Understanding women’s, caregivers’, and providers’ experiences with home-based records: A systematic review of qualitative studies

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Abstract

Mothers, caregivers, and healthcare providers in 163 countries have used paper and electronic home-based records (HBRs) to facilitate primary care visit. These standardized records have the potential to empower women, improve the quality of care for mothers and children and reduce health inequities. This review examines experiences of women, caregivers and providers with home-based records for maternal and child health and seeks to explore the feasibility, acceptability, affordability and equity of these interventions. We systematically searched MEDLINE, MEDLINE In-Process, MEDLINE Ahead of Print, Embase, CINAHL, ERIC, and PsycINFO for articles that were published between January 1992 and December 2017. We used the CASP checklist to assess study quality, a framework analysis to support synthesis, and GRADE-CERQual to assess the confidence in the key findings. Of 7,904 citations, 19 studies met our inclusion criteria. In these studies, mothers, caregivers and children shared HBR experiences in relation to maternal and child health which facilitated the monitoring of immunisations and child growth and development. Participants’ reports of HBRs acting as a point of commonality between patient and provider offer an explanation for their perceptions of improved communication and patient-centered care, and enhanced engagement and empowerment during pregnancy and childcare. Healthcare providers and nurses reported that the home-based record increased their feeling of connection with their patients. Although there were concerns around electronic records and confidentiality, there were no specific concerns reported for paper records. Mothers and other caregivers see home based records as having a pivotal role in facilitating primary care visits and enhancing healthcare for their families. The records’ potential could be limited by users concerns over confidentiality of electronic home-based records, or shortcomings in their design. Health systems should seize the opportunity HBRs provide in empowering women, especially in the contexts of lower literacy levels and weak health care delivery systems.
Introduction

The home-based record (HBR) offers an approach that women and countries can use to improve both the processes, such as communication and empowerment, and outcomes of health care, including pregnancy complications, child development and vaccination [1]. The HBR is a document that may include components of preventive or curative antenatal, postnatal, newborn, and child health. This type of record has been used in various paper or electronic formats since the introduction of the Japanese Maternal and Child Health Handbook in 1948 [2]. Today, over 163 countries have used HBRs [3]. New card designs and delivery approaches that span the spectrum of care, from pregnancy through to childhood, offer opportunities for countries that wish to enhance the continuity of care and reduce child and maternal mortality.

United Nation (UN) Sustainable Development Goals 3 and 5 aim to reduce the mortality rates of children under age 5 and improve maternal health by the year 2030 [4]. A pivotal component of Goal 5 is the realization of gender equality and the empowerment of women. Disempowerment is associated with poorer health and social outcomes for women and children [5]. Inequities in gender, age, socioeconomic status and ethnicity contribute to disempowerment [6, 7]. Empowerment is both a process and an outcome that allows individuals to take control over their lives, set their own agendas, gain skills, increase self-confidence, solve problems, and develop self-reliance [8].

To date, there is no global synthesis of evidence that incorporates the perceptions of caregivers and mothers in relation to these HBRs. Hence, the objective of this study is to examine and synthesize existing published research about mothers, caregivers, children and health care providers in terms of their use and acceptability of HBRs, and the value of using these records. This systematic review is one of a series of systematic reviews commissioned by the WHO to underpin forthcoming global guidance on home-based records for maternal, newborn and child health. Other reviews in the WHO series examine the effectiveness of HBRs on health outcomes [1].

HBRs are designed for use in primary and secondary-care encounters [9]. HBRs aim to bridge patients and providers; however, this is dependent on local feasibility, acceptability, applicability, and their value, such as vaccine-series completion and child-growth monitoring. Women who engage with these interventions are more likely to participate in primary care and to ensure the continuity of care [10]. The WHO and the United Nations Children’s Fund’s (UNICEF) Expanded Program on Immunisation (EPI) have supported cultural and language adaptations to HBRs, but evaluations are needed to assess the benefits and harms of HBRs [3]. To improve the implementation of HBRs, it is important to assess the perspectives of mothers, caregivers, and providers, and also to determine how these may vary across rural and urban areas, and private and public clinics in low-, middle- and high-income countries.

Electronic HBRs have begun to be used in middle- and high-income settings [11]. The use of this type of record prevents data loss and promotes information sharing between providers to improve integration in care [12]. Part of our review aims to compare paper-based HBRs to the newly emerging electronic records and looks at how women and caregivers perceive these electronic HBRs in terms of their value, security and ease of use. For health equity concerns, we aim to consider low-literacy populations and populations that do not speak their home country’s official language, as well as mobile populations, such as nomads, internally displaced persons, and refugees.

To achieve our study objective, this systematic review addresses the following key research question: Are HBRs for maternal, newborn and child health feasible, acceptable, affordable and equitable from the perspectives of women, family members, and health provider stakeholders? This review also aims to understand the values that women and caregivers hold in relation to the use of these HBRs.
Methods

We searched for qualitative studies exploring the experiences of mothers, caregivers and healthcare providers with home-based records for maternal, newborn and child health. We utilized the best fit framework analysis method for the synthesis of this systematic review [13]. We selected a framework *a priori* and searched for constructs of acceptability, feasibility, affordability and equity as defined by the Grading of Recommendations Assessment, Development and Evaluation (GRADE) [14]. We identified qualitative key findings and assessed the confidence of the key findings using GRADE-CERQual [15, 16].

Search strategy and selection criteria

This systematic review adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [17]. A team of experts developed a protocol that considered the use, implementation and values that are relevant to mothers, caregivers, and healthcare provider stakeholders in low-, middle- and high-income countries, in relation to the use of paper and electronic HBRs, which was published on the Cochrane Equity Methods website [18]. Using relevant search terms, searches of MEDLINE, MEDLINE In-Process, MEDLINE Ahead of Print, Embase, CINAHL, ERIC, and PsycINFO accessed articles that were published between January 1992 and August 2017. The search strategy is listed in Supplemental 1 (S1). We also searched the grey literature to identify relevant studies and published reports on prevention programmes of the World Health Organization (WHO), the Centre for Disease Control and Prevention (CDC), the European Centre for Disease Prevention and Control, the United States Agency for International Development, John Snow Inc. (JSI), and the Japan International Cooperation Agency (JICA).

We included qualitative and mixed-methods studies that reported on the values of and perceptions around HBRs and their access, use, feasibility, affordability, equity and acceptability. We focused on studies on mothers, caregivers, children and healthcare stakeholders and considered low-, middle- and high-income settings. Papers were eligible for inclusion if they addressed the research question, utilized qualitative methods, and included qualitative evidence (See Supplemental 2 (S2) for the full inclusion and exclusion criteria). These reports could be in any language or geographic setting.

Study selection and data extraction

An independent team screened titles and abstracts in duplicate, followed by full-text assessments for eligibility. Conflicts were resolved through discussion or the involvement of another reviewer. Citation information was downloaded into EndNote reference software. We assessed the methodological quality of papers using the U.K Critical Appraisal Skills Programme (CASP) checklist for qualitative studies [19]. While we used CASP to assess the quality of all included studies, we did not exclude any papers on the basis of quality assessment, rather, the methodological rigor of each contributing study contributed to the confidence assessments of each review finding.

We designed our data-extraction form according to a framework selected *a priori*: the social-ecological model (See Table 1) for behaviour change [20, 21]; which has been used in previous research that explores maternal and child health [22, 23]. This approach facilitated the exploration of maternal, caregiver and health care provider experiences with HBRs. The social-ecological model is a theory-based framework that considers the complex interconnections of the multiple levels of a social system and the interactions between individuals and their environment [22]. Understanding how HBRs influence social ecology, defined as the study of the relation between the developing human being and the settings and contexts in
which the person is actively involved [24], allows for the investigation of acceptability and usability of HBRs at multiple levels of a social system. Our data-extraction form reflects the model’s system levels, which include the individual, interpersonal and family, community and social, and organizational and policy levels. Within each of these levels, we examined the determinants of HBR use, acceptability, feasibility, affordability and equity. We pilot tested the data-extraction form to ensure the framework aligned with the data. Our team of reviewers extracted data, in duplicate, from the included studies. Discrepancies were resolved through discussion.

### Data synthesis

We contextualized the preliminary findings on HBRs and maternal, newborn and child populations, using the social-ecological framework [21]. We used the framework method as a systematic and flexible approach to analysing qualitative data [25] and grouped ideas of acceptability, feasibility, affordability and equity across key populations. Framework analysis is a five stage process of familiarisation with the data, identifying a thematic framework, indexing (applying the framework), charting and mapping, and interpretation [26]. Any relevant data that did not correspond to the components of our framework were incorporated as emerging themes. This coding was done in a matrix spreadsheet to facilitate analysis. Mapping involved examining concordant findings, disconfirmatory data, and associations between themes. Interpretations were guided by our review objectives as well as emerging themes.

We applied a qualitative methods lens that considered the saturation level (no new themes revealed in examining new papers) and the triangulation of the data between the mothers, caregivers, stakeholders and organizations within the health systems in the study. In judging the relevance to our research question, we considered the design of the HBR (for example, an integrated maternal and child record), the setting and the outcome. We used the data contained in the framework analysis to identify the key findings on the themes of feasibility, acceptability, affordability and equity. A key finding is defined as a synthesis of qualitative evidence that describes a recurring phenomenon found in primary studies [15, 16].

We used the Confidence in the Evidence from Reviews of Qualitative research (CERQual) tool [15] to assess the confidence of the key findings of this review. This tool is a new method used for assessing the strength of qualitative review evidence; it works similar to the way the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach
assesses the strength of quantitative evidence [14]. CERQual bases the evaluation on four criteria: the methodological limitations of the included studies that support a review finding; the relevance of the included studies to the review question; the coherence of the review findings; and the adequacy of the data that contributes to a review finding. The GRADE-CERQual assessment results in a final classification of confidence in the theme in four categories: 'high', 'moderate', 'low' or 'very low' (See Tables 2 and 3).

**Results**

Our search strategy identified 10,486 citations. After removing the duplicates, we screened 7,904 articles by title and abstract. We went on to screen 159 articles, using a full-text assessment for eligibility. Fig 1 shows the 19 studies that met our inclusion criteria.

Table 1 shows the characteristics of the included studies. These studies are heterogeneous in terms of sample size, home-based record design, setting and findings. Of the 19 included studies, four were set in low- or middle-income countries (Brazil, Palestine, South Africa, and Cambodia). The remaining 15 studies took place in the UK (5), the US (5), Australia (3), Canada (1), and New Zealand (1). Interventions included child health books (9), online child health portals (4), the Maternal and Child Health Handbook (2), women-held antenatal records (2), online antenatal records (1), and electronic child immunisation records (1). The majority of the included studies used qualitative techniques, and most data were collected by individual interviews and/or surveys. They represented the views of more than 2700 pregnant women, mothers, caregivers, and healthcare providers. The CASP summary of methodological assessment is also included in Table 4.

Findings were grouped according to the constructs of feasibility, acceptability, affordability and equity. The study findings were categorised into individual, interpersonal and family, community and social, organizational and health system levels of the SEM framework. From synthesising descriptions from included studies, we identified three broad types of HBRs used by mothers or caregivers: maternal health records, child health records, and immunisation records. The differences among these interventions played a role in the perceptions of mothers, caregivers and healthcare providers of the value of HBRs for maternal, newborn and child health. We categorised the emerging findings according to the intervention used (See Table 5).

Positive experiences with HBRs emerged as a composite outcome of our results. We identified ten key findings and assessed the confidence in these findings, using GRADE-CERQual (See Table 6). Confidence in findings ranged from very low to low. Confidence levels were downgraded due to the methodological limitations, the relevance to the setting, and the coherence and adequacy of the data.

In relation to our research question, these key findings generated the following: Given the widespread use of HBRs across contexts and its impact on knowledge and education,

| Component                      | Definition                                                                 |
|--------------------------------|---------------------------------------------------------------------------|
| Methodological limitations     | The extent to which problems were identified in the way in which the primary studies which contributed to the evidence for a review finding were conducted |
| Relevance                      | The extent to which the primary studies supporting a review finding are applicable to the context specified in the review question |
| Coherence                      | The extent to which the pattern that constitutes a review finding is based on data that is similar across multiple individual studies and/or incorporates (compelling) explanations for any variations across individual studies |
| Adequacy of data               | An overall determination of the degree of richness and/or scope of the evidence and quantity of data supporting a review finding |

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empowerment, and patient-provider interactions, HBRs are acceptable and useful for women, caregivers and healthcare providers. The feasibility of these interventions may vary greatly depending on geographic location, primary care setting in which they are implemented, and design of the record. No studies provided sufficient data on affordability, or focused on low-literacy or nomadic/refugee populations, limiting our ability to make conclusions about equity.

**Acceptability**

Evidence from various geographic contexts and different forms of HBRs indicate that women, caregivers and healthcare providers appreciate and value home-based records. Women from high-income countries valued the ease, speed and convenience of online HBRs [12, 27–29]. However, privacy in relation to online medical records was a consistent concern, except for one study that successfully used records as part of a rare disease network [30]. Health care providers in low-income settings value the design of home-based records and preferred them due to their appearance, practical information, convenience and long-term value [31, 32].

**Feasibility, affordability, equity**

The qualitative evidence synthesis did not identify findings on feasibility, affordability or equity from the perspectives of mothers, caregivers and healthcare providers.

**Healthcare provider values**

Healthcare providers valued the educational and logistical aspect of HBRs, as well as their design [27, 31–36]. In one low-income setting where card-type home-based records were available, healthcare providers preferred integrated handbooks in terms of its appearance, information, convenience and long-term value [32]. Clinical staff noted the importance of stakeholder engagement in card design to ensure its acceptability and use in primary care settings [31].

**Mother, caregiver and provider interactions**

HBRs facilitated communication between mothers/caregivers and health care professionals and improved person-centered care [12, 29, 30, 33–42]. Pregnant women and parents noted decreased fear and improved sense of empowerment during patient–provider interactions [12, 29, 35, 37–39, 41, 42]. HBRs also acted as a point of commonality between caregivers/mothers and nurses and allowed nurses to provide more comprehensive and tailored health education [32, 33, 35, 37, 39]. HBRs have the potential to foster closer relationships between mothers and their healthcare providers [37, 38].
**Improved knowledge and decision making**

Increased knowledge emerged as a key finding among pregnant women and caregivers. Parents agreed that they were better able to understand their child’s health status, and pregnant women felt that their increased knowledge helped them share in decision-making [27, 30, 32, 34, 35, 42, 43]. However, in one study [42], these views were expressed specifically towards the inclusion of a birth plan within a HBR, and not to the HBR as a whole.

Fig 1. PRISMA flow diagram.

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Table 4. Characteristics of included studies.

| Reference | Country       | Study Design                      | Population                                                                 | Intervention                                                                                                                                  | Focus of the Study                                                                                       | CASP Quality Assessment |
|-----------|---------------|-----------------------------------|-----------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|-------------------------|
| Byczkowski, 2014 | USA           | Mixed methods: Cross-sectional telephone survey with semi-structured interviews | N = 530 parents and caregivers; 215 intervention users, 315 non-users for telephone survey, and 126 of the 215 portal users for the survey | A secure web-based portal through which parents can access laboratory results, medication information, and their child’s visit history | Measures and understands parent concerns and perceptions of the usability and value of using a web-based portal to access their child’s health record | 8/10                    |
| Clendon, 2010 | New Zealand   | Oral History                      | N = 35 participants using the intervention                                   | Child health and development record books                                                                                                         | Examines the role and impact of the child health and development record book in New Zealand society and its inceptions | 10/10                   |
| Grippo, 2008 | Brazil        | Descriptive study                 | N = 89 family caregivers responsible for 0–39 month-old children             | Booklet that presents topics related to children’s development, including pregnancy and raising children healthy                                  | Evaluates the effectiveness, identifies people’s acceptance, characterizes family comprehension, and analyses relatives’ perceptions of child development and pregnancy booklet | 7/10                    |
| Hagiwara, 2013 | Palestine     | Mixed methods: Cross-sectional study with focus-group discussions | N = 67 participants: 42 women and 25 health professionals from the intervention areas | MCH handbook that monitors health of women, surveys use of health services, promotes health education, provides information when mother or child is referred | Evaluates the impact, satisfaction, and constraints of using the maternal child health handbook | 8/10                    |
| Hamilton, 2012 | Australia     | Mixed methods: Online survey with open-ended questions and semi-structured interview | N = 120 mothers did an online questionnaire; 6 mothers participated in interviews | Child Personal Health Record                                                                                                                  | Evaluates the effects of parent use of child personal health records on the parents’ experience, knowledge, engagement with child care | 9/10                    |
| Harrison, 1998 | South Africa  | Descriptive prospective study      | N = 185 interviews of 35 health personnel and 150 mothers/caregivers        | Revised version of the Road-to-Health card. It now contains a weight-for-age-chart, immunisation schedules and other health related data         | Describes the opinions of health personnel and parents on the accuracy and completeness of data recorded on the Road-to-Health card, and the information they would like recorded | 8/10                    |
| Hill, 2003    | Scotland      | Mixed methods. Self-completion questionnaires were used for data collection   | N = 871 participants: 12 health professionals, 749 children, 100 parents and 10 teachers | Child Health record                                                                                                                           | Determines the views of children, parents, teachers and health professionals on the Child Health profiles, and suggestions improvements | 8/10                    |
| Hully, 1993  | England       | Semi-structured questionnaire      | N = 18 parents of children from the paediatric oncology unit                 | Parent-held records for children                                                                                                               | Explores the efficiency of the patient held record                                                                 | 9/10                    |
| Hunter, 2008 | Scotland      | Semi-structured face-to-face interviews | N = 12 Residential Care Workers                                              | The BAAF common documentation form                                                                                                             | Explores why the shared documentation was not used routinely and the perceptions of residential care workers in their role of health improvement | 10/10                   |
| Kelly, 2016  | USA           | Cross-sectional study             | N = 90 parents                                                               | Online portal for parents of children                                                                                                           | Assesses parent use and perceptions of an inpatient portal application that provides information about a child’s hospital stay | 9/10                    |
| King, 2017   | Canada        | Prospective, mixed-methods study  | N = 23 participants: 18 caregivers, 5 service providers                      | Connect2care online health portal.                                                                                                             | Examines the use, utility, and impact of the connect2care portal                                                                 | 9/10                    |

(Continued)
Communication within the household

HBRs provided a mechanism for increasing husbands’ involvement with pregnancy and address other family members’ misconceptions about pregnancy [32–34]. HBRs similarly provided a mechanism for engaging family with childcare [36–38]. For example, HBRs provided opportunities for women to share information with husbands, partners, and grandparents [34]. In low-literacy settings, some husbands explained the contents of the handbook to their wives and advised them to obtain ANC, avoid salty food, or refrain from working too hard [32]. Among some families, the HBRs represented an intergenerational tool that could be passed down from mother to daughter as she transitioned to motherhood [37].
### Table 5. Framework analysis.

| Maternal Health | Child Health | Immunisation | Interpersonal Family | Table Core | Illustrative Quotes |
|-----------------|--------------|--------------|----------------------|------------|---------------------|
| **Theme (Ending)** | **Conceptual Model** | **Specific Interaction** | **Influence of Home-based Records** | **Action Core** | **Illustrative Quotes** |
| Individual | Characteristic of individuals that influence behavior, including knowledge, attitudes, behavior, self-efficacy, development, literacy, gender, age, religion, ethnicity, social environment, social network, social environment, financial resources, policy, perceptions, identity, stigma, and others. | | | | |
| Home-based records improve the knowledge of Maternal Health Record including mothers and help them share in pregnancy decision making, and improve everyday knowledge about their child’s health. | Maternal Health-related: | Enabling mothers to know what they need to know about their child’s health (Philip 2014). | The use of home-based records for maternal and child health (King 2017). | Maternal Health-related: | The use of home-based records for maternal health (Clendon 2010). |
| | Maternal Health-related: | Enabling mothers to know what they need to know about their child’s health (Philip 2014). | The use of home-based records for maternal and child health (King 2017). | Maternal Health-related: | The use of home-based records for maternal health (Clendon 2010). |
| | Maternal Health-related: | Enabling mothers to know what they need to know about their child’s health (Philip 2014). | The use of home-based records for maternal and child health (King 2017). | Maternal Health-related: | The use of home-based records for maternal health (Clendon 2010). |
| | Maternal Health-related: | Enabling mothers to know what they need to know about their child’s health (Philip 2014). | The use of home-based records for maternal and child health (King 2017). | Maternal Health-related: | The use of home-based records for maternal health (Clendon 2010). |
| | Maternal Health-related: | Enabling mothers to know what they need to know about their child’s health (Philip 2014). | The use of home-based records for maternal and child health (King 2017). | Maternal Health-related: | The use of home-based records for maternal health (Clendon 2010). |
| **The use of home-based records for maternal and child health (King 2017).** | **The use of home-based records for maternal and child health (King 2017).** | **The use of home-based records for maternal and child health (King 2017).** | **The use of home-based records for maternal and child health (King 2017).** | **The use of home-based records for maternal and child health (King 2017).** | **The use of home-based records for maternal and child health (King 2017).** |

(Continued)
| Table 5. (Continued) |
|----------------------|
| **Social/Community** |
| **Main Theme (Heading)** |
| **Subtheme (Heading)** |
| **Innovation Specific Supporting in Diagnosis** |
| **Innovation Specific Supporting in Management** |
| **Innovation Specific Supporting in Prevention** |
| **Innovation Specific Supporting in Support** |
| **Home-based records as a point of continuity** |
| **Home-based records and as a point of commonality** |
| **Organizational Health System** |
| **Organizational Health System** |
| **Organizational Health System** |
| **Organizational Health System** |

**Main Theme (Heading):** The use of home-based records for maternal and child health facilitated communication between mothers/caregivers and healthcare professionals and improved patient outcomes.

**Subtheme (Heading):** Maternal Health Record

**Innovation Specific Supporting in Diagnosis:**
- Maternal Health Record
  - Carrying their own records encouraged health care workers to better explain what was being recorded and why certain things were done, as they were aware women would go home and read the records again. (Phipps 2001)
  - Patients had fewer concerns with poor communication with health staff if personal records were held. (Hagiwara 2013)
  - Informed patients were more engaged and remained more in touch at home. (Lee 2016)
  - Patients had fewer concerns with poor communication with health staff if personal records were held. (Hagiwara 2013)

**Innovation Specific Supporting in Management:**
- Maternal Health Record
  - Like the mothers, all of the health centre staff, VHVs and TBAs preferred the MCH handbook to the current record system in terms of its appearance, information, convenience and long term value. (Clendon 2010)
  - Health providers expressed that they could provide more comprehensive health education and counseling with greater confidence and accuracy, when they used the MCH handbook—than if they concentrated instead on providing all the necessary information related to MCH in a book with the guidance of MCH handbook (Hagiwara, 2013). (Schuster 2001)
  - More than 90% of the mothers and infants were interested in the booklet and its format. The booklet was like a stepping stone between the both of you” (Clendon 2010)

**Innovation Specific Supporting in Prevention:**
- Maternal Health Record
  - Both midwives and doctors mentioned that the birth plan could support useful discussions with women between discharge and in follow-up. (Hull 1993, Lee 2016, King 2017, Phipps 2001, Quinlivan 2014, Sharp 2014)

**Innovation Specific Supporting in Support:**
- Maternal Health Record
  - Participants expressed an appreciation for having more detailed information and knowing the technical language, as they felt they could then communicate on a more level playing field with health care providers. (Lee 2016)

**Organizational Health System:**
- Organizations or social institutions with rules and regulations for operations that affect how care is delivered who also provide services are providers involved with the design and implementation of home-based records.

**Main Theme (Heading):** Experiences of home-based records

**Subtheme (Heading):** Maternal Health Record

**Innovation Specific Supporting in Diagnosis:**
- Maternal Health Record
  - Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Management:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Prevention:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Support:**
- Maternal Health Record
  - Maternal Health Record

**Online immunization record**

**Main Theme (Heading):** Online immunization record

**Subtheme (Heading):** Maternal Health Record

**Innovation Specific Supporting in Diagnosis:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Management:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Prevention:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Support:**
- Maternal Health Record
  - Maternal Health Record

**Online immunization record**

**Main Theme (Heading):** Online immunization record

**Subtheme (Heading):** Maternal Health Record

**Innovation Specific Supporting in Diagnosis:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Management:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Prevention:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Support:**
- Maternal Health Record
  - Maternal Health Record

**Online immunization record**

**Main Theme (Heading):** Online immunization record

**Subtheme (Heading):** Maternal Health Record

**Innovation Specific Supporting in Diagnosis:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Management:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Prevention:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Support:**
- Maternal Health Record
  - Maternal Health Record

**Online immunization record**

**Main Theme (Heading):** Online immunization record

**Subtheme (Heading):** Maternal Health Record

**Innovation Specific Supporting in Diagnosis:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Management:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Prevention:**
- Maternal Health Record
  - Maternal Health Record

**Innovation Specific Supporting in Support:**
- Maternal Health Record
  - Maternal Health Record

**Online immunization record**
Table 6. CERQual summary of findings.

| Review Finding | CERQual Assessment of Confidence in the Evidence | Explanation of CERQual Assessment | Studies Contributing to the Review Finding |
|----------------|-----------------------------------------------|----------------------------------|------------------------------------------|
| Home-based records improve the knowledge of mothers and help them share in pregnancy decision making, and improve caregiver’s knowledge about their child’s health status. Illustrative Quote: “Love the fact that [the child health record] kept me informed about my child’s health” (Kelly, 2017). | Low confidence | Knowledge consistently reported benefit for records even across a range of record styles. The major concern came with variance in record design (relevance), and the adequacy of the data, in that many studies did not show rich data, saturation or member checking. | Phipps 2001, Yanagisawa 2015, Byczkowski 2014, Kelly 2017, Lee 2016, Kitayama 2014, Whitford 2014 |
| The use of home-based records for maternal and child health facilitated communication between mothers/caregivers and healthcare professionals and improved person-centered care. Illustrative Quote: “I found the book worked really well, that it was like a communication between the both of you” (Clendon 2010). | Low confidence | The major concerns were with the relevance of the finding and its adequacy because of the limited number of participants in studies. | Byczkowski 2014, Clendon 2010, Grippo 2008, Hagiwara, 2013, Hamilton 2012, Hunter 2008, Hully 1993, Lee 2015, King 2017, Phipps 2001, Quinlivan 2014, Sharp 2014, Whitford 2014 |
| The use of home-based records for maternal and child health decrease fear among users and improve confidence and feelings of empowerment during patient-provider interactions. Illustrative Quote: “I think the Passport [health record] opened up a lot of doors” (Lee 2016). “I can control who sees it.” (Quinlivan 2014). | Low confidence | Across a variety of record types, increase in confidence and decrease in fear were consistently reported. The major concerns revolved around the setting limitation and the overall richness of data. | Clendon 2010, Grippo 2008, Quinlivan 2014, Whitford 2014, Hamilton 2012, Hully 1993, Lee 2016, Sharp 2014 |
| Mothers and caregivers had concerns with the privacy of online or electronic health records. Illustrative Quote: “I’m not sure I want all my medical information out there to be discovered. […] I’m not convinced it would be safe.” (Quinlivan 2014). | Low confidence | Fear of privacy reported inconsistently in 1 study. Relevance of settings is a concern as no studies performed in LMIC. | Byczkowski 2014, Kitayama 2014, O’Connor 2016, Quinlivan 2014, Sharp 2014 |
| Mothers that shared home-based records with partners or husbands for maternal health increased partners or husbands involvement with pregnancies and helped deal with misconceptions about pregnancy that other family members believed. Illustrative Quote: Authors stated the MCH handbook helped mothers and caregivers deal with rumours and misconceptions about pregnancy (Hagiwara 2017). | Low confidence | The major concerns revolved around the relevance of the finding to the research questions, the limited number of studies, and overall richness of data. | Hagiwara 2013, Phipps 2001, Yanagisawa 2015 |
| The use of home-based records for child health improved family engagement with child care. Illustrative Quote: The [record] provided a positive, inviting message to families about being engaged (King 2017). | Low confidence | Moderate concerns about relevance to the research question, major concern about relevance as low-middle income countries not represented | Clendon 2010, Grippo 2008, King 2017 |
| Home-based records acted as a point of commonality between caregivers/mothers and nurses, and allowed nurses to provide more comprehensive/tailored health education. Illustrative Quote: “[the book] was like a stepping stone between the both of you” (Clendon 2010). | Low confidence | The major concerns revolved around the relevance of the finding to the research question and limited number of studies. | Hagiwara 2013, Lee 2016, Yanagisawa 2015, Clendon 2010, Hamilton 2012 |
| The use of home-based records for maternal and child health facilitated continuity of care. Illustrative Quote: “I think it would help my GP know what the hospitals were doing and stop tests being repeated” (Quinlivan 2014). | Very low confidence | The major concerns revolved around the relevance of the research questions to the finding, setting limitation, limited number of studies and limited number of participants. | Hamilton 2012, Hully 1993, King 2017, Quinlivan 2014 |

(Continued)
Continuity of care

Finally, the use of HBRs for maternal and child health facilitated the continuity of care [29, 36, 39, 41] and facilitated a child’s transition to the adult healthcare system [36].

Discussion

The UN Sustainable Development Goals called for the adoption and strengthening of sound policies that promote gender equality, the empowerment of all women and improvements in maternal and child health [4]. The WHO is responsible for providing guidance on interventions that have the potential to improve outcomes in both health and empowerment at the primary-care level. The findings of this review confirm that women, caregivers and providers from a wide range of cultural and social contexts engage positively with HBRs.

Within our review we identified ten key findings, across individual, interpersonal, social and organizational levels, which showed connections operating at these levels with the core competencies of community primary care. The majority of our key findings were of low confidence, indicating that the findings may be a reasonable representation of our phenomena of interest. HBRs were valued for improving health knowledge and facilitating women’s communication with health care providers. Knowledge can bring power and vision to disadvantaged communities [44]. The lack of basic health literacy often limits interpersonal communication during health care visits. Improved communication can facilitate intervention outcomes in person-centred care and improve the satisfaction and continuity of care [45]. Continuity between patients and their providers or clinics is a core principle for primary care and an important determinant of the effectiveness of intervention [46].

Home-based records may give mothers and other caregivers a feeling of control and empowerment during clinic visits. Empowerment can improve health and social outcomes, when interventions are embedded in local contexts and are based on strong and direct relationships between people and their health providers [46]. In our review, we found that as mothers feel more in control, they also report feeling less fear during patient–provider interactions. This decrease in fear may lead to fewer barriers to health care access, more opportunities to ask questions, ensure follow-up visits, and help patients develop relationships with their health care providers. A well-maintained home-based record may provide a good first
impression, reflect positively on the mother, and be well-perceived by a nurse [47]. While primary care does mean the provision of acute care, the relationships established, the preventive interventions and the improvements in health literacy that come from regular visits provide communities with the most effective care [46, 48].

Clinic staff support the concept of the HBR, but they do not always support its composition [31]. A clinic may face a range of record formats and training may be limited. Also, there is a lack of coordination between the different units of health systems and this leads to reduced use of the HBR [40]. Since health providers value the educational and logistical aspect of home-based records, for the records to be able to meet their needs, it is important that HBRs be designed and implemented with their input [31, 33–36, 38]. It is also vital for health providers, at different levels, to be trained on the use of HBRs. Nurses in low- and middle-income countries and caregivers from low-income populations in the US noted that children’s home-based records should be in the parents’ home language and be free of medical jargon [27, 31]. There may be challenges in aligning HBRs with their feasibility at the country level [49]. HBRs, alone, do not lead to behavioural changes in, for example, smoking cessation, drinking alcohol or breastfeeding, without being linked to robust support programs. To ensure results, these elements may require programs in behaviour change [50]. Different levels of the social-ecological framework influence the feasibility, acceptability and use of the home-based record in different contexts. Individuals have their own characteristics and beliefs, but they may also be influenced by family practices and traditions. The engagement of men in pregnancies increases family-level involvement, and HBRs foster a sense of community and relationships between nurses and parents. At the health-system level, public clinics may be more likely to use these records than private clinics.

Health inequities, including barriers to healthcare, are a global challenge for many women and children, worldwide [51]. In different healthcare settings, many women struggle with low literacy and may feel disempowered in their relationships with health providers and in society [51]. When an intervention, such as a home-based record, is available for the entire population, this has implications for positive health equity and also presents opportunities [52]. When a home-based record provides new knowledge, and this new knowledge leads to improved communication, empowerment and continuity of care, we begin to see its importance to and potential for health equity. Ensuring HBRs are written at an appropriate literacy level will help foster this potential.

With the emergence of electronic records, some may argue that these technologies may be the future of health care [53]. This would depend on the scalability of this intervention in low- and middle-income countries, the availability of infrastructure, and individuals’ trust in online records. Mothers reported privacy concerns in relation to online records [12, 27–29]. However, in one study, parents had minimal concerns about confidentiality of online medical records [30]. Trust may vary in this study because the intervention is meant for a specialty based population—children with rare chronic disease in the US. Overall, in all populations, online records appear to offer opportunities for knowledge and engagement. For example, low-income Latina mothers indicated the usefulness of online immunisation records because they remove barriers to accessing and sharing health information [27]. With this increase in knowledge, they also reported wanting to gain more knowledge on the specific immunisations their children were receiving [27]. While the use of online records seems to be acceptable among low-income populations in high-income countries, there is a lack of evidence on their use in low- and middle-income countries. However, the adoption of the electronic health record would appear feasible, based on the widespread use of smartphones among low-income populations [12]. Nevertheless, there is concern about privacy and security; there is also a risk of harm to health equity when certain populations cannot take advantage of new technology.
Limitations
This review used secondary data, and as such is limited by the information provided in the published primary studies. Several studies included only basic qualitative data and did not provide clear evidence of saturation or data richness. Consequently, details around the core findings, the usability of the HBR and the depth of its community impact are less confident. Only four studies were conducted in low- or middle-income countries, limiting the generalizability of findings to resource-limited or fragile health system contexts. Finally, HBRs have emerged in many different cultural, linguistic and health-education formats, and this heterogeneity made it difficult to provide specific evaluations of HBR usability across regions.

Strengths
This review utilizes the social-ecological model as a framework for analysis and the GRADE CERQual approach to synthesize the qualitative findings and new understanding of the impact the home-based maternal and child health record has on knowledge, communication skills, and empowerment. The findings also inform the general principles behind the maternal, immunisation and child-health records, providing some basic insight into how and when these records may work and when they may not. The findings of this review also complement the concurrent review of effectiveness of HBRs on maternal newborn and child health outcomes [1], where HBRs were demonstrated to improve knowledge outcomes, communication, and agency. Unique to this review, HBRs increased husbands’ involvement with pregnancies and helped deal with misconceptions that other family members have about pregnancy. Combining this qualitative understanding with quantitative evidence collected to inform WHO recommendations offers a compelling body of knowledge on home-based records.

Conclusions
The experience of women, caregivers and providers clearly illustrates how HBRs can empower women and children. Women across countries spoke of improved maternal health, communication, and patient centeredness. Women living with low literacy and those in areas with less-developed health care systems reported positive interactions and care continuity. In general, women reported obtaining more learning from nurses and support during pregnancy, with decreased fear and increased empowerment, when HBRs were used. In general, frontline nurses confirmed the acceptability and value added of home-based records. Mothers who used online records had concerns about privacy; however, similar data on patients’ perceptions of online records is scarce and more research is needed. Policy makers need to take stakeholder’s perceptions on the value of home-based records into consideration when making decisions on the use of home-based records in their context.

Supporting information
S1 Table. Example search strategy.  
(PDF)

S2 Table. PICO inclusion and exclusion criteria.  
(PDF)

S3 Table. CERQual evidence profile.  
(PDF)

S4 Table. Table of excluded studies.  
(PDF)
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