Patient-held medical records for patients with chronic disease: a systematic review

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CRD summary
This review concluded that available evidence did not show a clear benefit, in clinical care or patient satisfaction, of implementing patient-held medical records for patients with chronic disease. This conclusion reflects the findings of all included studies and is likely to be reliable, with the caveat that the review may have missed some relevant studies.

Authors' objectives
To determine whether a patient-held medical record improved clinical care, patient outcomes or satisfaction in patients with chronic disease when compared with usual care.

Searching
MEDLINE, EMBASE, CINAHL, DARE, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials (CENTRAL) and ACP Journal Club were searched for English language publications from 1980 to 16 February 2009. Search terms were reported.

Study selection
All comparative studies with participants with any chronic disease, in which a patient-held medical record intervention was compared with no patient-held medical record (usual care) or ‘sham’ patient-held medical record (such as usual medication lists, blood glucose monitoring booklets) were eligible for inclusion. Eligible participants could be of any age and in any healthcare setting. Patient-held records were defined as an intervention in the form of a paper-based medical record held by the patient or their carer (with or without other interventions). Studies of advanced directives or electronic health records (including those held by patients) were excluded.

Outcomes that compared the effectiveness of the patient-held medical record on any measure relevant to patients, clinicians, or health services were considered relevant.

Most of the included studies were conducted in the UK or the Netherlands. Studies were conducted in six different clinical populations including diabetes, oncology, mental health, rheumatoid arthritis, stroke and palliative care. Various patient-held medical record interventions were implemented with varying degrees of patient and staff support and education, mainly for six months or less.

Two reviewers, in consultation with colleagues, assessed studies for inclusion.

Assessment of study quality
The methodological quality of included studies was assessed based on seven criteria: conflict of interest; study design; participant selection; allocation concealment and blinding; data collection; outcome attributable to intervention; and appropriate analysis. Each criterion was rated as 'met', 'partially met', 'not met', or 'unclear from the information provided'.

Two reviewers, in consultation with colleagues, assessed the methodological quality of included studies.

Data extraction
Outcomes were extracted as reported by the included studies. A wide range of measures were reported, including physiological measures, patient satisfaction, quality of life, psychological and behavioural measures. Study authors were contacted for further information where required.

The authors did not specify how many reviewers performed the data extraction.
Methods of synthesis
Studies were combined in a narrative synthesis, grouped by clinical population.

Results of the review
Fourteen studies, with 6,310 participants, were included in the review. The authors judged the quality of evidence to be low or very low; most included studies had a high risk of bias.

**Diabetes** (three studies, n=3,807 patients): All studies reported a small number of benefits for patient-held medical records. One study reported significant effects in favour of patient-held medical records for five out of 17 outcomes: receipt of foot examinations (OR 1.68; 95% CI 1.12 to 2.50); physical exercise advised (OR 1.84; 95% CI 1.16 to 2.92); smoking discussed or non smoking advised (OR 1.82; 95% CI 1.15 to 2.89); decrease in glycated haemoglobin (p<0.001) and a decrease in diastolic blood pressure (p<0.05). A second study reported significant effects in favour of patient-held medical records for seven out of 21 outcomes assessed: All benefits were for process indicators of checking glycated haemoglobin, creatinine, eye examination, cholesterol, weight or glucose within a certain time frame. The third study reported significant effects in favour of patient-held medical records in only two out of 19 outcomes assessed: decrease in glycated haemoglobin and body mass index.

**Oncology** (six studies, n=1,773 patients): Most outcomes measured by these studies showed no significant differences between groups with and without a patient-held medical record. One study found that patient-held medical record users felt less able to face future aspects of their illness (p=0.05); the only significant result of 22 outcomes measures. One study found that patient satisfaction with information received at the end of treatment was significantly greater in the control group (p=0.02); seven other outcome measures showed no significant difference. One study showed that fewer patient-held medical record users felt they needed more information about their disease and treatment (p≤0.05), but participants in the control group were less uncertain about tests, procedures and lifestyle issues (p≤0.05). One study showed that participants using a patient-held medical record found it less difficult to monitor their own progress (p=0.009) and were more likely to feel in control (p=0.03); however, 67 other measures in the same study found no significant differences.

**Mental health** (two studies, n=291 patients): No significant differences were identified in any outcome measure.

**Rheumatoid arthritis** (one study, n=141 patients): There were differences between groups in some of the eight process measures (visits to general practitioners, and physiotherapists' perceptions of co-ordination and continuity of care), but not in any other outcome measure.

**Stroke** (one study, n=252 patients): This study only reported data for 38% of recruited patients. Patient satisfaction was higher in the patient-held medical record group on three out of 16 measures. However, in the 23 measures of communication, the intervention group were less able to talk to staff or doctors about problems (p=0.01).

**Palliative care** (one study, n=46 patients): There were no significant differences between patient-held medical record and control groups for the five main outcome measures.

Authors' conclusions
There was no high-quality evidence that showed the effectiveness of patient-held medical records. The poor quality studies included in the review did not show a clear benefit of implementing a patient-held medical record.

CRD commentary
The review question and inclusion criteria were very broad. A range of sources were searched for relevant material. However, the restriction of the search to published English language material may have resulted in studies being missed and raised the possibility of language and/or publication bias. The review process included measures to minimise error and/or bias, although it was not clear whether these were applied to data extraction.

The methodological quality of included studies was assessed and incorporated in the description of results. The use of a narrative synthesis was appropriate, given the broad range of study types, interventions and outcome measures included.

The authors' conclusion reflects the results of included studies and is likely to be reliable, with the caveat that some
relevant studies may have been missed by the review.

**Implications of the review for practice and research**

**Practice**: The authors did not specify any recommendations for clinical practice.

**Research**: The authors stated that there was currently insufficient information to know what the components of a patient-held medical record should be, how it should be delivered, what support should be provided, and what education and training were required for staff. Future patient-held medical records should be developed, piloted and revised prior to implementation; assessment should be undertaken using high quality RCTs.

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This is a critical abstract of a systematic review that meets the criteria for inclusion on DARE. Each critical abstract contains a brief summary of the review methods, results and conclusions followed by a detailed critical assessment on the reliability of the review and the conclusions drawn.