

# **Use of home-based records for children in the countries of the WHO European Region**

**By: Shalmali Deshpande,  
Michael Rigby and  
Leyla Namazova-Baranova**

## ABSTRACT

A home-based record (HBR) system has long been promoted by WHO as an effective tool for child health. The record contents, design and operation are unique to each individual country. This report compares the contents and processes for HBR use in all countries of the WHO European Region, drawing on a study by the Models of Child Health Appraised (MOCHA) project for European Union (EU) and European Economic Area (EEA) countries and matched work by the European Paediatric Association/Union of National European Paediatric Societies and Associations (EPA/UNEPSA) Working Group on Social Paediatrics and Public Health for the other countries. As of 2019, 22 of the 28 EU countries had HBRs in use, one of two EEA countries, and 14 of the other 23 countries. The study reports for each of these 37 countries the means of issue, age range of children covered and health topics included, together with comment on scope for parental input. Estimates are given of the extent of usage. Finally, the recent literature on HBR use is summarized.

### Keywords

HOME BASED RECORDS  
CHILD HEALTH  
RECORD KEEPING  
HEALTH SYSTEMS  
VACCINATION  
DEVELOPMENT  
PERSONAL HEALTH PLANS

Address requests about publications of the WHO Regional Office for Europe to:

Publications  
WHO Regional Office for Europe  
UN City, Marmorvej 51  
DK-2100 Copenhagen Ø, Denmark

Alternatively, complete an online request form for documentation, health information, or for permission to quote or translate, on the Regional Office website (<http://www.euro.who.int/pubrequest>).

### © World Health Organization 2020

All rights reserved. The Regional Office for Europe of the World Health Organization welcomes requests for permission to reproduce or translate its publications, in part or in full.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use. The views expressed by authors, editors, or expert groups do not necessarily represent the decisions or the stated policy of the World Health Organization.

# CONTENTS

Acknowledgements .....	iv
Abbreviations .....	v
Introduction .....	1
Methodology.....	2
Results .....	3
The presence of HBRs in European countries.....	3
Age-range coverage of HBRs .....	3
Age of issuance of HBR.....	5
Method of record delivery to parents .....	6
Procedure for issuing HBRs to children moving into the country .....	8
Who issues the HBR?.....	11
Design and issuing of the HBR .....	13
Record content and parental entries .....	13
Parental entry in the record.....	18
HBR as an official document .....	19
Coverage and utilization of the HBR .....	20
Digital records and data-sharing .....	21
HBRs for health promotion .....	25
Parental involvement in design .....	26
Further information from countries that have HBRs.....	26
Further information from countries that do not have HBRs .....	28
Other forms of HBRs .....	28
Key points .....	29
Comparison of findings with TechNet-21 database.....	30
Discussion .....	32
Introduction.....	32
The effects of multiple HBRs.....	32
Design of the HBR .....	33
HBR utilization .....	34
Immunization-focused or holistic HBRs? .....	34
HBR digitalization .....	34
Health promotion and HBRs.....	35
HBRs and personalized care plans .....	35
The HBR as an official document .....	35
Limitations of the study.....	36
Conclusions .....	37
References .....	38

## Acknowledgements

The authors of this report are: **Shalmali Deshpande** (formerly Research Assistant, Imperial College London, United Kingdom); **Michael Rigby** (Emeritus Professor of Health Information Strategy, Keele University, United Kingdom, and Visiting Professor at Imperial College London, United Kingdom for the duration of the Models of Child Health Appraised (MOCHA) project); and **Leyla Namazova-Baranova** (formerly President of the European Paediatric Association/Union of National European Paediatric Societies and Associations (EPA/UNEPSA), Head of the Paediatric Department of the Russian National Research Medical University, and Head of the Institute of Paediatrics and Child Care, Central Clinical Hospital, Russian Academy of Science, the Russian Federation).

The initial European Union (EU)-focused phase of the work described in this report received funding from the EU's Horizon 2020 Research and Innovation programme under grant agreement 634201; the Principal Investigator was Mitch Blair, Professor of Paediatrics and Child Public Health, Imperial College London, United Kingdom. Guidance and coordination for the extended phase to cover the whole European Region was provided by Aigul Kuttumuratova and Martin M. Weber of the WHO Regional Office for Europe. Coordination and reporting for non-EU countries was undertaken without additional resources by EPA/UNEPSA (Leyla Namazova-Baranova and Massimo Petoello-Mantovani), with collation of data also involving Elena Vishneva (Institute of Paediatrics and Child Care, Central Clinical Hospital, Russian Academy of Science, the Russian Federation).

Acknowledgement is paid to the responding agents in all the countries of Europe. For EU and European Economic Area (EEA) countries, data were collected by the country agents of the former MOCHA project; for countries not in the EU or EEA, data were collected and provided by the Working Group on Social Paediatrics and Public Health of the EPA/UNEPSA and presidents of the national paediatric societies of those countries. Their contributions ensured that the findings of this report are based on detailed and local indigenous knowledge.

The authors also thank: Helen Bedford (University College, London, United Kingdom) for valuable advice on the initial survey design; Carla Peters (formerly of the WHO Regional Office for Europe) for critical review of the first 30-country version draft report; and Anayda Gararda Portelo (WHO headquarters) and Siddhartha Datta (WHO Regional Office for Europe) for review of the full final report.

## Abbreviations

ELGA	electronic health record system (Austria)
EEA	European Economic Area
EPA/UNEPSA	European Paediatric Association/Union of National European Paediatric Societies and Associations
EU	European Union
G-BA	Gemeinsamer Bundesausschuss [Federal Joint Committee] (Germany)
GP	general practitioner
HBR	home-based record
IIS	immunization information system
MOCHA	Models of Child Health Appraised (project)
OTC	over-the-counter (medication)
Registering PLDD	registering general practitioner for children and adolescents (Czechia)
UNICEF	United Nations Children's Fund
ZOP	Health and Vaccination Record of Child and Adolescent (Czechia)



## Introduction

A home-based record (HBR) system has long been promoted by WHO as an effective tool for child health (1), and such systems are present in many countries. This form of record is intended to facilitate parent and health-care professional collaboration for a comprehensive understanding of the child's health and development at consecutive life stages and to enable co-production of the child's health. Use of HBRs (initially often known as parent-held records) has been present in some countries for more than 25 years (2–4).

An HBR focuses on key aspects of a child's growth, development and utilization of public health/preventive health services (5), though the specific elements covered vary by country. The record traditionally is a paper booklet but can also be on a digital platform. A health professional adds key information about the child to the record, but in some cases the parent(s) and other professionals also make entries. HBRs are normally issued at birth and are held by the parents. Literature shows that HBRs can be useful for both parents and health-care professionals (6–8).

The record contents, design and operation are unique to each country. This study has endeavoured to compare the contents and processes applied in each country of the WHO European Region. It initially was undertaken to find out more about the existence and use of such records within the 30 countries of the European Union (EU) and European Economic Area (EEA) as one element of the Models of Child Health Appraised (MOCHA) project (9). Through encouragement from the WHO Regional Office for Europe, the opportunity then was taken to extend the methodology to the whole of the WHO European Region; comparable results are given here for all countries of the Region.

## Methodology

This study of the pattern of use and contents of HBRs in the countries of Europe was undertaken in two phases. The initial work was within the MOCHA study, to investigate the existence and use of HBRs and how they assist service delivery in EU and EEA countries.

A semi-structured survey design was used, with the data collection tool and study method being validated by the MOCHA Expert External Advisory Board (10). Data were collected by the regular country agents of the MOCHA project (11), who were funded for their time for MOCHA work and had two years' experience of working in the project. Data collection occurred from March until September 2018 for EU and EEA countries, with 27 responses collected from the 30 study countries.

Data collection for European countries not in the EU and EEA was organized by Leyla Namazova-Baranova through the European Paediatric Association/Union of National European Paediatric Societies and Associations (EPA/UNEPSA) Working Group on Social Paediatrics and Public Health and presidents of the national paediatric societies of those countries. Country respondents were knowledgeable about their own country's services but had neither reserved time nor remuneration for the study. The data collection tool applied in the MOCHA countries was used, and the data were collected in 2019.

The questionnaire first determined in which countries HBRs are used. An HBR was defined in this study 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 HBRs are normally issued at birth and held by the parents.

For those countries with HBRs, details were requested on the age range covered, when the record is issued and how the record is administered to the parent. The procedure for issuing records to children moving into the country was also queried. The questionnaire considered record-issuing methods, record design, the data items included and whether the parent could enter data. Official use of the record, coverage throughout the country, level of utilization of the record, digitalization, systematic data-sharing, health promotion activity through records and parent involvement in record design were considered. Finally, the questionnaire sought to determine whether there were other unofficial equivalents to HBRs.

Results were collected and analysed through descriptive statistics, using the same analytic frameworks for both groups of countries. As all respondents were well versed in child health in their own country, the structured answers are considered equally reliable for all respondent countries. The slight discordance in data collection dates is not considered a problem as record-keeping policy is very stable. Due to the availability of funded time for data collection only in the MOCHA study countries, however, it is recognized that there may be more extensive supplementary material available from open answers from those countries; these are presented as additional narratives in this report.

Responses were not received from three of the 53 European countries – Belgium, Slovakia and Sweden. Information obtained from indirect sources suggests that of these, only Belgium has HBRs. Core data for Belgium therefore have been added to some of the analyses, using the copy of the 2012 Belgian record as posted on the TechNet-21 website (12).



## Results

### The presence of HBRs in European countries

Data were obtained from 50 of the 53 European countries, with additional information identified for the remaining three. Results showed that of the 53 countries, 37 described the presence of an HBR or a parent-held record system, though in Ireland it was limited to some health areas only. Sixteen countries – Albania, Andorra, Belarus, Finland, Georgia, Kyrgyzstan, Latvia, Lithuania, North Macedonia, Norway, San Marino, Slovakia, Slovenia, Sweden, Tajikistan and Turkmenistan – reported (or were identified as) not having HBRs.

Table 1 shows the utilization of HBRs by sociopolitical grouping within Europe.

Table 1. Existence of HBRs by country sociopolitical grouping

Sociopolitical group	Number of countries	Number with HBRs	Percentage with HBRs
EU (2018)	28	22	78.6
EEA	2	1	50.0
Non-aligned	23	14	60.9
<b>TOTAL</b>	<b>53</b>	<b>37</b>	<b>69.8</b>

### Age-range coverage of HBRs

The age-range coverage was also considered by the survey. Countries were asked what age range the HBR covered: 0–5 years, 0–10 years, 0–18 years or other age groups (Table 2).

In overview:

- six countries (16.2%) started the process ahead of the birth and captured some data at that point;
- 24 countries (64.9%) commenced at birth;
- two countries (5.4%) commenced at age 1 month;
- two countries (5.4%) commenced at later ages; and
- three countries (8.1%) commenced with the first diagnosed illness.

As to upper age limit:

- four countries (10.8%) go to or a little above 5 years of age;
- two countries (5.4%) continue to 10 years of age;
- one country (2.7%) stops at 12 years of age;
- four countries (10.8%) stop at 14 years of age;
- three countries (8.1%) stop at 16 years of age;
- 21 countries continue (56.8%) to 18 years; and
- two countries (5.4%) continue to 19 years of age.

Overall, 18 countries (48.6%) cover the full age range of birth to 18 years, in accordance with the United Nations Convention on the Rights of the Child definition of childhood, and another three (8.1%) start at 1 month or first illness then continue to the full 18 years. Of the six countries that start the record before birth, half (8.1% of the total number of countries) have an earlier cessation date and an equal number continue to 18 years of age.

Table 2. The age-range coverage of HBRs

Country	Start age	Upper age
Armenia	Birth	5 years
Austria	Prebirth	5 years +/-2 months
Azerbaijan	Birth	18 years
Belgium	8 weeks	14 years
Bosnia and Herzegovina	1 month	16 years
Bulgaria	Prebirth	18 years
Croatia	Birth	18 years
Cyprus	Birth	18 years
Czechia	Birth	18 years + max. 364 days
Denmark	2 years	5 years
Estonia	Birth	18 years
France	Birth	18 years
Germany	Prebirth	5 years 4 months
Greece	Birth	18 years
Hungary	Birth	16 years
Iceland	Birth	18 years
Ireland <sup>a</sup>	Birth	10 years
Israel	First illness diagnosis	18 years + visitors
Italy	Birth	14 years
Kazakhstan	Prebirth	18 years
Luxembourg	Birth	12 years
Malta	Birth	18 years
Montenegro	Birth	16 years
Monaco	Birth/first diagnosis	18 years
Netherlands	Birth	18 years
Poland	Birth	19 years
Portugal	Birth	18 years
Republic of Moldova	Birth	18 years
Romania	Prebirth	10 years
Russian Federation	Prebirth	18 years
Serbia	Birth	18 years
Spain	Birth	14 years
Switzerland	Birth	14 years
Turkey	1 month	18 years
Ukraine	Birth	18 years
United Kingdom	Birth	18 years
Uzbekistan	First illness diagnosis	18 years

<sup>a</sup> Some health areas only.

Study respondents gave additional information for some countries that have specific variants.

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. The record is issued prebirth to include data from the 16th week of pregnancy onwards.

In **Czechia**, the record covers children aged 0–18 years and then up to a maximum of 364 days after (that is, before the 19th birthday).

Each of the 98 municipalities in **Denmark** decides to what extent the parent-held record system is used. The record, Barnets Bog [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 2–5 years, unless the electronic version is used. The electronic versions incorporate other data, such as linking school health journals, so in this case, the Child Book age coverage is to 15 years.

In **Germany**, the yellow booklet, or Untersuchungsheft, 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 and covers children for the first 64 months of life, including nine examinations (U1–U9). Other examinations can be added to the yellow booklet later in life. Examinations for 7–8-year-olds (U10) and 9–10-year-olds (U11) are voluntary and are only covered by certain health insurance companies. Two additional preventive check-ups are in place for teenagers at the ages of 12–14 (J1) and 16–17 (J2). The former is covered by health insurance but is voluntary, and the latter is covered only by some health insurance companies (it also is voluntary). These examinations are recorded in the HBR. The Untersuchungsheft is preceded by the Mutterpass [Mother's Pass], a maternity record issued to all pregnant women in paper format. A doctor or midwife records results from clinical examinations of both mother and child. Results recorded for the mother include medical history, laboratory tests, vaccination information, results of check-ups and ultrasound results. The first examinations of the child after birth are also entered in the same record.

The HBR in **Iceland** is issued at first contact with a preventive child health nurse at a home visit. The first regular preventive visit starts at 6 weeks of age or at the time of first vaccination.

A full HBR is available only in certain health service areas in **Ireland**. Public health nurses in these areas are responsible for giving the record to parents at the first postnatal visit. An immunization passport is universally present in Ireland and is given to parents by the maternity hospital, general practitioner (GP) or public health nurse, but there is no national system for ensuring all children moving into the country receive an HBR.

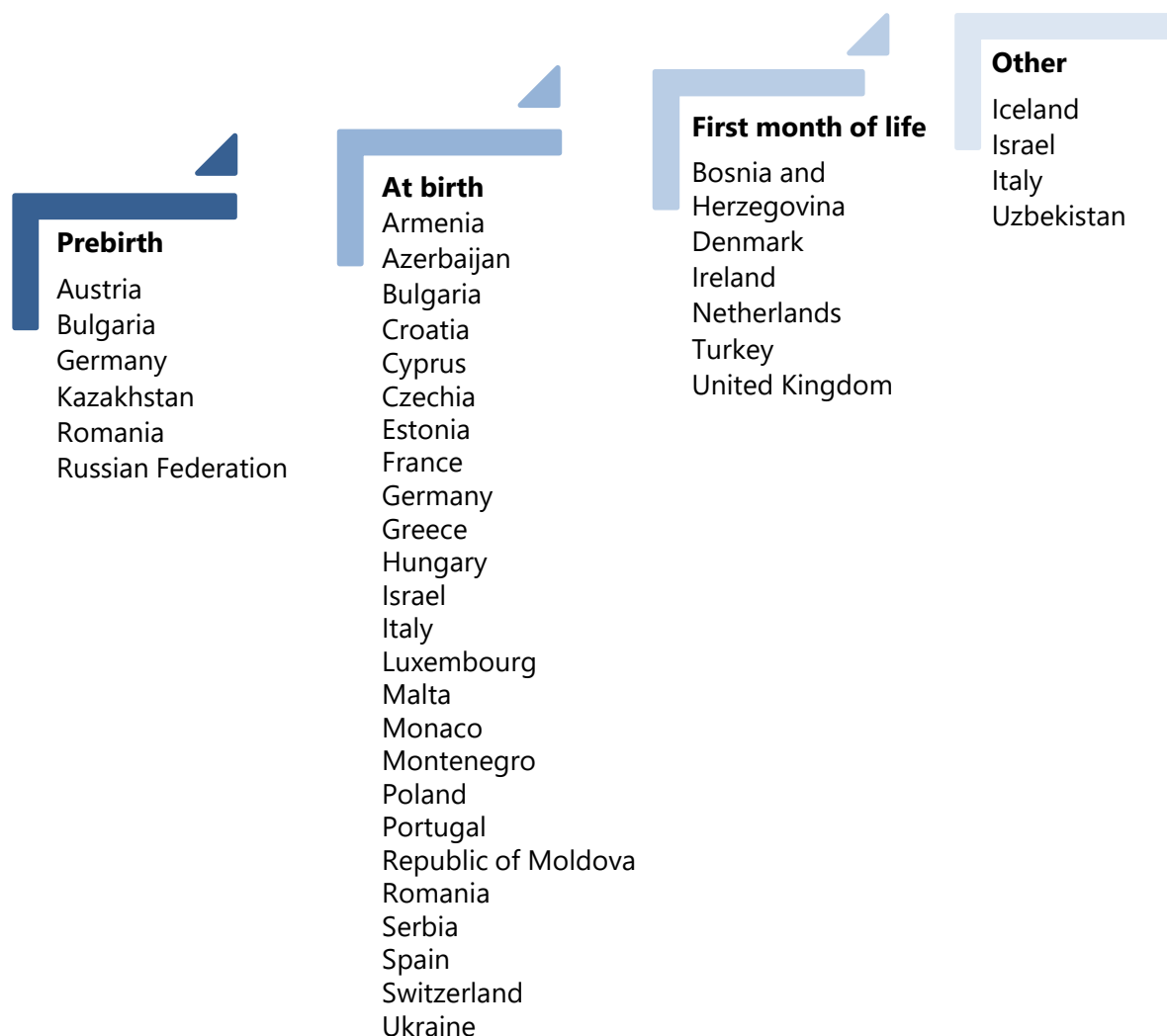
In **Israel**, the system is also used for special groups of people, such as travellers visiting the country. The home-based system of notes about the state of the child in **Israel** and **Uzbekistan** is initiated at illness diagnosis.

## Age of issuance of HBR

Countries were asked when the HBR was issued: prebirth, at birth, in the first month of life or after a specific diagnosis/health problem. This proved to correlate loosely with the age range covered in each country. Of the 36 countries reporting when HBRs are issued, six reported issuance prebirth, 25 at birth, six in the first month of life and four at other points. Five countries (Bulgaria, Germany, Israel, Italy (six regions) and Romania) deliver records at two separate time points. This is shown in

Fig. 1 and is discussed further below in the text on specific variants.

Fig. 1. The age at which HBRs are issued



In **Iceland**, the HBR 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. The record is issued at birth in Campania, Emilia-Romagna and Veneto, 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 **Israel** and **Uzbekistan**, the home-based system of notes about the state of the child is initiated at illness diagnosis. In Israel such system used for child travellers as well.

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

## Method of record delivery to parents

The questionnaire asked about how the HBR was given to parents – whether it was included in a discharge pack from the maternity service at birth, given at clinic attendance, sent by post or through another means.

Of the 36 countries reporting details of HBRs, 21 reported the HBR being included in the discharge pack at birth, nine that it was given at clinic attendance, and 11 reported other

methods of delivery. Five countries (Czechia, Italy, Monaco, Spain and Uzbekistan) reported two methods of delivery in their country (Fig. 2).

Fig. 2. 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 the record is available as an HBR, data-recording is not mandatory, so many parents opt out of using the booklet. An immunization record is also issued. It was reported that an e-immunization passport was implemented in 2017 to give a full overview of a patient's vaccination history. Previously, a paper copy was used, so guidance was given on renewing the immunization passport if it was lost.

The yellow booklet in **Germany** 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, but the data are less detailed than in the discharge document due to space limitations in the record. If the record is ever misplaced, an official document produced by visiting nurses is available, but it contains only details of compulsory vaccination, anthropometry and screening data.

### *Countries reporting having another method of HBR delivery to parents*

An electronic medical record of the child has been created for every newborn in **Azerbaijan** since 2006, with basic data about the child, delivery and parents completed directly in the maternity hospital. The electronic card contains all data about the state of the child at birth and at discharge (weight, height, Apgar score) and vaccination history. Parents get the record in outpatient departments of local paediatricians. Data on every subsequent doctor's appointment should be filled in by a medical worker at hospital outpatient visits. If parents move within the country, the child record is available in any health-care facility. In case of record loss, all data can be found by the child name, surname and date of birth.

In **Austria**, the HBR is usually given to the mother on her first check by a gynaecologist, but many other options are also available. The record may be given to the parent by their GP, district health offices, a specialized outpatient clinic of a health insurance institution or in counselling centres for pregnant women.

Children in **Bulgaria** receive a Personal Path-prophylactic Card at the first visit to the GP. This is a small book in which the GP enters information about the results of each appointment, anthropometric investigations and vaccinations given. This personal health-care card must be kept with the parents, not the GP.

Answers from **Czechia** indicated that the record is included in the discharge pack at birth but also via another method, a health and vaccination record of the child/adolescent that can be downloaded from the website of the National Institute of Public Health. Separate versions exist for boys and girls. It was also reported that the record is normally included in practically all discharge packs from maternity services following birth.

The Child's Book in **Denmark** is given to parents at the first visit from the health visitor. A paper or electronic version of the record is given, depending on the municipality in which the family resides, with guidance on how to maintain records.

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

In the Puglia region of **Italy**, the HBR is given to the parent upon registration with a family paediatrician at a district office.

Parents start the HBRs by themselves in **Kazakhstan** and the **Russian Federation**.

Parents in the **Netherlands** receive two sets of records for their child. The first is a card for vaccinations received and vaccinations remaining; these are paper records that are posted to the parent's home. The second is a growth booklet, which is available in digital format and in which parents can report the growth of their child, developmental milestones, information for issues relevant to the different stages of childhood and adolescence, and preparatory questions for well-child visits. The growth booklet increasingly is becoming digital and includes technologies such as an app for monitoring growth.

**Denmark** and **Finland** are among the countries that are starting overall online electronic records for all citizens.

### **Procedure for issuing HBRs 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. Children moving into another country after birth require structural processes in place to ensure their parents are issued an HBR so they are not disadvantaged compared to nationally born children.

Country contacts were asked if there was a reliable procedure for issuing HBRs for children moving into the country or region after birth. Fifteen countries reported that there was a

process, and the remainder reported they did not have a procedure in place. One country, the United Kingdom, reported uncertainty about such a process (Table 3).

Table 3. Procedure of issuing HBRs for children moving into countries

	Effective system	No system	Unsure
	Austria	Armenia	United Kingdom
	Azerbaijan	Bosnia and Herzegovina	
	Bulgaria	Croatia	
	Czechia	Cyprus	
	Estonia	Denmark	
	France	Ireland	
	Germany	Kazakhstan	
	Greece	Luxembourg	
	Hungary	Malta	
	Iceland	Monaco	
	Israel	Montenegro	
	Italy	Poland	
	Netherlands	Portugal	
	Romania	Republic of Moldova	
	Spain	Russian Federation	
		Serbia	
		Turkey	
		Ukraine	
		Uzbekistan	
<b>Totals</b>	<b>15 (41.7%)</b>	<b>20 (55.6%)</b>	<b>1 (2.8%)</b>

Of the 36 countries reporting details of HBRs, 15 reported having a process for issuing an HBR 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 that point are recorded. Reliable data from earlier examinations in a previous country are added to the record. This HBR is not required by law, but standard examination records are a prerequisite for obtaining childcare allowance.

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

In **Czechia**, 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.

There is a reliable procedure in **France** for issuing the HBR via the local maternal and child health service for children moving into the country after birth.

Children who move to **Germany** after birth receive the yellow booklet from the GP/paediatrician on their first visit to the doctor.



To obtain the record in **Greece**, parents/guardians of the incoming children must contact the Department of Prevention and Health Promotion. 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 are filled in by administrative personnel of the regional public health institute services, who complete the record from information from previous health-care providers or existing documentation to the best of their ability.

All children in **Iceland** who attend preventive child health services are given a small booklet in which parents may record items such as height and weight measurements and vaccinations. The booklet is also used in school health services when registering immunizations. 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 regions. Children who move to Italy after birth 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 HBR.

The **Netherlands** has separate processes for families moving to the country and those moving within the country. Those moving into the country are advised, if possible, to contact a local doctor before their move to compare vaccination schedules and adjust according to the national vaccination schedule. When moving within the country, the move is registered in the municipal population register, in which all citizens are registered. Families are legally obliged to report to the register when they move so that the register may inform preventive 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 health-care services are responsible for issuing and delivering HBRs. When children move into Spain from another country, the HBR 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.

## Who issues the HBR?

The survey queried who issued the HBR: a civil registration service, the health system, a health insurance company, a health-provider organization/clinic, an education authority, or someone else. Two respondent countries reported a civil registration process, 22 had HBRs being issued by the health system, 10 a health provider and four another issuer. Austria, Cyprus, France and Kazakhstan reported more than one body issuing the record (Table 4).

Table 4. Overview of who issues the HBR

Health system	Armenia, Azerbaijan, Bulgaria, Denmark, France, Germany, Greece, Ireland, Iceland, Israel, Italy, Luxembourg, Malta, Montenegro, Monaco, Poland, Portugal, Republic of Moldova, Romania, Serbia, Spain, United Kingdom
Health-provider organization	Bosnia and Herzegovina, Croatia, Cyprus, Czechia, Estonia, Hungary, Kazakhstan, Netherlands, Turkey, Ukraine
Civil registration service	Austria, France
Health insurance company	None
Individual attended clinician	Kazakhstan, <sup>a</sup> Russian Federation, <sup>a</sup> Switzerland, Uzbekistan <sup>a</sup>

<sup>a</sup> Also can be initiated by parents.

In **Austria**, the HBR is issued by a medical professional (a gynaecologist, GP or other in the health authority).

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, but in some rare instances private paediatricians also use their own booklet.

The Federal Joint Committee in **Germany**, Gemeinsamer Bundesausschuss (G-BA), is responsible for issuing the yellow booklet. The G-BA issues directives specifying which health-care services are provided under statutory health insurance in Germany and as 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 **Kazakhstan** and the **Russian Federation**, medical workers or parents start filling the child HBR and specify not only pathological conditions, but also physiological features of the growing child.

The National Institute for Public Health in the **Netherlands** provides the records used for recording vaccinations. GPs and preventive child health-care services issue an HBR. Both are regarded as health-provider organizations.

The HBR in **Poland** is given to parents by health-care providers in hospitals. The design and scope of the record is made consistent through a national regulation process by the Ministry of Health, so the record is issued from the health system.

In **Switzerland** and **Lichtenstein**, the Swiss Association of Paediatricians creates and usually updates the HBR.

In **Uzbekistan**, parents or specialists of private medical practices start filling child HBRs.

## Design and issuing of the HBR

The questionnaire asked whether the design and issuing system for the HBR was national or regional, or was done through another process. Twenty-seven of the responding countries stated they had a national design and issuing system, while three reported a regional system. (Fig).

Fig. 3. Overview of design and issuing system



In **Switzerland**, the design and format of the HBR has been developed by the Swiss Society of Paediatrics, which revises the content on a regular basis. An insurance company funds the printing of the booklet.

In **Kazakhstan**, the **Russian Federation** and **Uzbekistan**, parents play a role in creating the record design, including introducing some individual characteristics. No changes to the design of the vaccination certificate are possible.

## Record content and parental entries

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

### *Record content*

Countries reported on whether the following categories were in their HBRs: birth and postnatal data, allergies and other alerts, height and weight measurements, immunizations, developmental checks, long-term conditions, prescribed medication, urgent referral plans for long-term conditions, plan of care and services, and other items (Table 5).

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

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

Developmental checks in **Hungary** 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 immunization history of a child is recorded in the parent-held record called the Immunization Passport. The passport includes all primary childhood vaccinations and school vaccinations, a vaccination schedule and advice to parents about side-effects.

Regions in **Italy** vary greatly on 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 department), specialist referrals (recorded by the specialist) and vaccinations. In Puglia, periodic health examinations, occasional visits, possible therapies and hospital admissions are recorded. Specialist services rarely document the treatment carried out in the HBR and coordination from the region is lacking.

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

An HBR is mandatory for all children with health issues in **Kazakhstan**, the **Russian Federation** and **Uzbekistan**, while the initiation of an HBR for healthy newborns is optional and up to parents.

Table 5. Child health aspects present in an HBR

	Birth and postnatal data	Allergies and other alerts	Height and weight measurements	Immunization	Developmental checks	Long-term conditions	Prescribed medication	Urgent referral plans for long-term conditions	Plan of care and services	Other
Armenia	✓	–	✓	✓	✓	–	–	–	–	–
Azerbaijan	✓	–	✓	✓	✓	✓	–	✓	–	–
Austria	✓	✓	✓	✓	✓	✓	–	–	–	✓
Belgium <sup>a</sup>	–	–	–	✓	–	–	–	–	–	–
Bosnia and Herzegovina	–	–	–	✓	–	–	–	–	–	–
Bulgaria	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Croatia	✓	✓	✓	✓	✓	✓	✓	–	–	–
Cyprus	✓	✓	✓	✓	✓	✓	✓	–	–	–
Czechia	✓	✓	✓	✓	✓	–	–	–	–	✓
Denmark	✓	✓	✓	✓	✓	–	–	–	–	–
Estonia	✓	–	–	✓	–	–	–	–	–	–
France	✓	✓	✓	✓	✓	✓	✓	–	–	✓
Germany	✓	✓	✓	✓	✓	✓	–	–	–	✓
Greece	✓	✓	✓	✓	✓	✓	✓	–	–	✓
Hungary	✓	✓	✓	✓	✓	✓	✓	–	–	✓
Iceland	✓	✓	✓	✓	✓	✓	✓	–	–	–
Ireland <sup>b</sup>	✓	✓	✓	–	✓	✓	–	–	–	✓
Israel	✓	–	✓	✓	–	–	–	–	–	–
Italy	✓	✓	✓	✓	✓	✓	–	–	–	✓
Kazakhstan	–	–	–	✓	✓	✓	✓	–	–	✓
Luxembourg	✓	✓	✓	✓	✓	✓	✓	–	–	–

	Birth and postnatal data	Allergies and other alerts	Height and weight measurements	Immunization	Developmental checks	Long-term conditions	Prescribed medication	Urgent referral plans for long-term conditions	Plan of care and services	Other
Malta	✓	✓	✓	✓	✓	✓	–	–	–	–
Monaco	✓	✓	✓	✓	✓	✓	✓	–	–	–
Montenegro	✓	✓	✓	✓	✓	✓	✓	✓	✓	–
Netherlands	✓	✓	✓	✓	✓	✓	✓	✓	–	–
Poland	✓	✓	✓	✓	✓	✓	–	–	–	✓
Portugal	✓	✓	✓	✓	✓	✓	–	✓	–	✓
Republic of Moldova	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Romania	✓	–	–	✓	–	–	–	–	–	–
Russian Federation	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Serbia	✓	✓	✓	✓	✓	✓	✓	–	–	–
Spain	✓	✓	✓	✓	✓	✓	✓		✓	✓
Switzerland	✓	–	✓	✓	✓	–	–	–	–	✓
Turkey	–	–	✓	✓	–	–	–	–	–	–
Ukraine	✓	✓	✓	✓	✓	✓	–	✓	–	–
United Kingdom	✓	✓	✓	✓	✓	✓	–	–	–	–
Uzbekistan	–	✓	✓	✓	–	–	✓	–	–	✓

<sup>a</sup> 2012 data.

<sup>b</sup> Design features present in the full HBR present in some health service areas only.

### Countries reporting including other categories in the HBR

Additional to the main items listed in Table 5, some countries included further items, as shown in Table 6.

Table 6. Overview of countries with other health categories recorded in the HBR

Austria	• Prebirth and pregnancy items
Bulgaria	• Child hospitalizations, specialized examinations
Czechia	• Permanent and serious changes in health conditions, accidents, operations, physical growth charts, blood pressure
	• Accidents
	• Operations
France	• Physical growth charts
	• Blood pressure
	• Radiological examinations performed
Germany	• Extensive newborn screening (skin, thorax, lungs, etc.)
	• Observation of interaction (such as mood)
	• Current medical history
	• Relevant medical findings
	• Dentist referral
Greece	• Counselling on health topics (such as nutrition, media usage)
	• Competitive sports tests
	• Examination results
	• Hospitalizations
Hungary	• Oral health notes
	• Medical professional contact details
	• Family history for health issues
Ireland	• Dental record, such as date of first tooth extraction, recommendation to attend dentist at 12–18 months
Italy	• Varies according to region
Kazakhstan	• Diseases
	• Laboratory results
	• Radiological results
	• Other diagnostics
Poland	• Screening test results
	• Preventive dental work
	• Hospitalization
	• Past infectious diseases
Portugal	• Specialist consultations
	• Pregnancy and neonatal information
	• Registration of the state of teeth and gums
Spain	• Health advice for young people and parents/carers
	• Congenital diseases
	• Neonatal hearing screening
	• Developmental tips
	• Health promotion (such as breastfeeding, nutrition, sleep, exposure to second-hand smoke)
	• Unintentional injuries
	• Dental health care
• Rickets prevention	
Switzerland	• Special needs conditions register and care recommendations
	• Obstetric data
	• Breastfeeding
	• Acute and chronic conditions
	• Trauma
	• Surgery

## Parental entry in the record

Country contacts were asked if parents could enter the following data in the record: height and weight, achievement of specified milestones, prescribed medication, regular over-the-counter (OTC) 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. The findings are shown in Table 7.

Table 7. Overview of situations where parents can comment in the HBR

	Height and weight	Achievement of specified milestones	Prescribed medication	Regular OTC medication	Health observations	Medical appointment details	Questions for next appointment
Austria	–	–	–	–	–	–	✓
Cyprus	✓	✓	–	–	✓	✓	–
Czechia	✓	✓	✓	–			–
Denmark	✓	✓	–	–	✓	✓	–
Estonia	✓	✓	–	–	✓	✓	–
France	✓	✓	✓	✓	✓	✓	✓
Germany	–	–	–	–	✓	–	–
Hungary	✓	–	–	–	–	✓	–
Ireland <sup>a</sup>	✓	✓	–	–	✓	✓	–
Italy	–	✓	–	–	✓	✓	✓
Kazakhstan	–	–	All prescribed therapy	–	–	–	–
Malta	✓	–	✓	–	–	✓	–
Netherlands	✓	✓	–	–	✓	✓	✓
Portugal	–	✓	–	–	✓	✓	✓
Poland	Little allocated space, but in principle parents able to add notes on any item.						
Republic of Moldova	✓	✓	✓	✓	✓	✓	✓
Russian Federation	✓	✓	✓	✓	✓	✓	✓
Spain	✓	✓	✓	–	✓	✓	✓
Switzerland	✓	–	✓	–	–	–	–
United Kingdom	✓	✓	✓	✓	✓	✓	✓
Ukraine	✓	–	–	–	–	–	–
Uzbekistan	✓	–	✓	–	–	–	–

<sup>a</sup> Design features present in the full HBR utilized in some health service areas only.

In **Czechia**, parents can only make a record in the physical growth charts that are a part of the “Zopik – Internet friend”, an online platform to monitor the health of registered Czech children.



Parents in **Denmark** 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 developmental aspects can be recorded. A short guide for parents on topics such as nutrition, home pharmacy and how to treat mild illnesses is also included.

In **Ireland**, no specific prompts are given for parents to write questions they would like to raise at their child's next appointment, but notes pages that could be used for this purpose are available. This is the case only for health service areas using the full HBR, which is yet to be rolled out nationally.

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

Parents in **Poland** are not able to add data to the record, but there is no restriction on them adding comments. Parents are encouraged by health-care providers to add comments in the record, particularly in relation to child health and developmental processes. It is reported, however, that there is hardly ever enough space in the record for parents to write comments.

## HBR as an official document

The questionnaire asked whether HBRs were used as proof of eligibility for health services, proof of entitlement to discretionary health or welfare services, or as a prerequisite to accessing other services. Eligibility, as defined by the Oxford English Dictionary, is "the state of having the right to do or obtain something through satisfaction of the appropriate conditions," while entitlement is defined as "the fact of having a right to something".

The great majority of respondent countries did not use the HBR as proof of eligibility for health services, nor for proof of entitlement to discretionary health/welfare services. France did not answer unequivocally to sections of this question, but instead stated that the record might be used as an official document in every scenario, at the parent's discretion.

### *HBRs as proof of eligibility for health services or proof of entitlement to discretionary health or welfare services*

The HBR can be used as proof of eligibility for health services and for proof of entitlement for discretionary health or welfare services in **Austria**, **Bulgaria** and **Poland**.

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

In **Switzerland**, the HBR can be requested by medical staff of schools or other education institutions during screening visits.

In **Ukraine**, the HBR can be used to initiate rehabilitation support and additional social assistance when children have specific chronic conditions that demand long-term follow-up.

### *HBRs as a prerequisite to using other services*

The Personal Health Care Card in **Bulgaria** 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 immunization status to a health-care professional at the school health

office. The Personal Health Care Card is also a required document when checking the quality of GP work and when an adverse medical reaction occurs. The record enables assessment of how the GP is performing and how well the child's health status is reflected in the HBR.

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

A Student Personal Health Record is required for a child in **Greece** to gain admission to grades 1–4 of primary school and grade 1 of secondary school. This record, information for which is taken from the Child Health Booklet, includes relevant health information such as immunization status and serious health conditions.

When children attend day-care services or schools in **Hungary**, the HBR is given to the school nurse to check that the child has had all compulsory vaccinations.

The HBR can be used as evidence of medical contraindications for military service in **Kazakhstan**.

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

In **Poland**, the child's health booklet can be used as proof of ID to enable access to, for example, discounted transport.

The HBR can be used in particular cases in **Ukraine** to enable children with specific chronic conditions that demand long-term follow-up to access rehabilitation services and additional social assistance.

The HBR can be used for confirmation of child vaccination status at entry to education (school) in **Azerbaijan, Bosnia and Herzegovina, the Russian Federation, Turkey and Ukraine**.

The HBR can be requested by medical staff of schools or other education institutions in **Switzerland** during screening visits.

## Coverage and utilization of the HBR

The coverage and utilization of HBRs were also investigated.

### *Coverage of HBRs*

Country contacts were asked if HBR coverage was universal nationally, or whether it varied by region, by health insurance company or by health-care provider.

Almost all respondent countries stated that coverage was universal nationally.

In **Denmark, Ireland, Italy and Romania**, it varies by region, and coverage in **Croatia and Estonia** varies by health-care provider. Since the HBR in Estonia is optional, use of the record is dependent on how much encouragement parents receive from the health-care provider.

General coverage is universal nationally in **Germany** for all main examinations. A few additional check-ups are not covered by all health insurance companies, so these can vary.

Reach in **Kazakhstan, Turkey and Uzbekistan** depends on regional medical facilities (health-care providers).

### Utilization of HBRs

Utilization was also considered. Country contacts were asked if HBR utilization 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.

Most respondent countries reported over 90% of consistent use of the record. Approximate reach was estimated at:

- above 75% in **Bosnia and Herzegovina, Malta and Switzerland**
- 50–75% in **Romania**
- 50% in **Armenia**
- 25–50% **Denmark**
- only 25% in countries including **Kazakhstan, the Russian Federation and Uzbekistan.**

**Croatia, Estonia, Ireland, and Luxembourg** have no exact data on the utilization of HBRs.

### Digital records and data-sharing

Digitization and data-sharing from HBRs were also considered.

#### Digital HBRs

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 the standard system, or whether electronic versions were not yet official/competing with official systems.

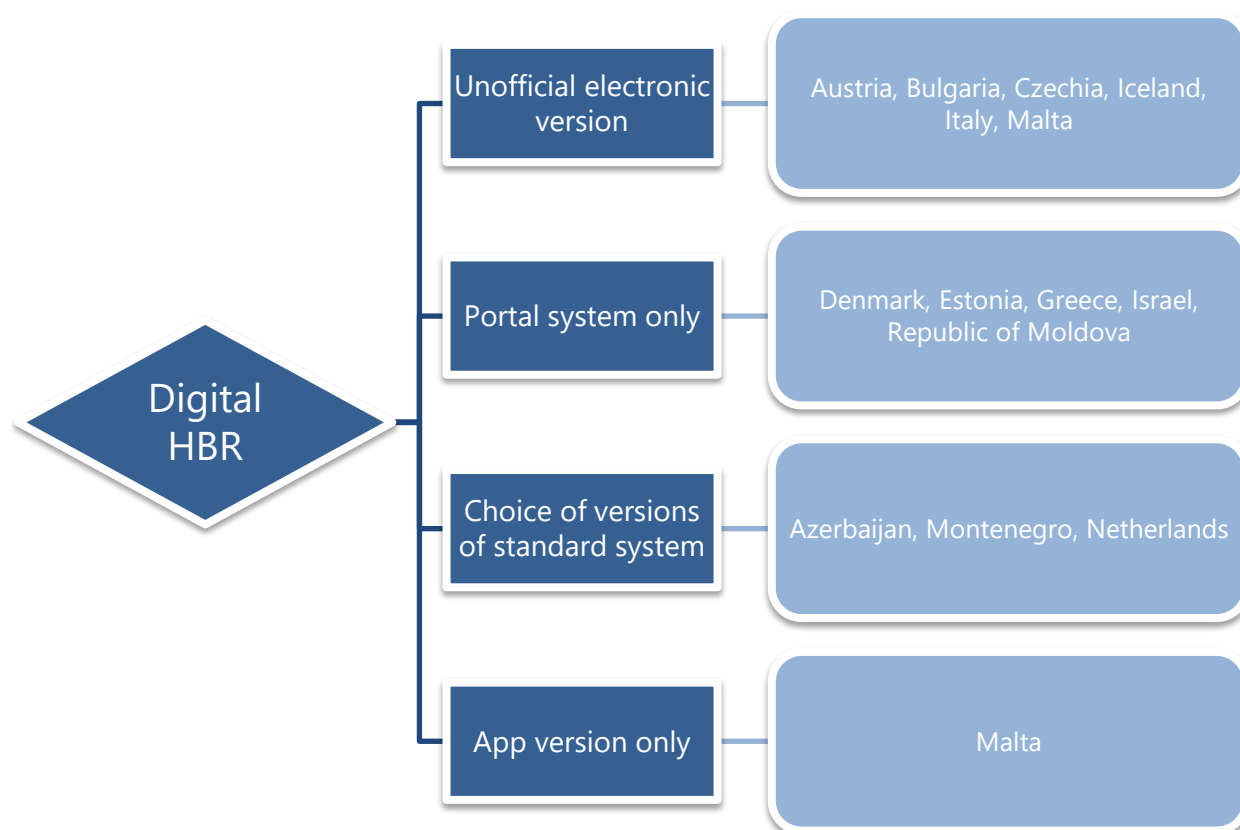
Most countries have only a paper booklet HBR, but some approaches to digitization are now being implemented (Fig. 4).

Future plans in **Austria** include integrating the mother–child passport into the Austrian electronic health record system (ELGA).

In **Bulgaria**, digital versions of the Personal Health Care Card have been developed as a means of furthering e-health initiatives. Although they are yet to be rolled out nationwide, a projected implementation date of 2019 had been set for use in broad practice.

**Czechia** has a paper copy but also an unofficial electronic version of the HBR. 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”. 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.

Fig. 4. An overview of digital forms of the HBR



Whether the record is paper or digital in **Denmark** is determined by the municipality in question.

Child health information in **Estonia** is recorded in a digital health record that is available to parents via the e-health system.

All vaccinations in **Iceland** 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 immunization records, appointments and drug prescriptions.

Most services in the **Netherlands** provide a paper booklet only, but some services are experimenting with parent-held child records that are similar to the growth booklet.

**Portugal** currently has only one standard paper version of the HBR, but 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.

### *Systematic data-sharing from HBRs – EU countries*

Country agents were asked whether there was a systematic means of sharing data between the HBR and: a) the child's primary care record; b) the child's public health/community health record; and c) the immunization information system. France did not answer unequivocally to sections of this question but instead stated that information from the record might be shared in every scenario, at the parent's discretion.

### Primary care record

Responses from country agents showed that 10 EU countries (Austria, Bulgaria, Czechia, Estonia, Hungary, Poland, Romania, Spain and the United Kingdom<sup>1</sup>) and Iceland shared data between the HBR and the primary care record, while 11 (Croatia, Cyprus, Denmark, Germany, Greece, Ireland, Italy, Luxembourg, Malta, the Netherlands and Portugal) did not.

In **Czechia**, the paper version of the record is given to the parents by the GP, who can fill it in themselves. The record, the Health and Vaccination Record of Child and Adolescent (ZOP), 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 immunization record that is separate from the ZOP, but the same data from the ZOP are entered into the electronic health records of the registering PLDD.

In **Estonia**, information is recorded by the health provider in the immunization booklet and also the health information system and an immunization passport, which is issued to family members by a health-care provider upon birth in the maternity ward. The health-care provider may record details in the passport and then must immediately return it to the family.

Primary care health professionals (such as GPs, primary care physicians and visiting nurses) in **Hungary** add data to the record by hand. The spaces for writing detail often are very small and data-sharing is opportunistic and less structured. The electronic health record of a Hungarian child is much more detailed and contains more information than the HBR.

During regular visits to the GP in **Poland**, information about the child's health status is added from the HBR to the primary care record by the doctor.

### Public health or community health record

Responses from country agents showed that nine countries shared data between the HBR and the public health record (Bulgaria, Denmark, Estonia, Germany, Iceland, Portugal, Romania, Spain and the United Kingdom), while 12 did not (Austria, Croatia, Cyprus, Czechia, Greece, Hungary, Ireland, Italy, Luxembourg, Malta, the Netherlands and Poland).

There are no child public health records in **Czechia**. The only longitudinal health record for children is the one managed by the registering PLDD.

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

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

### Immunization information system

Responses from country agents showed that 12 EU countries shared data between the HBR and the immunization information system (IIS) (Croatia, Czechia, Denmark, Germany, Hungary, Luxembourg, Malta, the Netherlands, Portugal, Romania, Spain and the United Kingdom), whilst six did not (Austria, Bulgaria, Cyprus, Estonia, Ireland and Italy). Three countries reported they did not have a separate IIS system (Greece, Poland and Iceland).

A Vaccination Record and Severe Illness Record holds information on children's vaccinations in **Czechia**. These data are also available on electronic health records from the child's respective registering PLDD, who is responsible for entering the data.

---

<sup>1</sup> The United Kingdom was an EU Member State at the time of the survey.

**Germany** has a separate immunization record called the Impfpass, but the yellow booklet also includes information about up-to-date vaccinations and those that remain to be administered.

All vaccinating health-care professionals (GPs, primary care physicians and school doctors) in **Hungary** must record the date and type of vaccine administered within the booklet. Primary caregivers must also enter this data in the electronic health record. Currently, however, school doctors have no access to the electronic health records nor to the Elektronikus Egészségügyi Szolgáltatási Tér [Electronic Health-care Service Portal] (a cloud-based health domain). School nurses register vaccinations given by the school doctor and transfer data to regional public health institute services.

The date and type of vaccine administered to the child in **Spain** is recorded within the HBR. These data are also entered in the child's HBR.

The immunization passport in **Austria** is part of the mother–child passport, but is separated and used alone when the child is in kindergarten or school.

**Cyprus** has no primary care, public health nor IIS record, so no data-sharing occurs.

There is no systematic sharing between the IIS and the HBR in **Italy**, except in Emilia-Romagna.

The IIS in **Greece** is still under construction.

The official vaccination card in **Poland** is kept by the health-care provider. A copy of the vaccination card is present in the HBR.

### Methods of data-sharing

The questionnaire asked by what means data-sharing is achieved, if appropriate. Most respondent countries (74%) that share data reported that the method was by the health professional writing in both records. Five countries said 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 the Netherlands reported having more than one method of data-sharing (Table 8).

Table 8. An overview of the methods of data-sharing from the HBR

	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	–	–	–	–	✓
Czechia	✓	–	–	–	–
Denmark	✓	✓	✓	–	–
Estonia	✓	–	✓	✓	–
France	✓	✓	–	–	–
Germany	–	–	–	✓	–
Greece	✓	–	–	–	✓
Hungary	✓	–	–	–	–
Iceland	✓	–	–	–	–

	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
Ireland	–	–	–	–	✓
Italy	✓	–	–	–	✓
Malta	✓	✓	–	–	–
Netherlands	✓	✓	✓	–	–
Poland	✓	–	–	–	–
Portugal	✓	–	–	–	–
Romania	✓	–	–	–	–
Spain	✓	–	–	–	–
United Kingdom	✓	–	–	–	–

Data on immunization in **Czechia** is entered by the registering PLDD into the electronic health records system. The system can provide alerts and keep track of necessary immunizations. The data, including the date and batch/lot identification, are then handwritten into the Vaccination Record and Severe Illness Record.

Health nurses in **Denmark** have their own system. Relevant data from their system are transferred to the HBR. When the paper-based record system is used, the information is first written in the paper book then 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, with some being transferred to the Child's Book.

Child health information in **Estonia** is stored in the digital health record, which can be shared among health-care providers through the e-health system.

**Germany** cited 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 individually how they record health results and notes.

There is less reported systematic sharing of data from the HBR in countries outside the EU. There is capability in **Azerbaijan, Israel and the Republic of Moldova** to share data about child status on vaccination between home-based system notes and information systems. Integration of data from the child HBR with the original medical record is possible in **Turkey**.

## HBRs for health promotion

The survey asked if there was any systematic health promotion activity linked to the HBR that was additional to that given at routine appointments. Only nine countries (Czechia, France, Germany, Ireland, the Netherlands, Poland, Spain and the United Kingdom) answered in the affirmative.

In **Germany**, the yellow book contains much advice for health promotion activity, including accident prevention, nutrition, rickets prophylaxis with vitamin D, vitamin K prophylaxis, information on vaccination/arrangement of vaccination appointments, information on available support, ultraviolet protection, addiction, media usage, language advice (supporting the mother's language and German) and advice on oral hygiene and tooth-friendly nutrition.

The HBR in **Ireland** includes health promotion content, such as information about infant feeding, promotion of breastfeeding, the immunization timetable, information about prevention of injuries and accidents, information on prevention of cot death and reminders

about schedules for dental review. These features are present only in the health service areas where the full HBR has been implemented; this has not yet been rolled out nationally.

The growth booklet in the **Netherlands** provides information on various topics that are linked to the different life stages of the child, such as infant feeding, safety, nutritional behaviour and hearing and speaking.

In **Poland**, the date of the next planned preventive visit is written in the HBR.

In the **United Kingdom**, letters or text messages are sent as reminders for appointments.

The HBR in **Switzerland** contains basic information about healthy lifestyle and general data on child development.

## Parental involvement in design

The survey asked whether there is a systematic means of parents being able to influence the design or use of the HBR. Estonia, Ireland and the Netherlands replied that there was.

In **Ireland**, the development of standardized health records for parents and professionals is part of “The Nurture Programme – Infant Health & Wellbeing”. A guiding principle of this programme 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 HBR has been implemented; the record has not yet been rolled out nationally.

The National Centre on Child Health in the **Netherlands** has set up panels of children and young people to comment on the various issues relevant for child health and co-create approaches and solutions.

Opportunities for parents’ involvement were cited by **Kazakhstan**, the **Russian Federation** and **Uzbekistan** where, if requested, parents can be allowed to help medical workers and fill additional data that can be useful in enhancing understanding of anamnesis and state dynamics.

## Further information from countries that have HBRs

Croatia, Czechia, Estonia, France, Ireland, Italy, Luxembourg, Portugal and Romania supplied additional information about HBRs in their countries.

**Croatia** has an HBR referred to as the child’s health booklet. Further information provided shows usage of the booklet is legislated through the 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 appointed by the Minister of Health. Aggregate data are submitted to the Croatian Institute of Public Health and reference centres for child growth and development.

HBRs in **Czechia** (ZOP) exist in paper form and are produced and authorized by the Ministry of Health in conjunction with other public health and child and adolescent health stakeholders (such as the Professional Society of Doctors for Children and Adolescents of the Czech Medical Association and the National Institute for Public Health).

In **Estonia**, parents are given the Child’s Health Journal (Lapse Tervisepäevik) in the maternity ward upon the birth of their child. Though this record is available as an HBR, data recording is not mandatory, so many parents opt out of using the booklet. It allows parents to record health-check results of every regular visit and developmental results and includes a short guide on topics such as nutrition, home pharmacy and how to treat mild illnesses. Other records include a paper or electronic immunization passport and digital e-health records generated upon visiting a doctor. The e-health records are made available to the Government and health professionals when required.



The HBR in **France** is called the carnet de santé, or health card. It contains a child's medical records up to the age of 18 and its use is reserved for health professionals; consultation is subject to parental consent.

The reported HBR in **Ireland** is a small vaccination booklet that only allows recording of immunization details. A more comprehensive record exists, but it is used only in some health service areas of the country and has not yet been rolled out nationally. "The Nurture Programme – Infant Health & Wellbeing" is an Irish initiative that aims to improve information to and professional support for parents from pregnancy through to the first three years of their baby's life. An action item of the programme is to develop a standardized health record for parents and professionals. There is a national policy intention to develop and roll out a standardized HBR across the whole country (13,14). Engagement with parents in the design and development of the record is also a stated policy intention.

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 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 that is updated for the child on every visit to the paediatrician. The record is paper-based and parent-held. The paediatrician must also have an electronic health card for every child.

Though the law is national, there is considerable regional variability. Responses received for this report cover six Italian regions (three from the north, one central region and two southern regions), which account for approximately 60% of the Italian population. The 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 health-care professionals in different parts of the health-care system, including at birth, by family paediatricians and in vaccination centres.

There is no universal HBR in Emilia-Romagna. Instead, each province manages its own record. Primary care programs for electronic records are used by some paediatricians.

Due to economic problems, there is no individual HBR in Lazio that is shared with parents. Instead, a computerized medical record that contains information about periodic health examinations exists. All this information is completed by a paediatrician.

The use of an HBR has been absent for many years in Lombardy. Instead, the paediatrician prints out reports from visits and selectively gives some to parents 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, an HBR called the health book is given to parents upon the birth of their child.

The HBR in **Luxembourg** is handed to parents at the time of their child's birth. Although there is no scientific evaluation surrounding use of the booklet, the emphasis has always been 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.

The HBR in **Portugal** is called the Child and Youth Health Bulletin.

**Romania** has two records: the vaccination booklet and the pregnant-women booklet.

In the **Russian Federation** and **Kazakhstan**, the home-based system of notes is used frequently for pathological condition diagnostics and for dynamic control and assessment of the effectiveness of therapy efficiency in a traditional paediatric approach.

## Further information from countries that do not have HBRs

Finland, Latvia and Norway, countries declaring that they do not have an HBR, gave details on the alternative records present in the countries.

There currently is no HBR in **Finland**. In its place are local solutions that are not yet linked to Finland's online electronic health record, the National Patient Data Repository. Plans and pilot projects are in place to add applications to the National Patient Data Repository so that parents may enter data about their children, but this will require an update to Finnish legislation (which currently is underway).

In **Latvia**, a separate paper-based immunization passport that gives a full overview of the patient's vaccination history is given. Parents do not make comments in this passport, which is issued by a health practitioner and is universal nationally. There currently is no HBR. Instead, a patient is given a medical record that is owned by the medical institution. The record travels with the patient 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. Patients only have the right to request this free of cost twice a year, under the Personal Data Protection Act. A fee is applied to any extra copies requested.

A medical document called the Mother's Passport is given to pregnant women. Information about the pregnancy, such as medical history, laboratory tests and ultrasound results, is recorded in the passport in accordance with a cabinet regulation (No. 25, Procedures for Keeping Medical Documents). The passport is a paper record and is given to the mother between week 16 and 18 of her pregnancy by the gynaecologist. It must be brought to the birth.

Children in **Norway** have a core medical record owned by health-care institutions rather than an HBR. Parents have permission to see and read the record but are restricted from writing in it. An immunization system also exists (the Norwegian Immunization Registry), from which a paper copy of essential information can be obtained. Neither of these are parent-held or owned.

## Other forms of HBRs

Countries were asked whether they had alternative unofficial equivalents to HBRs made available through the Internet, pharmacies, unregulated apps or other retail/commercial sources.

In **Austria**, a pilot test is being planned and prepared to link and share the HBR to the ELGA. An e-immunization and e-prescription system will also be linked to the ELGA.

The National Institute of Public Health in **Czechia** manages a server to link to the Zopik online platform. The programme, which is available on mobile phones, also sends notifications about future appointments and vaccinations and provides health literature written by doctors and experts.

No unofficial equivalents link to public health data in **Denmark**, but private companies offer paper-based and electronic solutions for parents who want to keep track of their child's development.

ICT devices are used in **Estonia** with overweight and obese children as a part of the clinical–community health promotion initiative spanning 2017 and 2018.

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

**Hungary** cited an unofficial HBR that was used in the late 1990s. This was a colourful book with advertisements placed between professional pages, information on nutrition and feeding,

and percentile charts and graphs. The HBR today is black and white and contains no graphs, advertisements, or supportive graphs or charts.

Numerous apps can be accessed in **Ireland** as alternative, unofficial equivalents of the HBR. Several hospitals have also developed patient passports for children with cancer and complex health-care needs. Cancer care for children is recorded in a passport that includes information about their condition, treatment, diagnostic records and a record of training delivered to parents.

**Italy** has periodic health examination sheets that interact with the management software used by primary health-care paediatricians.

Many apps that act as unofficial sources of HBRs exist in the **Netherlands**. The quality of the apps is evaluated by the Association of Regional Public Health Services.

Although **Norway** stated that it has no HBRs, there is a “Smart Caring” app that 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, a private Internet portal that allows medical data exchange between selected private providers. There are also a few apps that act as equivalents to HBRs. The “Hefi” app in particular is a promising project created by a Polish doctor that currently is in the testing phase.

A pilot project to create digital records for children has been set up in **Romania**, but it has not yet been implemented. An HBR developed by the United Nations Children’s Fund (UNICEF) exists for use in the **Republic of Moldova** but is written and developed in the Romanian language.

The development of electronic personal child health records in the **United Kingdom** is driving the development of alternative suppliers. The Royal College of Paediatrics and Child Health has published standards for an e-redbook (the Red Book being the term for the current HBR).

## Key points

The following presents a summary of the results from the study. All statistics refer to respondent countries that stated they had an HBR.

In this study, full data were obtained for 50 of the 53 countries of the WHO European Region, with core data being obtained from other sources for the other three. Of these 53 countries, 37 used some form of HBR for children.

Four countries – **Denmark, Italy, Romania** and **Spain** – cited some form of regional variations in HBRs, and **Ireland** has partial coverage of a single system.

Three countries – **Austria, Germany** and **Romania** – mentioned the inclusion of maternal health within the HBR.

Nearly all respondent countries with HBRs issue them at or close to birth.

The most common means of parents receiving the HBR is in a discharge pack from the maternity service at birth.

More EU than other countries had a means of creating an HBR for children moving into the country after birth.

Nearly all countries reported that the design and issuing system for their HBR is national, rather than regional or another process.

Enquiries into data items included in the HBR showed that the most commonly included data items are: birth and postnatal data; allergies and other alerts; height and weight measurements; immunizations; and developmental checks.

Two thirds of EU countries reported that parents could enter data themselves in the HBR, compared with a third of non-EU countries. The most commonly reported features are: height and weight; achievement of specified milestones; health observations; and medical appointment details.

Few countries reported using the records as proof of eligibility for health services, or for entitlement to discretionary health/welfare services. In **Bulgaria**, the HBR was reported as being used to check the quality of GP care or performance.

Most countries reported that they did not need the record as a prerequisite for using other services. Countries in which the HBR is needed for accessing services mainly reported its use in school admission procedures or in providing proof of immunisations for schools.

Most countries reported that home-based coverage was universal nationally. Three – **Denmark, Italy and Romania** – stated that coverage varies regionally. **Ireland** has partial coverage, and **Armenia, Kazakhstan, the Russian Federation and Uzbekistan** reported usage by 50% or fewer of children.

The great majority of countries reported that the HBR exists as a paper booklet only. Many countries, however, reported future plans for digitalizing the record.

Under half of countries share data between the HBR and primary care records, or with the child's public health record. When it comes to data-sharing between the HBR and an IIS record, however, the proportion is higher. Overall, sharing is more common in EU countries.

Most countries that share data do so through health professionals making entries to both records.

Nearly all countries reported there is no systematic means of parents being able to influence the design or use of the HBR.

## Comparison of findings with TechNet-21 database

The data for this report were collected directly from a contact in each country using a standard questionnaire. The website TechNet-21 (15), compiled primarily by immunization professionals and focusing on immunization issues, provides a second potential source. The TechNet-21 project views HBRs as a positive aid to child immunization and provides a catalogue and repository of PDF files of HBRs used in many countries around the world.

TechNet-21 describes an HBR as (15):

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.

The MOCHA definition of an HBR used in this report is (16):

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.

This study therefore takes a holistic view of child health that is not restricted to immunization.

A comparison of results between MOCHA and TechNet-21 is of interest. When the first analysis (for EU countries) was undertaken by the MOCHA study, comparison found good concordance, with more countries covered in the MOCHA study and no significant discordances (16).



# Discussion

## Introduction

An HBR is an important means of improving communications between parents and health professionals. HBRs are effective inexpensive tools that allow the tracking of child health information (17). They supplement medical records and provide a wider breadth of health information to improve clinical decision-making (18,19). Research shows that parents like owning a health record for their child and therefore find HBRs helpful (5). Mothers in particular have been reported as appreciating an HBR and were therefore considered reliable keepers of their child's record (20).

Challenges include the need to fit in with the child primary health-care system of the country and societal expectations. Consequently, as this study shows, policy and practice vary considerably across the range of European countries. Additional issues faced in particular countries include poor availability of the record, poor utilization and recording, and poor ownership by parents or health professionals (18,19).

HBRs covering normal health and development should not be confused with personalized care plans for children with serious or long-term conditions, where their specialist clinicians devise a specific care plan that is shared with the child and family and provides a means of communicating information around those conditions (including who to access for support and when, and when return to acute care may be necessary). The MOCHA study found these plans were being used in several respondent countries, but personalized care plans should not usurp the more general healthy development aspects of the HBR and primary care activity, except to indicate if specific aspects should not be applied to a specific case (this should be recorded). There is a risk – which must be avoided – that all other aspects of normal child health care can be overlooked because of a poor interface with specialist care. Where electronic systems are in place, it may be easier for the two personalized records to run in a complementary way.

The WHO definition of HBRs (21) 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.

This definition encompasses all types of records and shows the variety in existence globally, but the continued use of the word “patient” to describe a child in receipt of preventive services might no longer be considered the most appropriate option.

## The effects of multiple HBRs

The presence of multiple HBRs within a country is reported widely in literature (8,18,19,22–26). Global studies show that most records can be categorized as 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 (22).

Several countries in this study report the presence and use of multiple records. In Germany, for example, all details during pregnancy and the first examinations of the child after birth are recorded in the Mutterpass, a pregnancy booklet issued to all pregnant women. It would be more beneficial, however, to record first-examination information in the yellow booklet, in which all child health observations are recorded. This inefficiency is mirrored in studies conducted in Viet Nam that demonstrated the financial inefficiencies (23) associated with having multiple records and highlighted the negative impacts of fragmented HBRs (24).

The presence of multiple records becomes particularly chaotic when families move within and among countries (8). This study explored whether countries had processes to issue records to children who were not born in the country to which their family had moved, including the many children moving with families within Europe, as well as external migrants and asylum seekers. About half of countries reported the existence of a reliable process to receive an existing, or create a new, HBR to allow transfer of information from the HBR in the child's birth country. Such policies highlight countries' attempts to handle numerous HBRs. An extreme example is the ministerial decree passed in 2004 in Indonesia, which signified a single HBR as the only one to be used (26). The decree was credited with promoting an increase in immunization coverage and in HBR ownership.

It is likely that if HBRs are standardized and integrated to incorporate all child health information in one booklet, it will be beneficial for the country, its health-care services and child health. Improving and encouraging completed inclusive records will help prevent compromising the quality of care (19) and reduce health-care practitioners' confusion (20). Further studies of how design and standardized records could affect usage are required (18).

## Design of the HBR

Design is an important feature in ensuring the success of HBRs (19). This study explored the inclusion of data items present in HBRs in all European countries. Results showed great variability among countries, but health items such as birth and postnatal data, allergies, height and weight, and immunization were included almost universally in the records of respondent countries. A study based in the United Kingdom concluded that these data items were also perceived by parents as being most important in HBRs (8).

Design features such as font, big boxes for space to write and structure fields are very important for HBRs (22). Results from Hungary, Italy and Poland in this study indicated that there never was sufficient space for parents or health-care practitioners to add their own comments; this highlights the importance of record design. The capacity of some countries' HBRs to identify long-term conditions, care plans and emergency contacts for long-term conditions presents a further content element that resonates with other studies in the MOCHA project.

Literature emphasizes the importance of parental views of the HBR (5,8,20). Parents' opportunities (if any) to influence the design of the record were explored in the study. Results showed that most respondent countries did not allow parental contributions to determining the design. Contradictory evidence that showed too much emphasis on redesign had reverse effects. A study focused on professionally redesigning an HBR found that a redesign did not improve the efficacy of the record and actually led to parents and GPs using the record less than previously (27). Of the respondent countries that reported parental involvement, however, Ireland described a new initiative that creates a channel for parental involvement in record design. Even better, the Netherlands described a panel of children and young people that contributes to issues relevant to child health. An African study concluded that HBRs should be "periodically reviewed and critically assessed to determine whether the design and content is optimal for end user needs" (18).

Studies also show that HBRs have more potential for, and are more valued by, parents with children who require specialist medical services (18,28,29). A case study exploring the proportion of parents who brought their child's HBR to hospital appointments found that parents with children who had special needs or those who required specialist medical services were more likely to use their HBR. The study highlighted the importance of design of the record for parents of children with special health needs. The parents also requested HBRs with additional appendices to provide information about their child's health condition, records of the professionals involved in their child's care, appointment dates and details of their investigations (25).

Similarly, a study determining the effects of an HBR specifically designed for children with disabilities found that parents appreciated a tailored HBR that included 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 valued an HBR that was specifically designed for them more than a standard-issue record (25). From this study, only Bulgaria, the Netherlands, Portugal and Spain considered data items for special medical conditions or disabilities in their HBRs, though sharing between parents and professionals of treatments for individual children's health conditions was seen as important in Kazakhstan, the Russian Federation and Uzbekistan. Children with special health needs require more monitoring and, in this situation, HBRs are extremely beneficial for enhancing the child's health and facilitating health-care provider knowledge (28).

## HBR utilization

Further studies are required to determine factors that affect HBR usage (18). This study investigated record utilization, 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 utilization by 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 HBRs (30).

Respondent countries that did not report high utilization stated that this was due to regional influences and differences. A few countries (including 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 (25). A study conducted in the United Kingdom found that HBR usage is lower in women living in disadvantaged circumstances, young mothers, those with a larger family size, people with lower educational attainment or a history of mental health problems, and lone parents (31). These components were not studied here, but future studies could focus on this topic to see if results from the United Kingdom could be generalized to other European countries.

Though it is important to consider cultural and societal differences among European countries, the positive effects of HBRs seem to be universal. A study from 1996 described the importance of good record-keeping in times of civil unrest in Bosnia and Herzegovina. In this situation, an HBR provided essential epidemiological data and an accurate health record for children. HBRs are particularly useful in war situations, since hospital-based records frequently are destroyed or are inaccessible (32).

## Immunization-focused or holistic HBRs?

The approach taken within this study, in line with a child-centric and total primary care philosophy, was to focus on records for the child, and then ascertain the contents. This contrasts with some important groups in Europe and globally, such as TechNet-21, which focus solely on immunization records; indeed, recent EU initiatives have focused solely on immunization (33,34). Immunization, however, cannot and should not be considered outside of the child's overall health and health-care needs. It is noteworthy that of the 37 countries whose HBR contents are analysed in Table 5, only three (Belgium, Bosnia and Herzegovina and Estonia) solely record immunization (Germany has two companion HBRs, one of which is specifically for immunization). The distinction, which is important, is that immunization recording needs to be highly standardized for the best scientific evaluation to be undertaken and to facilitate important functions such as batch-tracing. Moves to pursue immunization HBRs in isolation, however, will cut across efforts to improve holistic and child-centric services and, indeed, is against the policies and practices of virtually all countries.

## HBR digitalization

Many countries are considering digitalizing the record for improved access and higher rates of recording. Investigation of digital HBRs in this study, however, showed that the great majority



of respondent countries currently use only paper HBRs. Countries mentioning digitalization do so in relation to future plans (Austria, Bulgaria, Israel and Portugal) or are at a transitional stage in the direction of a patient portal approach (including Azerbaijan, Denmark, Estonia, Greece, and the Netherlands). Finland currently has no HBR.

Other countries have unofficial products available for citizen use; in Czechia, for example, the unofficial electronic HBR “Zopik – Internet friend” provides a portal to oversee child health care and is accessible through a computer or smartphone. The portal records health events, provides an overview of the child’s health and development, sends parents reminders about mandatory health examinations and vaccinations, and supplies information through articles written by doctors and experts. Ireland reports the availability of unofficial apps that are neither validated nor regulated emerging to fill a vacuum; a separate study has shown how few European countries have the means of validating apps in child health (35).

Interestingly, a study conducted in the United Kingdom found that parents did not readily adopt an electronic HBR. Three digital engagement issues that need to be addressed before widespread successful implementation is possible were identified: technological challenges; social challenges; and health service challenges (36).

The first challenge the study identified was that parents found that some aspects of the electronic record were challenging and took longer to complete than a paper-based record. They also had concerns over the privacy and confidentiality of their child’s health data and were apprehensive about who owned the data. The second challenge related to families’ social circumstances. Factors such as the availability of Internet access and ownership of technological devices meant that electronic versions of the HBR were not available freely to all citizens, highlighting the digital divide in economically deprived areas. Lastly, the study found that poor digital literacy among parents and health-care professionals hindered the use of the technology and underlined the need for training, as with all new electronic adaptations.

These results show that digital versions of the HBR 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. Design suitability, operational reliability and trust will be key essentials, as will designing for the full range of citizen end-users (37).

## Health promotion and HBRs

HBRs globally are often supplemented by health promotion information, but only nine of the respondent countries reported having health promotion information associated with the HBR. A study concluded that the main value of an HBR is not as a health education tool (27).

## HBRs and personalized care plans

As was explained above, shared personalized care plans are very desirable to enable shared management for children with long-term conditions or those being treated for specific illnesses or accidents. Personalized care plans should not, however, replace the HBR as a means of providing reminders about and recording all other preventive health activity. Entries may be made in the HBR to indicate specific actions that should be delayed or not administered, but the HBR should not be allowed to be overlooked or overshadowed by a condition-specific personalized care plan, except in 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.

## The HBR as an official document

HBRs can occasionally be used as official documents for proof of entitlement to services. Results from this study show that most of the respondent countries do not use HBRs as an

official document, but that HBRs in Azerbaijan, Bosnia and Herzegovina, Bulgaria, Germany, Greece, Hungary, Malta, the Russian Federation, Turkey and Ukraine are presented, in some form, to education institutions (to support, for example admission processes or confirm immunization status). The literature suggests that the requirement of an HBR for school admissions may improve vaccination adherence and record retention, but further research is required to better understand this association (38). HBRs may be used in Ukraine to gain additional support for children with chronic conditions.

## Limitations of the study

The core method of this study was a questionnaire that was validated by an external expert panel and was completed by an informed local expert in each country. It therefore was based on common questions but exploited local knowledge. Complete returns were received for 50 of the 53 countries of the European Region, and core data from an external source for the remaining three countries enabled 100% coverage of key topics. Triangulation with an independent third-party source in the early stages showed good concordance.

While the questionnaire investigated which agency issued the HBR (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 HBRs, though Switzerland described how an insurance company funded printing. A recent study of 72 countries showed that HBRs varied in their sources of funding, which ultimately complicated matters and led to issues of inadequate supplies of records (17). Further research on this topic in Europe could explore whether funding bodies similarly affect HBR stocks in Europe. In this study, Hungary reported a reduction in funding, which resulted in diminished design.

A flaw of any study utilizing an in-country source is the potential misinterpretation of terminology used when asking a question. A question that was frequently misunderstood in this study was whether countries had a reliable procedure for issuing HBRs for children moving into the country or region after birth. Additionally, although a definition for HBRs was provided in the questionnaire, many countries reported records other than HBRs. This concurs with a previous study conducted by WHO and UNICEF in which similar misconceptions were reported (38) and which led to the creation of a common vocabulary/thesaurus for HBRs when working globally to reduce misunderstandings.

Parental views of HBRs were not investigated in this study, but literature shows that parents support them and see them as useful tools (5). This held true except for Norway, where a randomized controlled trial conducted in 2006 explored the effects of a parent-held HBR (4). The study found that use of the record did not affect usage of health-care services, parents' knowledge of their child's health, or parents' satisfaction with information from or communication with health-care professionals. Consequently, the record was deemed ineffective for full-scale roll out and implementation of HBRs in Norway was deferred. Unanimous support for the record nevertheless was received from parents of children living with chronic diseases.

## Conclusions

Results from this study show there is tremendous variety in HBRs in Europe. This finding is supported by the literature, which demonstrates global variability. The associated benefits and risks of multiple records are discussed in the report, allowing recommendations for integration of HBRs 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 intention of facilitating further co-production of health.

## References

1. WHO recommendations on home-based records for maternal, newborn and child health. Geneva: World Health Organization; 2018 (<https://apps.who.int/iris/bitstream/handle/10665/274277/9789241550352-eng.pdf?ua=1>).
2. Charles R. An evaluation of parent-held child health records. *Health Visitor* 1994;67(8):270–2. PMID:960831.
3. Jeffs D, Nossar V, Bailey F, Smith W, Chey T. Retention and use of personal health records: a population-based study. *J Paediatr Child Health* 1994;30(3): 248–52. doi:10.1111/j.1440-1754.1994.tb00627.x.
4. Bjerkeli Grøvdal LB, Grimsmo A, Ivar Lund Nilssen T. Parent-held child health records do not improve care: a randomized controlled trial in Norway. *Scan J Prim Health Care* 2006;24(3):186–90. doi:10.1080/02813430600819769.
5. Walton S, Bedford H. Parents' use and views of the national standard personal child health record – a survey in two primary care trusts. *Child Care Health Dev.* 2007;33(6):744–48. doi:10.1111/j.1365-2214.2007.00735.x.
6. Saffin K, Macfarlane A. How well are parent held records kept and completed? *Br J Gen Pract.* 1991;41:249–51.
7. Volkmer RE, Gouldstone MA, Ninnis CP. Parental perception of the use and usefulness of a parent-held child health record. *J Paediatr Child Health* 1993;29(2):150–3. doi:10.1111/j.1440-1754.1993.tb00470.x.
8. Hampshire AJ, Blair ME, Crown NS, Avery AJ, Williams EI. Variation in how mothers, health visitors and general practitioners use the personal child health record. *Child Care Health Dev.* 2004;30(4):307–16. doi:10.1111/j.1365-2214.2004.00433.x.
9. Models of Child Health Appraised (MOCHA) [website]. London: Imperial College; 2020 ([www.childhealthservicemodels.eu](http://www.childhealthservicemodels.eu)).
10. External advisory board. In: Models of Child Health Appraised (MOCHA) [website]. London: Imperial College; 2020 (<https://www.childhealthservicemodels.eu/partnerlisting/external-advisory-board/>).
11. Country agents. In: Models of Child Health Appraised (MOCHA) [website]. London: Imperial College; 2020 (<https://www.childhealthservicemodels.eu/partnerlisting/country-agents/>).
12. Home-based records for Belgium. In: TechNet-21 [website]. Geneva: World Health Organization; 2020 (<https://www.technet-21.org/en/topics/home-base-records/belgium>).
13. Committee on the Future of Healthcare. Sláintecare report. Dublin: Houses of the Oireachtas; 2017 (<https://s3-eu-west-1.amazonaws.com/govieassets/165/270718095030-1134389-Slaintecare-Report-May-2017.pdf>) .
14. VanDenHeuvel A, O'Reilly M, Perry IJ. Evaluation of the pilot parent-held personal child health record programme in the Mid-Western Health Board Region: final report (2002). Cork: University College Cork; 2002 (<http://hdl.handle.net/10147/44549>).
15. Home-based records. In: TechNet-21 [website]. Geneva: World Health Organization; 2020 (<https://www.technet-21.org/en/topics/home-base-records/>).

16. Deshpande S, Rigby M, Alexander D, Blair M. Work package 8: home based records. London: Imperial College; 2018 (<https://www.childhealthservicemodels.eu/wp-content/uploads/R15-Home-Based-Records-Report.pdf>).
17. Brown DW, Gacic-Dobo M. Occurrence of home-based record stock-outs – a quiet problem for national immunization programme continues. *Vaccine* 2018;36(6):773–8. doi:10.1016/j.vaccine.2017.12.070.
18. Brown DW, Tabu C, Sergon K, Shendale S, Mugoya I, Machekanyanga Z et al. Home-based record (HBR) ownership and use of HBR recording fields in selected Kenyan communities: results from the Kenya missed opportunities for vaccination assessment. *PLoS ONE* 2018;13(8):e0201538. doi:10.1371/journal.pone.0201538.
19. Hasman A, Rapp A, Brown DW. Revitalizing the home-based record: reflections from an innovative south-south exchange for optimising the quality, availability and use of home-based records in immunisation systems. *Vaccine* 2016;34(47):5697–9. doi:10.1016/j.vaccine.2016.09.064.
20. Cormack L, Morley C, Seward A, Vickers D. The personal child health record: attitudes to and usage by parents and professionals during the first year of a child's life. *Ambul Child Health* 1998;4(4):375–80.
21. Maternal, newborn and adolescent health. Home-based records for maternal, newborn and child health. In: World Health Organization [website]. Geneva: World Health Organization; 2018 ([http://www.who.int/maternal\\_child\\_adolescent/guidelines/development/home-based-records/en/](http://www.who.int/maternal_child_adolescent/guidelines/development/home-based-records/en/)).
22. Brown DW, Gacic-Dobo M, Young SL. Home-based child vaccination records – a reflection on form. *Vaccine* 2014;32(16):1775–7. doi:10.1016/j.vaccine.2014.01.098.
23. Aiga H, Pham Huy TK, Nguyen VD. Cost savings through implementation of an integrated home-based record: a case study in Vietnam. *Public Health* 2018;156:124–3. doi:10.1016/j.puhe.2017.12.018.
24. Aiga H, Nguyen VD, Nguyen CD, Nguyen TTT, Phuong Nguyen LT. Fragmented implementation of maternal and child health home-based records in Vietnam: need for integration. *Glob Health Action* 2016;9(1):29924. doi:10.3402/gha.v9.29924.
25. Moss AL. Is the personal child health record used in secondary care? *Child Care Health Dev.* 2005;31(5):627–8. doi:10.1111/j.1365-2214.2005.00533.x
26. Osaki K, Hattori T, Kosen S, Singgih B. Investment in home-based maternal, newborn and child health records improve immunization coverage in Indonesia. *Trans R Soc Trop Med Hyg.* 2009;103(8):846–8. doi:10.1016/j.trstmh.2009.03.011.
27. Wright CM, Reynolds L. How widely are personal child health records used and are they effective health education tools? A comparison of two records. *Child Care Health Dev.* 2006;32(1):55–61. doi:10.1111/j.1365-2214.2006.00575.x.
28. Moore J, Brindle A, Goraya P, Monk S, Rennie D, Tamhne R et al. A personal child health record for children with a disability. *Ambul Child Health* 2000;6(4):261–7. doi:10.1046/j.1467-0658.2000.00091.x.
29. Banister P. The child health record and its uses for epidemiological purposes. *Prog Clin Biological Res.* 1985;163B:33–8. PMID:29678100 3983161.
30. Brown DW, Gacic-Dobo M. Home-based record prevalence among children aged 12–23 months from 180 demographic and health surveys. *Vaccine* 2015;33(22):2584–93. doi:10.1016/j.vaccine.2015.03.101.

31. Walton S, Bedford H, Dezateux C, Millennium Cohort Study Child Health Group. Use of personal child health records in the UK: findings from the millennium cohort study. *BMJ* 2006;332(7536):269–70. doi:0.1136/bmj.332.7536.269.
32. McMaster P, McMaster HJ, Southall DP. Personal child health record and advice booklet programme in Tuzla, Bosnia Herzegovina. *J R Soc Med.* 1996;89(4):202–4. doi:10.1177/014107689608900408.
33. Proposal for a Council recommendation on strengthened cooperation against vaccine preventable diseases. Brussels: European Commission; 2018 (COM/2018/244 final; <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2018%3A244%3AFIN>).
34. Request for a mandate to the Expert Panel of effective ways of investing in health. Vaccination programmes and health systems in Europe (draft). Brussels: DG Health and Food Safety, European Commission; 2018 ([https://ec.europa.eu/health/expert\\_panel/sites/expertpanel/files/docsdire/mandate\\_vaccination\\_en.pdf](https://ec.europa.eu/health/expert_panel/sites/expertpanel/files/docsdire/mandate_vaccination_en.pdf)).
35. Deshpande S, Rigby MJ, Blair M. The presence of ehealth support for childhood obesity guidance. *Stud Health Technol Inform.* 2018;247:945–9. doi:10.3233/978-1-61499-852-5-945.
36. O'Connor S, Devlin AM, McGee-Lennon M, Bouamrane MM, O'Donnell CA, Mair FS. Factors affecting participation in the eRedBook: a personal child health record. *Stud Health Technol Inform.* 2016;225:971–2. doi:10.3233/978-1-61499-658-3-971.
37. Showell C, Turner P. Personal health records are designed for people like us. *Stud Health Technol Inform.* 2013;192(1):1037. doi:10.3233/978-1-61499-289-9-1037.
38. Young SL, Gacic-Dobo M, Brown DW. Results from a survey of national immunisation programmes on home-based vaccination record practices in 2013. *Int Health* 2015;7(4):247–55. doi:10.1093/inthealth/ihv014.

### The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

### **Member States**

Albania  
Andorra  
Armenia  
Austria  
Azerbaijan  
Belarus  
Belgium  
Bosnia and Herzegovina  
Bulgaria  
Croatia  
Cyprus  
Czechia  
Denmark  
Estonia  
Finland  
France  
Georgia  
Germany  
Greece  
Hungary  
Iceland  
Ireland  
Israel  
Italy  
Kazakhstan  
Kyrgyzstan  
Latvia  
Lithuania  
Luxembourg  
Malta  
Monaco  
Montenegro  
Netherlands  
North Macedonia  
Norway  
Poland  
Portugal  
Republic of Moldova  
Romania  
Russian Federation  
San Marino  
Serbia  
Slovakia  
Slovenia  
Spain  
Sweden  
Switzerland  
Tajikistan  
Turkey  
Turkmenistan  
Ukraine  
United Kingdom  
Uzbekistan

### **World Health Organization Regional Office for Europe**

UN City, Marmorvej 51, DK-2100 Copenhagen Ø, Denmark  
Tel: +45 45 33 70 00 Fax: +45 45 33 70 01  
Email: [eurocontact@who.int](mailto:eurocontact@who.int)  
Website: [www.euro.who.int](http://www.euro.who.int)