper or an electronic version of the record is given with guidance on how to maintain records.

In **France**, the 'carnet de santé' is issued at birth, either by the registrar of the town hall, or by the registrar of a public hospital. Otherwise, parents may request the record from the local maternal and child health service (PMI).

In **Italy**, in the Puglia region, the home-based record is given to the parent upon registration with a family paediatrician at the District Office.

In the **Netherlands**, parents receive two sets of records for their child. The first record: a card for vaccinations received and vaccinations remaining. These cards are paper records, which are posted to the parent's home. The second record: a growth booklet, is available in a digital format. In this record, they can report the growth of their child, developmental milestones, information for issues relevant for the different states of childhood and adolescence, and preparatory questions for well-child visits. The growth booklet is increasingly becoming digital, including for example a growth app for monitoring growth.

3.5 Procedure for issuing home-based records to children moving into the country

Often, families move within and between countries for different reasons, including and not limited to economic, social, political, and environmental causes. In this case, children moving into another country after birth require structural processes in place to ensure their parents are issued a home-based record.

Therefore, Country Agents were asked if there was a reliable procedure for issuing home-based records for children moving into the country or region, after birth. Thirteen countries reported that there was a process and eight reported there was not a procedure. One country, the United Kingdom, reported uncertainty about such a process (Figure 5).

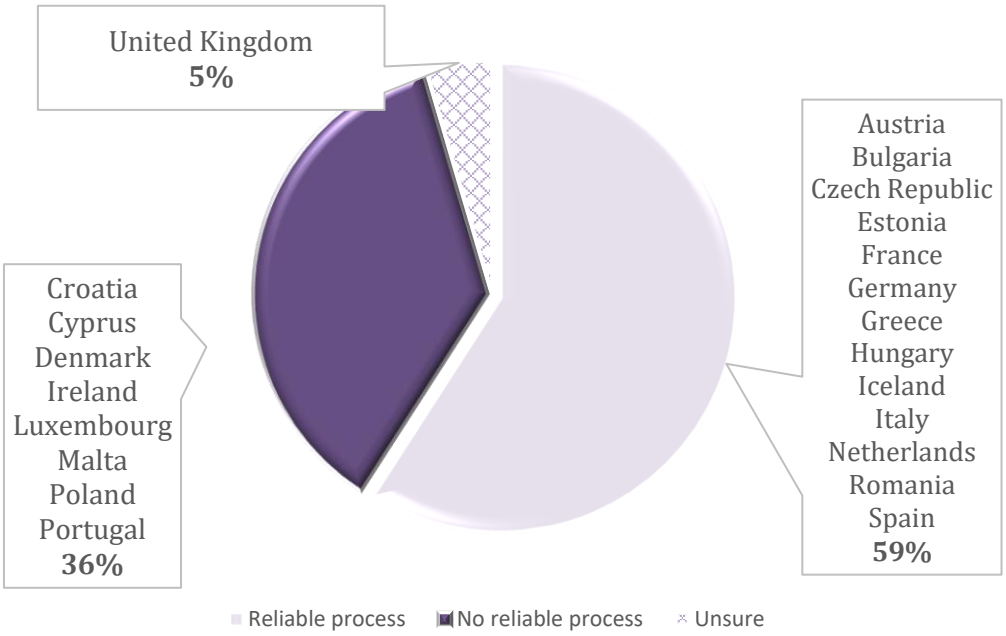

Figure 5: Overview of procedure for issuing records to children moving into the country

3.5.1 Countries with a procedure for issuing a record for children arriving

There are 13 countries, of the 22 countries reporting home-based records, that reported having a process for issuing a home-based record for children moving into a country after birth.

In **Austria**, the record (mother-child pass) is a free document that is issued regardless of nationality. This means that when a child moves into the country, they are issued this record and all health data from this point are recorded. If there are reliable data from earlier examinations from a previous country, then they are also added to the record. This home-based record is not required by law, but standard examination records are a prerequisite for obtaining childcare allowance.

In **Bulgaria**, parents have ownership of the 'Personal Health Care Card'. When they move, this card can be presented at medical establishments. When families move into Bulgaria with legal permission, they are issued identity documents and in turn must provide documents, for their child to receive the same healthcare as children born in Bulgaria. This includes being issued the 'Personal Health Care Card'.

In the **Czech** Republic, as soon as the child is registered with the registering GP for Children and Adolescents (registering PLDD), the parents will be given a stamped and completed record by the doctor.

In **France**, there is a reliable procedure for issuing the home-based record for children moving into the country after birth via the local maternal and child health service (PMI).

In **Germany**, children who move there after birth, receive the yellow booklet from the GP/paediatrician upon their first visit to the doctor.

In **Greece**, to obtain the record, parents/guardians of the incoming children must contact the Department of Prevention and Health Promotion. To obtain the record, parents are required to provide identification paperwork (ID card/passport) and the child's birth certificate.

In **Hungary**, children moving into the country would obtain a record from the local service of visiting nurses. After obtaining a record, data is filled in by administrative personnel of the Regional Public Health Institute Services, who complete the record from previous healthcare providers or existing documentation to the best of their ability.

In **Iceland**, all children who attend preventive child health services are given a small booklet. In this, parents may record items such as height and weight measurements, and vaccinations. This booklet is also used in school health services, when registering immunisations. If a child does not have a booklet or cannot find theirs, an appropriate solution is found for their situation.

In **Italy**, the record is given to parents and therefore travels with the family as they move within the country, from region to region. There is no other communication between different regions. When a child moves to Italy after birth, they are enrolled into the National Health Service, if their parents have acquired legal residence in an Italian region. Upon enrolment, the child receives the same rights as all other children, including the home-based record.

In the **Netherlands**, there are separate processes for families moving to the country and for families moving within the country. For those moving into the country, it is advised, if possible, to contact a local doctor before their move, to compare vaccination schedules and adjust according to the Dutch vaccination schedule. When moving within the country, the move is registered in the Municipal Population Register, in which all citizens are already registered. It is a legal obligation to report to the register when moving so that the register may inform preventative services and trigger the movement of electronic health records to the new city.

In **Spain**, regardless of the country of origin and the child's legal status, regional public health and healthcare services are responsible for issuing and delivering home-based records. When children move into Spain from another country, the home-based record is issued at clinical attendance in regional primary care services. Any relevant information provided by the family is recorded in the record and is also stored in an electronic record.

3.5.1 Countries without a procedure for issuing a record

Ireland and **Portugal** reported having no reliable processes for issuing a home-based record for children moving into the country, after birth. In **Ireland**, a full home-based record is available in certain health service areas, only. In these areas, the public health nurse is responsible to give the record to parents at the first post-natal visit. An immunisation passport is universally present in Ireland and is given to parents by the Maternity Hospital, GP, or public health nurse.

However, there is no national system for ensuring all children moving in to the country receive a home-based record. In **Portugal**, the 'National Child Health Plan' states that all children must have all required vaccinations. The first time a legal foreign child is administered these compulsory vaccinations, they are given a home-based record from the health centre.

3.6 Who issues the home-based record

The survey investigated who issued the home-based record: a civil registration service, the health system, a health insurance company, a health provider organisation/clinic, an education authority, or someone else. Two countries from the respondent countries reported a civil registration process, 15 reported health system issuances, six a health provider, and two another issuer. Austria, Cyprus, and France reported more than one body issuing the record (

Figure 6).

Health System	Bulgaria, Denmark, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, Malta, Poland, Portugal, Romania, Spain, UK
Health provider organisation	Croatia, Cyprus, Czech Republic, Estonia, Hungary, Netherlands
Civil registration service	Austria, France
Health insurance company	None
Education Authority	None

Figure 6: Overview of who issues the home-based record

In **Austria**, issuing takes place by a medical professional (i.e. a gynaecologist, a GP, the Health Authority, etc.).

In **Cyprus**, the record is issued by the Ministry of Health to all public clinics and private paediatricians, free of cost. All Cypriot children are issued the same booklet, however on some rare occurrences private paediatricians also use their own booklet.

In **Germany**, the Federal Joint Committee, Gemeinsamer Bundesausschuss (G-BA), is responsible for issuing the yellow booklet. The G-BA issues directives specifying which healthcare services are provided under statutory health insurance in Germany and is an annex to the G-BA Paediatrics Directive. The G-BA constitutes many stakeholders, including the National Associations of Statutory Health Insurance Physicians and Dentists, the German Hospital Federation, and the National Associations of Statutory Health Insurance Funds.

In the **Netherlands**, the National Institute for Public Health (RIVM) provides the records used for recording vaccinations. Both the general practitioner and the preventive child healthcare issue a home-based record. They are both regarded as a health provider organisation.

In **Poland**, the home-based record is given to parents by healthcare providers in the hospital. The design and scope of the record is unified by a national regulation process, by the Ministry of Health, so the record is issued from the health system.

3.7 Design and issuing

The questionnaire enquired whether the design and issuing system for the home-based record was national, regional or whether there was another process. Eighteen of the respondent countries stated they had a national design and issuing system, whilst three countries had a regional system. Croatia did not provide a response to this question (Figure 7).

Figure 7: Overview of design and issuing system

The questionnaire also asked whether the home-based record was issued to all new-born children, to children with specific long-term health problems, children in specific social/welfare groups, or other groups. All twenty-two respondent countries answered that records were issued to all new-born children.

3.8 Record design and parental entry

The survey also enquired which data items were included in the record and whether parents could enter data for certain categories.

3.8.1 Record design

Countries reported on whether the following categories were in their home-based records: birth and postnatal data; allergies and other alerts; height and weight measurements; immunisation; developmental checks; long term conditions; prescribed medication; urgent referral plans for long term conditions; plan of care and services; and other items (Table 1).

In **Denmark**, the reported categories are the ones that appear most frequently in the Child's Book. Each municipality decides which data should be included and excluded. Additional information is also written by the health visitor as a reminder for parents for the next appointment.

In **Germany**, the types of long-term conditions included in the record are restricted. The child is screened, and information is recorded for pulse oximetry, cystic fibrosis, hip joint dysplasia and luxation, and new-born hearing screening.

In **Hungary**, developmental checks are rarely documented above the age of 6 years because a separate record is created and used by school health personnel. Long term conditions and prescribed medications are also very rarely documented at all ages.

In **Ireland**, the immunisation history of a child is recorded in the parent-held record, called the 'Immunisation Passport'. The passport includes all primary childhood vaccinations and school vaccinations, as well as a vaccination schedule and advice to parents about side-effects from vaccinations.

In **Italy**, there is great variability amongst regions about the design of the record. In Veneto, other categories are: a diary of access/referrals for acute illness; admission to the Emergency Department (recorded by the ED); specialist referrals (recorded by specialist); and vaccinations. In Puglia, periodic health exams, occasional visits, possible therapies, and hospital admissions are recorded. Specialist services rarely document the treatment carried out in the home-based record and coordination from the region is lacking.

In the **Netherlands**, long term conditions are registered in the preventive child health record. However, prescribed medication and referrals are registered in the GP home-based record.

Table 1: A table showing the design elements present in a home-based record across EU/EEA countries

***represents design features present in the full home-based record, present in some health service areas only**

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

3.8.1.1 Countries reporting including other categories in the home-based record

Austria, Bulgaria, the Czech Republic, Germany, Greece, Hungary, Ireland, Italy, Poland, Portugal, and Spain described other health conditions in their home-based records (Figure 8).

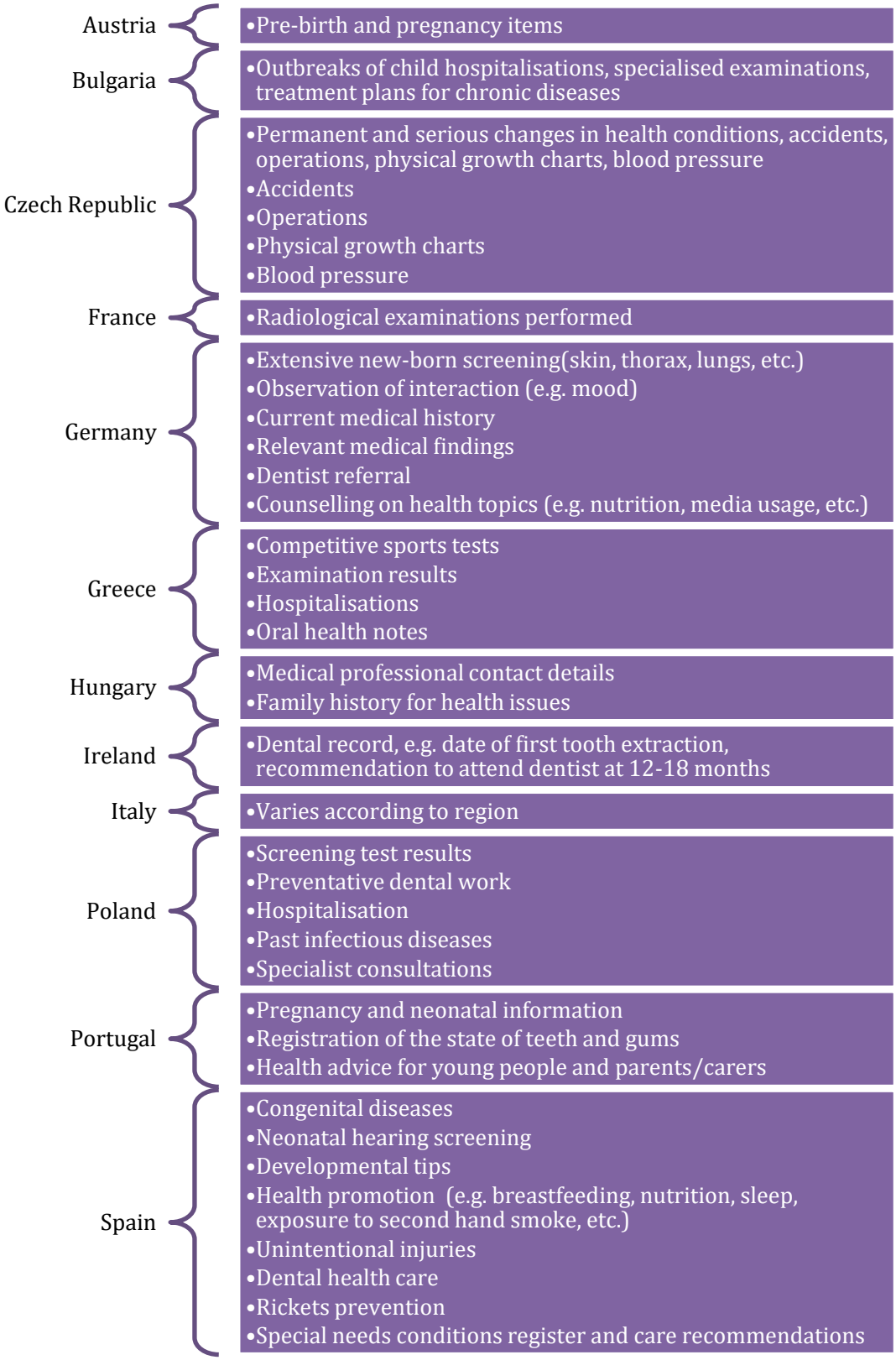

Figure 8: Overview of countries with other health categories recorded in home-based records

3.8.2 Parental entry in the record

Country Agents were also asked if parents could enter the following data in the record: height and weight; achievement of specified milestones; prescribed medication; regular over the counter medication; health observations or concerns; dates and times of medical appointments; and questions about the child they would want to raise at the next doctor's appointment (Table 2).

Bulgaria answered that parents could not enter data into the record. Croatia, Greece, Iceland, Luxembourg, Poland, and Romania did not respond to this question.

In the **Czech Republic**, parents can only make a record in the physical growth charts that are a part of the 'ZOP'.

In **Denmark**, parents can only write notes in the paper copy of the Child's Book, not the electronic version.

If the Child's Health Journal is adopted for use by parents in **Estonia**, data about the health check results of every regular visit and development aspects can be recorded. In addition to this, a short guide for the parent on topics such as nutrition, home pharmacy, and how to treat mild illnesses is also included.

In **Ireland**, are no specific prompts given for parents to write questions that they would like to raise at their child's next appointment. However, there are notes pages available that could be used for this purpose. This is true for health service areas using the full home-based record; this home-based record is yet to be rolled out nationally.

In the different regions of **Italy**, there are different parts of the record that parents can fill out. In Emilia-Romagna and Puglia, parents cannot record information in the home-based record and it is exclusively for paediatricians to complete. In Veneto, milestones and development phases, notes of health problems and questions for the next medical appointment can be recorded by parents. In Campania, personal notes by parents and data from occasional visits can be recorded but there is little space for their additions.

In **Poland**, parents are not able to add data to the record themselves, however it does not restrict them from adding their own comments. Parents are encouraged by healthcare providers to add comments in the record, particularly for child's health and developmental process. However, it is reported that there is hardly ever enough space in the record for parents to write comments.

Table 2: Overview of categories parents can comment on in home-based record

***represents design features present in the full home-based record, present in some health service areas only**

	Height and weight	Achievement of specified milestones	Prescribed medication	Regular OTC medication	Health observations	Medical appointment details	Questions for next appointment
Austria							✔
Bulgaria	No						
Croatia	No response						
Cyprus	✔	✔			✔	✔	
Czech Republic	✔	✔	✔				
Denmark	✔	✔			✔	✔	
Estonia	✔	✔			✔	✔	
France	✔	✔	✔	✔	✔	✔	✔
Germany					✔		
Greece	No response						
Hungary	✔					✔	
Iceland	No response						
*Ireland**	✔	✔			✔	✔	
Italy		✔			✔	✔	✔
Luxembourg	No response						
Malta	✔		✔			✔	
Netherlands	✔	✔			✔	✔	✔
Poland	No response						
Portugal		✔			✔	✔	✔
Romania	No response						
Spain	✔	✔	✔		✔	✔	✔
UK	✔	✔	✔	✔	✔	✔	✔

3.9 Home-based records as an official document

The questionnaire asked whether home-based records were used as proof of eligibility for health services, proof of entitlement to discretionary health or welfare services, or as a prerequisite to other services. Here eligibility is *'the state of having the right to do or obtain something through satisfaction of the appropriate conditions'*[1]. The definition of entitlement is *'the fact of having a right to something'*[2]. France did not answer yes or no to sections of this question and instead stated that the record might be used as an official document in every scenario, at the parent's discretion.

3.9.1 Home-based records as proof of eligibility for health services or proof of entitlement to discretionary health or welfare services

The majority of the respondent countries (82 %) did not use the home-based record as proof of eligibility for health services nor for proof of entitlement to discretionary health/welfare services (Figure 9). Only Austria, Bulgaria, the Netherlands and Poland mentioned that they might use records as a form of proof for either.

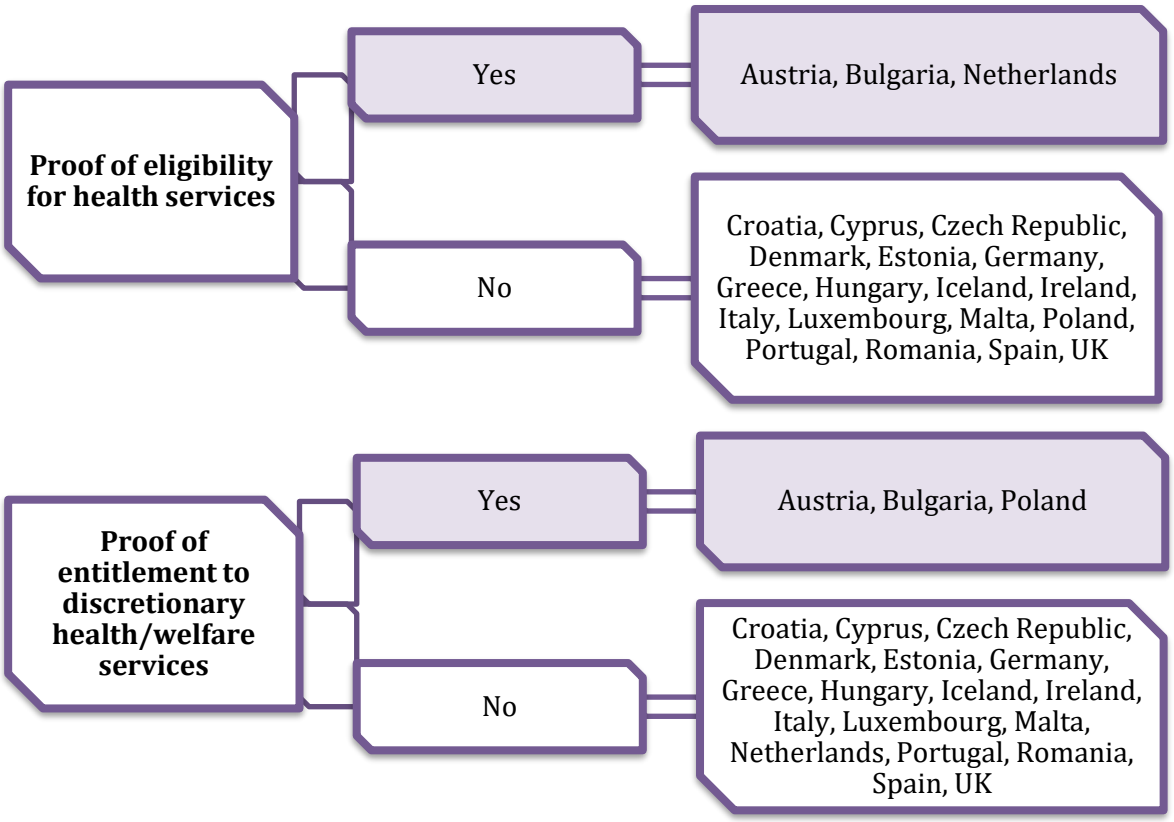

Figure 9: Overview of which countries use home-based records as proof for eligibility to health services or entitlement to welfare services

In **Bulgaria**, when checking the quality of GP work and when an adverse medical reaction occurs, the 'Personal Health Care Card' is required as a document. The record enables assessment of how the GP is performing their duties and how well the child's health status is reflected in the home-based record.

[1] Definition from the Oxford dictionary
[2] Definition from the Oxford dictionary

In **Poland**, the child's health booklet might be used as proof of the child's age when the family try to access welfare, such as financial benefits. In this case, the child's home-based record acts as a form of ID.

3.9.2 Home-based records as a prerequisite to use other services

The majority of respondent countries (64%) did not use the home-based record as a prerequisite to use other services (Figure 10). However, Bulgaria, Greece, Hungary, Malta, Poland, and Romania did mention that they might use records as a prerequisite.

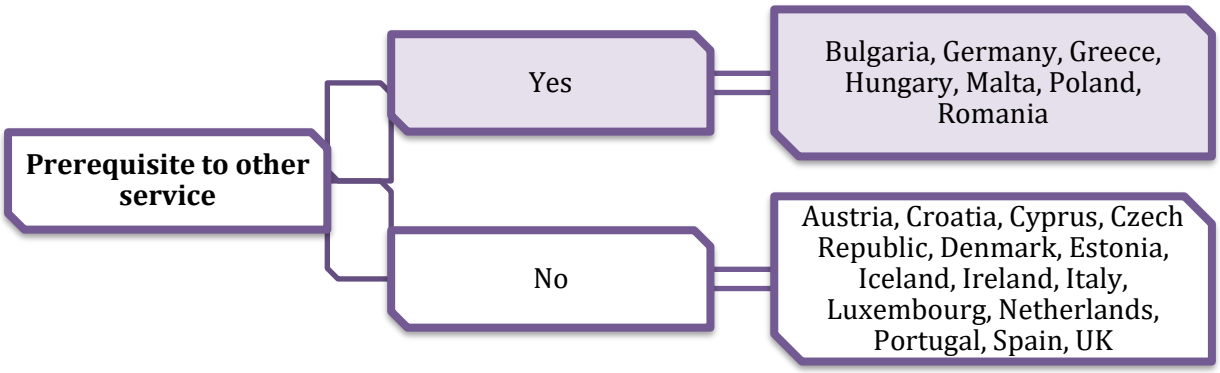

Figure 10: Overview of which countries use home-based records as a prerequisite to use other services

In **Bulgaria**, the 'Personal Health Care Card' travels with the patient. When a child starts kindergarten or school, and at the start of every academic year, the GP is required to send a report of the child's immunisation status to a healthcare professional at the School Health Office.

In **Germany**, the yellow booklet includes a detachable participation card. In some regions, sometimes, authorities, day-cares/nurseries, schools or the youth welfare office can ask for this participation card as proof of medical consultation for complete and age-appropriate vaccination.

In **Greece**, for a child to gain admission to school to 1st/4th grade of primary school, and 1st grade of secondary school a 'Student Personal Health Record' is required. This record includes relevant health information, such as immunisation and serious health conditions. This information is taken from the Child Health Booklet.

In **Hungary**, when children attend day-care services or schools, the home-based record is given to the school nurse so that she may check that the child has had all compulsory vaccinations.

In **Malta**, the record and vaccination certificate are sometimes used as a part of the admissions process to attend church run schools and independent schools.

In **Poland**, the child's health booklet can be used as proof of ID, e.g. for discounted transport.

3.10 Coverage and utilisation of the home-based record

The coverage and utilisation of home-based records was also investigated.

3.10.1 Coverage of home-based records

Country Agents were asked if home-based record coverage was universal nationally, whether it varied by region, varied by health insurance company, or whether it varied by health care provider.

The majority of the respondent countries (78%) stated that coverage was universal nationally. In Denmark, Italy, and Romania it varies by region and coverage in Croatia and Estonia varies by health care provider. Since the home-based record in Estonia is optional, the use of the record is dependent on how much encouragement parents receive from the healthcare provider.

In Germany, general coverage is universal nationally for all main examinations. There are a few additional check-ups in Germany that are not covered by all health insurance companies and therefore, these are the ones that vary (Figure 11).

Figure 11: Overview of how coverage of home-based records varies

3.10.2 Utilisation of home-based records

Utilisation was also considered. Country Agents were asked if home-based record utilisation was over 90%, over 75%, 50-75%, 25-50%, or under 25%. The value refers to consistent use by parents for recording their child's health and health behaviour. Fourteen of the respondent countries reported over 90% of consistent use of the record (Figure 12). Croatia, Estonia, Ireland, and Luxembourg have no exact data on the utilisation of home-based records.

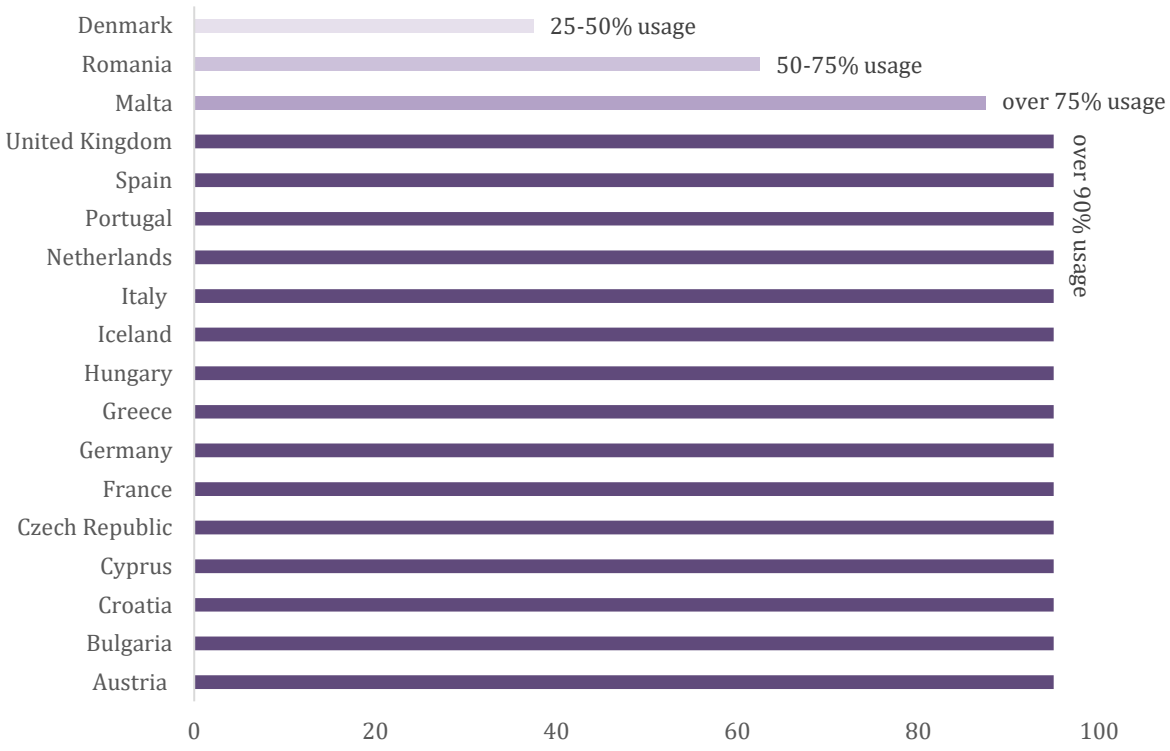

Figure 12: Parental utilisation of home-based records

Upon asking health visitors in **Denmark**, usage of the Child's Book is reported as 33%. The use of the book also depends on how and to which extent the parent's municipality uses the book in their healthcare work.

In **Germany**, utilisation of the record is over 90% for children under the age of 2 until the U7 examination. At later stages in life, when there are the other stated examinations, there is a decrease. At the U8 test, utilisation falls to 89% and 86.4% at U9.

In **Italy**, usage is over 90% in Emilia-Romagna and Veneto. The value of usage is not known at national level.

In **Poland**, research on the utilisation of the child's health booklet does not occur and therefore it is difficult to report an accurate utilisation percentage. However, primary care physicians state that health booklet usage is high in the first year of a child's life. As the child grows older, parents often forget to bring the record to medical appointments and usage decreases. Parents are obliged to use the home-based record to detail their child's progress, however there is no legal consequence if parents do not use it regularly.

3.11 Digital records and data sharing

When asking about home-based records, digitisation and data sharing from records were also considered.

3.11.1 Digital home-based records

Countries were asked whether the record existed as a paper booklet only, an electronic tablet or app version only, a portal system only, a choice of versions of standard system, or whether electronic versions were not yet official/competing with official systems.

The majority of the countries (87%) only have a paper booklet as the form of the home-based record (Figure 13).

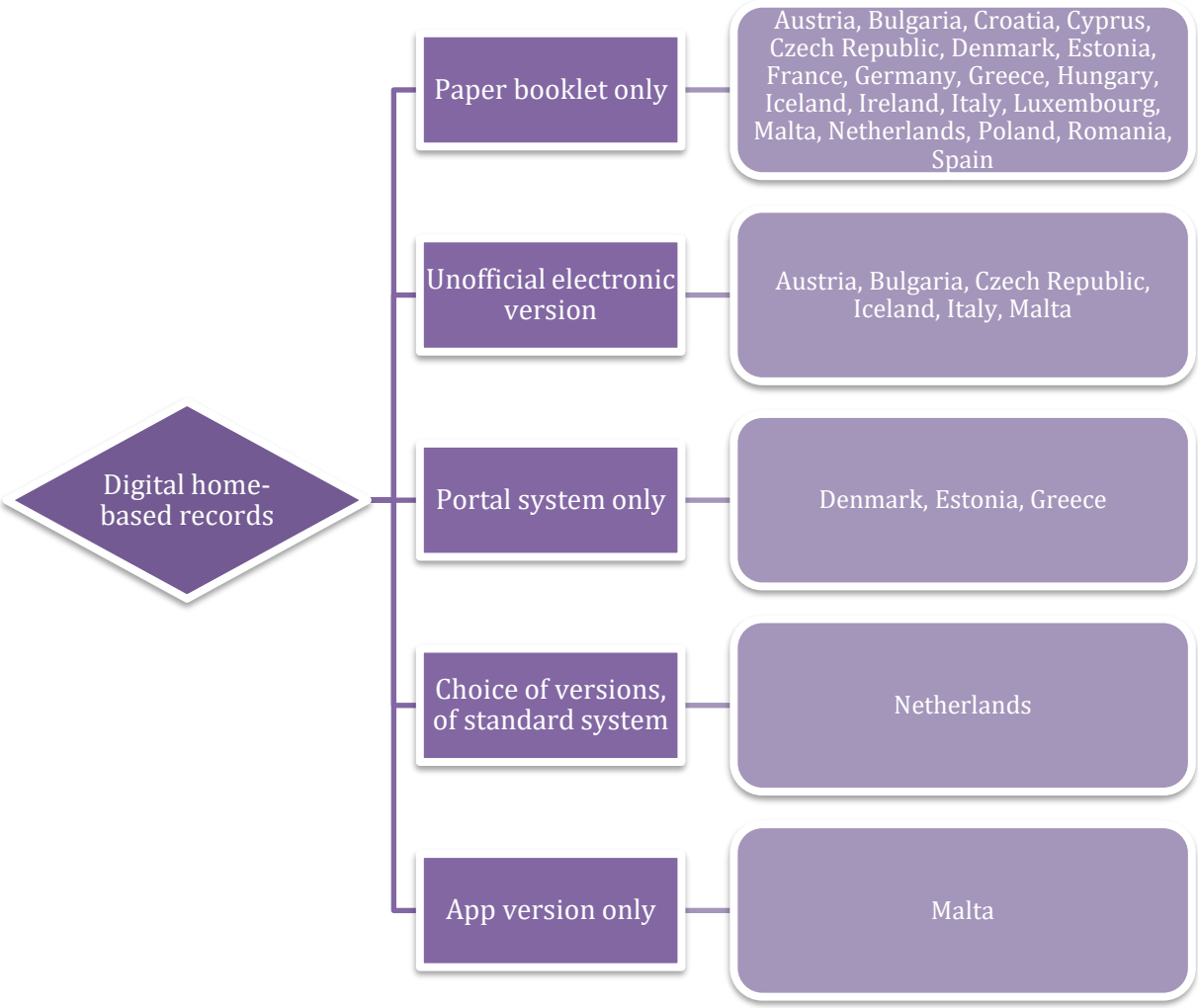

Figure 13: An overview of the form of the home-based record

Future plans in **Austria** include integrating the mother-child passport into the Austrian electronic health records, ELGA.

In **Bulgaria**, digital versions of the personal health care card have been developed as a means of furthering eHealth initiatives. Although they are yet to be rolled out nationwide, a projected implementation date of 2019 has been set for usage in broad practice.

The **Czech Republic** has a paper copy but also an unofficial electronic version of the home-based record. To access the electronic version, parents must login and register to the National Institute of Public Health managed server that gives access to 'Zopik- Internet friend', a programme to oversee child healthcare. The creation of a profile, with a password, allows parents to view this information on a computer or even on their smartphone. 'Zopik' allows health events to be recorded and provides an overview of the child's health development. It also sends parents reminders about mandatory health examinations and vaccinations and supplies information through articles written by doctors and experts.

In **Denmark**, whether the record is paper or digital is determined by the municipality in question.

In **Estonia**, child health information is recorded in a digital health record, available to parents via the eHealth system.

In **Iceland**, all vaccinations are electronically registered in the child's electronic health record. This information is available and accessible, in real time, to all state-run health institutions. Additionally, a specially designed portal for access to health services, 'Heilsuvera', gives parents access to their child's immunisation records, appointments, and drug prescriptions.

In the **Netherlands**, most services provide a paper booklet only. However, there are some services that experiment with parent-held child records, which mimic the 'growth booklet'.

In **Portugal**, there is currently only one standard paper version of the home-based record. However, a digital version, which includes an app, is being developed. Once this has been established, parents will be given the choice of paper or digital, depending on their preference.

3.11.2 Systematic data sharing from home-based record

Country Agents were asked whether there was a systematic means of sharing data between the home-based record and: a) the child's primary care record, b) the child's public health/community health record, and c) the Immunisation Information System. France did not answer yes or no to sections of this question and instead stated that information from the record might be shared in every scenario, at the parent's discretion.

3.11.2.1 Primary care record

Responses from Country Agents showed that ten countries shared data between the home-based record and the primary care record, whilst eleven countries did not (Figure 14).

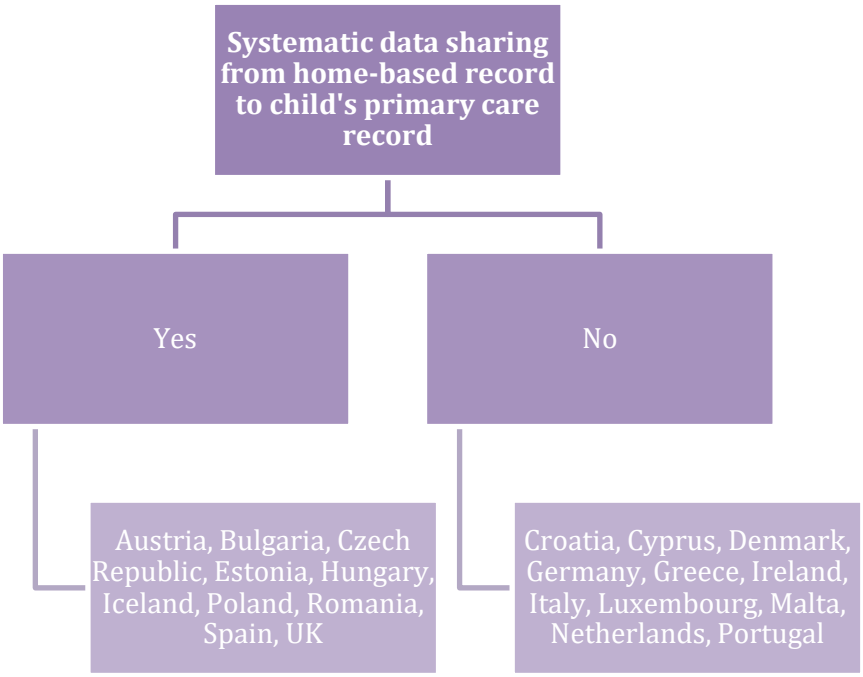

Figure 14: Overview of countries who share data between home-based records and primary care records

In the **Czech** Republic, the paper version of the record is given to the parents by the GP, who can fill this record in themselves. The record can only be filled out if the child is registered with the GP. Most parts of the 'ZOP' are filled in and stamped or signed by the GP. The electronic record is an immunisation record, which is separate to the 'ZOP'. However, the same data from the 'ZOP' are entered to the EHRs of the GP for Children and Adolescents (the Registering PLDD).

In **Hungary**, primary care health professionals (GPs, primary care physicians, visiting nurses, etc) add data to the record by hand. Often, the spaces for writing detail are very small and data sharing is accidental and less informative. The electronic health record of a Hungarian child is much more detailed and contains more information than the home-based record.

In **Poland**, during regular visits to the GP, information is added to the primary care record by the doctor about the child's health status, from the home-based record.

3.11.2.2 Public health or community health record

Responses from Country Agents showed that nine countries shared data between the home-based record and the public health record, whilst twelve countries did not (Figure 15).

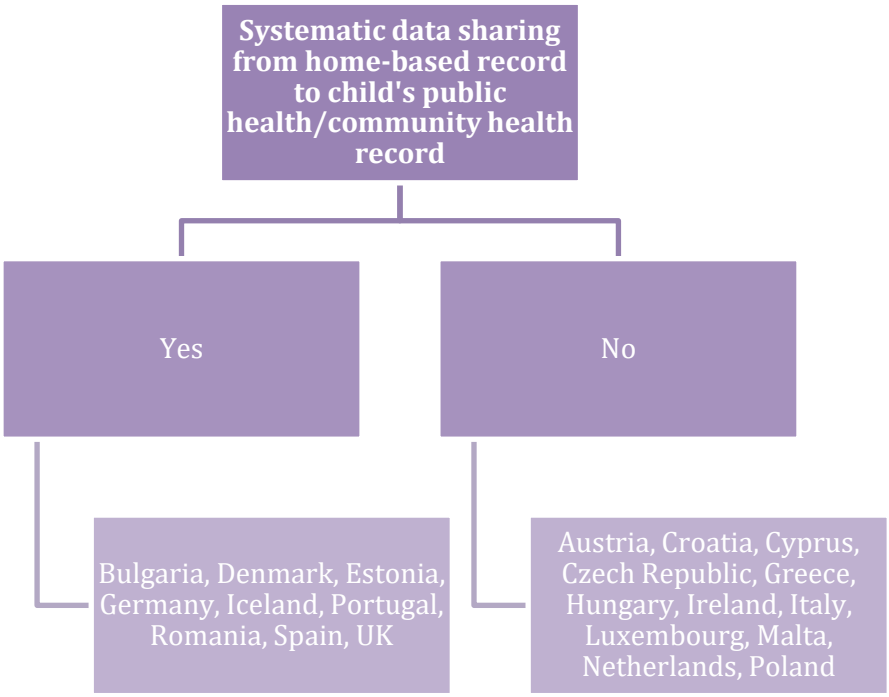

Figure 15: Overview of countries who share data between home-based records and public health records

There are no child public health records in the **Czech Republic**. The only longitudinal health record for children is the one managed by the registering GP for Children and Adolescents (registering PLDD).

In **Germany**, the examinations stated in the yellow booklet are highly recommended and have a high level of attendance. If parents miss their child's doctor's appointment, they will get a reminder, in some states. After this reminder, if they fail to attend once again, responsible authorities are informed to visit the parents and child. Though examinations may not be enforced in other states, child protective services check for child endangerment all over Germany.

In Italy, there is no sharing between the record and a child's public health record except in Emilia-Romagna.

3.11.2.3 Immunisation Information system (IIS)

Responses from Country Agents showed that twelve countries shared data between the home-based record and the IIS, whilst six countries did not, and three countries did not have a separate IIS system (Figure 16).

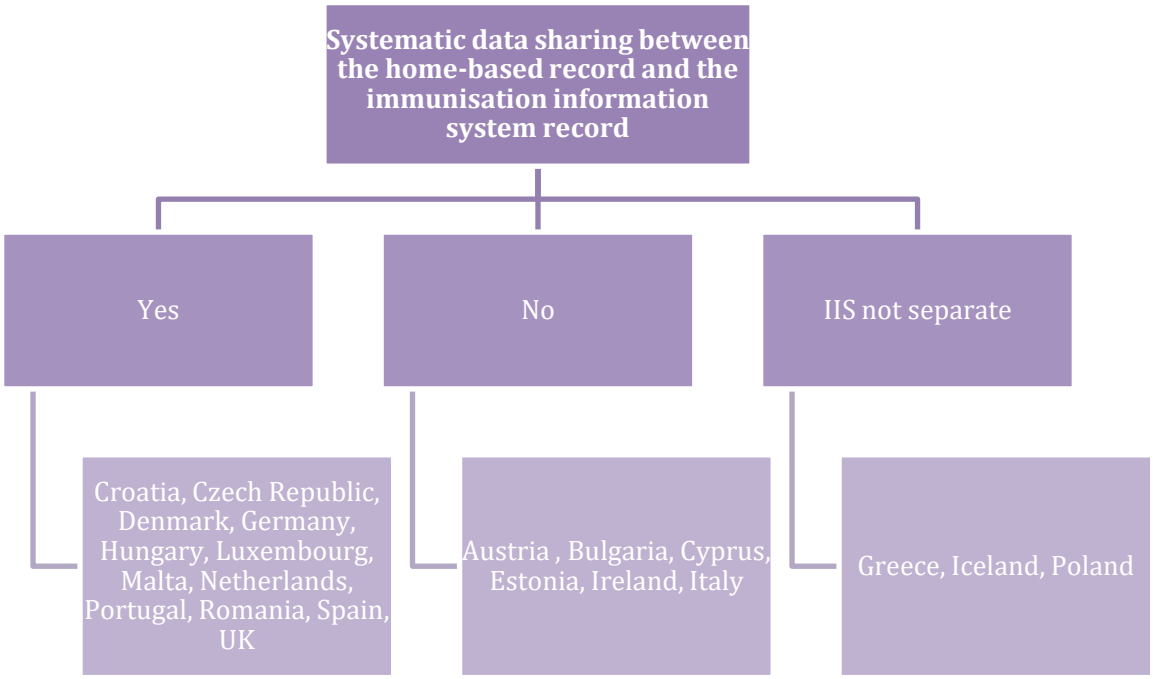

Figure 16: Overview of countries who share data between home-based records and the immunisation information system

Countries who have systematic sharing between the home-based record and the IIS

In the **Czech Republic**, a 'Vaccination Record and Severe Illness Record' hold information on children's vaccinations. This same data is also available on electronic health records from the child's respective registering GP for Children and Adolescents (registering PLDD), who is responsible for entering this data.

In **Germany**, there is a separate immunisation record called 'Impfpass'. However, the yellow booklet also includes information about up-to-date vaccinations and those that are remaining.

In **Hungary**, all vaccinating healthcare professionals (GPs, primary care physicians or school doctors) must record the date and type of vaccine administered within the booklet. Primary caretakers also must enter this data in the electronic health record. Currently, however, school doctors have no access to the electronic health records nor to the 'EESzT' (a cloud-based health domain). School nurses register vaccinations given by the school doctor and transfer data to regional public health institute services.

In **Spain**, the date and type of vaccine administered to the child is recorded within the home-based records. This data is also entered in the child's home-based record.

Countries who don't have systematic sharing between the home-based record and the IIS

In **Austria**, the immunisation passport is a part of the mother child passport, where it is separated and used alone when the child is in kindergarten or school.
In **Cyprus** there is neither a primary care record, nor a public health record, nor an IIS record, so no data sharing occurs.

In **Italy**, there is no systematic sharing between the IIS and the home-based record, except in Emilia-Romagna which is an exception.

Countries where the IIS is not separate from the home-based record

In **Greece**, the IIS is still under construction. In **Poland**, the official vaccination card is kept by the healthcare provider. A copy of the vaccination card is present in the home-based record.

3.11.3 Methods of data sharing

The questionnaire asked that if data sharing did occur, then by what means this was achieved. The majority of the respondent countries (74%) who share data reported that the method was by the health professional writing in both records. Five countries mentioned there was no data sharing and only Denmark and Estonia claimed to share via electronic transfer from one system to another. Denmark, Estonia, France, Greece, Malta, and Netherlands all reported having more than one method of data sharing (Table 3).

Table 3: An overview of the methods of data sharing from the home-based record

	Health professional writing in both records	Multi-copy forms: copy added to each record	Electronic transfer from one system to other(s)	Other means of sharing	There is no data sharing
Austria	✓				
Croatia					✓
Cyprus					✓
Czech Republic	✓				
Denmark	✓	✓	✓		
Estonia	✓		✓	✓	
France	✓	✓			
Germany				✓	
Greece	✓				✓
Hungary	✓				
Iceland	✓				
Ireland					✓
Italy	✓				✓
Malta	✓	✓			
Netherlands	✓	✓	✓		
Poland	✓				
Portugal	✓				
Romania	✓				
Spain	✓				
UK	✓				

In the **Czech** Republic, the data on immunisation is entered by the registering GP for Children and Adolescents (registering PLDD) into their electronic health records system. The system can provide alerts and keep track of necessary immunisations. This data is then hand written into the 'Vaccination Record and Severe Illness Record' and includes the date and batch/lot identification.

In **Denmark**, health nurses have their own system. Relevant data from their system is transferred to the home-based record. When the paper-based record system is used, the information is first written in the paper book and later in the health visitor's record system. If the electronic version is used, all information is registered in the health visitor's record system and some of this information is transferred to the 'Child's Book'.

In **Estonia**, child health information is stored in the digital health record, which can be shared between different health care providers through the eHealth system.

Germany mentioned other methods of data sharing. The Country Agent reported that there is no systematic means of sharing data between the yellow booklet and the child's primary care record. Every doctor decides themselves how they document health results and notes.

3.12 Home-based records for health promotion

The survey asked if there was any systematic health promotion activity linked to the home-based record, additional to that given at the routine appointments. Of the respondent countries, 14 countries answered that there was no health promotion activity and eight answered that there was (Figure 17).

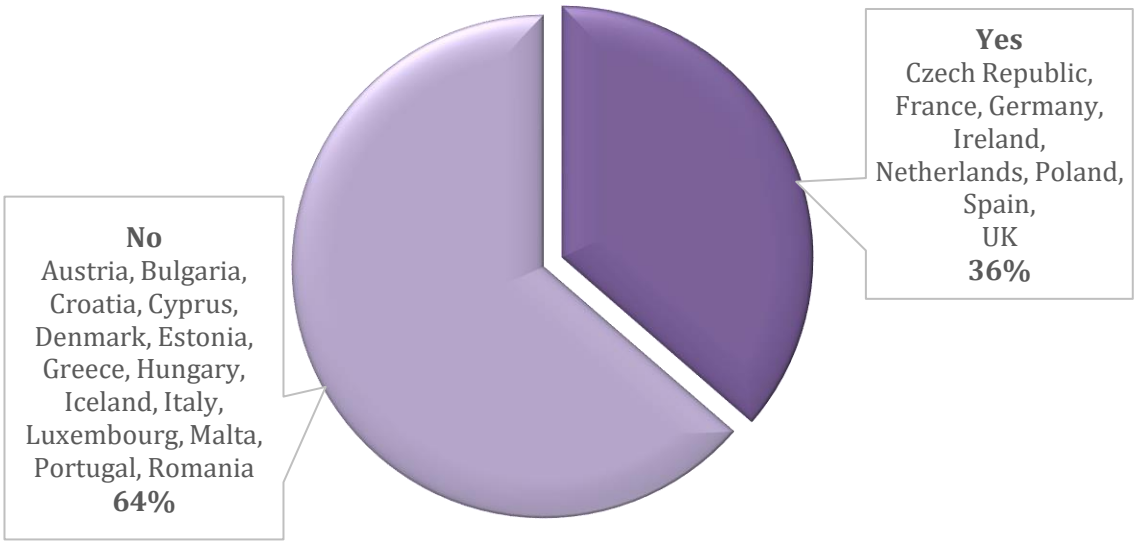

Figure 17: An overview of health promotion activity linked to home-based records

In **Germany**, the yellow book contains a lot of advice for health promotion activity. This includes areas such as: accident prevention, nutrition, rickets prophylaxis with vitamin D, vitamin K prophylaxis, information on vaccination/arrangement of vaccination appointments, information on available support, UV protection, addiction, media usage, language advice: supporting the mother's language and German, and advice on oral hygiene and tooth-friendly nutrition.

In **Ireland**, the home-based record includes health promotion content. For example, information about infant feeding, promotion of breast feeding, immunisation timetable, information of prevention of injuries and accidents, information on prevention of cot death, and reminders about schedules for dental review. These features are only present in the health service areas where the full home-based record has been implemented; this record has not yet been rolled out nationally.

In the **Netherlands**, the 'Growth booklet' provides information on various topics that are linked to the different life stages of the child, such as infant feeding, safety, nutritional behaviour, regulation, hearing and speaking, and so on. In **Poland**, the date of the next planned preventive visit is written in the home-based record. In the UK, letters or text messages are sent as reminders for appointments.

There is no health promotion in the record in **Denmark**. Instead, a health visitor uses the home-based record to remind parents about vitamin D drops and immunisations.

3.13 Parental involvement in design of record

The survey also asked whether there is a systematic means of parents being able to influence the design or use of the home-based record. Eighteen of the respondent countries replied no, whilst Estonia, Ireland and the Netherlands replied yes (Figure 18).

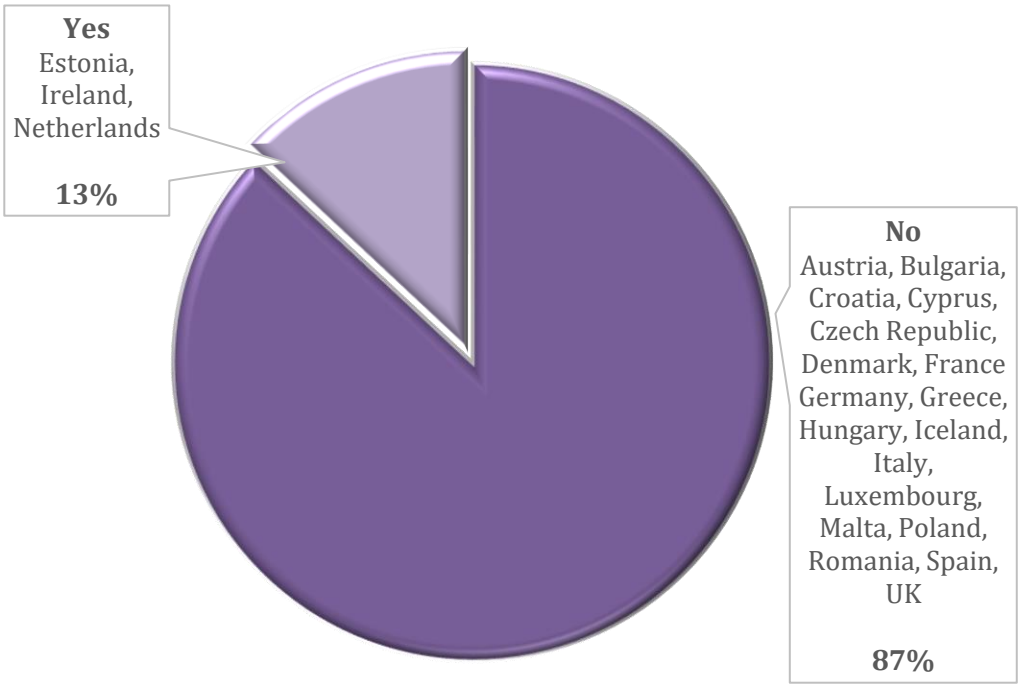

Figure 18: An overview of parental involvement in design elements of the home-based record

Ireland and the **Netherlands** have procedures in place for parental influence on the design of the home-based record. In **Ireland**, a part of 'The Nurture Programme: Infant Health and Wellbeing' is the development of Standardised Health Records for parents and professionals. A 'Guiding Principle' of this aim is engagement with parents, thereby creating a channel for parental involvement in record design. This is only present in the health service areas where the full home-based record has been implemented; this record has not yet been rolled out nationally. In the **Netherlands**, at national level, the National Centre on Child Health has panels of children and youth to comment on and co-create the various issues relevant for child health.

In the **Czech Republic** the home-based records are produced and authorised by the Ministry of Health and other professional bodies. Therefore, there is no parental involvement in record design in the Czech Republic.

3.14 Further information from countries who have home-based records

Croatia, the Czech Republic, Estonia, Ireland, Italy, Luxembourg, Portugal and Romania supplied additional information about home-based records in their countries.

Croatia

Croatia has a home-based record referred to as 'the child's health booklet'. Further information provided shows usage of this booklet is legislated through their Ministry of Health and Social Welfare. Article 122, paragraph 5 of the Health Care Act describes in detail how and why the booklet should be used, and specifies other details regarding data protection, issuance, and maintaining the record. A copy of each child's record is collected and registered by a county coordinator, who is appointed by the Minister of Health. Aggregate data is submitted to the Croatian Institute of Public Health and the Reference Centres for Child Growth and Development.

Czech Republic

Home-based records in the Czech Republic are termed the 'Health and Vaccination Record of Child and Adolescent', or 'ZOP'. These records exist in a paper form and are produced and authorised by the Ministry of Health, in conjunction with other public health and, child and adolescent health stakeholders (Professional Society of the Practical Doctors for Children and Adolescents of the Czech Medical Association, The National Institute for Public Health, etc.).

Estonia

In Estonia, parents are given the 'Child's Health Journal' or 'lapse tervisepäevik' in the maternity ward upon the birth of their child. Though this record is available as a home-based record, data recording is not mandatory and therefore many parents opt out of using the booklet. The booklet allows parents to record health check results of every regular visit, developmental results and includes a short guide on topics such as nutrition, home pharmacy, and how to treat mild illnesses is also included. Other records include a paper or electronic immunisation passport and digital eHealth records, generated upon visiting a doctor. These eHealth records are made available to the government and health professionals when required.

France

In France the home-based record is called the 'carnet de santé' or the health card. This document contains medical records of a child up to the age of 18. Its use is reserved for health professionals and its consultation subject to parental consent.

Ireland

The reported home-based record in Ireland is a small vaccination booklet, which allows recording of immunisation details only. A more comprehensive record exists but is only used in some health service areas of the country and has not yet been rolled out nationally. The Nurture Programme - Infant Health and Wellbeing is an Irish initiative to improve information and professional supports to parents from pregnancy through to the first three years of their baby's life. An action item of this programme is to develop a 'Standardised Health Record for Parents and Professionals'. There is a national policy intention to develop and roll out a standardised home-based record across the whole country [9,10]. Engagement with parents in the design and development of such a record is also a stated policy intention.

Italy
In Italy, a law regulates a national convention with Family Paediatricians. This law states that every child from birth to 14 years of age must be assigned to a Family Paediatrician, or a GP if no paediatricians are available in the geographic area. Each paediatrician is allocated up to 800 children and must provide both outpatient and home primary care visits. One of their responsibilities is to keep an individual 'health book', which is updated for the child upon every visit to the paediatrician. The record is paper based and is parent-held, however. Additionally, the paediatrician must also have an electronic health card for every child.

Though the law is national, there is considerable regional variability. Answers for this report cover six Italian regions (3 from the north, 1 central region, and 2 southern regions), which account for approximately 60% of the Italian population. These regions are: Campania, Emilia-Romagna, Lazio, Lombardy, Puglia, and Veneto.

In Campania, a regional 'Paediatric Health Booklet' is given to parents and is compiled by healthcare professionals in different parts of the healthcare system, e.g. at birth, by family paediatricians, and vaccination centres.

In Emilia-Romagna, there no universal home-based record. Instead, each province manages its own record. Additionally, there are some primary care programs for electronic records that some paediatricians use.

In Lazio, due to economic problems, there is no individual home-based record that is shared with parents. Instead, a computerised record of a medical record exists, which contains information about periodic health examinations. All this information is filled in by a paediatrician.

In Lombardy, the use of a home-based record has been absent for many years. Instead, the paediatrician prints out reports from visits and selectively gives to the parents some to take home.

In Puglia, the regional 'Health Book' is given to parents when they register with a family paediatrician at a District office.

In Veneto, a home-based record called the 'Health Book' is given to the parents upon the birth of their child.

Luxembourg
In Luxembourg, the home-based record is called the 'medical children booklet'. This record is handed to parents at the time of their child's birth. Although there is no scientific evaluation surrounding the usage of the booklet, there has always been an emphasis on the importance of good child care. Efforts in redesigning the record, based on France's design, have been made but are yet to be rolled out.

Portugal
The home-based record in Portugal is called the 'Child and Youth Health Bulletin'

Romania
In Romania, there are two records: the 'vaccination booklet' and the 'pregnant women booklet'.

3.15 Further information from countries who do not have home-based records

Finland, Latvia and Norway, countries who declared not having a home-based record, gave details on the records that are present in their country instead.

Finland

There is currently no home-based record in Finland. In its place, presently there are local solutions for the home-based record, which are not yet linked to Finland's online electronic health record, the 'National Patient Data Repository'. There are plans and pilot projects in place to improve this and add applications to the 'National Patient Data Repository' so that parents may enter data about their children, themselves. However, this will require an update to Finnish legislation, which is currently underway.

Latvia

In Latvia, a separate paper-based immunisation passport, which gives a full overview of the patient's vaccination history, is given. Parents do not make any comments in this passport, which is issued by a health practitioner and is universal nationally.

However, there is currently no home-based record. Instead, a patient is given a medical record, which is owned by the medical institution. The record travels with them if they change physician but is transferred from professional to professional. The patient can request to have extracts and copies of the record free of charge, which must be delivered within three working days, according to the 'Patients' Rights Act'. However, patients only have the right to request this free of cost twice a year, according to the 'Personal Data Protection Act'. A fee is applied to any extra copies requested.

Additionally, there is also a medical document given to pregnant women called the 'Mother's passport'. In this document, information about their pregnancy, such as medical history, laboratory tests, and ultrasound results, are recorded in accordance with a Cabinet Regulation (No. 25, 'Procedures for Keeping Medical Documents'). The 'Mother's passport' is a paper record and is given to the mother between week 16 and 18 by her gynaecologist. This record must be brought to the birth.

Norway

In Norway, children have a core medical record owned by healthcare institutions rather than a home-based record. Parents have permissions to see and read this record, but they are restricted from writing in the child's record. Alongside this, an immunisation system also exists (Norwegian Immunisation Registry, SYSVAK), from which a paper copy of essential information can be obtained. Neither of these are parent held or owned.

3.16 Other forms of home-based records

Whether countries have alternate unofficial equivalents to home-based records, made available on the internet, by pharmacies, through unregulated applications (apps), or other retail/commercial sources, was questioned.

Seven countries, Croatia, Cyprus, Greece, Iceland, Luxembourg, Malta, and Portugal did not know of or mention any other forms of home-based records. Additionally, Germany and Spain mentioned there were no known reliable forms.

In **Austria**, a pilot test is being planned and prepared to link and share the home-based record to the Austrian Electronic Health Record, ELGA. Alongside this, an e-immunisation and e-prescription system will also be linked to the ELGA.

In the **Czech Republic**, as mentioned before, the National Institute of Public Health manages a server to link to 'Zopik', an online platform to monitor the health of a registered Czech child. The programme, available on mobile phones, also sends notifications about future appointments and vaccinations, and provides health literature written by doctors and experts.

In **Denmark**, no other unofficial equivalents link up to public health data. There are however, private companies that offer paper based and electronic solutions who may want to keep track of their child's development.

In **Estonia**, ICT devices are used with overweight and obese children as a part of the Clinical-Community Health Promotion spanning 2017 and 2018.

In **France**, trials for electronic vaccination certificates have been rolled out in some regions, such as in Auvergne-Rhone Alpes. Additionally, it is anticipated that a shared medical record will be available electronically for all patients, by 2020.

Hungary mentioned a previous unofficial home-based record used in the late 90's that was a colourful book with advertisements placed between professional pages, information on nutrition and feeding, and percentile charts and graphs. The home-based record today is black and white, and contains no graphs, advertisements, or supportive graphs or charts.

In **Ireland**, there are numerous apps that can be accessed as alternative, unofficial equivalents. Additionally, several hospitals have developed patient passports for children with cancer and complex healthcare needs. In Ireland, cancer care for children is recorded in a passport, which includes information about their condition, treatment, their record of diagnostics, and a record of training that has been delivered to the parents.

In **Italy**, there are 'Periodic Health Examination' sheets that interact with the management software of the Primary Health Care Paediatrician.

In the **Netherlands**, many apps exist as unofficial sources of home-based records. The quality of these apps is evaluated by the association of regional public health services.

Although **Norway** stated having no home-based records, there is a 'Smart Caring' app, which gives information on child development and how to care for children with diseases. The app is developed and owned by the Norwegian University of Science and Technology.

Poland gave examples of individual cases using electronic solutions. One is an e-booklet for child health, which is a private internet portal that allows medical data exchange between selected private providers. There are also a few apps that act as equivalents to home-based records. The 'Hefi' app in particular is a promising project created by a Polish doctor, which is currently in the testing phase.

In **Romania**, there is a pilot project to create digital records for children, but this has not yet been implemented. Additionally, a home-based record, developed by UNICEF Moldova, exists for use in Moldova but is written and developed in the Romanian language.

In the **UK**, the development of electronic personal child health records is driving the development of alternative suppliers. There are published standards for an e-redbook, publish by the Royal College of Paediatrics and Child Health.

3.17 Key Points

The following presents a summary of the results from this questionnaire. The statistics all refer to respondent countries who stated having a home-based record.

- In this MOCHA study, twenty-seven out of thirty response were collected. Of these twenty-seven countries, 22 countries reported having some form of home-based records that matched the MOCHA definition[3], in all or parts of the country.

- Five countries- Finland, Latvia, Lithuania, Norway, Slovenia- reported having no home-based record.

- Four countries- Denmark, Italy, Romania, Spain- mentioned some form of regional variations in home-based records.

- Three countries- Austria, Germany, Romania- mentioned the inclusion of maternal health within the home-based record.

- 50% of countries cover children from birth to 18 years of age.

- 73% of respondent countries with home-based records issue them at birth. Four countries report issuing them at two separate time points.

- 59% of countries reported that parents received the home-based record in the discharge pack from the maternity service at birth. Other reported methods include digital downloads and home-visits from health visitors.

- 59% of countries reported that they had a reliable process for issuing children moving into a country after birth with a home-based record. Most of these countries describe this process as parents having to register with a primary care physician to receive the record.

- 68% of countries reported that their home-based records were issued by their health system. Other methods include delivery by healthcare professionals or the Ministry of Health.

- 86% of countries reported that the design and issuing system for their home-based record was national, rather than regional or another process.

- 100% of countries reported that home-based records were given to all new-born children, and not just to a specific category (e.g. children with specific long-term health problems).

[3] a record, traditionally a paper booklet, but possibly on a digital platform, in which a health professional records key information about the child including administration of routine preventive services, growth data and development data; in some cases, the parent(s) and also other professionals can also make entries. The home-based records are normally issued at birth and held by the parents.

- Results from enquiring about data items included in the home-based record showed that the most commonly included data items were: birth and postnatal data; allergies and other alerts; height and weight measurements; immunisations; and developmental checks.

- 68% of countries reported that parents could enter data themselves, in the home-based record. The most commonly reported features are: height and weight; achievement of specified milestones; health observations; and medical appointment details.

- 82% of countries reported not using the records as proof of eligibility for health services, nor for entitlement to discretionary health/welfare services. Surprisingly, in Bulgaria, the home-based record was reported as being used to check the quality of GP care or performance.

- 64% of countries reported that they did not need this record as a prerequisite to use other services. Countries reporting they did need the home-based record for services mainly reported its need for school admission or proof of immunisations for schools.

- 78% of countries reported that home-based coverage was universal nationally. Three countries- Denmark, Italy, and Romania- mentioned that coverage varies regionally.

- 74% of countries reported that home-based record utilisation was over 90%. According to this MOCHA study, this value refers to consistent use of the record by parents for recording their child's health and health behaviours. Of these countries, Germany provided figures to show the decline of usage as the child grows older.

- Currently, 87% of countries reported that the home-based record exists as a paper booklet only. Many countries however, reported future plans for digitalising the home-based record.

- 52% of countries did not share data between the home-based record and the primary care record, and 57% did not share data with the child's public health record. However, when it came to data sharing between the home-based record and the IIS record, 57% countries reported that they did share data.

- 74% of countries who share data, do so by health professionals writing in both records.

- 64% of countries reported that there was no systematic health promotion activity linked to the home-based record.

- 87% of countries reported there was no systematic means of parents being able to influence the design or use of the home-based record.

4. Comparison of Findings with TechNet21 Database

This report provides an overview of the current home-based records available to children and parents in the 30 EU and EEA countries studied by the MOCHA project. A second source is a website called TechNet21 [11], compiled primarily by immunisation professionals, providing a catalogue and repository of home-based records used in many countries around the world. The methodology used for MOCHA was a semi-structured questionnaire (Chapter 2. Methodology), whilst TechNet21 provides PDF files of home-based records.

TechNet21 describes a home-based record as a "vaccination record issued by a health authority on which an individual's history of vaccinations received from all healthcare providers is recorded and is maintained in the household by an individual or their caregiver and brought to the health clinic/post to be completed by a health worker at each time of vaccination" [11].

The MOCHA definition of a home-based record is "a record, traditionally a paper booklet, but possibly on a digital platform, in which a health professional records key information about the child including administration of routine preventive services, growth data and development data; in some cases, the parent(s) and also other professionals can also make entries. The home-based records are normally issued at birth and held by the parents". Thus, the MOCHA study takes a holistic view of child health, not restricted to immunisation.

A comparison of results between MOCHA and TechNet21 must consider these differences in definitions and methodologies.

An overview of the results from the two sources shows that MOCHA was still awaiting data from three countries and had five countries report no home-based records. Meanwhile, TechNet21 was missing data from fourteen countries (Table 4).

Table 4: A comparison between MOCHA and TechNet21 for home-based records

COUNTRY	MOCHA results	TechNet21 results
Austria	✓	No data
Belgium	Awaiting response	✓
Bulgaria	✓	No data
Croatia	✓	✓
Cyprus	✓	No data
Czech Republic	✓	✓
Denmark	✓	✓
Estonia	✓	✓
Finland	No HBR reported	No data
France	✓	✓
Germany	✓	✓
Greece	✓	No data
Hungary	✓	✓
Iceland	✓	No data
Ireland	✓	✓
Italy	✓	No data
Latvia	No HBR reported	✓
Lithuania	No HBR reported	No data
Luxembourg	✓	No data

Malta	✓	✓
Netherlands	✓	✓
Norway	No HBR reported	No data
Poland	✓	No data
Portugal	✓	No data
Romania	✓	✓
Slovakia	Awaiting response	No data
Slovenia	No HBR reported	✓
Spain	✓	✓
Sweden	Awaiting response	No data
United Kingdom	✓	✓
Total	22	16

The comparison indicates both sources match on having a home-based record in thirteen countries. In five countries, the sources are either awaiting a response, have reports of no records, or have no data available. In three instances, TechNet21 indicates the presence of a home-based record where MOCHA is either awaiting a response or where Country Agents have reported no records. Finally, in nine cases, MOCHA has results where no data is present from TechNet21.

In addition to reporting the presence of home-based records, countries also reported the name of the record (Table 5).

Table 5: Overview of the names of the home-based record in each country

COUNTRY	MOCHA- record name	TechNet21- record name
Austria	'Mutter-Kind-Pass'	No data
Belgium	Awaiting response	'Vaccineatiekaart'
Bulgaria	'Personal Path-Prophylactic Card'	No data
Croatia	'The Child's Health Booklet'	'Iskaznica imunizacije' (certificates of immunisation)
Cyprus	'The Booklet'	No data
Czech Republic	'Health and Vaccination Record of Child and Adolescent', or 'ZOP'	1. International certificate of vaccination 2. 'ockovaci prukaz' (certificate of vaccination) 3. 'Zdravotni a Ockovaci prukaz' (health record, separate versions for girls and boys)
Denmark	'Child's Book'	'Vaccinationer' (immunisation record)
Estonia	'Child's Health Journal' and 'Immunisation passport'	'Eesti Immuniseerimispass' (passport of immunisation).
Finland	No HBR reported	No data
France	Carnet de santé	1. 'Carnet de vaccination' (immunisation card)- for adolescents and adults 2. 'Carnet de santé' (health record)
Germany	1. 'Untersuchungsheft' or 'the yellow booklet' 2. 'Mutterpass', a maternity record 3. 'Impfpass', immunisation record	1. International Bescheinigungen uber impfungen oder prophylaxemassnahmen' (International certificates of vaccination or prophylaxis) 2. 'Kinder Untersuchungsheft'
Greece	'Student Personal Health Record'	No data
Hungary	Name not mentioned	1. 'oltasi konyv' (vaccination booklet for children under 14 years of age)

		2. 'Védőoltások adatlapja' (vaccine administration card)
Iceland	'Heilşufars-skrá Barna' (HBR) and 'Bólusetninga-skírteini' (immunisation record)	No data
Ireland	'Immunisation Passport'	'Pas Imdhionta' (immunisation pass)
Italy	'Health Book'	No data
Latvia	No HBR reported	'Potēsanas Pase' (Passport of Immunisation)
Lithuania	No HBR reported	No data
Luxembourg	'Medical Children Booklet'	No data
Malta	Name not mentioned	'The Child Health Guide'
Netherlands	'Vaccination card' and 'Growth booklet'	'Vaccinatiebewijs' (vaccination certificate)
Norway	No HBR reported	No data
Poland	'Child's Health Booklet'	No data
Portugal	'Child and Youth Health Bulletin'	No data
Romania	'Vaccination booklet' and 'Pregnant woman booklet'	'Carnet de Vaccinari' (Vaccination Booklet, 2013)
Slovakia	Awaiting response	No data
Slovenia	No HBR reported	'Knjižica o cepljenju' (Certificate of vaccination)
Spain	'Documento de Salud Infantil'	1. 'Documento de Salud Infantil' 2. 'Carnet de Salut'
Sweden	Awaiting response	No data
United Kingdom	'Personal child health record'	'Personal child health record'

Of the thirteen matching results from MOCHA and TechNet21, nine countries report the same home-based record, under the same name. Of these countries, four countries report similar immunisation records.

It is worth mentioning here that due to TechNet21's heavy interest in vaccinations, most of their reported records are immunisation based, rather than a holistic child health approach. In this case, TechNet21 shows 13 countries reporting immunisation records under their definition of home-based records.

Further to this, the validity of the records is an area neither sources studied. It is assumed that the records reported through MOCHA are the most recent versions and therefore the most up-to-date information on the topic. However, this was not a question in the MOCHA questionnaire. With the PDF files of the records, TechNet21 also provides the year of issuance of that record (Figure 19).

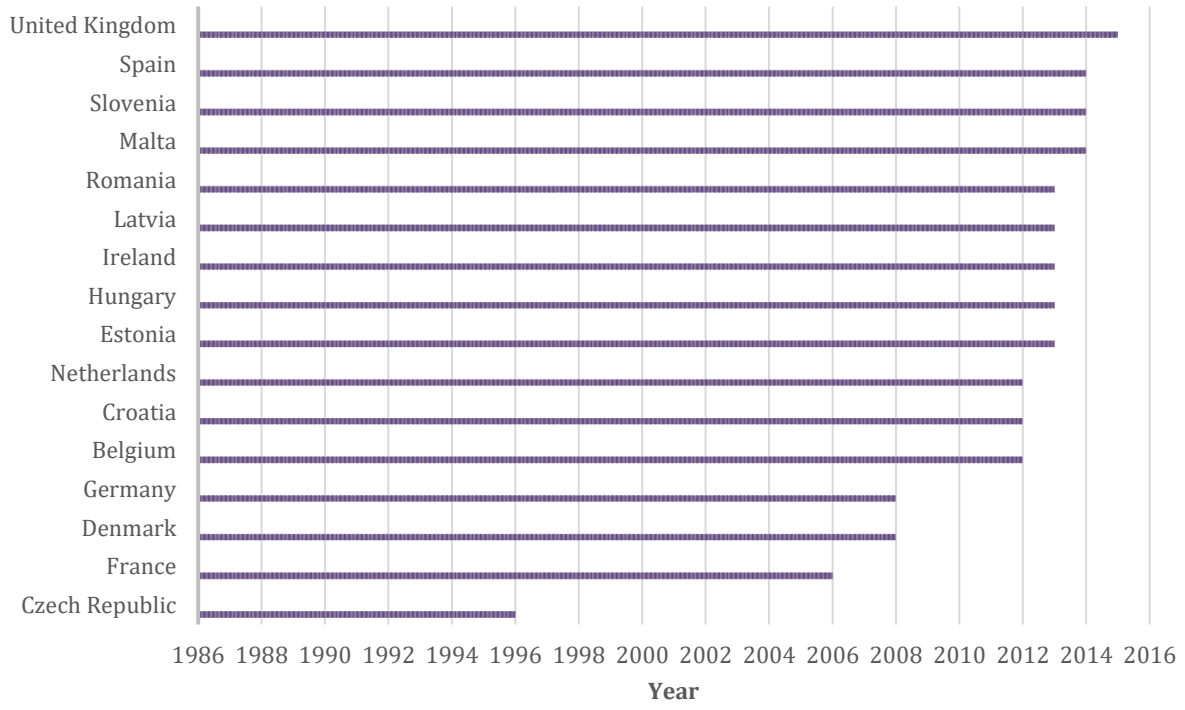

Figure 19: An overview of the latest home-based record reported by TechNet21

Due to the nature of the MOCHA methodology, a wide variety of questions could be investigated regarding home-based records. Since TechNet21 is a site where copies of records are available, the level of detail is considerably lower. However, information about the language the record is written in and maternal health information are two areas MOCHA did not investigate (Figure 20).

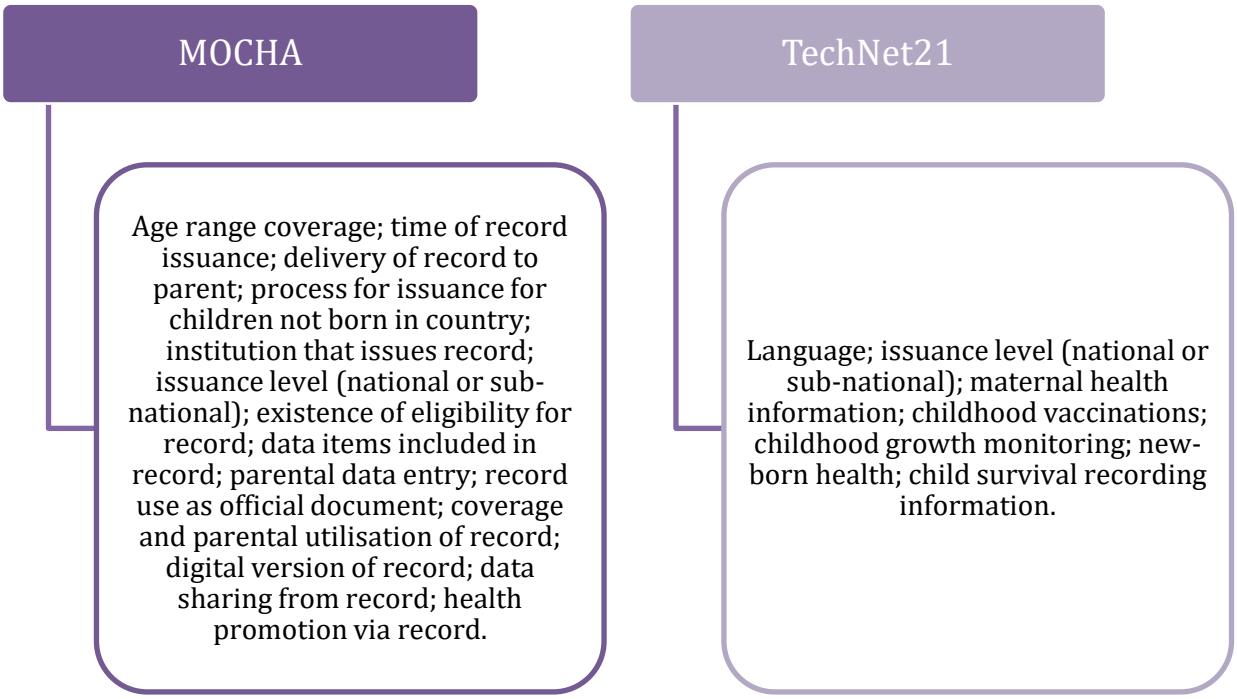

Figure 20: Overview of data items present in MOCHA and TechNet21 records

5. Discussion

5.1 Introduction

A home-based record is an important means of improving communications between parents and health professionals. They are an effective, inexpensive tool, and allow the tracking of child health information [12]. Additionally, home-based records supplement medical records and provide a wider breadth of health information to improve clinical decision making [13, 14]. Research shows that parents like owning a health record for their child and thus, find home-based records helpful [4]. In particular, mothers have been reported as appreciating a home-based record and were therefore considered reliable keepers of their child's record [15].

However, challenges include the need to fit in with the child primary health care system of the country, and with societal expectations. Consequently, as this study shows, there is considerable variation of policy and practice across the EU and EEA countries. Additional issues faced in particular countries include poor availability of the record, poor utilisation and recording, and poor ownership by parents or health professionals [13,14].

Such home-based records covering normal health and development should not be confused with personalised care plans for children with serious or long-term conditions, where their specialist clinicians devise a specific care plan which is shared with the child and family, and provides a means of communicating about those conditions - including when and who to seek, and return to acute care when necessary. This MOCHA study found that this was in practice in about half of the respondent countries. However, this personalised care plan should not usurp the more general healthy development aspects of the home-based record and primary care activity, except in so far as specific aspects should not be applied in a specific case, and this should be specifically recorded. There is a risk, to be avoided, that all other aspects of normal child health care are overlooked because of poor interface with specialist care. Where electronic systems are in place it may be easier for the two personalised records to run in a complementary way.

The WHO definition of home-based records is "*a document on which patient data can be recorded, and health education messages can be shared. It is kept by the patient, rather than the health facility, making it unique in that respect. In maternal and child health, HBRs can take multiple different forms such as antenatal care records, immunization cards, child health booklets, and antenatal and child health books*" [16]. The definition encompasses all types of records and shows the variety that is present globally. However, the continued use of 'patient' to describe a child in receipt of preventive services might be considered no longer the most appropriate.

5.2 The effects of multiple home-based records

The presence of multiple home-based records within a country is reported widely in literature [7, 13, 14, 17-21]. Global studies show that most records can be categorised into either a simple vaccination record booklet; a more in-depth vaccination booklet that records other growth and developmental information; or a child health booklet that is a comprehensive record of all facets of child health [17].

This is present within results from this MOCHA study, where five countries report the presence and use of multiple records within a country. For example, in Germany, all details during pregnancy and details of the first examinations of the child after birth are recorded in the 'Mutterpass'- a pregnancy booklet issued to all pregnant women. However, the existence of 'the

yellow booklet' to record all child health observations means that it would be more beneficial to record first examination information of the child in this booklet. This inefficiency is also mirrored in studies conducted in Vietnam, which demonstrated the financial inefficiencies [18] associated with having multiple records and also highlighted the negative impacts of fragmented home-based records [19].

The presence of multiple records becomes particularly chaotic when families move within and amongst countries [7]. This MOCHA study explored whether countries had processes to issue children records who were not born in the country their family moved to – this includes the many children moving with families within Europe, as well as external migrants and asylum seekers. Fifteen countries reported the existence of a reliable process to receive a new home-based record to allow transfer of information from the child's birth country's home-based record. The existence of these policies shows countries attempts to handle numerous home-based records. An extreme example is the ministerial decree passed in 2004 in Indonesia, which ruled one home-based record as the only one to be used [21]. This decree was attributed to an increase in immunisation coverage and in home-based record ownership.

It is likely that if home-based records are standardised and integrated in order to incorporate all child health information in one booklet, it will be beneficial for both the country, healthcare services, and child health. Improving and encouraging completed, wholesome records will help prevent compromising quality of care [14] and reduce healthcare practitioner's confusion [20]. However, further study is required into how design and standardised records could affect usage [13].

5.3 The design of the home-based record

In order to ensure the success of home-based records, one important feature is the design of the record [14]. This MOCHA study explored the inclusion of data items present in home-based records in 30 European countries. Results showed great variability amongst countries but health items such as: birth and postnatal data, allergies, height and weight, and immunisation were almost universally included in records amongst respondent countries. A study based in the UK concluded that these data items were also perceived as most important in home-based records by parents [7]. Design features such as font, big boxes for space to write, and structure fields, are very important for home-based records [17]. From the MOCHA study, results from Hungary, Italy and Poland stated that there was never enough space for parents or healthcare practitioners to add their own comments; thus, highlighting the importance of record design. A further content element which strikes resonance with other studies within the MOCHA project is the ability in some countries' records to identify long term conditions, care plans, and emergency contacts for long-term conditions.

Literature emphasises the importance of parental views on the home-based record [4, 7, 15]. Whether or not parents could influence the design of this record was explored within this MOCHA study. Results showed the majority of respondent countries did not allow parental contributions to design. Contradictory evidence showed too much emphasis on redesign had reverse effects. A study focused on professionally redesigning a home-based record and found that a redesign did not improve efficacy of the record and actually led to parents and GPs using the record less than previously [22]. However, of the respondent MOCHA countries who reported parental involvement, Ireland described a new initiative that creates a channel for parental involvement in record design. Even better still, the Netherlands stated the presence of a child and youth panel,

who contribute to issues relevant to child health. An African study concluded that home-based records should be "periodically reviewed and critically assessed to determine whether the design and content is optimal for end user needs" [13].

Studies also show that home-based records have more potential for and are more cherished by parents with children who require specialist medical services [13, 23, 24]. A case-study exploring the proportion of parents who brought their child's home-based record to hospital appointments, found that parents with children who have special needs or those who require specialist medical services, were more likely to use their home-based record. This study highlighted the importance of record design for parents of children with special health needs. These parents also requested home-based records with additional appendices to inform parents on the health condition of their child, records of the professionals involved in their child's care, appointment dates, and details of their investigations [20]. Similarly, a study determining the effects of a home-based record specifically designed for children with disabilities found that parents appreciated a tailored home-based record including supplements for further information and extra space for recording similar details to those mentioned above. The study found that families with a disabled child used, retained and appreciated a home-based record that was specifically designed for them more than a standard issue record [23]. From the MOCHA study, only Bulgaria, Netherlands, Portugal, and Spain considered data items for special medical conditions or disabilities in their home-based records. Children with special health needs require more monitoring and, in this situation, home-based records are extremely beneficial for the child's health and to facilitate healthcare provider knowledge [24].

5.4 Home-based record utilisation

Further studies are required to determine factors that affect home-based record usage [13]. This MOCHA study investigated record utilisation, which was described as consistent use by parents for recording their child's health and health behaviour. Results showed that just over half of the respondent countries reported utilisation over 90% in their country. A global study investigating records administered versus records used concluded that the European region had the highest prevalence of administered home-based records [25]. This could support the reported high usage in fourteen MOCHA countries.

Other respondent countries that did not report high utilisation stated this was due to regional influences and differences, such as Denmark and Italy. A few countries (Germany and Poland) reported that usage of the record decreased as the child grew, which is supported by a study that found this decrease in all age groups [20]. A study conducted in the UK found that home-based record usage is lower in women living in disadvantaged circumstances, young mothers, larger family size, lower educational attainment, a history of mental health, or if they were a lone parent [26]. These components were not studied within MOCHA, however future studies could focus on this topic to see if results from the UK could be generalised to other European countries.

Though it is important to consider cultural and societal differences amongst countries within Europe, positive effects of home-based records seem to be universal. A study from 1996 described the importance of good record keeping in times of civil unrest in Bosnia Herzegovina. In this situation, a home-based record provided essential epidemiological data and an accurate health record for children. In war situations, home-based records are particularly useful since hospital-based record are frequently destroyed or are inaccessible [27].

5.5 Immunisation-focused or holistic home-based records?

The approach taken within the MOCHA study, in line with its child-centric and total primary care philosophy, has been to focus on records for the child, and then to ascertain the contents. This contrasts with some important groups within Europe and globally, such as Technet21, who focus solely on immunisation records, and indeed recently European Union initiatives have focussed solely on immunisation [28, 29]. However, immunisation cannot and should not be considered outside of the child's overall heath and health care needs. It is noteworthy that of the 22 EU and EEA countries home-based records contents analysed in Table 1, only one (Estonia) records solely immunisation (Germany has two companion home-based records of which one is specifically for immunisation). The distinction, which is important, is that immunisation recording needs to be highly standardised if the best scientific evaluation can be undertaken, and to facilitate important functions such as batch tracing. However, moves to pursue immunisation home based records in isolation will cut across efforts to improve holistic and child-centric services, and indeed against the policies and practice of virtually all countries.

5.6 Home-based record digitalisation

To increase the utility of home-based records, many countries are considering digitalising the record for improved access and higher rates of recording. However, investigation in digital home-based records within this MOCHA study showed that the majority of respondent countries (87%) currently only used paper home-based records. Countries mentioning digitalisation discuss future plans (Austria, Bulgaria, and Portugal) or are at an in-between stage and moving in the direction of a patient portal approach, including Denmark, Estonia, Greece, and the Netherlands; and also, Finland, which is currently without a home-based record. Others have unofficial products available for citizen use; for example, in the Czech Republic an unofficial electronic home-based record called 'Zopik- Internet friend' exists as a portal to oversee child healthcare and is accessible through a computer or a smartphone. The portal records health events, provides an overview of the child's health development, sends parents reminders about mandatory health examinations and vaccinations, and supplies information through articles written by doctors and experts. Ireland reports availability of unofficial apps, which are neither validated nor regulated, and such solutions will emerge to fill a vacuum – a separate study has shown how few European countries have means of validating apps in child health [30].

Interestingly, a study conducted in the UK found that parents did not readily adopt an electronic home-based record. Three digital engagement issues were presented, which need addressing before widespread, successful implementation [31]. The three hurdles identified were: technological challenges, social challenges, and health service challenges. Parents found that some aspects of the electronic record were challenging and took longer to complete than a paper-based record. Additionally, parents had concerns over the privacy and confidentiality of their child's health data and were apprehensive about who owned their child's health data. The second challenge faced were the social circumstances of families. Factors such as the availability of internet and the ownership of technological devices meant that electronic versions of the home-based record were not available freely to all citizens and highlighted the digital divide in economically deprived areas. Lastly, the study found that poor digital literacy amongst parents and healthcare professionals hindered the use of this technology and underlined the need for training, as with all new electronic adaptions. Results from this study and the MOCHA study show that digital versions of the home-based record require further consideration before implementation. It will be interesting to see how successful these electronic approaches are, and

whether implementing from a zero baseline, or as part of an integrated patient portal, will be enabling factors. Certainly, design suitability, operational reliability, and trust, will be key essentials, as well as designing for the full range of citizen end-users [32].

5.7 Health promotion and home-based records

Globally, home-based records are often supplemented with health promotion information. However, only eight of the respondent MOCHA countries reported having health promotion information associated with the home-based record. A study concluded that the main value of a home-based record is not as a health education tool [22]. Since home-based records are different in different parts of the country, it has been encouraged that records should contain a minimal amount of health promotion information, to prevent location specific health promotion information (regional vs. national health promotion) [9].

5.8 Home-based records and personalised care plans

As explained previously, where a child has a long-term condition, or is being treated for specific illness or accident, shared personalised care plans are very desirable for the shared management of that condition. However, they should not replace the home-based record as a means of reminding and recording all other preventive health activity. Entries may be made in the home-based record to indicate specific actions which should be delayed or not applied, but the home-based record should not be allowed to be overlooked or overshadowed by a condition-specific personalised care plan except in those cases where screening and preventive actions are brought across into the care plan. Electronic record and patient portal applications may facilitate coordination, if appropriately designed.

5.9 Home-based records as an official document

Home-based records can occasionally be used as official documents for proof or entitlement to services. Results from this MOCHA study show that majority of the respondent countries do not use home-based records as an official document. However, in Bulgaria, Germany, Greece, Hungary, and Malta the home-based record is presented, in some form, to educational institutions (admission, immunisation status, etc.). The literature suggests that requirement of home-based records for school admissions may improve vaccination adherence and record retention. However, further research is required to better understand this association [32].

5.10 Limitations of the study

Whilst the MOCHA questionnaire investigated who issued the home-based record (a civil registration service, the health system, a health insurance company, a health provider organisation/clinic, an education authority, or someone else), there was no further exploration into the source of funding for home-based records. A recent study of 72 countries showed that home-based records varied in their sources of funding, which ultimately complicated matters and led to issues of inadequate supplies of records [12]. Further research on this topic within the MOCHA countries could explore whether funding bodies similarly affected home-based records stock within Europe. In this MOCHA study, Hungary did report a reduction in funding which resulted in diminished design.

A flaw of any study utilising a country source is the inevitable misinterpretation of terminology used when asking a question. In this MOCHA study, a question that was frequently misunderstood was whether countries had a reliable procedure for issuing home-based records for children

moving into the country or region, after birth. Additionally, although a definition for home-based records was provided in the questionnaire, many countries reported records other than home-based records. This is in accordance with a previous study conducted by WHO and UNICEF where similar misconceptions were reported [33]. This has led to the creation of a common vocabulary/thesaurus for home-based records when working globally, in an effort to reduce misunderstandings.

Parental views of home-based records were not investigated in this study since it was out of the scope of MOCHA. However, literature shows parents support home-based records and think they are useful tools [4]. This held true except from in Norway where a randomised controlled trial conducted in 2006 explored the effects of a parent held home-based record [34]. The study found that use of the record did not affect usage of healthcare services, parents' knowledge of their child's health, or parents' satisfaction with information or communication with healthcare professionals. Consequently, the record was deemed ineffective for full scale roll out and implementation of home-based records in Norway was deferred. However, unanimous support was received for the record from parents with children suffering from chronic diseases.

6. Conclusions

Results from this study show there is tremendous variety amongst home-based records within Europe. This finding is supported by the literature, which demonstrates global variability. The associated benefits and risks of multiple records are discussed within this report allowing recommendations for integration of home-based records, and evolution towards locally optimal solutions as evidence and experience are shared. This will allow a holistic record of child health rather than partial, fragmented recording of health information, with the further intention of facilitating further co-production of health.

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