**Title: Should patients still be copied into their letters? A rapid review.**

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# Abstract

*Objective:* **To systematically identify, synthesise and evaluate the strength of the international evidence on copy letter practice.**

*Methods:* **A systematic search identified original research studies on copy letters.** **Searches were limited by date and language as permitted in rapid review methods guidance**.Article screening, data extraction and strength of evidence assessment were completed independently **by multiple authors**.

*Results:* Thirty-seven studies were included. **There was a lack of information about copy letter content.** Many patients report being satisfied with copy letters, understand them and find them useful. However, there is a lack of objective, high quality evidence to suggest that copy letters increased patient understanding or improved **physical or psychological** health outcomes.Many letters were written at a level which would make them inaccessible to patients with low health literacy. **The strength of evidence was either “emerging” or “acceptable” practice for most studies (n=30).**

*Conclusion:* **There is a lack of objective, high quality evidence to demonstrate the benefits of copy letters as described in health policy.**

*Practice Implications:* **Personalising letters and using lay rather than medical terms appears to be useful for improving copy letter readability. Further research is required to explore this, especially in people with low health literacy levels.**

Key words: patient letters; copy letters; patient discharge summaries; doctor and patient communication; patient satisfaction; person centred care; patient education.

# Introduction

The World Health Organisation (WHO) framework identifies five overarching strategies to encourage health services across the globe to become better integrated and more people-centred (Box 1). The first strategy describes the need to engage and empower people and communities in decision-making about their health [[1](#_ENREF_1)].

In England, empowering patients (see Box 1) has been a consistent theme across health policies for almost two decades, including the National Health Service (NHS) Constitution [[2-4](#_ENREF_2)].

**The practice of copying letters to patients was implemented in England in 2004 following the release of the Department of Health *“copying letters to patients Good Practice Guidelines”* [**[**5**](#_ENREF_5)**]. Thismarked an important step towards promoting patient empowerment. Copy letters are defined as letters sent between healthcare professionals about a patient’s care and treatment, with the patient copied in, following either hospital discharge (inpatient discharge copy letter/summary) or after a consultation or treatment (outpatient copy letter) [**[**5**](#_ENREF_5)**]. International health policy on the provision of paper-based copy letters is lacking. Rather there is an increased focus upon the adoption of electronic medical records accessed by patients through web portals [**[**6**](#_ENREF_6)**], despite a lack of clarity about the impact of adopting such health information systems on care quality [**[**7**](#_ENREF_7)**].**

**The potential benefits of copy letter practice stated in the Department of Health guidelines were based on existing research evidence and experiences from healthcare professionals who were already engaged in this practice [**[**5**](#_ENREF_5)**,** [**8**](#_ENREF_8)**]. Benefits include health promotion by reinforcing advice on self-care and lifestyles, improved communication and trust between patients and professionals, more informed patients and accurate records, and better decision-making, compliance, consultations, and reduced patient anxiety.** **However, these potential benefits had not been fully assessed in randomised controlled trials (RCTs). Two previous reviews on copy letter practice published over ten years ago, concluded that there was limited evidence to support this practice, as most studies had focused on patient views and attitudes rather than patients’ psychological reactions and behaviour after receiving a copy letter [**[**9**](#_ENREF_9)**,** [**10**](#_ENREF_10)**]. The generalisability of findings to the wider population is also questionable because existing studies had not assessed participants’ health literacy levels, defined as *“the personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health”* [**[**11**](#_ENREF_11)**]. Nonetheless, there was no evidence indicating that copy letters were in any way detrimental and self-reported understanding and satisfaction was high amongst the majority of participants [**[**9**](#_ENREF_9)**,** [**10**](#_ENREF_10)**].**

**Despite the widespread implementation of copy letter practice in the UK there remain several gaps in our understanding [**[**9**](#_ENREF_9)**,** [**10**](#_ENREF_10)**]. Therefore, an updated review on copy letter practice is warranted to add new and original insights on the content and usefulness of copy letters, and the impact that copy letter practice has on patients’ physical and psychological health outcomes, behaviour and self-care/self-management. An important addition is the evaluation of the strength of current evidence, which has not been previously reported. This should be a priority given the significant cost of sending copy letters which is estimated to be £13 million per year for outpatient letters [**[**12**](#_ENREF_12)**] and £15 million per year for GP referral letters, in the UK alone [9].**

**This review aims to systematically identify, synthesise and evaluate the strength of the international evidence on copy letter practice to answer the following questions:**

1. **What content is included in copy letters?**
2. Are copy letters acceptable, understandable and useful to all patients?
3. What are patients’ psychological responses to receiving a copy letter?
4. Does receiving a copy letter lead to patient behaviour change, improved health outcomes or enhanced self-care/management?

**Box 1. The World Health Organisation Framework on integrated people-centred health services [**[**13**](#_ENREF_13)**].**

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| **The WHO Framework Five Strategies** [[13](#_ENREF_13)] | |
| 1. **Engaging and empowering people and communities;**   ***Definition:*** *“a process through which people gain greater control*  *over decisions and actions affecting their health” [*[*14*](#_ENREF_14)*]*  Approaches | |
| 1. Strengthening governance and accountability; 2. Reorienting the model of care; 3. Coordinating services within and across sectors; 4. Creating an enabling environment. | Health education  Self-management support  Informed consent  Shared decision-making  Provision of services to disadvantaged populations |

# Methods

A rapid review was undertaken using a comprehensive and systematic search strategy to identify international published primary research related to patient letters. A rapid review provides a critical evaluation of existing literature on a policy or practice using systematic review methods, whilst allowing for a reduction in the breadth and depth of a full systematic review [[15](#_ENREF_15)]. To support the quality of this review, the WHO practical guide for rapid reviews [[16](#_ENREF_16)] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were implemented (**PRISMA checklist available on request**) [[17](#_ENREF_17)].

# Search strategy

**Search strategies were piloted, refined and then systematically applied to three databases**; PsycINFO, CINAHL, and PubMed. **In keeping with rapid review methodology [**[**15**](#_ENREF_15)**,** [**16**](#_ENREF_16)**], searches** were limited to English language articles and those published from January 2004, the year that the UK Department of Health implemented the practice of copy letters. **Research evidence that precedes this date can be accessed in two earlier reviews [**[**9**](#_ENREF_9)**,** [**10**](#_ENREF_10)**]**. To support the robustness of the search the reference lists of included articles were also searched and scanned. **The review protocol including the search strategy is available on request.**

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| --- | --- |
| **PICO Framework** | **Inclusion criteria** |
| **Patient** | **Adult >18 years old** |
| **Intervention** | **The article must include a copy letter which is defined as letters sent between healthcare professionals about a patient’s care and treatment, with the patient copied in, following either hospital discharge (inpatient discharge copy letter/summary) or after a hospital consultation or treatment (outpatient copy letter). The letter can also be addressed to the patient with the healthcare professional copied in.** |
| **Control** | **All control or comparison groups** |
| **Outcome** | **The article must include at least 1 of the following outcomes that was measured after the practice of copy letters was implemented:**  **Patient outcomes**   * **Patient understanding and comprehension, acceptability, satisfaction, psychological distress, recall of consultation, and preference for receiving a copy letter.**   **Letter characteristics**   * **Letter readability** * **Letter content**   **Health outcomes**   * **Patient health outcomes (e.g. mortality)** * **Behaviour related outcomes (e.g. compliance with doctor’s advice).** |
| **Article type** | * **Full-text journal articles written in English language and published since 1/1/04** * **Quantitative methodology except where letter content was assessed.** * **Studies that used patient questionnaires conducted by telephone or face-to-face interviews were included.** |

**Table 1. Eligibility criteria for article inclusion into the rapid review.**

# Article selection process

Relevant articles, defined as those with titles relating to doctor-patient letters were selected by one author (E.H) and duplicates deleted. Abstracts from the selected articles were independently reviewed for eligibility against pre-set inclusion criteria (**Table 1**) by two authors (E.H, P.R). Research of any design was included. Full-text screening was conducted independently by E.H. and P.R. Where disagreement occurred between raters, consensus was achieved through discussion with a third author (FA).

# Data extraction and synthesis

Data were extracted by one author (E.H) and independently checked for accuracy and completeness by two authors (J.U and P.R). Authors of included articles were contacted if further information or data was required. Data from the included articles were synthesised into three tables and presented as narrative.

# Strength of evidence assessment

Criteria (Appendix **A**) published in other rapid reviews [[18](#_ENREF_18)], was used to assess the strength of evidence of included articles. Two authors (E.H and J.U) independently appraised the included articles; where disagreement occurred consensus was reached through discussions with a third author (P.K) who conducted an independent appraisal.

# Results

# Characteristics of included articles

Figure 1 shows details of the study selection process. The search identified 4,794 articles with 37 articles conducted across 10 countries contributing to the review. Most studies were conducted in England (20), Australia (5) or the USA (3).

Articles were divided into three categories according to study design and purpose:

* cross-sectional surveys of patients’ opinion of copy letters (20 articles; Table 2);
* intervention studies (11 articles; Table 3);
* studies assessing letter content (7 articles; Table 4).

The findings of one study were included in both Tables 2 and 4 [[19](#_ENREF_19)].

## Summary of cross-sectional surveys

Most cross-sectional surveys (n=18) assessed patient opinion on receiving an outpatient copy letter. Only two studies involved inpatient discharge copy letters [[20](#_ENREF_20), [21](#_ENREF_21)]. Different medical specialities were represented across studies (including mental and physical health conditions) and patients’ ages ranged from 18 to over 80. However, 15 of the 20 studies did not provide any patient demographics. Seventeen studies assessed outcomes using a self-report questionnaire, which was created by the authors. One study used a telephone questionnaire [[22](#_ENREF_22)] and two studies conducted the questionnaire through patient interview [[23](#_ENREF_23), [24](#_ENREF_24)]. **Patient-reported measures** included comprehension, utility and accuracy of the letter and satisfaction, emotion and consultation recall after receiving it. All studies were classified as “emerging practice” due to the use of non-validated questionnaires and absence of independent assessment of outcomes.

## Summary of intervention studies

Four of the eleven intervention studies included in the review used a RCT design [[25-28](#_ENREF_25)], six a quasi-experimental design [[29-34](#_ENREF_29)] and one a cross-sectional study [[35](#_ENREF_35)]. Interventions were targeted at either healthcare professionals [[29](#_ENREF_29), [30](#_ENREF_30), [32](#_ENREF_32)] or patients [[25-28](#_ENREF_25), [31](#_ENREF_31), [33-35](#_ENREF_33)] **and all studies included a copy letter as one element. Interventions focussed on either improving the readability of copy letters or compared other communication methods in comparison to copy letters.** **Three RCTs compared patient and health outcomes between a group of patients receiving a copy letter and a control group who did not receive a letter [**[**25**](#_ENREF_25)**,** [**27**](#_ENREF_27)**,** [**28**](#_ENREF_28)**]. Studies recruited both outpatients [**[**25**](#_ENREF_25)**,** [**27**](#_ENREF_27)**,** [**28**](#_ENREF_28)**,** [**31**](#_ENREF_31)**,** [**32**](#_ENREF_32)**,** [**34**](#_ENREF_34)**,** [**35**](#_ENREF_35)**] and inpatients [**[**26**](#_ENREF_26)**,** [**29**](#_ENREF_29)**,** [**30**](#_ENREF_30)**,** [**33**](#_ENREF_33)**] across a range of clinical specialties (detailed in Table 3). Participants were aged from 15 to 92 years with demographic data not reported in four studies [**[**30-32**](#_ENREF_30)**,** [**35**](#_ENREF_35)**].**

**Patient-reported outcome measures included anxiety, depression, satisfaction and understanding. Other outcome measures included health resource utilisation, adherence to doctor’s recommendations, patient recall of information, letter readability and content and patient mortality rates.** The strength of evidence across studies ranged from low (“emerging practice”) to high (“supported practice”).

## **Summary of studies assessing letter content**

**Table 4 shows studies that focused upon copy letter content [**[**19**](#_ENREF_19)**,** [**36-41**](#_ENREF_36)**]. Both outpatient copy letters [**[**19**](#_ENREF_19)**,** [**41**](#_ENREF_41)**] and inpatient discharge letters [**[**36-40**](#_ENREF_36)**] were evaluated across a range of clinical specialities. Few studies reported the specific content of the copy letters and the clinical settings in which they were delivered [**[**19**](#_ENREF_19)**,** [**38**](#_ENREF_38)**,** [**39**](#_ENREF_39)**]. Copy letter readability [**[**36**](#_ENREF_36)**,** [**41**](#_ENREF_41)**] and errors in medication lists were the focus of the other studies [**[**37**](#_ENREF_37)**,** [**40**](#_ENREF_40)**]. Patient demographics were not consistently reported across all studies, but of those that did, the age range was from 24 to 100 years [**[**36-38**](#_ENREF_36)**,** [**40**](#_ENREF_40)**]. The strength of evidence of studies were classed as “emerging practice” [**[**19**](#_ENREF_19)**], “acceptable practice” [**[**36-39**](#_ENREF_36)**,** [**41**](#_ENREF_41)**] or “promising practice” [**[**40**](#_ENREF_40)**].**

# What content is included in copy letters?

The precise content and format of copy letters was difficult to establish because only **4** out of the 37 included studies reported the content of copy letters. **In outpatient copy letters to cystic fibrosis patients, >95% of letters included patients’ clinical status and date of next appointment [**[**19**](#_ENREF_19)**].** In discharge letters from psychiatrists to GPs, 59% of letters did not include diagnostic information, nearly half omitted psychotherapeutic recommendations and 38% psychosocial recommendations **(Table 3)** [[29](#_ENREF_29)]. Similar findings were observed in maternity department discharge summaries; educational information for the mother and advice about support services was rarely provided at discharge and no postnatal care information given [[39](#_ENREF_39)]. **An objective assessment of discharge copy letters in America reported that although 63% of letters contained all 6 Joint Commission elements (USA organisation that creates standards for healthcare organisations) none included all 7 TOCCC (Transitions of Care Consensus Conference) elements (see Table 4 for details)** [[38](#_ENREF_38)].

Two studies reported on medication errors found in discharge letters [[37](#_ENREF_37), [40](#_ENREF_40)]. Discrepancies were found between the medications listed in discharge letters and those in patients’ hospital notes [[37](#_ENREF_37)]. Moreover, a list of new medications prescribed during hospitalisation was 3 times more likely to be missing from paper discharge summaries than electronic summaries [[40](#_ENREF_40)].

# Are copy letters acceptable, understandable and useful to all patients?

## Patient-reported understanding of copy letters

Patient-reported understanding of copy letter content was reported in 20 studies with a low strength of evidence due to the use of non-validated self-reported questionnaires and absence of a comparison group [[19-24](#_ENREF_19), [27](#_ENREF_27), [42-54](#_ENREF_42)]. In most studies at least 80% of participants found copy letters clear or easily understandable [[19](#_ENREF_19), [20](#_ENREF_20), [22](#_ENREF_22), [23](#_ENREF_23), [27](#_ENREF_27), [42-45](#_ENREF_42), [47-52](#_ENREF_47), [54](#_ENREF_54)]. However, up to 20% of patients reported difficulty in understanding the medical terminology [[21](#_ENREF_21), [23](#_ENREF_23), [24](#_ENREF_24), [44](#_ENREF_44), [47](#_ENREF_47), [50](#_ENREF_50), [53](#_ENREF_53)]. A glossary of medical terms supplied with the letter was reported as useful for 89% of respiratory outpatients in one study, but 16% of participants found words they needed were missing from it [[35](#_ENREF_35)]. **None of these studies measured patients’ health literacy levels and many tended to recruit participants with high levels of education.**

## Copy letter readability

The readability of copy letters was assessed in six studies with strength of evidence classifications from “emerging” to “supported practice” [[19](#_ENREF_19), [31](#_ENREF_31), [32](#_ENREF_32), [34](#_ENREF_34), [36](#_ENREF_36), [41](#_ENREF_41)]. The readability scores Flesch-Kincaid Grade Level (FKGL) and Flesch Reading Ease score (FRE) ranged from 9.0 to 11.75 and 44 to 61.8, respectively [[31](#_ENREF_31), [32](#_ENREF_32), [34](#_ENREF_34), [36](#_ENREF_36), [41](#_ENREF_41)], representing an average reading age of 14-18 years, and a reading ease score of ”standard” to “difficult”. A higher FKGL or a lower FRE score indicates that words and sentences are more difficult to read.

In one study, 65% of inpatients had reading levels below the level required to read their discharge copy letter [[36](#_ENREF_36)]. Readability scores of outpatient letters did not improve following staff education [[32](#_ENREF_32)]. In a randomised cross-over trial, the average FKGL of the translated (i.e. reduced medical terminology) copy letters was 0.32 less than the original copy letter, with the translated letter being reported as significantly easier to read [[34](#_ENREF_34)]. Similarly, specially written personalised patient letters contained significantly fewer medical terms/phrases and were easier to read than standard outpatient copy letters [[31](#_ENREF_31)].

## Copy letter usefulness

Most participants found copy letters useful (the proportion ranged from 60-100%) [[19-22](#_ENREF_19), [24](#_ENREF_24), [43](#_ENREF_43), [45-51](#_ENREF_45), [53](#_ENREF_53)]. Patients reported that copy letters helped **their** recall of consultation discussions [[43](#_ENREF_43), [44](#_ENREF_44), [50](#_ENREF_50)] and their understanding of their medical condition and treatments [[19](#_ENREF_19), [50](#_ENREF_50), [53](#_ENREF_53)]. **These studies were rated** as “emerging practice”.

**Three RCTs provide mixed evidence about the usefulness of copy letters for patients [**[**25-27**](#_ENREF_25)**]. The first reported no significant differences in patients’ understanding of their condition between a group of patients who received a consultation copy letter and endoscopy report and a group who received no correspondence** [[25](#_ENREF_25)]. In a second RCT, patients’ understanding of their hospitalisation increased significantly immediately after the doctor read and explained the patient-directed discharge letter, compared to before the explanation [[26](#_ENREF_26)]. However, thiseffect was not sustained at 3 or 6 months later **compared to** patients **receiving a** standard discharge letter. **In a third RCT, there was no significant difference in patient recall of information at 10-12 weeks after patients received either, a patient-directed copy letter or a personal thank-you note** [[27](#_ENREF_27)]. Poorer consultation recall was significantly associated with older age and lower level of education [[27](#_ENREF_27)].

## Patient satisfaction and acceptability

More than 90% of participants stated that offering a copy letter was good practice [[19](#_ENREF_19), [42](#_ENREF_42), [44](#_ENREF_44), [47](#_ENREF_47), [50](#_ENREF_50), [52](#_ENREF_52), [53](#_ENREF_53)], and 70-97% of patients would like to receive copy letters [[19](#_ENREF_19), [21](#_ENREF_21), [25](#_ENREF_25), [42](#_ENREF_42), [43](#_ENREF_43), [47](#_ENREF_47), [49](#_ENREF_49), [51](#_ENREF_51), [52](#_ENREF_52), [55](#_ENREF_55)]. **However, receiving a copy letter did not change patients’ satisfaction with care in two controlled intervention studies [**[**25**](#_ENREF_25)**,** [**33**](#_ENREF_33)**].**

**Patient preferences for receiving a patient-directed letter rather than a copy of the letter addressed to their GP, ranged from 45% to 75% of patients [**[**31**](#_ENREF_31)**,** [**44**](#_ENREF_44)**,** [**47**](#_ENREF_47)**]**. In a cross-over trial, 78% of medical outpatients (with high health literacy) preferred the simplified version of their copy letter (i.e. reduced medical terms), rather than the standard version [[34](#_ENREF_34)].

# What are patients’ psychological responses to receiving a copy letter?

The evidence, rated as “emerging practice”, from cross-sectional surveys indicated no association between receiving a copy letter and self-reported symptoms of worry or anxiety for most patients [[24](#_ENREF_24), [42](#_ENREF_42)]. Indeed, one study found that 36% of patients felt less anxious after reading their copy letter [[46](#_ENREF_46)]. However in two studies, up to 13% of patients reported feeling worried or anxious after reading their copy letter [[51](#_ENREF_51), [53](#_ENREF_53)]. Some studies reported that patients felt upset after reading their copy letter (between 1-18% patients) with one carer asking for the letter not to be sent again [[48-50](#_ENREF_48), [54](#_ENREF_54)].

**Changes in levels of anxiety or depressive symptoms in response to copy letters, were only observed in patients with pre-existing symptoms of anxiety or depression, in higher quality studies (“supported practice”) that used validated patient-reported outcome measures (PROMs)** [[25](#_ENREF_25), [28](#_ENREF_28), [29](#_ENREF_29), [34](#_ENREF_34)]. A pilot RCT assessed symptoms of anxiety and depression in a sample of patients seen by a psychiatrist, using the Depression Anxiety Stress Scale (DASS-21) and found that scores were significantly reduced at 1 and 3 months post-consultation in patients who had received a copy letter [[28](#_ENREF_28)]. **Similarly, in a pseudo-randomised study of patients with symptoms of depression or anxiety, Hospital Anxiety and Depression (HADS) subscale scores were significantly improved in all three groups (telephone call, consultation report or standard discharge letter to GP) with no significant difference between the groups** [[29](#_ENREF_29)].

In contrast, HADS scores did not differ significantly between the control and correspondence groups of endoscopy patients immediately after and 1 month post-consultation [[25](#_ENREF_25)]. **In a crossover trial, anxiety and depression scores were not significantly different after reading a standard copy letter (addressed to GP) compared to a translated version of the letter with minimised medical terminology** [[34](#_ENREF_34)].

# Does receiving a copy letter lead to patient behaviour change, improved health outcomes or enhanced self-care/management?

Few studies examined the effect of receiving a copy letter on patient behaviour [[28-30](#_ENREF_28), [34](#_ENREF_34), [46](#_ENREF_46)] or health outcomes [[33](#_ENREF_33)] and those that did showed inconsistent results. Less than half of a cohort of 25 learning disability service users agreed that receiving a copy letter improved their ability to self-care [[46](#_ENREF_46)]. In contrast, 80% of outpatients reported a significant increase in their ability to manage their chronic health condition after reading a copy letter that contained fewer medical terms [[34](#_ENREF_34)]. The sample had a high level of health literacy, confirming the importance of this variable.

Three studies measured behaviour change after receiving a copy letter by assessing the impact of the correspondence on the implementation of recommendations [[28-30](#_ENREF_28)]. The provision of a copy letter with information on medicines management in a psychiatric care setting had no effect upon medication tailing behaviour at 1 and 3 months, compared to a group who did not receive a copy letter **[**[**28**](#_ENREF_28)**]**. **In contrast, an audit study that evaluated the number of patients with fully implemented treatment plans following hospital discharge, found a 63% increase in compliance when the letter was also copied to community pharmacists** [[30](#_ENREF_30)]. **The implementation of consultant recommendations, by GPs, was lowest when the GP received a standard letter from the psychiatrist, compared to a telephone call or a consultation report** [[29](#_ENREF_29)]. Findings must be viewed with caution as the measures used to evaluate implementation of recommendations were subjective.

**The use of personalised letters compared to standard care (i.e. telephone call or standard copy letter) had no effect on health resource** **utilisation (hospital readmissions and GP and emergency department visits)** in two controlled studies [[26](#_ENREF_26), [33](#_ENREF_33)]. The all-cause mortality rate within 30 days after hospital discharge was 4% for patients who received a telephone call compared to 0% for those who received the personalised discharge letter and verbal patient education (*p*=0.06) [[33](#_ENREF_33)]. However, at least 65% of patients in both groups, in both studies, had completed either University or higher education [[26](#_ENREF_26), [33](#_ENREF_33)], **which** limits the generalisability of findings to the wider population.

# Table 2. Summary of findings: Cross-sectional patient survey studies

| **Author, year, country** | **Participants** | **Letter type, Method of assessment** | **Understanding of (% participants)** | **Useful/ helpful (% participants)** | **Worry/ upset (% participants)** | **Accuracy (% participants)** | **Letter preference (% participants)** | **Other findings** | **Strength of evidence** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Ansari et al. [[42](#_ENREF_42)] 2011, England. | Hepatobiliary dept. outpatients.  Malignant disease (n=48): mean(range) age: 64 (31-80) years.  Benign disease (n=52): mean(range) age: 56 (21-81) years. | Outpatient letter from HCP to GP & copied to patient.  Retrospective 15-item paper questionnaire about most recent copy letter. | letter content:  Malignant:  All: 48%.  Most: 36%.  Some: 16%.  Benign:  All: 50%.  Most: 38%.  Some: 12%. |  | Letter did not increase worry:  Malignant:  78%.  Benign:  82%. |  | Wish to receive future letters:  Malignant:  84%.  Benign:  88%. | No significant differences between groups using chi-square test.  94% all patients thought offering copy letters is a good idea:  92 patients offered letters, 5 not and 3 unsure. 10 did not receive even though 4 requested one. | Emerging practice |
| Brockbank. [[20](#_ENREF_20)] 2005, England | 660 patients at a District hospital.  PDSA service improvement study. | Outpatient & discharge letter from HCP to GP & copied to patient.  Cross-sectional 6-item paper postal questionnaire sent with copy letter. | letter:  99%. | Useful:  96% |  | Accuracy with consultation:  99% |  | 97% patients found the letter told them what was going to happen next. | Emerging practice |
| Brodie & Lewis [[43](#_ENREF_43)] 2009, New Zealand | 68 of 100 vascular disease outpatients responded.  Respondents:35% F, 65% M; Median(range) age: 73 (22-86) years.  Primary diagnosis:  PAD: 35%.  AAA: 24%  Venous disease: 12%.  CAS: 9%  Non-vascular: 6%  Other: 15%. | Outpatient letter from surgeon to GP & copied to patient.  Cross-sectional 9-item paper postal questionnaire sent with copy letter. | letter content:  96% | Helpful:  93% |  |  | 97% Wish to receive future letters. | - Letter reinforced information received during consultation in 94% patients.  - 93% kept letter for future reference. | Emerging practice |
| Cassini et al. [[44](#_ENREF_44)] 2011, France | 226 outpatients after clinical genetics consultation (71% adults, 69% F, 31% M). Education stopped before end of high school in 88/204 (43%) patients. | Outpatient letter from geneticist or genetic counsellor to GP & copied to patient.  Cross-sectional 10-item paper postal questionnaire sent with copy letter. | letter:  - 201/207 (97%) patients understood words.  - improved understanding of clinical situation in 162/225 (72%).  - 31/152(20%) found words too medical.  - 4/144(3%) found words shocking. |  |  | 177/217 (82%) patients thought letter accurately reflected the consultation. | - 99% thought offering copy letter is good idea.  - 58% would prefer patient-directed letter. | - Helped consultation recall in 39/220 (18%) patients.  - 148/158 (94%) would use the letter in future to/for:  -inform family (83%)  -inform other doctors (86%)  -as reminder (96%)  -admin purposes (46%) | Emerging practice |
| Clark et al. [[45](#_ENREF_45)] 2008, England | 31 outpatients cared for by the older people’s mental health service and 38 family carers | Outpatient letter from consultant psychiatrist to GP & copied to patient.  Cross-sectional 4-item paper postal questionnaire sent with copy letter. | letter: (for patients)  Very clear: 61%.  Fairly clear: 26%.  A little clear: 3%.  Unclear: 0%. | Useful for pts:  Very: 58%.  Fairly: 29%.  Little: 3%.  Not useful: 0%. |  | 23% patients reported the letter missed things out. |  | Carers responses  Very clear 84%  Fairly clear 16%  Very useful 82%  Fairly useful 16%  Omissions 18% | Emerging practice |
| Hovey & Cheswick [[46](#_ENREF_46)] 2009, England | 25 learning disability service users.  12 (60%) carers responded. | Outpatient letter from HCP to GP & copied to patient.  Cross-sectional paper questionnaire. | letter:  Easy to understand: 28%.  Not easy: 52%.  48% gained better understanding of care. | Helped patient to self-care: 40%.  Helped patient to make decisions: 48%.  Helped report if something wrong: 32% | Less anxious: 36%. |  |  | Increased trust between patient and HCP for 76% patients.  76% pts happy that carers received letters.  58% carers found letters helpful.  42% did not receive letter but would have liked to. | Emerging practice |
| Krishna & Damato [[23](#_ENREF_23)] 2005, England | 30 ocular oncology outpatients. | Outpatient letter from HCP to referring specialist, GP & copied to patient.  Retrospective face-to-face interview. | letter:  Completely understood: 80%.  Fair extent: 13%.  Little unsure: 7%. |  |  |  | 97% prefer letter to be sent to patient & GP. | - 100% reported adequate information given.  - 17% wanted medical terms explained. | Emerging practice |
| Liapi et al. [[24](#_ENREF_24)] 2007, England | 81 ENT adult outpatients. | Outpatient letter to GP & copied to patient  Prospective 4-question telephone interview 4 weeks post-consultation. | letter:  2 adult patients complained about not understanding medical terminology. | Useful:  60% patients | Worried/ anxious: 0% patients |  | 38% patients thought letters should only be sent to patients with complex/ long-term conditions. | - 43% accepted a copy letter.  - 3 patients concerned that Dr might not disclose all information in the letter. | Emerging practice |
| Mahadavan et al. [[47](#_ENREF_47)] 2009, England | 101 surgical outpatients. | Outpatient letter from clinician to patient & copied to GP.  Cross-sectional 22-item paper questionnaire & VAS.  Letter and questionnaire hand given to patient at end of clinic. | letter terminology:  Friendly: 93%.  Unfriendly: 7%. | Useful:  92% |  |  | - 78% wished to receive future letters.  - 75% would prefer patient-directed letter. | - 94% satisfied/very satisfied.  - The presenting problem was detailed in 96% of letters and reflected the examination findings in 93% of letters. | Emerging practice |
| Mason & Rice [[48](#_ENREF_48)] 2008, England | 45 outpatient & carers attending appointments with the older adults’ community mental health team. | Outpatient letter from HCP to GP & copied to patient.  Cross-sectional 8-item paper postal questionnaire. | letter clarity:  100%. | Useful:  Very: 71%.  Quite: 29%. | Upsetting:  1 carer asked for letter not to be sent in future as it upset patient | letter:  Contained inaccurate patient details (4%).  2 carers disagreed with the Dr’s account of the patient’s symptoms. |  |  | Emerging practice |
| Nandhra et al. [[49](#_ENREF_49)] 2004, England | 40 psychiatry outpatients. | Outpatient letter from psychiatrist to GP & copied to patient.  Cross-sectional 5-item paper postal questionnaire. | letter:  Very easy: 75%.  Quite easy: 23%.  Not very easy: 3%. | Helpful:  Very: 45%.  Quite: 33%.  Neutral: 18%.  Not very: 5%.  Not at all: 0%. | Upsetting:  Very: 5%.  Quite: 13%.  Neutral: 25%.  Not very: 20%.  Not at all: 38%. | with consultation:  Very: 40%.  Quite: 48%.  Neutral: 13%.  Not very/at all: 0%. | Wish to receive future letters: Yes: 83%.  No: 8%.  Not sure: 10%. |  | Emerging practice |
| O’Hanlon et al. [[50](#_ENREF_50)] 2008, England | 342 outpatients at Parkinson’s disease clinics. | Outpatient letter from HCP to GP and copied to patient.  Retrospective 20-item paper postal questionnaire. | letter:  - Too much terminology for 4% patients.  - 85% understood medical terms always or most of time.  - 9% often had difficulty understanding terms.  - Helped to understand benefits/side-effects of drugs in 42%.  - letter caused more confusion 4% | Helped to understand:  - Condition in 59%.  - Which drugs to take in 58%.  - Why medication is needed in 79%.  - 5% felt confused by letter. | Upsetting:  1% offended by letter. |  | 95% patients thought offering copy letter was good idea. | - Consultation reminder in 41%.  - Patients rang up to clarify information frequently (1%), once/twice (18%), never (77%).  - 88% would like a glossary of commonly used medical terms.  - 9% received new information in letter. | Emerging practice |
| Pinder et al. [[51](#_ENREF_51)] 2013, England | 83 patients orthopaedic/ fracture clinics (44% F, 56% M).  Age range 18 – 83 years.  60% patients had attended fracture clinic. | Outpatient letter from HCP to GP and copied to patient.  Retrospective 6-item paper questionnaire completed in the clinic waiting area. | letter:  90% | Helpful:  86% | Worried by letter:  13% |  | Wish to receive future letters: 70-80% | 96% patients read the letter. | Emerging practice |
| Pothier et al. [[52](#_ENREF_52)] 2007, England | 241 ENT outpatients | Outpatient letter from HCP to GP and copied to patient.  Retrospective 5-item paper questionnaire hand delivered in clinic. | letter:  All content understood: 69%.  Most content: 25%.  Only some content: 7%.  93% helped to understand consultation. |  |  | Secretaries reported 3 telephone calls/letters from patients about copy letter accuracy. | 85% would request a copy letter.  96%: offering copy letter is good idea | - 2% did not read the letter.  - 14% contacted someone about the letter. | Emerging practice |
| Rao & Fogarty [[21](#_ENREF_21)] 2007, Northern Ireland | 78 gynaecology day-case surgery patients. | Discharge letter from HCP to GP and copied to patient.  Cross-sectional paper postal questionnaire sent with letter. | letter:  Confused n=2.  Alarmed n=1. | Helpful: 86%.  Informative: 83%. |  |  | Wish to receive future letters: 95%. | Reassured: 79%.  Not-reassured: 5%. | Emerging practice |
| Sharma et al. [[53](#_ENREF_53)] 2007, England | 220 diabetes outpatients. | Outpatient letter from HCP to GP and copied to patient.  Cross-sectional 9-item paper postal questionnaire. | Felt confused:  8% | Helped to:  - understand condition/treatment: 93%.  - check letter for accuracy: 93%. | Anxious:  6% |  | Offering copy letter is good idea: 97%. | More informed/ involved in treatment/care: 89%. | Emerging practice |
| Tomkins et al. [[22](#_ENREF_22)] 2004, England | 46 dermatology outpatients. | Outpatient letter from consultant to GP and copied to patient.  Prospective telephone questionnaire 14 days post-consultation. | letter:  Understood most or all: 98%. | Useful or very useful:  100% |  | with consultation:  98% agreed  2% unsure |  | - 74% had given the letter to another person to read. | Emerging practice |
| Treacy et al. [[19](#_ENREF_19)] 2008, Northern Ireland \* | 50 adult CF patients. | Outpatient letter from HCP to GP and copied to patient.  Retrospective paper questionnaire. | words/terms:  80%. understood all | Helped improve knowledge of condition: 88%. |  | with consultation: 96% | - Receiving copy letter was a “good thing”: 94%.  - Wish to receive future letters:  96%. | 92% felt more involved. | Emerging practice |
| Treloar & Adamis [[54](#_ENREF_54)] 2005, England | 102 (62 carers, 40 patients) older adults’ psychiatry & dementia care (48 had received a previous copy letter).  Dementia: n=52.  Non-dementia mental illness: n=50. | Outpatient letter from HCP to GP and copied to patient.  Retrospective 9-item paper questionnaire completed in clinic waiting area. | letter:  Very easy: 90%.  Fairly easy: 10%. |  | Upsetting:  A bit: 6%.  Very: 0%.  Unsure: 15%. | with consultation:  Very: 69%.  Fairly: 27%.  Unsure: 2%.  Inaccurate: 2%. | Please to receive letter:  Very: 88%.  A bit: 8%.  Unsure: 4%.  Not pleased: 0%. | Reassured: 77%. | Emerging practice |
| Wood et al. [[55](#_ENREF_55)] 2006, England | 100 urology surgery patients (19% F, 81% M).  25% 41-60 yrs.  35% 61-80 yrs.  10% >80 yrs.  Group 1: received copy letter (n=48).  Group 2: never received a copy letter (n=52). | Outpatient letter from clinician to GP and copied to patient.  Retrospective 9-item paper postal questionnaire sent in post. |  |  |  | with consultation:  98% in group 1. | Wish to receive future letters:  Group 1: 83%.  Group 2: 83%. | Some patients concerned about additional cost of sending letter. | Emerging practice |

**Abbreviations**: AAA= Abdominal aortic aneurysm; CF= Cystic Fibrosis; CAS= Carotid artery stenosis; ENT= Ear Nose Throat; F= female; GP= General Practitioner; HCP= Healthcare Professional; M= male; PAD= Peripheral arterial disease; PDSA= Plan, Do, Study, Act; VAS= visual analogue scale.

**Definitions:** Cross-sectional: copy letter and questionnaire distributed to patient at the same time; Prospective: copyletter sent to patient and assessment completed after specified period of time. Retrospective: questionnaire distributed to patients for opinion of previous copy letter received**.**

\*indicates study is also included in Table **4**. a A blank cell indicates the variable is not examined or reported.

# Table 3. Summary of findings: Intervention studies

| **Author, year, country, study design** | **Participants (N, mean age, sex)** | **Intervention** | **Outcome measures** | **Findings** | **Strength of evidence** |
| --- | --- | --- | --- | --- | --- |
| Brown et al. [[35](#_ENREF_35)] 2007, England, Cross-sectional study | 93 outpatients from respiratory clinics. | Glossary of medical terms sent with outpatient copy letter to patients (letter addressed to GP with patient copied in). | Patient opinion of glossary assessed post-intervention by paper patient questionnaire sent with copy letter and glossary. | - 89% found glossary useful  - 84% found words needed in glossary  - No. words looked-up/patient (median-range): 3 (0-14) words.  - 144 words/terms reported from letters as not understandable but not included in the glossary. | Emerging practice |
| Burian et al. [[29](#_ENREF_29)] 2016, Germany, prospective comparative study (pseudo-randomisation) | - 116 inpatients referred to psychiatrist from internal medicine, neurology, surgery for depressive/anxious symptoms (age: 62 ± 16 yrs)  - Telephone call (TC) group: n=39 (22-88 yrs; 64% F).  - Consultation report (CR) group: n=39 (34-86 yrs; 73% F).  - Usual care (UC) group: n=38 (21-92 yrs; 56% F). | - TC group: telephone call between psychiatrist and GP within 5 days post-consultation.  - CR group: post-discharge consultation report given to patients to pass on to GP immediately after consultation.  - UC control: Standard discharge letter to GP. | - Discharge letter content assessed for the presence of categories documented in the EURO-QaCL at pre-intervention.  - Anxiety/depression assessed by HADS questionnaire at pre and 6-wk post-consultation (HADS administered by telephone post-consultation).  - Implementation of consultant recommendations by GP assessed 6 wk post-consultation by patient telephone interview.  - GP-concordance rate calculated at 6 wk post-consultation using the patient-reported implementation of recommendations. | Letter content (% letters):  - Psychiatric diagnoses: 81%  - Medication recommendations: 80%  - Psychotherapeutic recommendations: 53%  - Psychosocial recommendations: 62%  - Diagnostic action: 41%  - Referral to psychiatric outpatient treatment: 68%  Anxiety/depression (mean ± SD)  - HADS improved in all groups after 6 weeks. NS between groups.  -Pre HADS-A: 9.21 ± 4.2; Post HADS-A: 5.6 ± 3.9.  -Pre HADS-D: 10.1 ± 3.9; Post HADS-D: 7.2 ± 4.7.  -Patients with highest GP-concordance had greater reduction of depressive symptoms, compared with lower GP-concordance (*p* < 0.05).  Implementation recommendations  - Implementation rates for medication and psychotherapeutic recommendations highest in TC and lowest in UC group (*p* < 0.05).  - NS between groups for implementation of psychosocial, diagnostic, referral recommendations.  GP-concordance  TC group had highest GP-concordance rates and UC group had lowest (*p* < 0.05). | Supported practice- low sample size & high drop-out (22%) |
| Fenton et al. [[25](#_ENREF_25)] 2017, Australia, pilot RCT | - 70 urgent endoscopy patients (age median, range: 44, 19-70 yrs, 61% F).  -Correspondence group: n=36, 72% F, 44% had HE/Uni qualifications.  - Control group: n=34, 50% F, 53% had HE/Uni qualifications. | - Correspondence group: initial & post-endoscopy consultation copy letter (from clinician to referring Dr with patient copied in) and endoscopy report.  - Control group: no correspondence. | - Anxiety/depression assessed by HADS questionnaire & VAS at initial consultation, post-endoscopy consultation & 1- month post-endoscopy consultation.  - Patient understanding of medical condition assessed using VAS at initial consultation, post-endoscopy consultation & 1-month post-endoscopy consultation.  - Patient satisfaction of care at clinic assessed using VAS at 1-month post-endoscopy consultation. | Anxiety/depression  - NS difference in HADS between groups at any time-point.  Patient understanding of condition  - NS difference in understanding of condition (VAS) between groups at any time-point.  Patient satisfaction of care  - NS difference in satisfaction with care (VAS) between groups at 1-month post-endoscopy consultation but larger proportion of correspondence group rated 10/10 satisfaction  - Both groups: 97% want to receive correspondence.  - Correspondence group (% patients): 80% understood report, 90% understood letter, 43% discussed endoscopy report with GP, 94% gained better understanding of condition. 19% discussed report with gastroenterologist. | Supported practice- pilot with low sample size and potential high recall bias |
| Gray et al. [[30](#_ENREF_30)] 2008, England, group comparison study | - Control group: 45 inpatients.  - Intervention group: 41 inpatients. | - Control group: discharge letter to GP copied to patient.  - Intervention group: discharge letter to GP copied to patient & community pharmacist. | - Pharmacist-led audit of implementation of consultant recommended medications, 6 weeks after receiving letter. | Implementation of treatment plan  - Control group: 51% implemented, 18% partially implemented, 11% not implemented, 18% lost to follow-up, 2% died.  - Intervention group: 83% implemented, 5% partially implemented, 2% not implemented, 5% lost to follow-up, 5% died. | Acceptable practice |
| Lin et al. [[26](#_ENREF_26)] 2014, Australia, RCT | - 67 cardiology, respiratory, endocrinology inpatients.  - Control group: n=35 (age: 63 ± 18 yrs, 37% F). ≥high school education: 68%.  - Intervention group: n=32 (age: 62 ± 18 yrs, 44% F). ≥high school education: 75%. | - Control group: patients received standard discharge letter from HCP to give to GP.  - Intervention group: patients received PADDLE (patient-directed discharge letter) plus standard discharge letter to GP. PADDLE contained 4 domains:  i) reason for hospitalisation, ii) tests & results undertaken, iii) treatments received and iv) discharge recommendations. PADDLE was read to patient by clinician and explanation of content provided. | - Patient understanding of hospital recent admission and discharge assessed at 4 time-points:  1. Pre-discharge in both groups by paper questionnaire.  2. Post-PADDLE in intervention group only by paper questionnaire.  3. 3-months post-discharge in both groups by telephone questionnaire.  4. 6-months post-discharge in both groups by telephone questionnaire.  - Patient understanding of the 4 domains from the paper/telephone questionnaire were scored by 2 physicians.  - Patient self-rated understanding & satisfaction with hospitalisation assessed in both groups at pre-discharge and post-PADDLE on 1-5 Likert scale.  - Readmissions rates in both groups by telephone interview at 3 and 6-months post-discharge. | Patient understanding of hospitalisation  - Patient self-rated understanding & satisfaction with hospitalisation was high at pre-discharge in both groups and did not change immediately post-PADDLE in intervention group (*p* >0.05).  - Understanding scores for “reasons for hospitalisation” and “treatments in hospital” increased post-PADDLE (*p*<0.05).  - Understanding scores for “tests in hospital” and “recommendations at discharge” were low at pre-discharge and increased post-PADDLE (*p*<0.001).  - 3 & 6 months’ post-discharge: NS between groups in understanding or knowledge of 4 domains.  - PADDLE helpful/very helpful for 94% patients.  Readmissions  - 20% patients readmitted in both groups within 6 months.  Association with understanding  - Age –ve correlation with understanding at pre-discharge, 3 & 6-months (6-mo: -0.54, *p* < 0.001).  - Gender, level of education or cognitive load did not influence the level of understanding.  - Readmissions associated with worse understanding at 6-months (*p* < 0.05). | Supported practice- low sample size and subjective scoring used |
| O’Reilly et al. [[27](#_ENREF_27)] 2006, Ireland, RCT | - 137 haematology outpatients first consultation.  - Intervention group: n=71 (age mean, range: 50, 15-90 yrs; 59% F). Primary education only: 39%.  - Control group: n=66 (age mean, range: 49, 15-87 yrs; 66% F). Primary education only: 24%. | - Intervention group: outpatient copy letter from Dr to patient and copied to referring GP/HCP.  - Control group: personal patient thank you note for attending clinic from Dr and standard outpatient letter to GP only. | - Primary outcome: patient recall of information given by clinician at 1st consultation. Recall assessed at 2nd outpatient consultation (mean 10-12 weeks post 1st consultation) by interview with researcher who had observed the patient’s 1st consultation.  - Patient satisfaction with letter assessed by interview at 2nd outpatient consultation.  - Letter dictation time recorded by consultant. | Recall:  - Recall more than 60% of information: NS between groups (difference 12%; 95% CI –3 to 9%).  - Recall associated with age (*p* = 0.01) and educational status (*p* = 0.01).  Patient satisfaction  - Intervention group:  - 80% pleased/very pleased with letter  - 81% useful/very useful  - 6% upset  - 3% worried  - 57% understood all of letter content, 29% understood most, 8% understood some, 6% understood none.  - 10% identified inaccuracies.  - 6% consulted GP  - 8% showed letter to family.  - Control group:  - 75% wanted a personal letter  Dictation time  - mean (range): 6.8 (3 – 15) min. | Supported practice- low sample size |
| Roberts & Partridge [[31](#_ENREF_31)] 2006, England, Comparison study | - 84 new & follow-up cardiology and respiratory outpatients.  - 62 patients returned questionnaires & letter.  - 63 patients returned the letter. | - Patients sent two post-consultation letters:  - Standard outpatient letter to GP and copied to patient (SL).  - Personalised outpatient letter to patient and copied to GP (PL). | - Dictation time by stopwatch.  - Letter readability assessed by FKGL, FRE & word count. Patients circled unknown words/terms on both letters.  - Letter preference by postal questionnaire. | Dictation time  - SL took longer than PL.SL= 3.3 ± 2.2 min, PL= 2.6 ± 1.4 min (n= 82, *p* = 0.019).  Readability  - Pl was easier to read than SL.  - FKGL: SL= 10.8 ± 1.4, PL= 11 ± 1.4 (n=84, NS).  - FRE: SL= 49.8 ± 9.1, PL= 55.4 ± 9.3 (n=84, *p* < 0.001).  - Circled words: SL= 90 circled items not understood (14 about content). 31/63 patients circled 1-12 words.  PL= 32 circled items not understood (22 queries about terms and 10 about factual content). 16/63 patients circled 1-5 words (*p* < 0.001).  - Word count: SL= 444 ± 170 words, PL= 352 ± 129 words (n=84, *p* < 0.001).  Letter preference  - 45% patients preferred PL, 34% preferred SL. 58% wanted to receive both letters. | Acceptable practice |
| Selzer et al. [[28](#_ENREF_28)] 2010, Australia, pilot RCT | - 39 psychiatry (anxiety and/or depression) outpatients’ first consultation for depression/ anxiety.  - Intervention group: n=21 (age: 41 ± 13 yrs, 76% F)  - Control group: n=18 (age: 34 ± 13 yrs, 61% F) | - Intervention group: outpatient letter from psychiatrist to GP and copied to patient.  - Control group: outpatient letter from psychiatrist to GP only and not copied to patient. | - Depression/anxiety/stress assessed byDASS-21 questionnaire at baseline and 1 and 3 months’ post-letter by telephone interview.  - Adherence to management/ treatment items listed in the letter assessed at baseline and 1 & 3 months’ post-letter by telephone interview. Adherence score derived from 2 clinicians independently rating patient-reported adherence on 3-point scale (0=nil, 3= complete adherence). | Depression/anxiety/stress  - Total DASS-21: Reduced over time in both groups but only significantly in the intervention group (*p* = 0.002).  Adherence  - Adherence: NS between groups (*p* = 0.15). | Supported practice- low sample size |
| Todhunter et al. [[32](#_ENREF_32)] 2010, England, group comparison study | - 596 ENT outpatient letters.  - Control group: 295 letters (pre-intervention).  - Intervention group 2: 301 letters. | - Control group: retrospective audit of ENT outpatient letters to GP and copied to patient before implementation of intervention.  - Intervention group: post-teaching sessions: re-audit of ENT outpatient letters to GP and copied to patient, following clinician seminar-based teaching sessions on improving letter readability | - Letter readability assessed by the FKGL & FRE scores. | FKGL score  - Control group: 9.0 ± 1.7. 2.4% achieved target of <6.0.  - Intervention group: 9.2 ± 1.8, 3.3% achieved target of <6.0 (NS between groups).  FRE score  - Control group: 61.8 ± 8.7. 16.9% achieved target of >70.  - Intervention group: 61.4 ± 9.3. 18.3% achieved target of >70 (NS between groups). | Acceptable practice |
| Verhaegh et al. [[33](#_ENREF_33)] 2014, The Netherlands, group comparison study | - 428 inpatients.  Medium socioeconomic status.  - Control group: n=224 (age: 55 ± 17 yrs, 45% F).  ≥ high school education: 79%  - Intervention group: n=204 (age: 58 ± 16 yrs, 47% F).  ≥ high school education: 72% | - Control group: telephone call 48 hrs post-discharge to address critical questions or health problems. Discharge letter sent to GP only.  - Intervention group: discharge bundle included i) plan and communicate date of discharge to patient <48hrs from admission, ii) clinician discharge checklist, iii) personalised patient discharge letter (copied to GP), iv) verbal patient education by HCP. | - Primary outcome: unplanned hospital readmission within 30 days of discharge assessed from medical records and patient self-report (via telephone interview 4 weeks after discharge).  - Secondary outcomes:  - Patient satisfaction of discharge by paper questionnaire at discharge.  - No. of GP and emergency dept. visits within 30 days of discharge assessed from medical records and patient self-report.  - Patient mortality within 30 days of discharge. | Readmission rates within 30 days  - 13% hospital unplanned readmissions for both groups, NS.  - GP visits: Control group 53%, Intervention group 59%, NS.  - ED visits: Control group 25%, Intervention group 21%, NS.  Patient satisfaction  - Control group: 7.5 ± 1.4.  - Intervention group: 7.4 ± 1.5, NS between groups.  Mortality within 30 days  - Control group: 4%  - Intervention group: 0%, *p* =0.06. | Acceptable practice |
| Wernick et al. [[34](#_ENREF_34)] 2016, New Zealand, randomised crossover trial | - 59 medical outpatients for management of chronic health condition.  - Group 1: n=30 (age: 69 ± 12 yrs, 37% F).  - Group 2: n=29 (age: 61 ± 14 yrs, 57% F). | - 2 study visits (2 weeks apart).  - Most recent outpatient copy letter (original) modified to minimise medical terminology (translated). Both letters were addressed to the GP and copied to the patient.  - Group 1: visit 1 translated letter read, visit 2 original letter read by patient.  - Group 2: visit 1 original letter read, visit 2 translated letter read by patient. | - Anxiety/depression assessed by the EQ-5D health questionnaire at visit 1 & 2.  - Letter readability assessed by the FKGL score and patients circled words in the letters that they didn’t understand.  - Health literacy assessed by REALM questionnaire at visit 1. | Anxiety/depression  - EQ-5D scores: NS for both the original and translated letter.  Readability  - FKGL score: original: 11.75 ± 2.8, translated: 11.43 ± 2.6, *p* < 0.05.  - Circled words: original: 7.8 ± 10 terms, translated: 1.8 ± 3.3 terms, *p* < 0.001.  - 78% preferred translated letter.  - 80% perceived increased ability to self-manage after reading translated letter (*p* < 0.05 compared to before reading the letter). This was not assessed for the original letter.  Health literacy  - Patients had a high level of health literacy. REALM (all patients): mean 65.2 out of 66 (SD 1.9).  - 70% perceived enhancement of relationship with GP. | Supported practice |

**Abbreviations:** DASS-21= Depression Anxiety Stress Scale; ED= emergency department; HADS= Hospital Anxiety and Depression Score; HE/Uni= Higher education/ university; ENT= Ear, Nose, Throat; EQ-5D= European Quality of Life five dimensions questionnaire; EURO-QaCL= European Quality Assurance Documentation System for consultation liaison; F= female; FKGL= Flesch-Kincaid Grade Level **(higher number indicates text is more difficult to read, e.g. 7 means 7th Grade which is equivalent to ages 12-13 years)**; FRE= Flesch Reading Ease Score **(1-100, higher score indicates text is easier to read, e.g. <60 is difficult to read)**; GP= General Practitioner; HADS= Hospital Anxiety and Depression Scale; HCP= Healthcare professional; NS= not significant; PADDLE= Patient-Directed Discharge Letter; RCT= Randomised Controlled Trial; REALM= Rapid Estimate of Adult Literacy in Medicine; SD= standard deviation; VAS= visual analogue scales.

# Table 4. Summary of findings: Letter content studies

| **Author, year, country, study design** | **Participants/letters (N, age, sex)** | **Letter type** | **Outcome measures** | **Findings** | **Strength of evidence** |
| --- | --- | --- | --- | --- | --- |
| Choudhry et al. [[36](#_ENREF_36)] 2016, USA, retrospective cross-sectional study | - 497 trauma inpatients (age: 56 ± 22 yrs, 37% F).  Education status (n=314)  - 4% patients functionally illiterate.  - 40% marginally literate.  - 90% had high school education.  - 22% had HE/Uni education. | - Hospital discharge summaries for both care providers and the patient. | - Primary outcome: hospital readmissions and documented calls to the service within 30 days’ post-discharge.  - Letter readability assessed by the FKGL & FRE scores.  - Patient education data | Readmissions  - 30-day hospital readmissions: n = 40.  - Documented calls: n=113.  Readability  - FKGL: 10 ± 1 (range: 8.1-12.7).  - FRE: 44 ± 7 (range: 24.1-59.3).  - 26% letters classed as fairly or very difficult to read.  - 65% had functional reading skills at a grade level less than their letter.  - Functional reading grade was not related to 30-day readmissions or calls (*p* > 0.05). | Acceptable practice |
| Jenkinson et al. [[39](#_ENREF_39)] 2014, Australia, Cross-sectional study | - 25 de-identified discharge summaries from maternity department at 25 different hospitals (24 public and 1 private hospitals). | - Discharge summary from maternity department written by a doctor or midwife to the patient’s GP or Child and Family Health Nurses.  - Letter not always copied to patient. | - Content analysis of discharge summaries  - Gaps in information on the discharge summary. | Letter content  - All summaries included basic personal (name, contact details etc.) and biophysical information of patient and baby.  - No summaries included information about postnatal care offered by the hospital.  - Psychosocial information included in 44% of summaries and indicated by a tick box for whether the Edinburgh Postnatal Depression Scale had been completed.  - Post-discharge information frequently omitted including destination upon discharge, access to support services, patient/family’s cultural background, educational information given to patient and care advice for sick babies.  - n = 2 indicated consent to disclosure of patient’s information.  -n = 3 included advice about community organisations. | Acceptable practice |
| Lehnbom et al. [[40](#_ENREF_40)] 2014, Australia, cross-sectional group comparison study | - Discharge summaries from inpatient wards (except emergency dept.).  - 162 paper discharge summaries for inpatients: age (median, IQR): 72, 58 – 81 yrs; 49% F. Length of hospital stay (median, IQR): 8 (5 – 17) yrs.  - 177 electronic discharge summaries for inpatients: age (median, IQR): 69, 58 – 82 yrs; 47% F. Length of hospital stay (median, IQR): 7 (5 – 13). | - Paper discharge summary: Handwritten by Dr with medication list print-out sent to GP and hand given to patient.  - Electronic discharge summary: created electronically by Dr and sent electronically or by post to GP and uploaded to patient electronic medical record. | - Discrepancies and completeness of discharge medication assessed by research pharmacist. | Medication completeness  - Paper: 9.1% of medication orders had 1 or more incomplete fields. Of these, 81% would require the GP to seek further info for clarification.  - Medication discontinuations, dose changes and frequency changes were no more likely to be explained in paper or electronic summaries.  - Electronic: 6.6% of medication orders had 1 or more incomplete fields. Of these, 99% would require the GP to seek further info for clarification.  - OR of medication orders having 1 field incomplete was ~77% lower than paper summaries (OR 0.23, 95% CI: 0.09-0.59).  - Medications added during hospitalisation were 3X more likely to be explained compared with paper summaries. | Promising practice |
| Glintborg et al. [[37](#_ENREF_37)] 2007, Denmark, cross-sectional study | - Letters and hospital notes from 200 surgical & medical inpatients. Age (median, range): 75 (24 – 100) yrs, 70% F.  - 79% admitted with acute illnesses. | - Discharge letter to GP and patient copied in. | - Discrepancies in medications between discharge letter and hospital notes assessed by verbal interview with patient (1 week post-discharge) and document comparisons. | Medication completeness  - 33% of patients on POM therapy had no medication list in discharge letter.  - Discrepancies between hospital notes/discharge letter and patient drug regime in 34 patients (prescribed drugs were not used in 10 patients; 7 patients continued to use a range of drugs that had been discontinued by hospital; 13 patients did not manage medication as prescribed).  - In 34 patients, POM prescribed during hospitalisation were not mentioned in discharge letters. | Acceptable practice |
| Horwitz et al. [[38](#_ENREF_38)] 2013, USA, prospective observational cohort study | - Letters from 377 inpatients with acute coronary syndrome, community-acquired pneumonia, heart failure (age: 77 ± 8 yrs, 46% F) | - Discharge summaries sent to a physician and copied to patient.  - 38% of discharge summaries were only sent to the patient and not to any physician. | - Letter content and quality assessed by measuring letter compliance with Joint Commission mandates and TOCCC recommendations. Composite score created by assigning 1 point for each Joint Commission (JC) or TOCCC item. Max of 6 for JC and 7 for TOCCC. | Letter content  - Included in >90% letters: diagnosis, discharge diagnosis, hospital course, tests during admission and patient & family instructions.  - Included in <50% letters: social support of patient, functional & cognitive capacity at discharge, physical exam and laboratory results at discharge, discharge status, pending test results, number for physician, discharge weight, target weight range, discharge creatinine or GFR.  Letter compliance with guidelines  - Joint commission: average 5.6/6, 63% letters included all 6 elements.  - TOCCC: average 4/7, 0% included all 7 elements.  - Summaries dictated on the day were more likely to include more TOCCC elements (ave: 4.2, OR 1.92, (95% CI 1.23, 2.99). | Acceptable practice |
| Treacy et al. [[19](#_ENREF_19)] 2008, Northern Ireland, cross-sectional study | - - 80 letters from adult CF clinic | - Outpatient letter from HCP addressed to GP and copied to patient. | - Letter content & readability assessed using Drivel Defence computer software to calculate:  - Sentence length  - Minimal use of  abbreviations (<3)  - Meaningful (easy to  understand) explanation  of clinical status & test  results.  - Date of next appointment. | Readability  - 96% of letters had ≥50% of sentences with <20 words.  - Sentence length: 15 ± 3 words.  - Minimal abbreviations in 89% of letters.  Letter content  - Meaningful clinical status: 95% letters.  - Date of next appointment: 96% letters. | Emerging practice |
| Wu et al. [[41](#_ENREF_41)] 2013, USA, cross-sectional study | - 50,000 letters for haematology/oncology patients. | - Letters from hospital specialists describing findings and recommendations for care, addressed to referring doctor (usually GP) and copied to patient. | - Letter readability assessed by:  - Average number of words/letter.  - Average sentence length.  - Vocabulary size.  - FKGL, SMOG & GFI scores. | Letter readability  - Average letter length: 623.6 words.  - Average sentence length: 10.9 words.  - Vocabulary size: 184,448 words.  - FKGL: 9.44 ± 1.30.  - SMOG: 12.30 ± 1.09.  - GFI: 13.18 ± 1.52. | Acceptable practice |

**Abbreviations:** CI= confidence interval; CF= Cystic Fibrosis; F= female; FKGL= Flesch-Kincaid Grade Level **(higher number indicates text is more difficult to read, e.g. 7 means 7th Grade which is equivalent to ages 12-13 years)**; FRE= Flesch Reading Ease score **(1-100, higher score indicates text is easier to read, e.g. <60 is difficult to read)**; HE/Uni= Higher education/ university; GFI= Gunning-Fog Index; IQR- Interquartile range; OR= odds ratio; POM= prescription only medication; SMOG= simple measure of gobbledygook; TOCCC= Transitions of Care Consensus Conference.

# Discussion and Conclusion

# Discussion

**The findings from this review update those reported in earlier reviews [**[**9**](#_ENREF_9)**,** [**10**](#_ENREF_10)**] and offers new insights on copy letter practice, including an evaluation of the strength of the international evidence. In summary, thirty-seven studies from ten countries were included in this review. From an international perspective** **the practice of sending copy letters to patients appears to be somewhat variable by country and within each country. In Australia, England, France, Ireland, New Zealand, Northern Ireland and USA, some but not all hospitals and healthcare professionals routinely send copy letters [**[**5**](#_ENREF_5)**,** [**19**](#_ENREF_19)**,** [**25**](#_ENREF_25)**,** [**27**](#_ENREF_27)**,** [**34**](#_ENREF_34)**,** [**36**](#_ENREF_36)**,** [**38**](#_ENREF_38)**,** [**41**](#_ENREF_41)**,** [**44**](#_ENREF_44)**]. In the studies conducted in Germany, Denmark and the Netherlands it was not possible to determine whether or not copy letters were routinely sent [**[**29**](#_ENREF_29)**,** [**33**](#_ENREF_33)**,** [**37**](#_ENREF_37)**].** **The level of published evidence was classified predominantly as either “emerging” or “acceptable” practice suggesting that the available evidence supporting copy letter practice is relatively weak. This is a significant finding given the widespread adoption of this practice.**

**Providing patients with a copy of their letters offers an opportunity to create a more informed patient, in part because the letter can include information about diagnosis, treatments, medications and self-care/management [**[**5**](#_ENREF_5)**].** However, **only four studies reported details about the content of copy letters.** Although copy letters regularly included basic personal, diagnosis and test results information, key information was frequently omitted including post-discharge care such as advice about community organisations, social support, access to support services and educational information [[19](#_ENREF_19), [29](#_ENREF_29), [38](#_ENREF_38), [39](#_ENREF_39)]. **The omission of this information in copy letters constitutes a missed opportunity to ‘make every contact count’ and maximise on an important ‘teachable moment’.**

**In considering the accuracy of copy letter content, studies conducted in Australia and Denmark reported errors** **and omissions** in the medication lists of copy letters **[**[**37**](#_ENREF_37)**,** [**40**](#_ENREF_40)**]. Studies that investigated the accuracy of medication-related information in discharge letters (not copied to patients) report similar findings [**[**56-58**](#_ENREF_56)**].** **Up to half of patients had one or more medication error in the discharge letter with the most common error being drug omission [**[**56-58**](#_ENREF_56)**]. Inconsistencies increased significantly with greater numbers of prescribed medications [**[**56-58**](#_ENREF_56)**].** This has important implications for patient safety. An ageing population with multiple comorbidities and associated polypharmacy [[59](#_ENREF_59)] requires accurate copy letter content to avoid harm, especially following hospital discharge. The use of automated electronic forms and **involving pharmacists in the generation of medication information in discharge letters may reduce errors [**[**40**](#_ENREF_40)**,** [**60**](#_ENREF_60)**,** [**61**](#_ENREF_61)**].**

**In agreement with previous reviews, this review identified that the majority of evidence on copy letters is weighted towards patient views rather than psychological reactions, emotions and behaviour after receiving a copy letter [**[**9**](#_ENREF_9)**,** [**10**](#_ENREF_10)**]. In considering how acceptable, understandable and useful copy letters are to patients, findings show that** a relatively high proportion of patients (>80%) report that they understand **and find their letters useful**, although no studies have validated this objectively with techniques that assess patients’ comprehension of letter content. **It is also possible that many participants in the studies in this review had good levels of health literacy. Indeed, in the only study included in this review that measured health literacy levels, all participants scored very highly [**[**34**](#_ENREF_34)**].**

Despite most patients reporting good understanding and satisfaction with their letters, up to 20% have described difficulty in understanding the medical terminology. Objective assessments of the readability scores of 51,379 patient copy letters across 5 studies **revealed that they** were written at a reading level of between 14-18 years, and ranged between “standard” to “difficult” to read [[31](#_ENREF_31), [32](#_ENREF_32), [34](#_ENREF_34), [36](#_ENREF_36), [41](#_ENREF_41)]. **Variations in health literacy levels are widespread across Europe with an estimated 47% of people aged over 15 years with limited health literacy [**[**62**](#_ENREF_62)**].** In the UK, a reported 61% of adults have literacy and numeracy skills below the level expected by age 16 [[63](#_ENREF_63)]. This indicates that a large proportion of people may not have the ability to fully understand their letters. Indeed, one study found that the reading levels for 65% of patients were lower than required to read their discharge letters [[36](#_ENREF_36)]. **Therefore, the potential benefits from copy letters described in health policy are unlikely to be equally shared, which could widen existing health inequalities. The inconsistent reporting of sample characteristics, such as participant age, level of education, and health literacy level, make the interpretation of findings problematic given that such variables are major determinants of how well people access, understand and use health information [**[**62**](#_ENREF_62)**,** [**64**](#_ENREF_64)**]. The lack of these data significantly limit the generalisability of findings.**

**Interventions aimed at improving the readability and patients’ understanding of copy letters included personalised letters [**[**31**](#_ENREF_31)**], translated letters (i.e. complex medical words replaced with lay terms) [**[**34**](#_ENREF_34)**], a glossary of medical terms provided with the copy letter [**[**35**](#_ENREF_35)**] and healthcare professional education [**[**32**](#_ENREF_32)**].** **The translated and personalised letters had significantly better readability scores (i.e. easier to read) and fewer words were not understood by patients compared to the original copy letters [**[**31**](#_ENREF_31)**,** [**34**](#_ENREF_34)**]. Although this difference was statistically significant, in real terms it is likely to be relatively meaningless, as both the original and ‘easier to read’ copy letters were found to require a reading age of approximately 17 years old [**[**34**](#_ENREF_34)**], and both were still classed as ‘difficult’ to read [**[**31**](#_ENREF_31)**]**. **Patients found the glossary useful but many words were still not understood [**[**35**](#_ENREF_35)**]. Clinician seminar-based teaching sessions on improving letter readability had no effect on the readability scores of copy letters [**[**32**](#_ENREF_32)**].**

The psychological responses to receiving a copy letter were objectively measured in only four studies **with inconsistent findings** **[**[**25**](#_ENREF_25)**,** [**28**](#_ENREF_28)**,** [**29**](#_ENREF_29)**,** [**34**](#_ENREF_34)**]. Improvement in symptoms of anxiety and depression were reported only in patients who experienced these symptoms prior to receiving a copy letter [**[**28**](#_ENREF_28)**,** [**29**](#_ENREF_29)**]. The contrasting results might be explained by the use of different PROMs and different study designs, or the differences in patient education, health literacy levels, patient conditions (psychiatry patients already had existing anxiety and/or depressive symptoms) and effect of medications and additional visits to the GP.**

The UK Department of Health proposed that copying patients into their letters would be useful for health promotion by reinforcing advice on self-care and lifestyles and would create more informed patients, better consultations, more accurate records, better compliance and reduce patient anxiety [[5](#_ENREF_5)]. Although most patients (60-100%) self-reported that letters were useful, results from RCTs and controlled trials found that copy letters did not increase consultation recall or improve patient understanding of their health condition or recent hospitalisation [[25-27](#_ENREF_25)] or reduce hospital readmissions or health service resource utilisation [[26](#_ENREF_26), [33](#_ENREF_33)]. No studies assessed patients’ self-care/management behaviour and only one study measured health outcomes and found no significant effect on mortality rates [[33](#_ENREF_33)]. The absence of any changes observed in these studies might be due to weak study design (i.e. control group also received correspondence or contact with a doctor [[26](#_ENREF_26), [27](#_ENREF_27), [33](#_ENREF_33)]) and the content of the letters. Providing patients with health information alone without support from healthcare professionals has been shown to have little effect on behaviour [[65](#_ENREF_65)]. This concept is further supported by one study in this review, which found that the number of patients with fully implemented treatment plans increased by 30% when the copy letter was also sent to the pharmacist, as well as the patient and GP [[30](#_ENREF_30)]. Including advice and personalised care information in the copy letter together with additional support might improve the usefulness of the letter and lead to more effective self-management for people with health conditions.

## Strength of the existing evidence

To our knowledge this is the first review to assess the strength of the evidence on patient copy letters, which overall, was low. Most studies [[19-24](#_ENREF_19), [35](#_ENREF_35), [42-55](#_ENREF_42)] were classified as “emerging practice” and only 7 studies were rated as either promising or “supported practice” [[25-29](#_ENREF_25), [34](#_ENREF_34), [40](#_ENREF_40)]. Nearly all of the studies that assessed patient self-reported understanding of their letter or condition were rated as “emerging practice” due to the use of non-validated questionnaires and absence of an independent assessment of outcomes. Only four RCTs were included in the review but were not given the highest strength of evidence rating due to low sample size, high drop-out rates and subjective methods of assessment. The strongest outcomes measures reported across all studies were those that were objective, which included readability scores using validated formulas, hospital readmissions, GP and emergency department visits and mortality rates. **It is important to note that copy letters may have other benefits that have not been assessed in published studies, such as increased trust between patients and healthcare professionals and better continuity of care.**

## Strengths and limitations of this review

This rapid review used a search strategy with several limits; therefore, relevant research studies might not have been identified. Nonetheless, recommendations for conducting rapid reviews [[16](#_ENREF_16)] and the PRISMA guidelines were consulted to support the methodological rigour of the search strategy [[17](#_ENREF_17)]. Moreover, we searched multiple databases and hand searched reference lists to increase the yield [[66](#_ENREF_66), [67](#_ENREF_67)]. Multiple raters were also used to increase the reliability of sifting and data extraction decisions.

This review only included research articles which explored copy letters sent from secondary care in order to reduce its scope, but thereby restricting the external validity of the review. Future reviews should synthesise evidence on other types of patient letters, such as those from primary care, as these have a different purpose and content to letters sent from secondary care. Furthermore, as the main focus of this review was the patient’s perspective, further reviews would usefully understand healthcare professionals’ views on, and experiences with copy letters.

Quality appraisal of studies is not always undertaken in rapid reviews however, considering the quality of the studies enables greater judgements and conclusions to be drawn and thus reduces misinterpretation of evidence [[68](#_ENREF_68)]. **Therefore, a strength of evidence assessment was completed based on published criteria** [[18](#_ENREF_18)]. Although this is a strength of this review, a risk of bias assessment was not completed as this was beyond the scope of the review.

# Conclusion

There is little objective, high quality evidence to suggest that copy letters increase patient understanding of their health and treatment or effect any improvement in **physical or psychological** health outcomes. Patients were generally satisfied with copy letters, which is important in the provision of person-centred care. However, many letters were written at a level which would make them inaccessible to patients with low health literacy, **potentially leading to health inequalities.** **Few studies assessed discrepancies in copy letter content, but of those that did, errors in the medication lists and omission of lifestyle advice were reported.** The lack of information in copy letters to promote self-management support may represent a missed opportunity to improve patient health outcomes. The **usefulness** of this communication approach, which costs the NHS alone at least £13 million per year, is unclear due to a lack of robust research.

# Practice Implications

**A decade on from previous reviews, evidence to support the benefits of copy letter practice as described in health policy remains unclear. However, there is no evidence to suggest copy letters harm patients. Personalising letters and using lay rather than medical terminology appears to be useful for improving copy letter readability. Future research is required to explore this further. This review has identified several other research evidence gaps. To maximise the educational potential of copy letters, further research is required, especially in people with low health literacy levels. Little is known about the impact of copy letters on health outcomes and the value of copying letters to the wider multi-disciplinary team. Future studies should explore the content and accuracy of copy letters, how they are used and how patients respond to them.**

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# Appendix A.

# Strength of Evidence [[18](#_ENREF_18)]

1. Well-supported practice: Evaluated with a prospective randomised controlled trial (including cluster control) and reported in a peer-reviewed publication with no major design flaws evident. **\***
2. Supported practice: Evaluated with a control group and reported in at least a government report or peer-reported journal**\***; systematic literature review including meta-analysis.
3. Promising practice: Evaluated with a comparison to another comparable health system, service or group; systematic literature review supported by a systematic search strategy.
4. Acceptable practice: Evaluated with an independent assessment of outcomes, but no comparison group (e.g. pre- and post-comparisons, post-reporting only or qualitative methods) or historical comparison group (e.g., normative data).
5. Emerging practice: Evaluated without an independent assessment of outcomes (e.g. formative evaluation, qualitative evaluation conducted internally; reviews of key articles not supported by a systematic search strategy).
6. Routine practice (e.g. analysis of routine data for the service).
7. Expert opinion (e.g. peak bodies, government policy, individual opinion pieces).
8. Case-study (e.g. one-shot case studies or a group of case-studies that are largely anecdotal).
9. Other (e.g. psychometric analyses, economic evaluations and service utilisation studies).

**\*** Where a controlled trial has design or implementation issues this will be noted and the strength of evidence classification will be lessened.

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# Figure Caption

# Figure 1. PRISMA flow diagram of article selection.

Modified from [[17](#_ENREF_17)]