Self-reported medication intake vs information from other data sources such as pharmacy records or medical records: Identification and description of existing publications, and comparison of agreement results for publications focusing on patients with cancer - a systematic review

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Abstract

Purpose: To identify and describe publications addressing the agreement between self-reported medication and other data sources among adults and, in a subgroup of studies dealing with cancer patients, seek to identify parameters which are associated with agreement.

Methods: A systematic review including a systematic search within five biomedical databases up to February 28, 2019 was conducted as per the PRISMA Statement. Studies and agreement results were described. For a subgroup of studies dealing with cancer, we searched for associations between agreement and patients’ characteristics, study design, comparison data source, and self-report modality.

Results: The literature search retrieved 3392 publications. Included articles (n = 120) show heterogeneous agreement. Eighteen publications focused on cancer populations, with relatively good agreement identified in those which analyzed hormone therapy, estrogen, and chemotherapy (n = 11). Agreement was especially good for chemotherapy (proportion correct ≥93.6%, kappa ≥0.88). No distinct associations between agreement and age, education or marital status were identified in the results. There was little evaluation of associations between agreement and study design, self-report modality and comparison data source, thus not allowing for any conclusions to be drawn.

Conclusion: An overview of the evidence available from validation studies with a description of several characteristics is provided. Studies with experimental design...
which evaluate factors that might affect agreement between self-report and other data sources are lacking.

**KEYWORDS**
drug prescriptions, medical records, pharmaceutical preparations, pharmacies, pharmacoepidemiology, self-report, validation studies

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1 | BACKGROUND

Data on medication use is required in several research areas to enable researchers to analyze use patterns and medication-related costs. Relevant information can be obtained from healthcare provider records or health insurance claims, for instance. Each source has its specific limitations, with claims only including reimbursed medications and provider records only covering documentation for one healthcare provider, thus requiring several institutions to be covered to gain complete documentation of one patient’s treatment. Furthermore, in some cases patients’ consent is required to gain access to data. Finally, claims and medical records reflect the receipt or filling of prescriptions, whereas patients’ self-reports are likely the most accurate reflection of actual intake of medication. Researchers therefore sometimes have to rely on self-reported medication use. Obtaining this information via interview or questionnaire is resource-intensive and at risk of interviewer or recall bias. As no data source provides complete information, there is no general reference standard. Depending on the research question, one source might be more appropriate than another. Scientific knowledge about agreement of self-reported medication intake and information from other sources is needed to help interpret results from a single source. To date, numerous studies have examined agreement between two or more sources, but only two systematic reviews published over 20 years ago were found. Harlow and Linet compared questionnaire data with medical records, while Evans and Crawford compared any self-report (eg, questionnaires, interviews) with any other data source. Both reviews only analyzed medication use as part of healthcare utilization. Given these limitations and the obsolete systematic data, we decided to conduct a systematic review.

The objectives were: (a) to identify publications comparing self-reported medication use and medication information from other data sources for adult individuals and to describe their key characteristics; (b) seek to identify parameters which might be associated with agreement in a subgroup of studies dealing with cancer patients.

2 | METHODS

We conducted this review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.

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**KEY POINTS**

- Over 100 publications compare agreement of self-reported medication intake with other data sources among adult populations. However, there is no current systematic review on this topic.
- The included publications reported wide differences in population samples, analyzed outcomes, and focused medications.
- Patients with cancer were most frequently studied and chemotherapy, hormone therapy in general, and the specific hormone estrogen were the most frequently analyzed medication groups among them.
- Agreement is relatively good among patients with cancer for the three medication groups, especially for chemotherapy.
- Authors’ results did not show possible associations between agreement and age, education or marital status among patients with cancer. Possible associations between agreement and study design, self-report modality or comparison data source could not be analyzed.

2.1 | Eligibility criteria

Six eligibility criteria were defined: (a) adult population: at least 18 years of age; (b) participants self-report medication use; (c) medication data available from at least one other data source; (d) agreement measurement between self-reports and other data source(s); (e) full-text language: English, and; (f) publication type: original study, excluding, for example, reviews, short reports, letters or comments.

2.2 | Systematic literature search

The systematic literature search was conducted in October 2014 and updated on February 28, 2019. We searched all records published up to this date without any restrictions in time, except for Embase which only lists records published since 1974. Five data- bases were included: Medline via PubMed, Embase (initially via OVID and via Scopus for the update), Journals@Ovid via OVID,
identified further potentially eligible records. Checked and relevant articles known by the authors included to
ey for each database is provided in File S1. Reference lists were
other data sources,” and “agreement.” The complete search strategy for each database is provided in File S1. Reference lists were checked and relevant articles known by the authors included to identify further potentially eligible records.

2.3 | Selection of publications meeting the eligibility criteria

Two researchers independently checked title, abstract and full text for relevance according to the eligibility criteria and subdivided the records into “included” or “excluded”. Every disagreement was discussed for consensus. The inter-rater reliability was calculated using Cohen’s kappa.

2.4 | Critical appraisal and risk of bias within publications

We assessed the quality of all included publications using the Scottish Intercollegiate Guidelines Network (SIGN) methodology checklist for diagnostic studies. We were therefore able to use one tool irrespective of different study designs. To apply the checklist, we had to define which data source should be used as the index test and which as reference standard. The reference standard defined by the authors was used to do so. Where authors did not indicate a reference standard, the non-self-report data source was taken as reference.

The checklist appraises the methodological quality to minimize bias (high, acceptable, low, unacceptable) and the direct applicability/external validity (yes, no) using 13 items in four domains: (a) patient selection, (b) index test, (c) reference standard, and (d) flow and timing. As described in detail in File S2, three items were excluded as not applicable to our review. Accordingly, the quality of the publications was rated high if 9 to 10 criteria were met, acceptable if 6 to 8 were met, low if 1 to 5 were met and unacceptable if no criteria were met. Direct applicability was given if all three relevant criteria were fulfilled. Two researchers completed the checklist for half of the articles each, with an overlap of every fifth article. Differences were discussed and resolved. Results are presented in Table 1.

2.5 | Data extraction

Key characteristics are provided for all included publications. As described below, we also focused on a subgroup of studies dealing with cancer patients and three medication groups, namely estrogen, hormone therapy (HT) and chemotherapy. We analyzed the degree of agreement in these subgroup studies and tried to identify factors which are associated with agreement such as study design aspects and patient characteristics.

We extracted key characteristics, namely sample size and description, analyzed medications, comparison data source, and outcome, for all included publications. Furthermore, we extracted the authors’ main findings concerning agreement. Detailed study characteristics such as data collection period, cancer type, study design, self-report modality, comparison data source, analyzed patient characteristics, analyzed medication, statistic methods, and type of outcome/s were extracted for publications focused on patients with cancer. We focused on the underlying original study design, for example case-control study or cohort study, when extracting data regarding study design. The study design of the validation study, which in most cases is cross-sectional, was not considered here.

All information was extracted by one researcher using piloted forms and was subsequently checked by another researcher to reduce errors or bias. We did not contact any of the corresponding authors for further information. No meta-analysis was performed due to the high methodological heterogeneity of the included studies.

Given the large number of inclusions and their high heterogeneity, it was necessary to set a narrower focus and go into greater detail. To do so, we looked for the largest possible set of homogeneous and comparable studies. We were unable to identify homogeneous studies when starting at the level of the analyzed drugs. We therefore decided to look for an appropriate population as a starting point and identified patients with cancer. Furthermore, we considered the three most frequent medication groups within these studies, namely the hormone estrogen as specific active agent, and hormone therapy (HT) and chemotherapy as two sub-ordinate medication groups, where HT comprises estrogen. Additionally, we focused on the proportion correct and kappa values as an agreement measurement, as most researchers calculated those estimates.

In order to identify parameters which might affect or be associated with agreement, we searched among these studies which analyzed agreement with estrogen, HT and chemotherapy in cancer patients for any which had performed regression analyses or stratified analyses. We expected that these analyses would focus particularly on patient characteristics as age, sex, and sociodemographic position. Since patient characteristics are generally not modifiable, we considered it reasonable to look for further parameters upon which researchers have an influence in study planning, such as (a) study design, (b) comparison data source and (c) self-report modality.

3 | RESULTS

3.1 | Selection of publications and assessment of the risk of bias

Database searching retrieved 3261 records and a further 131 publications were identified as potentially eligible. A total 120 studies met
| References, country | CA\(^a\) result: methodological quality | CA\(^a\) result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors’ main findings |
|--------------------|-----------------------------------------|----------------------------------------|-------------|------------------------|---------------------|------------------------|---------|------------------------|
| Allin et al,\(^2\) Canada | High | Yes | 32 848 | Ontario residents living in private dwellings who responded to the cross-sectional Canadian Survey aged ≥65 | Antihypertensives, Oral diabetes medication | Pharmacy claims data | Current use | Overall agreement was “good” to “very good” for oral diabetes medications, but “moderate” for antihypertensive medications |
| Andersen et al,\(^3\) Denmark | High | Yes | 81 | Hospital patients from regions of Copenhagen aged ≥18 | All | Medical records (clinic) | Current use | Second interviews and GP lists reveal extra information in two-thirds of cases |
| Andrews,\(^1\) Australia | Acceptable | Yes | 385 | Subjects of the 1999 Victorian Population Health Survey aged ≥18 | Vaccination (Influenza, Pneumococcus) | Medical records (all nominated providers) | Previous use | The kappa coefficients indicated self-reported pneumococcal vaccination was less reliable than self-reported influenza vaccination |
| Banks et al,\(^4\) United Kingdom | High | No | 570 | Female patients in the million woman study aged ≥50 | HRT\(^b\), medication for hypertension, heart disease, diabetes, asthma, depression/anxiety, and thyroid disease | Medical records (general practitioners) | Current use, ever use, type of HRT\(^b\) | This study indicates, that compared to general practice prescription records, self-reported current and recent use of HRT is extremely accurate |
| Barat et al,\(^5\) Denmark | High | Yes | 348 | Seniors living in their own homes in a municipality of Aarhus aged 75 | All | Medical records (general practitioners) | Current use | Disagreement concerning drugs was found in 22%, concerning doses in 71%, and concerning regimens prescribed by the GP in 66% |
| Barisic et al,\(^6\) Canada | High | Yes | 939 | Women diagnosed with incident breast cancer from the Ontario Cancer Registry aged 23 to 69 | Hormone therapy, chemotherapy | Medical records (clinic) | Previous use | Agreement measures for a broad category of therapy were above 0.80. The specific type of hormonal or chemotherapy was reported with low-to-moderate agreement |
| Barrett-Connon et al,\(^7\) United States | High | No | 4994 | Postmenopausal women | Osteoporosis medication | Medical records (physician) | Current use | For monotherapy patients, concordance was lowest for patients prescribed estrogen therapy (70%) or calcium/vitamin D (72%) |
| Boudreau et al,\(^8\) United States | Acceptable | Yes | 403 | Female participants of a case-control study of medications and breast cancer risk aged 65 to 79 | Antihypertensives, statins, antidepressants | Pharmacy claims data | Previous use, duration | Self-reported use of antihypertensives and statins appears to be relatively accurate among older women |
| Boudreau et al,\(^9\) United States | Acceptable | Yes | 3610 | Enrollees in GHC\(^c\): Medicare + Choice program aged ≥67 | Antidepressant, antihypertensive, acid suppressant, cardiac, diabetic, hormone, and lipid lowering drugs | Pharmacy claims data | Current use | Our study indicates that health plan pharmacy records are a reliable data source for seniors receiving care within an integrated group practice |
| References, country | CA* result: methodological quality | CA* result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors' main findings |
|---------------------|-----------------------------------|---------------------------------|-------------|------------------------|---------------------|------------------------|---------|-----------------------|
| Brooks et al.20 United States | High | Yes | 321 | Patients of the Boston Medical Center reporting lifetime epilepsy aged ≥18 | Medication for epilepsy | Medical records (clinic) | Current use | Sensitivity was 90% and specificity 74%. The PPV (93.9%) was higher than the negative predictive value (62.1%) |
| Brown et al.21 United States | Acceptable | No | 7918 | Members of the Kaiser Health Plan in San Diego aged ≥45 | Lipid-lowering medication | Pharmacy claims data | Current use | Self-reported measure of lipid-lowering medication exposure was accurate |
| Cadarette et al.22 Canada | High | Yes | 858 | Community-dwelling women from two regions of Ontario aged 66 to 90 | Osteoporosis pharmacotherapy and other agents that may impact bone density | Pharmacy claims data | Current, past, never | Agreement between self-report and claims-based osteoporosis pharmacotherapy was very good |
| Carroll et al.23 Australia | Acceptable | Yes | 1231 | Released prisoners in Queensland | All | Medical records (prison) | Current use | Medication knowledge among prisoners is poor, with a quarter of participants in this study unable to correctly identify any of their medications |
| Caskie et al.6 United States | Acceptable | No | 294 | Participants of a clinical trial on cognitive training aged ≥65 | 10 major drug classes + specific cardiovascular and CNS drug classes | Pharmacy records | Current use | Congruence was generally high |
| Caskie et al.7 United States | High | Yes | 1430 | Subset of participants of the Seattle Longitudinal Study who responded to a cross-sectional study of adult cognitive development aged 23 to 97 | 16 selected drug classes | Pharmacy claims data | Current use | Overall, the congruence of the brown bag data and pharmacy records was high |
| Caverly et al.24 United States | Low | No | 11 | Individuals with cystic fibrosis | Oral antibiotics | Medical records | Current use | Medical record reflected the self-reported use of episodic oral antibiotics the majority of the time |
| Cheung et al.25 The Netherlands | High | Yes | 2637 | Pregnant women from a prospective birth cohort study | SSRIs (antidepressants), Benzodiazepines, Folic acid, Antibiotics, Antiallergics, Antihistamines | Pharmacy records | Current use | Medications required for managing chronic conditions had a good or substantial concordance. Medications taken for acute conditions had a substantial to moderate concordance |
| Chin et al.26 Australia | Acceptable | Yes | 102 | Patients from Melbourne with chronic heart failure and at least two prescribed medications for heart failure | Heart failure medication | Medical records (clinic) | Current use, dose | There were mismatches in the medications (49%) and dosages (57.8%). The number of mismatches increased with the number of prescribed medications |

(Continues)
| References, country | CA result: methodological quality | CA result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors’ main findings |
|---------------------|----------------------------------|----------------------------------|-------------|------------------------|---------------------|------------------------|---------|-----------------------|
| Clegg et al.,27 United States | High | Yes | 3196 | Male participants of a population-based cohort study with prostate carcinoma from six regions in the United States aged 39 to 89 | Hormone pills and shots | Medical records (hospitals, outpatient clinics, HMOs, private physicians’ offices); cancer registries if medical records not available | Previous use | The chance-corrected agreement for hormone pills was moderate, while for hormone shots it was substantial |
| Cohen-Glickman et al.,28 Israel | High | Yes | 75 | Hemodialysis patients (HD) assigned to the largest health provider in Israel aged ≥18 | 13 groups of oral drugs commonly prescribed to HD patients | Pharmacy claims data | Current use, adherence | The mean overall drug adherence was 56.7%. Drug prescription, documentation and adherence are incongruent |
| Colantonio et al.,29 United States | High | Yes | 899 | Elderly participants of a United States-nationwide population-based cohort study about stroke | Lipid lowering medication (statins, ezetimibe, niacin, fibrates, bile acid sequestrants) | Pharmacy claims data | Current use | Substantial agreement assessed by self-report or through a medication inventory, however, about one in five participants had a discordance |
| Coleman et al.,30 United States | Low | No | 375 | Community-dwelling adults aged ≥65 | All | Medical records (health delivery system and hospital separately) | Current use | A total of 14.1% of patients experienced 1 or more medication discrepancies |
| Collet et al.,31 Switzerland | High | Yes | 210 | Adults with diabetes, participating in a community-based survey about diabetes care | Vaccination (Influenza) | Medical records (physician) | Previous use | Processes of care, physicians’ reported data showed more missing values and appeared slightly better than when considering patients’ reported data |
| Cotterchio et al.,32 Canada | High | Yes | 130 | Female participants of a case-control study for cancer from Ontario aged 20 to 74 | Antidepressants | Medical records (physician) | Ever/never-use, duration, dose, date first taken | Substantial agreement was found for medication use, while moderate agreement was observed for duration of use, and date of first use |
| Coulter et al.,33 United Kingdom | Acceptable | No | 99 | Female participants of the Oxford Family Planning Association cohort study aged 25 to 39 | Oral contraceptives | Medical records (general practitioners) | Duration, brand name | Accuracy of recall of total duration of use was sufficiently good |
| Curtis et al.,34 United States | High | Yes | 2363 | Chronic glucocorticoid users from the United States as members of a national managed care organization aged ≥18 | Osteoporosis medication | Pharmacy claims data | Current use | Underreporting of current osteoporosis medication use was uncommon, and agreement was high |
| References, country | CA\(^a\) result: methodological quality | CA\(^a\) result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors’ main findings |
|---------------------|----------------------------------------|-------------------------------------|-------------|------------------------|---------------------|-----------------------|--------|------------------------|
| Demoré et al,\(^35\) France | High | Yes | 653 | Customers of 15 pharmacies of northeastern France | Antibiotics | Pharmacy records | Current use | Participant’s self-reports were relatively reliable (agreement 81% and k 0.60). On the other hand, they very often misnamed the drug and there was substantially more underreporting than overreporting |
| Drieling et al,\(^36\) United States | High | Yes | 223 | Older women from Seattle, United States, participating in the Women’s Health Initiative cohort study | Statins, calcium channel blockers, \(β\)-blockers, and bisphosphonates | Pharmacy records | Current use, duration | In a population of older women, a mailed medication inventory appears to be a highly accurate means of assessing current use and duration of use of four classes of chronically used medications |
| Enlund et al,\(^37\) Finland | Acceptable | No | 570 | Hypertensive inhabitants of Joensuu or Kuopio aged 30 to 64 | Antihypertensives | Pharmacy claims data | Current use, brand name | Self-reports gave accurate information about the number and type of drugs in use |
| Fogel et al,\(^38\) United States | Acceptable | Yes | 482 | HIV-infected individuals from Indonesia, Ukraine, Vietnam | Antiretroviral treatment | Biosamples | Current use | Self-reported data may not be accurate |
| Fujita et al,\(^39\) Japan | High | Yes | 54 712 | Japanese beneficiaries of National Health Insurance receiving a health check-up | Antihypertensives, lipid lowering drugs, antidiabetics | Pharmacy claims data | Current use | High validity for predicting actual prescriptions for drugs used to treat hypertension, diabetes and dyslipidemia |
| Gee et al,\(^40\) Canada | Acceptable | Yes | 161 | Hypertensive people with and without diabetes aged \(≥20\) | Antihypertensives | Medical records (clinic) | Current use (number of antihypertensives) | Numbers of prescribed antihypertensive medications showed fair agreement |
| Gnjidic et al,\(^41\) Australia | High | No | 500 | Randomly sampled participants from the 45 and Up Study | Prescribed medications | Pharmacy claims data | Current use | Sensitivity and positive predictive values are good overall, and vary by medication type |
| Goodman et al,\(^42\) United States | Acceptable | No | 942 | Japanese and white women with and without breast cancer aged 45 to 74 | Hormone replacement therapy, estrogen | Medical records (physician or clinic) | Ever use, duration, age at initial use | Results suggest that women can recall estrogen use with a high degree of accuracy |
| Gordon et al,\(^43\) United States | Acceptable | No | 961 | Current or former Kaiser Permanente health plan members of aged 66 to 85 | Vaccination (Pneumococcus) | Pharmacy claims data | Ever use | Sensitivity was significantly lower for Blacks and Latinos than for Whites |
| Gordon et al,\(^44\) Australia | Low | No | 76 | Colorectal cancer survivors | Medicines for gastrointestinal conditions, cardiovascular disease, psychological conditions and COPD, chemotherapy | Pharmacy claims data (national insurance administrative data, medicare Australia) | Previous use | Medication use by self-report appears to be unreliable |
| References, country | CA result: methodological quality | CA result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors’ main findings |
|---------------------|----------------------------------|-------------------------------|-------------|-----------------------|---------------------|------------------------|---------|-----------------------|
| Grimaldi-Bensouda et al,45 France | Acceptable | No | 2702 | French residents with and without myocardial infarction aged ≥18 | Cardiovascular and diabetic drugs | Medical records (physician) | Previous use (2 years, 2 months, 2-12 months, 12-24 months) | Agreement was excellent overall |
| Grimaldi-Bensouda et al,46 France | Acceptable | No | 4152 | General practitioners’ patients aged ≥18 | Drugs for musculoskeletal disorders: nonsteroidal anti-inflammatory drugs, nonopioid analgesics, drugs for osteoarthritis and muscle relaxants | Medical records (physician) | Previous use | Differences varied by the type of drug and the elapsed time from the index date |
| Guerriere et al,47 Canada | Acceptable | No | 110 | Cystic fibrosis care recipients aged ≥18 | Insulin, antibiotics/antifungals, gastrointestinal therapy, pulmonary therapy | Pharmacy claims data | Current use | The results indicate that there was good agreement for prescription medications |
| Gupta et al,48 China | High | No | 5042 | Women with diagnosed breast cancer aged 20 to 75 | Chemotherapy | Medical records (clinic) | Previous use | Agreement tended to be higher for less commonly used drugs compared with more commonly used drugs |
| Guzman et al,49 Canada | Acceptable | Yes | 48 | Workers with lower back pain aged ≥18 | NSAIDs, narcotics, relaxants, topical, OTC analgesics, benzodiazepines | Medical records (physician) | Current use | Agreement on prescription medications was fair (k = 0.29-0.46) |
| Haapea et al,50 Finland | Acceptable | Yes | 7625 | Participants of the Northern Finland 1966 Birth Cohort | Antipsychotics, antidepressants, antiepileptics, antidiabetics and beta-blocking agents | Pharmacy claims data | Current use | The congruence was substantial for antipsychotics and antidepressants, and almost perfect for antiepileptics |
| Hafferty et al,4 United Kingdom | High | Yes | 10 244 | Adult participants in the Generation Scotland population-based cohort, recruited 2009 to 2011 | Antidepressants, mood stabilizers, cholesterol-lowering medication, antihypertensives, Aspirin, insulin, HRT, oral contraceptives | Pharmacy records | Current use | Substantial to very good agreement for most medications studied. Agreement for mood stabilizers was indeed considerably worse |
| Hanigan et al,51 United States | Acceptable | No | 152 | Clinic cancer patients | All | Medical records (clinic) | Current use | Paper charts recorded only 69% of the prescription drugs taken by the patient |
| Harde et al,52 Germany | Acceptable | ? | 102 | Diabetic patients with three or more chronic prescriptions aged ≥39 | Various prescription drugs (ie, antidiabetics, cardiovascular drugs, antidepressive agents) and various OTC drugs | Medical records (physician) | Current use | We found a mismatch between general practitioner’s documentation and the medications taken by the patient |
| References, country | CA result: methodological quality | CA result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors' main findings |
|---------------------|----------------------------------|-------------------------------|-------------|------------------------|---------------------|------------------------|---------|----------------------|
| Haukka et al, 53 Finland | Acceptable | No | 905 | Persons with schizophrenia and their siblings and parents | Psychotropic medication | Pharmacy claims data | Current use | The concordance was good for most psychotropic drugs |
| Heerdink et al, 54 The Netherlands | Acceptable | No | 100 | Residents of a medium-sized municipality of the Netherlands aged ≥65 | All (prescription and OTC), that is, cardiovascular drugs, analgesic drugs and NSAIDs, psychotropic drugs, respiratory drugs | Medical records (physician), pharmacy records | Current use | Pharmacy record contained 80% of all the prescriptions found at the interview, while in general-practitioner data 40% could be traced |
| Hopkins et al, 55 United States | Acceptable | Yes | 178 | Women having given birth one or more times, aged 40 to 74 | Oxytocin, regional anesthesia | Pharmacy claims data | Previous use | Oxytocin had particularly low concordance for all values except NPV which was moderate |
| Horwitz et al, 56 United States | High | No | 133 + 191 | Female participants of a case-control study with and without endometrial cancer | HRT (estrogen) | Medical records (clinic) | Ever use | The interview data disagreed with previously recorded medical information in 18% of patients |
| Horwitz, 57 United States | Acceptable | No | 462 | Postmenopausal participants of a case control study of breast cancer aged ≥65 | HRT (estrogen), thiazides, beta-blocking agents, reserpine, oral contraceptives, thyroid | Medical records (clinic) | Ever use | We discovered considerable variability between the two data sources |
| Hulka et al, 58 United States | Acceptable | Yes | 357 | Adult patients with diabetes or congestive heart failure | All prescription drugs | Medical records (physician) | Current use | The combined average error was 58% |
| Hutchison, 59 United States | Acceptable | No | 535 | Patients enrolled in a group family practice aged ≥65 | Influenza vaccine | Medical records (physician) | Previous use | Kappa statistic was 0.74 for 1984 to 1985 and 0.88 for 1985 to 1986 |
| Jain et al, 60 Canada | High | Yes | 653 | Participants of a case-control study of endometrial cancer in Toronto and surrounding regions of Halton, Peel and York aged 30 to 79 | Menopausal hormone replacement therapy | Medical records (physician) | Ever/never use, duration, brands | Information obtained by interview provides a reasonable measure of ever use and duration |
| Johnson et al, 61 United States | Acceptable | No | 83 | Frail elderly HMO enrollees of Kaiser Permanente aged ≥65 | All | Pharmacy claims data | Current use (number of medications, number of different therapeutic drug classes) | An automated prescription system is an adequate source of information |
| References, country | CAa result: methodological quality | CAa result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors’ main findings |
|---------------------|-----------------------------------|---------------------------------|-------------|-----------------------|---------------------|------------------------|---------|------------------------|
| Kaboli et al.62 United States | Acceptable | No | 493 | Veteran Affairs patients aged ≥65 | All | Pharmacy claims data | Current use | There was complete agreement for only 5.3% of patients |
| Kehoe et al.63 United States | Acceptable | No | 1380 | Participants of a cataract case-control study | Insulin, oral hypoglycemics, regular Aspirin use, oral steroids, gout medications, hypertensive medication | Medical records (physician) | Current use | Results suggest an accurate recall in well-defined chronic conditions |
| Klungel et al.64 The Netherlands | High | Yes | 372 | Hypertensive subjects from three dutch cities as participants of a study of cardiovascular risk factors aged 20 to 59 | Antihypertensive drugs | Pharmacy records | Current use, ever use | Agreement was consistently high for all classes of antihypertensive drugs |
| Klungel et al.65 The Netherlands | High | Yes | 372 | Hypertensive subjects from three Dutch citites as participants of a study of cardiovascular risk factors aged 20 to 59 | All | Pharmacy records | Current use | Recall sensitivity was higher for questions about medications used for a specific indication (88%) than for the open-ended question (41%) |
| Korthuis et al.66 United States | High | Yes | 1548 | HIV-positive participants of the HIV Cost and Services Utilization Study receiving care in the United States aged ≥18 | Medications for HIV-patients | Pharmacy records, medical records (separately) | Previous use | For specific medications, agreement is fair to substantial, but is lower for key drug classes |
| Kropp et al.67 Germany | High | Yes | 449 | Postmenopausal women who participated in a breast cancer case-control study from the german regions of Rhein-Neckar and Hamburg aged 50 to 74 | Postmenopausal hormone therapy | Medical records (physician) | Current use, ever use, duration, type of medication at first use, age at first/last use | Overall, the self-reported HT of the study participants corresponded well with physicians' reports |
| Kwon et al.6 United States | High | Yes | 164 | Participants of a longitudinal depression study from the metropolitan area of Boston aged ≥18 | Antidepressants | Pharmacy claims data | Current use | Self-report and claims showed good concordance, but they reflect different truths |
| Lacasse et al.68 Canada | High | Yes | 272 | Chronic pain patients enrolled in the Quebec Pain Registry | Analgesic medication | Pharmacy claims data | Current use, previous use | Accuracy of current pain medication was accurate for the main therapeutic classes. Accuracy of the past year was somewhat lower |
| References, country   | CA¹ result: methodological quality | CA¹ result: direct applicability | Sample size | Sample characteristics                              | Analyzed medication | Comparison data source                                                                 | Outcome                                                              | Authors’ main findings                                                                 |
|----------------------|----------------------------------|---------------------------------|-------------|-----------------------------------------------------|---------------------|----------------------------------------------------------------------------------------|----------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| Langendam et al, 69  | Acceptable                       | No                              | 505         | Participants of the Amsterdam AIDS cohort study aged 21 to 52 | Methadone           | Administrative data (Amsterdam Central Methadone Register)                             | Current use, dosage, previous use                                      | Current methadone usage was accurately reported                                      |
| Lau et al, 70        | Acceptable                       | No                              | 115         | Elderly people living in Amsterdam ≥70              | All prescription drugs | Pharmacy records                                                                       | Current use                                                          | Computerized pharmacy records can be a reliable source of the true drug exposure    |
| Law et al, 71        | High                             | Yes                             | 123         | Homosexual men with AIDS or HIV from Victoria aged 23 to 68 | HIV-related treatment | Medical records (clinic, physician: inpatient, outpatient) and pharmacy records (combined) | Previous use, current use (cross-sectional and longitudinal for at least 3 months) | Data collected prospectively on prescription of drugs were reasonably accurately reported by patients |
| Lindberg et al, 72   | High                             | Yes                             | 204         | Swedish hemo- or peritoneal dialysis patients aged 23 to 88 | All (excluding natural remedies, homeopathic products, foodstuffs, naturopathic drugs, i.e., medicines, anticoagulants) | Medical records (clinic)                                               | Current use, brand name, dosage                                                    | Discrepancies were prevalent in 80.4% of cases, with a median of three discrepancies per patient |
| Liu et al, 73        | High                             | Yes                             | 726         | Low-income and underinsured women with breast cancer from California aged 25 to 85 | Hormone therapy, chemotherapy | Medical records (each cancer provider)                                                    | Previous use                                                           | Self-reporting of key treatment is relatively accurate                               |
| Lloyd et al, 74      | Acceptable                       | No                              | 403         | United Kingdom-resident South Asian diabetic people | All (medications for diabetes, blood pressure, high cholesterol and other conditions) | Medical records (general practitioners)                                      | Current use                                                           | Nonconcordance with medications was common                                             |
| Lokkegard et al, 75  | High                             | Yes                             | 2694        | Participants of the Danish Nurse Cohort Study living in the Counties of Funen and North Jutland aged 50 to 69 | Hormone replacement therapy | Pharmacy claims data                                                                     | Current use, type of current medication, previous use, duration       | Relatively high validity of self-reported data on HRT use was found                   |
| Loo et al, 76        | Acceptable                       | No                              | 4630        | 17 population samples in Japan, China, United Kingdom, United States aged 40 to 59 | Analgesics (acetaminophen, ibuprofen) | Urine specimens                                                                       | Current use                                                           | The overall rate of concordance was 81% to 84%                                          |
| References, country | CA result: methodological quality | CA result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors’ main findings |
|---------------------|----------------------------------|-------------------------------|-------------|------------------------|---------------------|------------------------|---------|-----------------------|
| Lubeck et al, United States | High                             | Yes                           | 123         | Community-dwelling seniors as participants of a longitudinal study of physical disability in alumni of Pennsylvania University aged 73 to 87 | All (number of prescriptions), chemotherapy (number of visits) | Medical records (clinic and physician) | Previous use | Near-perfect agreement for the frequency of high-cost chemotherapy visits and substantial agreement for prescriptions |
| Mac Donald et al, United States | High                             | Yes                           | 195         | High-risk outpatients from Minneapolis enrolled in two different health care systems with similar vaccination programs aged 65 | Vaccination (influenza, pneumococcus) | Medical records (clinic and physician) | Ever use (pneumococcus), current use (influenza) | SR of influenza vaccination is highly sensitive and moderately specific. SR of pneumococcal vaccination is also highly sensitive but less specific |
| Mangtani et al, United Kingdom | Low                              | No                            | ?           | Participants of a cost-of-illness study aged 65 to 84 | Influenza and pneumococcal vaccine | Medical records (general practitioners) | Previous use | Influenza vaccine uptake (past year) had very good agreement; Pneumococcal vaccination (ever) had only moderate agreement |
| Margolis et al, United States | Acceptable                        | Yes                           | 161 808     | Postmenopausal women aged 50 to 79 | Diabetic medication | Pharmacy records | Current use, previous use | Self-reports of “treated diabetes” are sufficiently accurate to allow use in epidemiologic studies |
| Maunsell et al, Canada | Acceptable                        | No                            | 103         | Female breast cancer survivors aged 60 at diagnosis | Chemotherapy, hormone therapy | Medical records (clinic) | Previous use, start of chemotherapy | Agreement of self-report with medical record data was very high |
| Metlay et al, United States | High                             | Yes                           | 103         | Veterans receiving primary care within the VA Healthcare System in Philadelphia aged ≥18 | Antibiotics, antihypertensive drugs, NSAIDsd | Pharmacy claims data | Previous use | Assessment of antibiotic exposure appears comparable to other chronic and episodic drugs. Multistep assessment improves Sensitivity |
| Mevaag et al, Norway | Acceptable                        | No                            | 174         | Patients at the National Center for Epilepsy, Oslo | Antiepileptic drugs | Medical records (physician) | Current use, dose | 32% of the patients had one or more discrepancies in either the type or the dosages |
| Midthjell et al, Norway | High                             | Yes                           | 169 + 108   | Norwegian participants of the population-based Nord-Trondelag health survey with and without diabetes aged ≥20 | Diabetes treatment, hypertension treatment | Medical records (physician) | Current use | Patient-administered questionnaires may be a very reliable source of information in a well-defined chronic disease |
| References, country  | CA² result: methodological quality | CA² result: direct applicability | Sample size | Sample characteristics                                                                 | Analyzed medication                                      | Comparison data source                      | Outcome                           | Authors' main findings                                                                 |
|---------------------|----------------------------------|---------------------------------|-------------|----------------------------------------------------------------------------------------|----------------------------------------------------------|--------------------------------------------|-------------------------------------|--------------------------------------------------------------------------------------|
| Monster et al.³⁵     | High                             | Yes                             | 7568        | Subjects with microalbuminuria as a subset of an ongoing population-based study from the Netherlands aged 28 to 75 | Antihypertensives, lipid lowering drugs, antidiabetics, nitrates, oral contraceptives, hormone replacement therapy, painkillers | Pharmacy records                           | Current use (in general), ever use (for sublingual tablets/nitrates), previous use (for painkillers) | Good agreement for chronically used drugs and lower agreement for drugs used for shorter periods |
| Monte et al.³⁶ United States | Acceptable          | No                              | 55          | Adult patients with nausea or pain in an emergency department                           | Prescribed drugs, OTC drugs (without herbals, supplements, vitamins) | Urine comprehensive drug screen               | Current use                         | Self-reported drug ingestion histories were poor. Prescription drugs were concordant in 58.2%, OTCs in 60% |
| Moore et al.³⁷ France | High                             | Yes                             | 797         | Hospital patients participating in a case-control-study of hip fracture aged ≥65        | Benzodiazepine                                           | Medical records (clinic and physician) and plasma assays (separately) | Current use                         | Questionnaires had 80% Sens and 83% Spec, with 11% false negatives and 28% false positives. Concordance was $\kappa = 0.63$ |
| Nielsen et al.³⁸     | Low                              | No                              | 1654        | Female participants of the Danish Nurse Cohort Study aged ≥44                           | Hormone therapy                                          | Pharmacy records                           | Current use, never-use, previous use, duration | The study showed only a moderate disagreement on hormone therapy exposure across the different exposure definitions |
| Nissen et al.³⁹ United States | High                             | Yes                             | 474 + 353   | Breast and colorectal cancer survivors from the metropolitan area of Minneapolis aged 25 to 98 | Chemotherapy, hormone therapy                            | Cancer registry and medical records (combined) | Previous use                        | Several gaps in adult cancer survivors' knowledge of details of their treatment were identified but high accuracy in the indication of received chemotherapy |
| Noize et al.⁴⁰ France | Acceptable          | Yes                             | 4112        | Participants of a cohort study into the relationship between vascular risk factors and dementia aged ≥67 | All                                                      | Pharmacy claims data                       | Current use                         | Both sources estimate exposure to chronically used drugs similarly. Self-medication was better described with interviews whereas reimbursement data seem more useful for drugs used topically or intermittently |
| Noize et al.⁴¹ France | High                             | Yes                             | 2985        | Patients of the French three city cohort study (Bordeaux, Dijon or Montpellier) who responded to two consecutive cross-sectional interviews aged 65 to 94 | All                                                      | Pharmacy claims data                       | Current use/chronic exposure (longitudinal) | Interviews as a proxy for chronic exposure was valid for drugs used regularly but not so for drugs used more irregularly |
| References, country | CA\(^a\) result: methodological quality | CA\(^a\) result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors' main findings |
|---------------------|---------------------------------------|--------------------------------------|-------------|------------------------|---------------------|------------------------|---------|-----------------------|
| Norell et al.\(^{92}\) Sweden | High | Yes | 427 | Community-based sample of Swedish women from the county of Jämtland aged 20 to 34 | Oral contraceptives | Pharmacy records | Current use, ever use, total duration, duration in three “time windows,” time since first/last use | High levels of agreement for any OC use, current use, time since first and last use, total duration of use, and for duration of use in different “time windows.” |
| Opdycke et al.\(^{93}\) United States | Acceptable | No | 101 | Patients with at least two chronic medical problems aged ≥60 | All | Medical records (clinic) | Current use | Prescription drugs: agreement scores were high. Nonprescription drugs: use was frequently omitted from the medical record |
| Orrico\(^{94}\) United States | Acceptable | No | 85 | Health plan members calling a nurse advice line | All | Medical records (clinic) | Current use | Discrepancies in the outpatient setting were common and predominantly system generated |
| Paganini-Hill et al.\(^{95}\) United States | Acceptable | Yes | 334 | Female participants of a case-control study on breast cancer | Thyroid, reserpine, other hypertensives, steroids, barbiturates/ataretics, estrogen | Pharmacy records, medical records (general practitioners) | Current use (for most drugs), ever use and duration for estrogens | Agreement for ever use varied considerably with the type of drug studied, from low to high. Better correspondence was observed for medical record than for pharmacy records |
| Paganini-Hill et al.\(^{96}\) United States | Acceptable | No | 3087 | Female participants of a case-control study for breast cancer aged 53 to 71 | Estrogen, progestogen (from menopausal hormone therapy, oral contraceptives) | Medical records (general practitioners) | Ever/never-use, duration | Interviews provide a moderately reliable measure for ever use for estrogen and progestogen |
| Persell et al.\(^{97}\) United States | High | Yes | 119 | Patients with hypertension from three primary care clinics in Grand Rapids, Michigan aged ≥18 | Antihypertensive medication | Medical records (clinic) | Current use | Patients with inadequate health literacy were less able to name any of their antihypertensive medications |
| Persson et al.\(^{98}\) Sweden | Acceptable | No | 116 | Women with estrogen treatment for climacteric symptoms aged ≥55 | Hormone replacement therapy (estrogen) | Pharmacy records | Brand name, dosage, total duration, treatment schedule | Questionnaire information was highly concordant with the prescription data with respect to name of brand, dosage, treatment schedule, total duration and time of start of medication |
| Phillips et al.\(^{99}\) Australia | High | Yes | 895 | Breast cancer patients of a case-control study in Melbourne and Sydney aged 23 to 69 | Hormone therapy, chemotherapy | Medical records (clinic) | Previous use | SR questionnaire can be used to collect accurate data on broad categories of cancer treatment and for more detailed information on specifics of treatment |
| References, country | CA\textsuperscript{a} result: methodological quality | CA\textsuperscript{a} result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors’ main findings |
|---------------------|-----------------------------------------------|-----------------------------------------------|-------------|------------------------|----------------------|------------------------|---------|------------------------|
| Pisa et al\textsuperscript{100}, Italy | High | No | 767 | Pregnant women from a prenatal clinic in Trieste | All | Pharmacy claims data | Previous use | Agreement varied greatly by therapeutic class. It was almost perfect to substantial for medications taken for chronic conditions, while it was moderate to slight for OTC medications |
| Pit et al\textsuperscript{101}, Australia | Acceptable | No | 566 | Community-dwelling, general practice patients aged $\geq 65$ | Drugs/drug classes commonly used in the elderly | Pharmacy claims data | Current use | High agreement and accuracy were demonstrated |
| Rauma et al\textsuperscript{102}, Finland | High | Yes | 11 031 | Postmenopausal female residents of Kuopio Province participating in a cohort study for osteoporosis | Psychoactive medication, antidepressants, diuretics | Pharmacy records | Current use | Only 44%, 55%, 29% reported their use of psychoactive medication, antidepressants or other psychoactive medications when compared to a 4-month time window |
| Richardson et al\textsuperscript{103}, Ireland | Acceptable | Yes | 2621 | Community-dwelling adults aged $\geq 50$ | 19 therapeutic drug classes | Pharmacy claims data | Current use | Agreement was good or very good for 15 medication classes, and moderate or poor for antiinflammatory and antirheumatic products, analgesics, psychotropics, and ophthalmologicals |
| Rolfink et al\textsuperscript{104}, United States | Acceptable | No | 11 760 | Community-dwelling health-plan enrollees aged $\geq 18$ | Various vaccines | Pharmacy claims data | Ever use | Considerable variation was found by vaccine. Under-reporting was relatively low, while over-reporting varied by vaccine |
| Sandini et al\textsuperscript{105}, Finland | Acceptable | No | 11 377 | Female inhabitants of Kuopio, Finland aged 57 to 67 | Estrogen hormone therapy | Pharmacy claims data | Previous use, duration, brand name | A postal inquiry is a reliable method of recording long-term hormone therapy use |
| Sarangarm et al\textsuperscript{106}, United States | Low | No | 404 | Pregnant women recruited from prenatal care clinics | Drugs within the most common therapeutic classes | Medical records (clinic) | Previous use | High concordance for chronically used medications and poor agreement for medications used as needed |
| Saunders et al\textsuperscript{107}, United States | Acceptable | No | 164 | GHC enrollees starting antidepressant treatment and participating in an RCT\textsuperscript{6} to improve depression treatment in primary care | Antidepressant treatment | Pharmacy claims data | Current use, dose, acute phase treatment adequacy | Results indicated that the two methods provided similarly complete information on current usage and overall acute phase treatment adequacy |
| Shalansky et al\textsuperscript{108}, Canada | Acceptable | No | 194 | Outpatients with heart failure aged 27 to 94 | All prescription medication | Pharmacy records | Current use | Discrepancies were identified for 71.1% of the patients |

\textsuperscript{a}CA = Critical Appraisal
| References, country | CA result: methodological quality | CA result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors' main findings |
|---------------------|----------------------------------|-------------------------------|-------------|------------------------|---------------------|------------------------|---------|------------------------|
| Shenson et al,109    | United States                    | High                          | Yes         | 135                    | Noninstitutionalized civilian respondents of a random digit dialed survey living in Dutchess or Columbia County, New York aged ≥ 65 | Vaccination (pneumococcal polysaccharide vaccine) | Medicare claims, medical records (physician), when no claims available | Ever use | Self-reporting of pneumococcal immunization is a moderately sensitive and specific measure |
| Shahid et al,110     | The Netherlands                   | High                          | No          | 1682                   | Participants of the Rotterdam Elderly Study aged ≥ 55 | Cardiovascular drugs | Pharmacy records | Current use | The agreement is good for prescription only drugs |
| Spangler et al,7     | United States                    | High                          | Yes         | 1399                   | Female participants of a population-based case-control study of the association between oral contraceptive use and fracture risk aged 45 to 59 | Oral contraceptives | Pharmacy claims data | Ever use | Results show moderate agreement for up to 15 to 20 years before the interview |
| Spangler et al,111   | Canada                            | Acceptable                    | Yes         | 101 + 153              | Cases and controls with newly diagnosed cancer of the endometrium aged 40 to 74 | Estrogen use | Medical records (clinic), medical records (physician) | Current use | Agreement for physician's records was 83%, for hospital records 85% |
| Stewart et al,112    | United States                    | Acceptable                    | No          | 219                    | Adult patients of primary care clinic | All | Medical records (clinic-outpatient care) | Current use | 74% had at least one discrepancy |
| Tisnado et al,113    | United States                    | Acceptable                    | No          | 1270                   | Managed care patients with at least one of five chronic conditions | All | Medical records (physician) | Previous use | The medical record and patient self-report do not measure quality comparably across patient cohorts |
| Tisnado et al,114    | United States                    | Acceptable                    | No          | 1270                   | Managed care patients with at least one of five chronic conditions | All | Medical records (physician) | Previous use | Concordance was good: total agreement was 85%, and kappa was 0.6 |
| Tisnado et al,115    | United States                    | Acceptable                    | No          | 1270                   | Managed care patients with at least one of five chronic conditions | All | Medical records (physician) | Previous use | The medical record and patient survey do not measure quality comparably across organization types |
| Uiters et al,116     | The Netherlands                   | High                          | Yes         | 7012                   | Patients of different ethnicities as part of the Dutch Second National Survey of General Practice aged ≥ 18 | All prescribed medications (excluding contraceptive prescriptions and OTCs) | Medical records (general practitioners) | Current use | The percentage of agreement above chance was in general relatively low |
| References, country | CAa result: methodological quality | CAa result: direct applicability | Sample size | Sample characteristics | Analyzed medication | Comparison data source | Outcome | Authors’ main findings |
|---------------------|-----------------------------------|---------------------------------|-------------|------------------------|---------------------|------------------------|---------|-----------------------|
| van den Brandt et al.117 The Netherlands | Acceptable | No | 207 | Participants of a prospective cohort study aged 55 to 69 | All prescribed drugs | Pharmacy records | Previous use | Questionnaire recall of drug use amounted overall to 61.2% of drugs prescribed to the subjects for at least 6 months |
| van den Brink et al.118 The Netherlands | Acceptable | No | 94 | Patients with resectable rectal cancer | All | Pharmacy records | Previous use | The percentage reported by both was quite low, at approximately 25% |
| Varkey et al.119 United States | High | Yes | 104 | Primary care patients at Mayo Clinic in Rochester aged ≥18 | All | Medical records (clinic) | Current use, drug frequency, dosage, route | Interventions resulted in a statistically significant over-all decrease in errors |
| Voss et al.120 United States | High | No | 200 | HIV patients from two urban public health clinics in the Pacific Northwest | Antiretroviral treatment | Medical records (clinic) | Current use | Only 43% were able to recall their ART regimens accurately |
| West et al.121 United States | High | No | 454 | GHCf enrollees aged 50 to 80 | NSAIDs, noncontraceptive estrogen | Pharmacy claims data | Previous use | This study suggests significant under ascertainment of self-reported prescription drug exposure but little evidence that exposures are overreported |
| West et al.122 United States | Acceptable | Yes | 454 | GHCf enrollees aged 50 to 80 | NSAIDs, short-term NSAIDs, noncontraceptive estrogen | Pharmacy claims data | Previous use | Predictors of recall accuracy for previous medication use differ by the type of drug and the repetitiveness of its use |
| Yasein et al.122 Jordan | High | Yes | 400 | Patients attending the family practice clinic at Jordan University Hospital in Amman aged 65 to 102 | All | Medical records (clinic) | Previous use | Almost one-third of the patients had full agreement regarding the total number of drugs, whereas 43.4% underestimated and 21.8% overestimated these numbers |
| Zhou et al.123 United States | Acceptable | Yes | 2905 | Adult participants of the Atherosclerosis Risk in Communities (ARIC) Study from five United States communities | Atenolol, Lisinopril, Metformin, Amlodipine, Valsartan | Pharmacy claims data | Current use | Claims for medications were more likely to match with self-reports |
| Zimmerman et al.124 United States | High | Yes | 820 + 819 | Primary care patients from Pennsylvania aged ≥65 | Vaccination (influenza, pneumococcus) | Medical records (physician) | Ever use (pneumococcal, previous use (influenza)) | For influenza vaccine, sensitivity was 98% and specificity 38%. For pneumococcal polysaccharide vaccine, sensitivity was 85% and specificity 46% |

aCritical appraisal.
bHormone replacement therapy.
cHealth Maintenance Organization.
dNonsteroidal antiinflammatory drug.
eOver the counter.
fGroup health cooperative.
gRandomized controlled trial.
the inclusion criteria, of which 50 were not found by database searching. The inter-rater reliability for full-text-screening was 0.84. The selection process is presented in Figure 1.

Critical appraisal found 56 publications (47%) to be of high quality and another 58 (48%) to be of acceptable quality. Results are shown in Table 1.

3.2 | Data extraction

Among the 120 included publications, we found 18 articles dealing with cancer patients. Results regarding the three selected medication groups were found in 11 of them. All but one of the 11 articles provide information on the association of study design aspects or patient characteristics with agreement.

3.2.1 | Characteristics of publications

We included 120 full-text articles and described their characteristics in Table 1. The years of publication range from 1976 to 2019. The number of annual publications on this subject began to rise as of 1998, with a total 100 publications in 22 years, giving an average annual number of 4.5. Most studies stem from the United States (n = 54), followed by Canada (n = 12) and the Netherlands (n = 11).

The studies often evaluate data from cancer patients (n = 20). No other patient group is so strongly represented. Accordingly, hormones are often the focus of analyses (n = 27), although oral contraceptives are also included. Other commonly analyzed medication groups are antihypertensives (n = 20), antihyperglycemic medications (n = 15), drugs for depression or anxiety (n = 14), cardiovascular drugs (n = 10), lipid-lowering medications (n = 10), and vaccines (n = 9).

**FIGURE 1** Flow diagram of systematic literature searching and publication inclusion process
| References, country | Data collection period | Sample description with type of cancer | Original study design | Self-report modality | Comparison data source | Analyzed patient characteristics | Analyzed medication | Statistic methods | Outcome |
|---------------------|------------------------|----------------------------------------|-----------------------|---------------------|------------------------|---------------------------------|-------------------|-----------------|---------|
| Barisic et al. 26 Canada | 1996 to 2000 | Women diagnosed with incident breast cancer from the Ontario Cancer Registry aged 23 to 69 | Cross-sectional validation study | Questionnaire | Medical records (clinic) | Age, education, marital status, English-speaking, alcohol, smoking, family cancer history, menopausal status, cancer recurrence, recall period | Chemotherapy (general), Cyclophosphamide, Flurouracil, Methotrexate, Epirubicin, Docetaxel, Hormone therapy (general), Tamoxifen, Megestrol, Anastrozole, MA12 | Proportion correct, sensitivity, specificity, PPV, NPV, kappa | Previous use |
| Boudreau et al. 18 United States | 1990 to 1999 | Female participants of a case-control study of medications and breast cancer risk aged 65 to 79 | Case-control study | Face-to-face interview | Pharmacy claims data | None | Antihypertensives (general), statins (general), antidepressants (general) | Sensitivity, specificity, intraclass correlation coefficient | Previous use, duration |
| Clegg et al. 27 United States | 1994 to 1995 | Male participants of a population-based cohort study with prostate carcinoma from six regions in the United States aged 39 to 89 | Cohort study | Questionnaire | Medical records (hospitals, outpatient clinics, HMOs, private physicians' offices); cancer registries if medical records not available | Age, education, marital status, ethnicity, income, registry area | Hormone pills (finasteride, flutamide, estrogen, bicalutamide, prednisone/steroids, aminolutetethimide, ketoconazole) and hormone injections (leuprolide acetate and goserelin) | Sensitivity, specificity, PPV, NPV, kappa | Previous use |
| Cotterchio et al. 32 Canada | 1995 to 1996 | Female study participants of a case-control study for non-Hodgkin's lymphoma, breast, or kidney cancer from Ontario aged 20 to 74 | Case-control study | Questionnaire | Medical records (physician) | Age, education, marital status, income, cancer site, depression, smoking | Antidepressants (general, amitriptylin, fluoxetine, imipramine, desipramine, mapiotrine, sertraline, doxepin, paroxetine) | Kappa, weighted kappa, percent agreement, percent perfect agreement, mean difference of duration | Ever use, duration, dose, date first taken |
| Goodman et al. 42 United States | 1975 to 1980 | Japanese and white women with and without breast cancer aged 45 to 74 | Case-control study | Face-to-face interview | Medical records (physician and clinic combined) | Age at interview, education, marital status, ethnicity, home ownership, cigarette use, case-control status, family history of cancer, duration of estrogen use, age at initial use of estrogens, length of recall, and the number of physician records reviewed on the agreement between subject recall and physician information | Estrogen | Proportion correct, kappa, intraclass correlation coefficient | Ever use, duration, age at initial use |

(Continues)
| References, country | Data collection period | Sample description with type of cancer | Original study design | Self-report modality | Comparison data source | Analyzed patient characteristics | Analyzed medication | Statistic methods | Outcome |
|---------------------|------------------------|----------------------------------------|-----------------------|---------------------|------------------------|---------------------------------|---------------------|-------------------|---------|
| Gordon et al, Australia | 2009 to 2010 | Colorectal cancer survivors | RCT | Telephone interview | Pharmacy claims data (national insurance administrative data, medicare Australia) | Age, sex, income, paid work, living arrangement, private health insurance, type of surgery, chemotherapy, radiotherapy, visit frequency, intervention allocation | Any prescriptions, medicines (in general) for gastrointestinal conditions, cardiovascular disease, psychological conditions and COPD | Proportion of absolute agreement, kappa, differences (%) | Previous use |
| Gupta et al, China | n.a. | Women with diagnosed breast cancer aged 20 to 75 | Population-based prospective cohort study | Face-to-face interview | Medical records (clinic) | Age, education, income, time since diagnosis, stage of disease at diagnosis | Fluorouracil, cyclophosphamide, epirubicin, methotrexate, calcium folinate, piraubicin, novel drugs, vinorelbine, docetaxel, paclitaxel | Kappa, percent agreement | Previous use |
| Hanigan et al, United States | n.a. | Clinic patients with any cancer | Cross sectional study | Questionnaire | Medical records (clinic)—Paper and electronic form separated | Sex, paper charts/electronic charts, participating in clinical trials | All (prescribed, nonprescribed, vitamins/others) | Percent agreement, sensitivity, specificity | Current use |
| Jain et al, Canada | 1994 to 1998 | Participants of a case-control study of endometrial cancer in Toronto and surrounding regions of Halton, Peel and York aged 30 to 79 | Case-control study | Face-to-face Interview | Medical records (physician) | Age, education, marital status, smoking, family history of cancer | Hormone therapy (general), estrogen, progestogen | Proportion correct, kappa, ICC $^f$ | Ever use, duration |
| Kropp et al, Germany | 2002 to 2005 | Postmenopausal women who participated in a breast cancer case-control study from the German regions of Rhein-Neckar and Hamburg aged 50 to 74 | Case-control study | Face-to-face interview | Medical records (physician) | Age, education, study region, BMI, case-control status, mother with breast cancer, validation period | Hormone therapy (general), estrogen, cyclical hormone therapy, continuous hormone therapy | Kappa, sensitivity, specificity, proportion correct, ICC $^f$, differences in years, no/partial/perfect agreement | Current use, ever use, duration, type of medication at first use, age at first/fast use |
| Liu et al, United States | 2003 to 2005 | Low-income and underinsured women with breast cancer from California aged 25 to 85 | Cohort study | Telephone interview | Medical records (each cancer provider) | Age, education, marital status, ethnicity, health status, communication with physician | Hormone therapy (general), chemotherapy (general) | Proportion correct, kappa | Previous use |
| References, country       | Data collection period | Sample description with type of cancer | Original study design | Self-report modality | Comparison data source | Analyzed patient characteristics | Analyzed medication                  | Statistic methods | Outcome                          |
|--------------------------|------------------------|----------------------------------------|-----------------------|----------------------|------------------------|----------------------------------|-------------------------------------|-----------------|----------------------------------|
| Maunsell et al,          | 1996 to 2002           | Female breast cancer survivors aged <60 at diagnosis | Population-based retrospective cohort study | Telephone interview | Medical records (clinic) | None                            | Hormone therapy (general), chemotherapy (general) | Proportion correct, kappa | Previous use, start of chemotherapy |
| United States            |                        |                                        |                       |                      |                        |                                  |                                     |                  |                                  |
| Nissen et al,            | 1999 to 2008           | Breast and colorectal cancer survivors from the metropolitan area of Minneapolis aged 25 to 98 | Cross-sectional validation study | Questionnaire        | Medical records and cancer registry (combined) | Age at diagnosis, years since diagnosis, use of medical records or notes | Hormone therapy (general), Doxorubicin, Tamoxifen, Aromatase inhibitor, Trastuzumab, Oxaliplatin, chemotherapy (general) | Proportion correct | Previous use                      |
| United States            |                        |                                        |                       |                      |                        |                                  |                                     |                  |                                  |
| Paganini-Hill et al,     | 1977 to 1978           | Female participants of a case-control study on breast cancer | Case-control study | Face-to-face interview | Medical records (physician) and pharmacy records separated | None                            | Estrogen (oral forever use, conjugated for dose, estrogen in general for duration), thyroid, reserpine, other antihypertensives, steroids, barbiturates/atacatics | Proportion correct, kappa, difference of years, correlation | Ever use, dose, duration                |
| United States            |                        |                                        |                       |                      |                        |                                  |                                     |                  |                                  |
| Paganini-Hill et al,     | 1987 to 1993           | Female participants of a case-control study for breast cancer aged 53 to 71 | Case-control study | Face-to-face interview | Medical records (physician) | Age, education, marital status, ethnicity, socioeconomic status, religion, smoking, alcohol consumption, parity, case-control status, mammogram history, family history of breast cancer, type of menopause, age at last menstrual period | Estrogen, progestogen (from menopausal hormone therapy, oral contraceptives) | Proportion correct, kappa | Ever use                          |
| United States            |                        |                                        |                       |                      |                        |                                  |                                     |                  |                                  |
| Phillips et al,          | 1999                   | Breast cancer patients of a case-control study in Melbourne and Sydney aged 23 to 69 | Case-control study | Questionnaire        | Medical records (clinic) | Age at diagnosis, education, marital status, country of birth, disease recurrence, year of diagnosis | Hormone therapy (general), tamoxifen, chemotherapy (general), CMF/cyclophosphamide, methotrexate, fluorouracil; AC/adriamycin, cyclophosphamide; EC/epirubicin, cyclophosphamide | Proportion correct, sensitivity, specificity, PPV, NPV, kappa | Previous use                     |
| Australia                |                        |                                        |                       |                      |                        |                                  |                                     |                  |                                  |

(Continues)
Self-reports were compared to pharmacy claims ($n = 36$), MR/physician ($n = 28$), MR/clinic ($n = 22$), pharmacy records ($n = 21$), and combined MRs from different sources ($n = 9$). In addition, some publications use other data sources, such as information from biosamples or cancer registries.

The outcome consisted of either current use ($n = 77$), previous use ($n = 39$), ever use ($n = 19$) or duration ($n = 14$). Some publications additionally investigated brand names or dosage. Research concerning change of medication regimen is entirely lacking.

The results of the studies regarding agreement between self-reports and comparison data sources are very heterogeneous and range from poor to excellent, with most studies finding moderate or good agreement.

Table 2 lists 18 publications in which the patient population has cancer. Two studies by Horwitz et al$^{56,57}$ do not analyze the population with cancer separately from the controls and were therefore not included.

Table 3 shows agreement estimates for patients with cancer where HT, estrogen or chemotherapy is analyzed ($n = 11$). In general, authors report relatively good agreement estimates for patients with cancer (PC $\geq 81.9\%$, kappa $\geq 0.57$, with kappa being $>0.80$ in half of the analyses), with two exceptions, namely Nissen et al/hormone therapy (PC = 51.7%)$^{89}$ and Paganini-Hill et al/Estrogen (PC = 65%, kappa = 0.34)$^{95}$ The descriptive presentation of authors’ agreement estimates shows the best agreement results for chemotherapy (PC $\geq 93.6\%$, kappa $\geq 0.88$).

### 3.2.2 Factors associated with agreement for patients with cancer

Table 4 shows studies which analyzed factors associated with the agreement. The factors include study design aspects and patient characteristics. Among the 10 publications, the authors used either stratification methods or regression models to analyze possible associations.

Age, education, and marital status were the most frequently analyzed patient characteristics. Nevertheless, no consistent association between these three factors and agreement can be derived. Younger age is associated with better agreement in 2 of 11 analyses,$^{89,96}$ higher education in 2 of 10,$^{67,99}$ and being married in 2 of 10.$^{16,96}$ It must be considered that confidence intervals concerning education overlap in one of the two studies.$^{67}$ Furthermore, two publications found cancer recurrence to be associated with lower agreement,$^{16,99}$ and being a nonsmoker$^{42}$ or being born in Australia$^{99}$ were associated with higher agreement in one publication each.

With regard to study design, two publications were found in which self-reports were compared to different data sources. Firstly, the Paganini-Hill et al$^{95}$ study into ever use of estrogen found better agreement estimates for MR/physician (PC = 83% and kappa = 0.62) than for pharmacy records (PC = 65% and kappa = 0.34). Secondly, Spengler et al,$^{111}$ who analyzed current use of estrogen, found slightly
| First author    | Results for agreement | Kappa value (95% CI) | Outcome | Type of cancer | Original study design | Self-report modality | Comparison data source |
|-----------------|-----------------------|----------------------|---------|----------------|-----------------------|----------------------|----------------------|
| **Hormone therapy (in general)** |                       |                      |         |                |                       |                      |                      |
| Barisic         | 92.6                  | 0.88                 | Previous use | Cross-sectional | Questionnaire         | MRb (clinic)         |
| Jain            | 87                    | 0.74 (0.67-0.81)     | Ever use | Case-control   | Face-to-face interview | MRb (physician)     |
| Kropp           | 86.6                  | 0.68 (0.58-0.79)     | Ever use | Case-control   | Face-to-face interview | MRb (physician)     |
| Liu             | 95.3                  | 0.90                 | Previous use | Cohort         | Telephone interview   | MRb (combination of different providers) |
| Maunsell        | 96                    | 0.92 (0.85-0.99)     | Previous use | Cohort         | Telephone interview   | MRb (clinic)         |
| Nissen          | 51.7                  | n.a.c                | Previous use | Cross-sectional | Questionnaire         | MRb combined with cancer registry |
| Phillips        | 94                    | 0.87                 | Previous use | Case-control   | Questionnaire         | MRb (clinic)         |
| **Estrogen**    |                       |                      |         |                |                       |                      |                      |
| Goodman         | 87.2                  | 0.74                 | Ever use | Case-control   | Face-to-face interview | MRb (combination of different providers) |
| Kropp           | 86.3                  | 0.57 (0.36-0.77)     | Current use | Case-control   | Face-to-face interview | MRb (physician)     |
| Kropp           | 81.9                  | 0.63 (0.50-0.77)     | Ever use | Case-control   | Face-to-face interview | MRb (physician)     |
| Paganini-Hill 1982 | 83                  | 0.62                 | Ever use | Case-control   | Face-to-face interview | MRb (physician)     |
| Paganini-Hill 1982 | 65                  | 0.34                 | Ever use | Case-control   | Face-to-face interview | Pharmacy records     |
| Paganini-Hill 2007 | 87                  | 0.63                 | Ever use | Case-control   | Face-to-face interview | MRb (physician)     |
| Spengler        | 83                    | n.a.c                | Current use | Case-control   | Face-to-face interview | MRb (physician)     |
| Spengler        | 85                    | n.a.c                | Current use | Case-control   | Face-to-face interview | MRb (clinic)         |
| **Chemotherapy (in general)** |                       |                      |         |                |                       |                      |                      |
| Barisic         | 93.6                  | 0.88                 | Previous use | Cross-sectional | Questionnaire         | MRb (clinic)         |
| Liu             | 99.6                  | 0.99                 | Previous use | Cohort         | Telephone interview   | MRb (combination of different providers) |
| Maunsell        | 100                   | 1.00 (1.00-1.00)     | Previous use | Cohort         | Telephone interview   | MRb (clinic)         |
| Nissen          | 97.5                  | n.a.c                | Previous use | Breast        | Cross-sectional       | Questionnaire         | MRb combined with cancer registry |
| Nissen          | 95.2                  | n.a.c                | Previous use | Colorectal     | Cross-sectional       | Questionnaire         | MRb combined with cancer registry |
| Phillips        | 99                    | 0.98                 | Previous use | Case-control   | Questionnaire         | MRb (clinic)         |

aConfidence interval.
bMedical record.
cNot available.
| First author | Outcome | Analyzed factors | Statistical method | Associated factors |
|--------------|---------|------------------|-------------------|--------------------|
| **Hormone therapy (in general)** | | | | |
| Barisic | Previous use | Age, education, marital status, English-speaking, alcohol, smoking, family cancer history, menopausal status, cancer recurrence, recall period | Regression | • Cancer recurrence: lower agreement (OR = 0.19 [0.09-0.34])<br>• Being married: higher agreement (OR = 1.95 [1.12-3.40]) |
| Jain | Ever use (cases) | Age, education, marital status, smoking, family history of cancer, case/control-status | Stratification | No association |
| Kropp | Ever use (cases + controls) | Age, education, marital status, study region, BMI, case-control status, mother with breast cancer, validation period, menopausal symptoms | Stratification | Higher education: higher agreement (k = 0.85 (0.73-0.98) vs 0.54 (0.32-0.75)) |
| Liu | Previous use | Age, education, marital status, ethnicity, health status, communication with physician | Regression | • Fair or poor health status: lower agreement (OR = 0.43, p = 0.003)<br>• Lower self-efficacy: lower agreement (OR = 0.44, p = 0.04) |
| Nissen | Previous use (breast cancer patients) | Age at diagnosis, years since diagnosis, use of medical records or notes | Regression | • Younger age: higher agreement (OR = 2.0 [1.1-3.5])<br>• Time since diagnosis <9 years: higher agreement (OR = 1.9 [1.1-3.1]) |
| Phillips | Previous use (cases) | Age at diagnosis, education, marital status, country of birth, cancer recurrence, year of diagnosis | Stratification | • Cancer recurrence: lower agreement (80% correct vs 94%, p = 0.009) |
| **Estrogen** | | | | |
| Goodman | Ever use (cases) | Age at interview, education, marital status, ethnicity, home ownership, cigarette use, case-control status, family history of cancer, duration of estrogen use, age at initial use of estrogens, length of recall, number of physician records reviewed on the agreement between subject recall and physician information | Stratification | • Ethnicity Japanese: higher agreement (k = 0.79 vs 0.67, p < 0.01)<br>• Being a non-smoker: higher agreement (k = 0.79 vs 0.64, p < 0.01) |
| Kropp | Ever use (cases) | Broad medication group (hormone therapy) vs specific medication (estrogen) | Stratification | Broad medication group: higher agreement (k = 0.68 vs 0.63, statistical significance not calculated) |
| Paganini-Hill, 1982 | Ever use (cases) | Comparison data source (medical record/physician, pharmacy records) | Stratification | Medical record: higher agreement (k = 0.62 vs 0.34, statistical significance not calculated) |
| Paganini-Hill, 2007 | Ever use (cases) | Age, education, marital status, ethnicity, socioeconomic status, religion, smoking, alcohol consumption, parity, case-control status, mammogram history, family history of breast cancer, type of menopause, age at last menstrual period | Stratification | • Older age: lower agreement<br>• Being unmarried: lower agreement<br>• Naturally menopausal: lower agreement (no data shown) |
| Spengler | Current use (cases) | Comparison data source (medical record/physician, medical record/clinic) | Stratification | Medical record/clinic: higher agreement (85% correct vs 83%, statistical significance not calculated) |
better proportion correct values for MR/clinic (85%) than for MR/physician (83%).

Another publication, Kropp et al., provides cautious hints that agreement might be slightly better for the broad medication group HT than for the specific agent estrogen.

4 | DISCUSSION

4.1 | Main findings

This systematic review strengthens the assumption that there are numerous publications which compare self-reported drug intake with other data sources. The 120 articles that met our inclusion criteria covered a broad range of comparisons, such as populations, analyzed medications and outcomes. Agreement results range from poor to excellent, where the majority were rated moderate to very good. Studies among populations with cancer and their most frequently studied medications estrogen, hormone therapy (HT) and chemotherapy showed relatively good agreement. Studies analyzing factors which may be associated with agreement mostly investigated patient characteristics, namely age, education and marital status. They did not identify a consistent pattern.

4.2 | Agreement of self-report with other data sources in patients with cancer

Overall, agreement for estrogen, HT, and chemotherapy in cancer patients was relatively good. This may be due to cancer likely being a very serious diagnosis for patients.

In the studies included in our review, agreement was best for chemotherapy. This may be due to patient characteristics or study design. However, chemotherapy can probably be deemed a drastic experience and might therefore be better remembered. Tentative suggestions were found that agreement might be slightly better for the broader HT medication group than for the specific agent estrogen. This observation is based solely on the Kropp et al. publication, the only study in our review to have analyzed HT and estrogen in the same sample. On the one hand, it could be assumed that broader medication classes are easier to recall. However, in their study into antidepressants, Cotterchio et al. found that patients might misunderstand which type of medication they use. This is supported by Nissen et al. who described that specific medications such as tamoxifen were not identified as hormone therapy, and that agreement was therefore better at a specific level in this case. While we were unable to compare chemotherapy as a superordinate class with specific agents in our analysis, Barisic et al. and Phillips et al. did and found better agreement for the broader medication class. They assume that, specific drug-level information may be very complex for patients, for instance where several drugs are combined for chemotherapy.
4.3 Factors associated with agreement

Among the studies dealing with cancer patients, 10 studies analyzed associated factors by using stratification or regression analysis. They most commonly tried to identify possible associations of different patient characteristics with the agreement. Although a number of studies assessed age, education and marital status, we could not find a consistent association between these factors and agreement.

Only two studies analyzed design-related factors, comparing self-reports with two other data sources, therefore only allowing for a cautious comparison of data sources. It must be considered, however, that the Paganini-Hill et al study, which found better agreement estimates for MR/physician than for pharmacy records, was conducted over three decades ago. In the meantime, data quality from each of the sources may have improved. The second study, Spengler et al, dates from the same era, and shows marginally better proportion correct estimates for MR/clinic (85%) than for MR/physician (83%). With regard to MR/clinic, the authors stated that records may have been incomplete.

4.4 Strengths and limitations

Our work has a number of strengths. To the best of our knowledge, this is the first systematic review to identify studies which compare self-reports and other data sources specifically for medications. Unlike the two existing reviews on this topic, we did not analyze healthcare utilization overall but focused on medications. That focus enabled us to provide an overview of this research area and identify a considerable number of relevant publications and describe their characteristics. Furthermore, the subsequent focus on studies including patients with cancer enabled us to provide a descriptive overview of different parameters and the agreement estimates.

However, our review also has some weaknesses. Firstly, we were unable to detect a number of relevant articles by routine database searching (50 out of 120), despite searching five different databases and including specific medications in our search strategy. This may be due to some publications having conducted agreement measurements as a piggy-back analysis and not reported it in the title/abstract/keywords. A number of potential improvements to the search strategy can be gleaned by taking a closer look at the nondetected publications. Firstly, “drug taking” would complement the terms “use/utilization/consumption.” Secondly, in addition to “drug/medication,” specific treatment methods should be added, such as “breast cancer treatment/hormone therapy/vaccination/chemotherapy.” Thirdly, the definition of a specific comparison data source might be helpful, for example “prescriptions/medical records.” The majority of non-routinely identified publications came from reference lists (37 of 50). Researchers looking to reproduce the search will thus be able to find most matches systematically.

Secondly, the 120 studies included are hardly comparable due to great methodological differences. We therefore did not perform a meta-analysis, instead opting to describe study characteristics to provide an overview of methods and analyzed aspects.

5 CONCLUSION

This review includes 120 publications that measure the agreement between self-reports and other data sources and focuses on 18 of them which refer to cancer patients. We identified relatively good agreement for hormone therapy, estrogen, and especially for chemotherapy. No consistent pattern could be found regarding factors associated with agreement for either patient characteristics or design-related parameters. The latter was rarely analyzed, indicating approaches for further research. Studies with experimental design can be helpful to counteract the impact of different comparison data sources or self-report modalities under otherwise identical conditions.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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SUPPORTING INFORMATION
Additional supporting information may be found online in the Supporting Information section at the end of this article.

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