

## Systematic review on the use of patient-held health records in low-income and middle-income countries

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# BMJ Open Systematic review on the use of patient-held health records in low-income and middle-income countries

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## ABSTRACT

**Objective** To review the available evidence on the benefit of patient-held health records (PHRs), other than maternal and child health records, for improving the availability of medical information for handover communication between healthcare providers (HCPs) and/or between HCPs and patients in low-income and middle-income countries (LMICs).

**Methods** The literature searches were conducted in PubMed, EMBASE, CINAHL databases for manuscripts without any restrictions on dates/language. Additionally, articles were located through citation checking using previous systematic reviews and a grey literature search by contacting experts, searching of the WHO website and Google Scholar.

**Results** Six observational studies in four LMICs met the inclusion criteria. However, no studies reported on health outcomes after using PHRs. Studies in the review reported patients' experience of carrying the records to HCPs (n=3), quality of information available to HCPs (n=1) and the utility of these records to patients (n=6) and HCPs (n=4). Most patients carry PHRs to healthcare visits. One study assessed the completeness of clinical handover information and found that only 41% (161/395) of PHRs were complete with respect to key information on diagnosis, treatment and follow-up. No protocols or guidelines for HCPs were reported for use of PHRs. The HCPs perceived the use of PHRs improved medical information availability from other HCPs. From the patient perspective, PHRs functioned as documented source of information about their own condition.

**Conclusion** Limited data on existing PHRs make their benefits for improving health outcomes in LMICs uncertain. This knowledge gap calls for research on understanding the dynamics and outcomes of PHR use by patients and HCPs and in health systems interventions.

**PROSPERO registration number** CRD42019139365.

## INTRODUCTION

To meet Sustainable Development Goals<sup>1</sup> and deliver quality care,<sup>2</sup> health systems in low-income and middle-income countries (LMICs) need to be redesigned and strengthened.<sup>3</sup> In line with this agenda, the World Health Organization (WHO) has formulated a health systems framework that describes six

## Strengths and limitations of this study

- Study design that enabled the accumulation and presentation of current evidence on the use of patient-held health records other than maternal and child health records in low-income and middle-income countries.
- Thorough literature search of three major electronic databases and reporting as per Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.
- Inconclusive results due to no evidence from trials.
- Small number of studies and no reporting on health outcomes, making it difficult to determine usefulness for patients with non-communicable diseases.

building blocks for health systems; of these, good service delivery comprises the delivery of effective, safe, quality healthcare and continuity of care is an important characteristic for delivering quality care.<sup>4</sup>

In many LMICs, healthcare delivery is usually organised around acute and single episode care, from different facilities and healthcare providers (HCP).<sup>5</sup> Such a model of healthcare delivery is inadequate due to increasing non-communicable disease (NCD) burden in LMICs.<sup>6</sup> Continuity of care needed for efficient and effective care, is simply defined as 'the seamless provision of healthcare between settings and over time'.<sup>7</sup> Informational continuity represents the cornerstone of continuity of care and is defined as the use of information on past events and personal circumstances to make current care appropriate for each individual.<sup>8</sup> Handover communication relates to the process of passing patient-specific health information between HCPs, from one visit to another, and from HCPs to the patient and family for ensuring patient care continuity and self-management.<sup>9</sup>



Complete and accurate clinical information about previous management and treatment is necessary for managing all patients but especially patients with chronic conditions due to a need for ongoing care from a range of HCPs.<sup>10</sup> Inadequate documented handover for HCPs often results in adverse events<sup>11 12</sup> or increased inpatient visits,<sup>13</sup> repeated tests or examinations leading to costly healthcare, burdensome to patients and a waste of resources.<sup>13</sup> The ability to view patients' medical records, across healthcare visits and facilities helps to facilitate health information exchange.<sup>14</sup> The absence of outpatient medical records,<sup>15 16</sup> difficulties in retrieval of facility-based records for outpatient visits<sup>17</sup> and lack of integrated patient electronic medical records between departments and between health facilities in LMICs contribute to poor informational continuity for HCPs.<sup>18</sup>

A patient-held health record (PHR) can be a viable solution for improving sharing of documented medical information across HCPs.<sup>19</sup> For the purpose of this review, PHRs are formal records given to patients in the form of booklets, which contain patients' medical information. Our hypothesis is that such PHRs with documented medical notes from HCPs can be used as a tool for improving medical information availability for HCPs.<sup>15 20</sup>

Paper-based PHRs are used extensively in maternity care, as home-based records or maternal and child health handbooks for sharing information across antenatal, labour and postnatal care by all HCPs even in LMIC settings.<sup>21</sup> Three systematic reviews on maternity and child records indicate that PHRs improve HCP-patient communication and facilitate referrals, and both HCPs and women give positive feedback on their use.<sup>22–25</sup>

There are several systematic reviews<sup>19 26–29</sup> of PHRs for chronic conditions from high-income countries (HIC), which evaluated their usefulness in cancer care,<sup>28</sup> and chronic conditions,<sup>26 27</sup> and for people with severe mental illness<sup>29</sup> or undocumented immigrants.<sup>19</sup> These condition-specific PHRs were designed to mainly improve communication between HCP and patients.<sup>28</sup> The reviews found that PHRs may improve a patient's sense of control and empowerment, leading to better involvement in their own care.<sup>28 29</sup>

There is no systematic review of PHRs for conditions other than maternal and child health from LMICs, while there is evidence that generic PHRs do exist in some LMICs.<sup>30</sup> A study in India found that patients were carrying unstructured sheets of paper to outpatient visits and patient-held health booklets were an acceptable and pragmatic intervention to improve information exchange for patients with chronic NCD by patients and HCPs.<sup>15</sup>

The current review aimed to investigate the benefits of generic PHRs used in LMICs to ensure the availability of medical information for clinical handover communication and continuity of care between HCPs or outpatient health facility visits, with or without their use for communication between HCPs and patients. This review investigated non-maternal-child health PHRs, designed to record patient histories and healthcare information

across a range of conditions and HCPs, including primary and secondary care and not specific to one facility or one specialty.

## METHODS

The protocol for this review is registered with the PROSPERO International Prospective Register of Systematic Reviews (CRD42019139365).<sup>31</sup>

### Selection criteria

The published literature was searched for quantitative randomised controlled trials (RCTs), cluster RCTs, quasi-experimental studies, cross-sectional and pre-post study designs, qualitative and mixed-method studies. Case reports, commentaries and review articles were excluded studies. The eligibility criteria are provided in [table 1](#).

### Search strategy

The search strategy (online supplemental file 1) was developed for the electronic databases MEDLINE (Ovid) to identify journal articles. The search strategy was made following previous reviews regarding PHRs<sup>26 28</sup> EMBASE (Ovid EMBASE Classic + EMBASE (1947 to present)) and CINAHL (via EBSCO (1980 to present)) were searched for studies reporting PHR in LMICs without a librarian. Additionally, citations were hand searched using relevant systematic reviews<sup>19 28</sup> to locate further relevant studies. Key search terms related to PHRs and LMICs were used to build the search strategy. The search terms used for PHRs were “patient-held book\* or handbook\* or card”, “patient passport”, “log book” and “home based records”. Searches in the electronic databases were conducted from database inception until September 2020. No limits on language or publication year were applied during the search. Grey literature search was done by contacting authors of papers, which reported the use of patient-held records, discussion with experts and using the website of WHO and Google Scholar.

### Study selection

The search results were uploaded to the reference management software Zotero to remove duplicates. Two reviewers (LJ and DB) independently screened the remaining studies' titles. The initial title screening was broad and retained all studies that referred to PHRs. Two reviewers (LJ and DB) independently screened the abstracts and full texts against the inclusion criteria. Any uncertainty surrounding the inclusion of a study or disagreement following discussions between reviewers were resolved through the assessment of an additional reviewer (SM-H).

### Data extraction

Two reviewers (DB and PJ) independently extracted data from the included studies. LJ reviewed all the data extraction tables. If there were any discrepancies during this sampling check, discussion took place and for final

**Table 1** Inclusion and exclusion criteria

Title	Inclusion criteria	Exclusion criteria
Population	<ul style="list-style-type: none"> <li>▶ Participants (patients, carers and/or healthcare HCPs) from any health background, of 18 years or more, using a PHR were considered.</li> <li>▶ All healthcare settings within LMICs (as defined by the World Bank 2018)<sup>67</sup> were considered.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Children and pregnant women</li> <li>▶ Patients/carers/HCPs from HIC</li> </ul>
Intervention	<ul style="list-style-type: none"> <li>▶ Studies which include design, implementation or evaluation of formalised PHRs, with the purpose of improving information exchange and communication between visits to the same facility for HCPs, across different healthcare facilities (primary to secondary/vice versa) and documented information from HCPs to patients (for patients' own care).</li> <li>▶ Studies which describe PHRs which are clinically focused and person specific or generic PHRs. Studies which describe condition-specific PHRs, they should include NCDs such as diabetes mellitus, hypertension, cardiovascular diseases, chronic respiratory diseases or cancer.</li> <li>▶ PHRs are defined as any formal medical document in the form of a booklet held by patients, which can be used across healthcare settings or visits, contain patient histories and healthcare information to guide healthcare workers providing care.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Facility-based medical records, which are for HCP use.</li> <li>▶ Home-based records used for maternal and child healthcare.</li> <li>▶ Patient-held diaries used for monitoring values such as home-based blood pressure monitoring booklets or patient instructional booklets, for example, for diabetic foot care or patient-held records for single communicable disease such as tuberculosis.</li> <li>▶ Studies that focus on record use for specific and isolated transitions of care, such as hospital shift-change or discharge. Interventions such as a discharge summary or referral letter alone.</li> <li>▶ Studies that focus on a single function of patient-held medical records such as medication prescriptions, lab results, blood pressure or blood sugar monitoring or outpatient registration papers.</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>▶ Outcome relevant to the quality of verbal and/or documented patient-specific information and communication. Standards of information and recording (completeness, accuracy and clarity) of the documented handover information was included.</li> <li>▶ Patients' and HCPs' views on how PHRs enabled/did not enable communication and documented information exchange was also included. Patients carrying records to consultation, availability of documented medical information for HCPs during consultation was also included.</li> <li>▶ Patient and HCP satisfaction with PHR, patient-centred communication outcomes such as patient satisfaction, recall, understanding and adherence have been included.</li> <li>▶ Clinical outcomes and adverse events associated with quality of handover communication were also of interest, including (but not limited to) readmissions, diagnostic delays, healthcare utilisation or improved appointment rates and death. Intermediate outcomes such as blood pressure/blood glucose monitoring, medication management/reconciliation and/monitoring of lab values were included.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Descriptive studies which describe the distribution of PHRs without information on outcomes of PHRs.</li> </ul>

HCPs, healthcare providers; HIC, high-income countries; LMIC, low-income and middle-income countries; NCD, non-communicable diseases; PHR, patient-held health record.

clarification a third, impartial reviewer (PJe or SM-H) was consulted.

Data were extracted from published studies using a data extraction form in Microsoft Excel and included details of authors, study settings and country, the objectives and features of the PHR, use of PHRs and outcomes.

### Quality assessment

Quality assessment was done by two reviewers (LJ and DB) using the Mixed Methods Appraisal Tool.<sup>32</sup> This provided an overall description of the quality of studies and used descriptors 'low', 'medium' and 'high' to provide an indication of the quality of the included studies. For quantitative, qualitative and cross-sectional studies, all five criteria

needed to be met to be classified as 'high quality'. Studies that met three to four criteria were classified as 'medium quality' and studies that met one or two criteria were regarded as 'low quality'. For mixed-methods studies, the overall score was dependent on the lowest score of each of the study components (qualitative and quantitative); therefore, scores were determined by the quality of the weakest component. In case of disagreements on quality assessment, the final decision was taken after discussion with an independent third reviewer (PJe or SM-H).

### Data analysis

Given the diversity of populations, settings, the non-uniformity of interventions and the variations in outcome

**Table 2** Description of results

Result	Description of the result
Patients carrying the PHRs to HCP visits	Presented as frequencies or no of patients carrying the records to visits or as prevalence of written clinical information availability for HCPs at visits.
HCPs' recording of information and quality of information recorded	HCPs' recording of information in the PHR is presented as information availability for patients on leaving the facility or patient/HCP self-reported availability of documented information. The quality of information recorded for this review is defined as the completeness of the information on key elements such as diagnosis, medication/treatment details (including lab values) and follow-up information, clarity or legibility of the information recorded and accuracy of the information being recorded based on treatment guidelines (eg, mismatch of diagnosis and treatment prescribed)/ comparison of data with facility-based records. Completeness data are reported as frequencies and stand-alone or comparative data based on key missing components.
Utility of PHR to HCPs and patients	For the review, utility as perceptions of patients and HCPs about using PHRs, satisfaction with use, usability in terms of ease of reading the records and the functions they serve (for information exchange, clinical information recording at each HCP visit, patient education or as an aide memoire for patients).

HCP, healthcare provider; PHR, patient-held health record.

measures, a statistical meta-analysis was not appropriate. Hence, the review used a narrative synthesis. Papers in the review have been summarised descriptively as follows (table 2).

### Patient and public involvement

This research was done without patient or public involvement.

## RESULTS

### Study selection

The findings of the search strategy are summarised in figure 1 as a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart.<sup>33</sup> A total of 2286 titles were screened and 466 abstracts were included. One hundred and twenty-one full papers were reviewed and six studies were included in the final review. The references of included studies were reviewed for potential studies and no new studies were included. We excluded 115 articles because: studies that described PHRs but were not conducted in LMICs (56); studies that described maternal or child health records in LMICs (29); papers that described patient—health education booklet for NCDs (3); studies that described electronic health record implementation (21) and studies that described facility-based records (12).

### Characteristics of included studies

Studies were from Zambia (n=1),<sup>34</sup> Lesotho (n=1),<sup>35</sup> South Africa (n=2),<sup>36 37</sup> China (n=1),<sup>38</sup> and Mongolia (n=1)<sup>39</sup> (table 3). The designs of included studies were mixed methods (n=1),<sup>39</sup> observational (n=2)<sup>34 35</sup> and qualitative (n=3).<sup>36–38</sup> Three studies<sup>35 38 39</sup> evaluated PHRs that were implemented and routinely used by the health department in those countries and one study evaluated PHR using diabetes mellitus and hypertension as tracer conditions for NCDs. All the studies described the use of PHRs in outpatient settings, while none measured changes in health outcomes following the use of PHRs.

### Quality appraisal

Of the six studies included, five were judged to be of 'medium quality' and one was of 'low quality' (online supplemental file 1, table S2). For the three qualitative studies,<sup>36–38</sup> the methods and data collection were appropriate to answer the research question. However, the studies did not mention the use of a specific method of data analysis or provide a rationale for using an analytic method. Therefore, coherence between data sources, collection, analysis and interpretation could not be fully assessed. The single mixed-methods study<sup>39</sup> did not adequately explain the method of qualitative data analysis and was marked down on that criterion. Of the two cross-sectional studies, one<sup>34</sup> provided no information on the sampling strategy and hence it was not possible to make judgements on the representativeness of the sample. Further, no information was reported regarding the non-response rate. The other cross-sectional study provided information on sampling strategy, a reasonable description of the target population and response rate. However, the study was marked down due to insufficient information on measurement variables.<sup>35</sup>

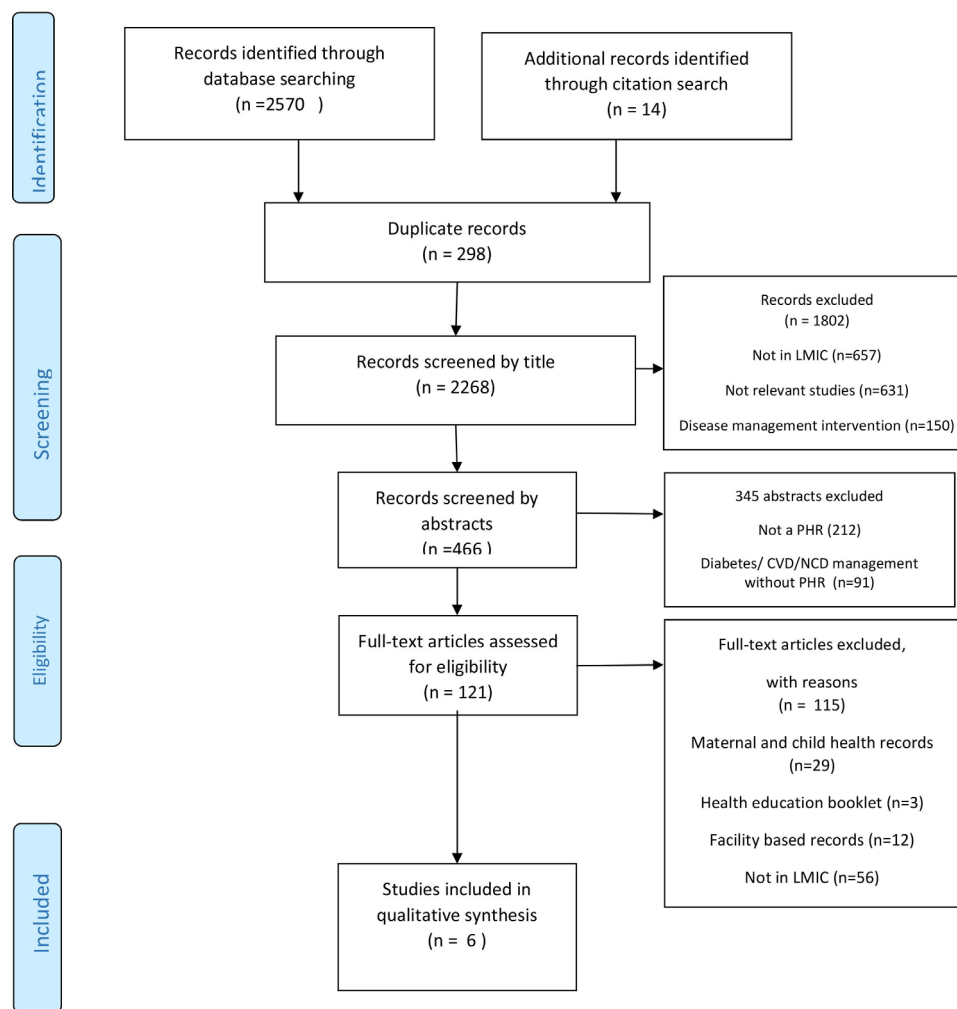
### Synthesis of results from included studies

Overall, the included studies were inadequate to demonstrate a clear benefit of using PHRs to improve information availability to HCPs and patients. However, based on the patients' perspective, PHRs were beneficial to the management of their own care. Further, based on the HCPs' perspective, PHRs improved the availability of key clinical information for providing care.

### Patients carrying their PHRs

Overall, most patients carried their PHRs to healthcare visits. Of the six studies, two reported data on the prevalence of patients bringing their PHR to subsequent visits. In Mongolia, Ibrahim *et al*<sup>39</sup> reported that 94% (373/395) of patients with chronic NCD brought their PHR to their outpatient visits. This was measured by examining the documents brought to the visit by the patients.

In Lesotho, Henbest and Fehrsen<sup>35</sup> used a survey with patients and HCPs to report on the practice of carrying records to consultations and HCPs' opinions on the availability of PHRs at consultations. Patients' self-reported practice of carrying PHRs to healthcare consultations was



**Figure 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram. CVD, cardiovascular disease; LMIC, low-income and middle-income countries; NCD, non-communicable disease; PHR, patient-held health record.

71% (n=672) and HCPs self-reported the availability of the PHR at visits as 62% (doctors, n=81) and 59% (nurse clinicians, n=68), respectively.

In China, Chen and Pine<sup>38</sup> used interviews with, and observation of, patients to report patients' perspectives on, and patterns of, carrying records to consultations. They found that the patients with chronic NCDs had different PHRs, according to particular conditions/diseases and clinics or hospitals. Patients often carried only specific PHRs to consultations based on the condition/HCP/clinic they visit.

#### HCPs' recording information and the quality of information recorded

The HCPs' recording in PHRs was suboptimal. Of the six studies, only one from Mongolia<sup>39</sup> evaluated HCPs' documenting of information in PHRs and the quality of the information recorded for patients with diabetes and hypertension. The overall written information, across three categories (diagnosis, prescription and follow-up), within the PHR after the consultation was 37% (n=367). The completeness of PHRs with respect to medication and follow-up information were 61% and 40%, respectively.

No studies reported the clarity, legibility or accuracy of the recorded information.

#### Utility of PHR to HCPs

Generally, HCPs perceived PHRs to be useful in recording patients' medical information. In Mongolia, Ibrahim *et al.*<sup>39</sup> did not formally assess HCPs' perspectives on the use of PHR, but they did find that HCPs in the two public outpatient hospitals wrote in the booklets in spite of also having to enter information in other electronic record systems. Further, more than three-quarters (77.4%, n=106) of patients reported that private HCPs they had visited recorded clinic notes in the PHR.

In Lesotho, Henbest and Fehrsen<sup>35</sup> described HCPs' satisfaction with using PHRs. This was measured in terms of preference for PHRs, practicality (size, durability and confidentiality) and comparison with facility-based records (quality of care, access to patient information). Both doctors and nurse clinicians reported a preference for PHRs over facility-based paper records. The HCPs perceived that having a PHR contributed to improving quality of care, by preventing the unnecessary repetition of tests and treatments (86% of nurse clinicians (n=71)

**Table 3** Characteristics of included studies

Author, year, Country	Study design, sample size	Study objective	Settings	Participants	PHR description	Results
van der Hoek, 1994, Zambia <sup>34</sup>	Cross-sectional (n=176, n=184)	To describe the views of patients on the newly introduced health passports by health management in Sesheke district, Zambia.	Household surveys (n=2), conducted in the catchment areas of one hospital and two health centres.	Patients	Hardcover booklet with 32 pages known as a health passport, size—14.5x10 cm. Demographic information on the cover page. Referral letters and discharge letters are replaced with health passports.	68% of the respondents bought a health passport within 4 months of their introduction and 91% within 16 months. 36% (64/176) and 30% (55/184) of the respondents felt that the passports were expensive.
Henbest, 1995, Lesotho <sup>35</sup>	Cross-sectional (n=878) Patients (n=691) Nurse clinicians (n=74) and doctors (n=104)	To inform the recommendations for the use of PHR in healthcare services in changing Africa, using the PHR in Lesotho.	Healthcare Centres and household survey	Patients, nurses and doctors	PHR, in the form of a health booklet about the size of a passport (10.5x15 cm) with a brightly coloured plasticised cardboard cover. The front cover contains the patient's name, address, date of birth and instruction on the record's use. The back cover has the common symptoms and signs of tuberculosis. The inside printed pages contain forms for recording information such as immunisations, previous significant history drug sensitivity and screening activities. There are 16 blank pages for HCP notes. When one record is full, it is stapled to the next record.	89% of patients preferred to have a PHR than a facility-based record. 79% of doctors and 70% of nurses rated the use of PHR as excellent. Doctors and nurses perceived that having a PHR reduces unnecessary repetitions of tests and treatments. They also felt that availability of patient medical information from other HCPs leads to less errors.
Norden, 2004, South Africa <sup>36</sup>	Qualitative study Focus group discussions with patients (n=24)	To understand the patients' thoughts on the PHR introduced. It was introduced due to the difficulty in retrieval of medical information at HCP visits from facility-based records.	Primary care clinic	Patients	Pocket size booklet with 10 pages (14x8 cm) Demographic information, problem list and allergies recorded in the first page. Blood pressure, blood glucose, body mass index, peak expiratory flow rates are recorded in the subsequent visits. Prescribed treatment and follow-up dates are also documented.	Patients felt that the records function as 'medical identification' and are useful in an emergency, provide important background information, and that they enable continuation of care at other facilities. Patients reported that PHRs could motivate them to act on the advice given, and the records also served as a reminder to take their medication and about the dates of follow-up visits.

Continued

Table 3 Continued

Author, year, Country	Study design, sample size	Study objective	Settings	Participants	PHR description	Results
Kerry, 2006, South Africa <sup>37</sup>	Quality assurance methods with Focus group discussions (n=13) no of participants not stated	To assess, document and improve the PHR system in the Ermtshezi subdistrict, South Africa.	Healthcare facilities at subdistrict level	Patients, nurses, doctors, administrators and pharmacists	Proposed better PHR: A single booklet PHR for every patient in the district. Size—10x21 cm named as Health Book; at least 32 pages for clinical notes; a problem list; pages for laboratory and X-ray results and incorporation of the health card for women, TB card and antenatal card. The booklet should have a plastic cover.	Patients and HCPs reported that communication of clinical information between health facilities was poor. HCPs described there were difficulties in retrieval of information and recording at hospitals, the current PHRs were unstructured and multiple PHRs were brought by patients. Patients and HCPs felt that having a single, common PHR to be the definitive ambulatory health record for every patient at district level. Feedback from the FGDs were used to design a better PHR.
Chen, 2014, China <sup>38</sup>	Qualitative study (semistructured interviews and observations Doctors (n=4), patients (n=13), family members (n=4)	To examine and explore practices surrounding PHR in a setting where medical records have long been managed by patients: the Chinese healthcare system.	Outpatient departments of hospital	Patients, family members and doctors	Pocket size book which had chief complaint and history handwritten by the clinician. Diagnosis and prescription are documented on the electronic health system and printouts of the same are provided for the patients.	The findings suggest that through engaging in practices of managing and sharing records, patients were able to obtain familiarity with their own records and to provide necessary assistance to locate information for HCPs to use at the point of care. Clinicians felt that a verbal history by the patient was insufficient, as was a history based solely on their own clinic's records.
Ibrahim, 2019, Mongolia <sup>39</sup>	Mixed methods, (n=395)	To describe Mongolia's universal patient-held health booklets and their use, explore patients' views on using them and explore training and protocols using tracer conditions diabetes and hypertension.	Outpatient departments of two public hospitals	Patients	Booklet with 40 pages (14.8x21 cm). Demographic information on the cover page, history or handover information in subsequent pages.	94% of patients had PHRs with them at OPD visits. Provision of written information for the three categories of key information items (ie, diagnosis, prescription/management and follow-up information) for the consultation was low at around 37% in the PHR—61% had notes related to medication required and 40% contained information about follow-up. Patients (316, 80.0%) reported consulting their PHRs and associated 'documents' at home. They reported using them for understanding their own condition and communicating it to others

FGD, focus group discussion; HCP, healthcare provider; LMIC, low-income and middle-income country; OPD, outpatient department; PHR, patient-held health record; TB, tuberculosis.





and 88% of doctors (n=89)) and that the availability of medical information from other HCP visits helped in the clinical management of patients (78% of nurse clinicians (n=71) and 84% of doctors (n=89)). The qualitative study by Chen and Pine<sup>38</sup> from China reported that a patient's verbal history of past medical information was perceived as insufficient for providing effective care by doctors. Further, access to previous documented clinical information was perceived by doctors as essential to make appropriate clinical decisions. The other two studies<sup>36,37</sup> did not report the HCPs' perspectives on PHRs.

#### Protocols and HCP training

The studies reported very limited protocols and training available for HCPs on the use of PHRs. The study from Mongolia<sup>39</sup> explored the role of protocols and policy directions, with a government order reinforcing the use of PHRs. However, no written guidelines or training materials regarding the use of PHRs or training for clinical handover were reported by HCPs. Another study reported 1-day training for health workers, with practical instructions on how to use the PHR.<sup>34</sup>

#### Health outcomes

The included studies do not report measuring changes in health outcomes such as improvement in blood pressure, blood glucose or patients receiving foot examinations or healthcare advice following the use of PHR.

#### Utility of PHRs for patients

All included studies reported some use of the information in the PHRs by patients and in general, found that patients regarded PHRs as important documents containing their own medical information. Ibrahim *et al*<sup>39</sup> described how Mongolian patients (316, 80.0%) consulted their PHRs at home. Patients reported that written information from doctors was important for their own understanding of their condition. van der Hoek *et al*<sup>34</sup> reported that some Zambian patients (n=176, 16% (at 6 months) and n=183, 14% (at 18 months)) preferred to keep their records at the clinic itself, due to a fear of damaging the records at home but they did not report whether the patients used the PHRs at home or not. Henbest and Fehrsen<sup>35</sup> found that most (n=691, 89%) of Lesotho (South African) patients preferred to have a PHR and perceived the record as belonging to them. They reported that having a PHR was important to making information available to the other HCPs they visited. They highlighted that this was very useful in case of travel and emergencies. Norden *et al*<sup>36</sup> also reported similar findings for South African patients. Patients viewed their PHR as a document containing their own medical information and a tool for continuation of care between HCPs. Additionally, the PHR helped these patients and their families to remember how to manage their own care at home. In their qualitative study, Chen and Pine<sup>38</sup> found that Chinese patients regarded PHRs as useful. They reported that patients read their documents,

organised them chronologically and brought them to each subsequent visit.

## DISCUSSION

### Summary of findings

This systematic review identified that there is limited literature from LMICs on the use of PHRs for improving information availability to HCPs and patients for handover communication. This paucity of published research limits our ability to draw conclusions on the benefits or challenges of PHRs in the care of patients with NCDs. Importantly, none of the studies included in the review investigated, reported or evaluated changes in health outcomes after using PHRs in LMICs. Consistent with studies of maternal and child PHRs,<sup>40-42</sup> in general, patients brought their PHRs to each clinical consultation. PHRs being in the form of a booklet in Mongolia and China and attaching medical reports (in the form of papers) to the booklet, both reduced the risk of losing them. Although only one study addressed these, the inadequate completeness of the information documented by HCPs, and a lack of protocols and training on the use of PHRs, are both likely to be prominent issues in all the settings as evidenced by the wider literature on training and protocols for medical records documentation.<sup>43-45</sup>

The PHRs were perceived as useful by HCPs for documenting the medical history of patients, thus improving the availability of medical information. From the patient perspective, the PHR functioned as a reminder for medication, improved self-care efficacy and enabled continuity of care by providing relevant clinical information to all HCPs involved in patient care. Consistent findings on the use of PHR in improving self-care for the management of chronic conditions were reported and equally reflected in HIC studies.<sup>27,28</sup>

### Implications for research and practice

The findings from the review suggest that PHRs may be particularly useful in health systems where little or no medical record keeping occurs at outpatient level, where record retrieval is difficult, or where multiple HCPs may be involved in a person's care for chronic conditions. This is especially important in LMICs as most have pluralistic health systems and no 'gate-keeping', so that patients often change their HCPs, or shop around, and receive care at both public and private facilities.<sup>15,16,43</sup> Patients' provision of a verbal medical history as the only means of transferring previous clinical information during HCP visits is, however, insufficient. In LMICs patients' communication of medical history may be adversely affected by a lack of health literacy, inability to articulate the clinical procedures received, and a lack of confidence against a background of profound power differentials between patients and HCPs.<sup>46-48</sup>

A well-completed PHR may in principle improve medical information availability for HCPs. However, no trials, which assessed the availability of medical

information for HCPs, were reported from LMICs. In Germany, Straßner *et al*<sup>49</sup> conducted a trial investigating the utility of PHRs for asylum seekers in reception centres for improving medical information availability for HCPs. The trial found that a PHR for asylum seekers increased the availability of health information for HCPs (aOR 4.22, 95% CI: 2.64 to 6.73), reduced missing information (aOR 0.89, 95% CI: 0.42 to 1.88) and reduced HCP dissatisfaction (aOR 0.43, 95% CI: 0.16 to 1.14).<sup>49</sup> Previous HIC studies have shown that the use of PHRs for patients with diabetes and hypertension have led to decreases in glycosylated haemoglobin (HbA1c) ( $p < 0.001$ ),<sup>50–52</sup> decrease in diastolic blood pressure ( $p < 0.05$ )<sup>50</sup> and improvement in receiving foot examinations (OR: 1.68; 95% CI 1.12 to 2.50),<sup>52</sup> having physical activity or exercise advised (OR: 1.84; 95% CI: 1.16 to 2.92),<sup>52</sup> and monitoring of weight, blood glucose and cholesterol.<sup>50</sup> Similar results may be achieved in LMICs for monitoring blood pressure/glucose/cholesterol, improving foot/eye examination if PHRs are well documented.

Patients, especially those with chronic diseases, usually carry the records they have to HCP visits, especially if they know HCPs will use them.<sup>15 16 43 53</sup> However, in the absence of an organised PHR, patients either bring very little information, such as a prescription alone (common in LMICs), or they bring all the previous pieces of paper that form their home held medical records, making it difficult for HCPs to find the relevant information.<sup>16</sup> Many patients with chronic disease have multimorbidities and often have numerous papers or clinic-specific PHRs from the different clinics and hospitals they visit, but they often only carry notes from previous visits to the clinic they are going to visit.<sup>28</sup> Thus, the HCPs do not receive the information about medication and management plans produced by other doctors in other clinics or hospitals. Therefore, it is necessary to develop generic/universal and pragmatic PHRs and create awareness of the importance of using a single generic PHR for all healthcare visits, irrespective of the clinic/hospital, so that all HCPs have the necessary medical information available to make the best clinical decisions.

WHO recommends that ideally a PHR should be used as complementary to a facility-based medical record.<sup>54</sup> Prior reviews from HICs showed that, when HCPs had to enter information in facility-based records (electronic or paper based) and PHRs, this multiple recording was an unwelcome burden.<sup>55 56</sup> However, documented discharge information for patients /families (eg, summaries/letters) from HCPs has been found to reduce postdischarge complications<sup>57</sup> and readmissions,<sup>58</sup> and to improve patient satisfaction<sup>59</sup> and health outcomes.<sup>60</sup> Arguably, it would more efficient and accurate if there were one record system accessible and useful to both patients and HCPs.

Many LMICs are progressing with the implementation of electronic health records, which may enable health systems to overcome difficulties in retrieving information from paper-based facility-based medical records.<sup>61 62</sup>

Despite such advancements in technology and information technology capability in some middle-income countries, paper records will remain the prominent form of medical records and are unlikely to be completely replaced by electronic records at least for the near future. Furthermore, the issues of integrating electronic health records across different levels of care in health systems and public–private information exchange are often not addressed in existing health information management systems.<sup>63</sup> Therefore, PHRs having a minimum of data such as diagnosis, medication, lab results and follow-up will enable better information transfer in the health systems transitioning to electronic health records.

### Strengths and limitations

Our systematic review has several strengths and limitations. The review protocol was registered at PROSPERO and we followed PRISMA guidelines in our systematic review. A comprehensive search strategy was employed to locate studies from LMICs. Furthermore, our search from the grey literature and discussion with experts in the field helped us to identify generic PHRs from Malawi,<sup>64</sup> Namibia<sup>65</sup> and South Africa.<sup>66</sup> However, these PHRs have not been evaluated systematically, and we have limited information on the usefulness of these records. However, our study also has some limitations. Given the small number of relevant articles, we found very few RCTs on which to base conclusions of robust experimental findings. Scarce data on generic PHRs from LMICs limit our ability to interpret the usefulness of these records in improving health outcomes of patients with NCDs.

### CONCLUSION

Available data on the use of non-maternity PHR for handover communication between HCPs and HCPs with patients in LMICs are sparse. Existing studies on PHR in LMICs are of medium to low quality, and heterogeneous in terms of study design, population and context. Further, health outcome assessments after the introduction of PHRs are not available. The available studies show that patients value PHRs for their own use and are likely to carry them to HCPs. HCPs, in turn, consider that PHRs enhance documented information transfer from previous visits specifically when there is difficulty in retrieving past medical information. With LMICs progressing with electronic health record implementation, the role of paper-based PHRs in overcoming issues of integration and for improving adherence to effective self-care needs re-evaluating. Future research should explore minimum information requirements for major conditions, the format and types of PHRs of most utility to patients and HCPs (electronic or paper based), and barriers and facilitators to effective use of PHRs across all HCPs for any one patient. Further, the content and HCP training and protocols need to be developed and evaluated for the effective scale-up of interventions to promote the effective use of PHRs for continuity of care and patient self-care.

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