

A systematic review on the prevalence of physical activity, and barriers and facilitators to physical activity, in informal carers in the UK

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Abstract

Background: It is estimated that 17% of the UK adult population are informal carers, usually for a family member, with a majority reporting that they are not able to engage in physical activity as

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much as they would like. The aim of this review is to provide a greater understanding of the prevalence of, and barriers and facilitators to, physical activity of informal carers in the UK.

Methods: A systematic review of relevant databases and grey literature was undertaken, following PRISMA guidance, from inception until 17/07/20.

Results: Barriers to physical activity include increasing aging, not wanting to leave the caree alone, the caree being unable to take part in activities, health conditions, fatigue, lack of time, and difficulties in changing routine for the caree. Facilitators include an appreciation of the benefits of engaging in exercise, previous participation in activities, group activities with similar people, and having some free time.

Conclusions: Due to the paucity of research into the prevalence of, and barriers and facilitators to, PA in informal carers in the UK, this systematic review highlights the need for further research focusing primarily on the physical activity of informal carers, caring for individuals with a range of conditions. An international systematic review into these areas would also be justified.

Introduction

The New Policy Institute states that “Informal carers provide care on an unpaid basis, often to family members” (1). Carers UK (2) estimated that in 2019 there were 8.8 million informal carers in the UK (17% of the adult population), an increase of 2.5 million since 2011. However, this figure could be

1 much higher as individuals often do not identify themselves as being carers, with research showing
2 that over half of carers (54%) took over a year to recognise their caring role, with almost a quarter
3 (24%) taking over five years and 9% over ten years (3). Informal carers often face economic and
4 societal pressures, particularly due to budget cuts (2). Importantly, the literature suggests that a
5 majority of carers suffer from loneliness and social isolation, require support to stay in work, and
6 have multiple physical health complications as a result of their caring role [4]. Indeed, one study
7 found that 22% and 27% of carers studied described their physical and mental health as bad or very
8 bad, respectively (4). Research has found that informal carers often suffer from sleep disturbance,
9 fatigue, pain, loss of strength, loss of appetite, and weight loss (5, 6). In relation to mental health,
10 informal caregivers have been reported to suffer from anxiety, depression, and stress (5-8).
11 Importantly, carers are known to focus less on their own health needs and report more negative
12 health behaviours than non-carers (9). Moreover, two thirds of informal carers state that they have
13 focussed on the care needs of the person they care for, rather than their own needs (2).

14 It has been reported that the majority (81%) of informal adult carers are not able to do as much PA
15 as they would like to do (4). National Health Service (NHS) statistics suggest that 67% of adults in
16 England are classed as 'Active' and 11% as 'Fairly active' according to Government guidelines, with
17 only 21% of adults in the general population being classed as 'Inactive'. It appears, therefore, that
18 informal carers are likely to have activity levels that are not only below their own desired levels, but
19 also below Government guidelines and those of the general population. Regular and sustained
20 participation in PA is beneficial for almost all facets of health including, for example, reduced risk of
21 cardiovascular disease, certain cancers, stress and depression, and improved mental / cognitive
22 health, wellbeing and sleep (10, 11). Therefore, the potential of PA to enhance caregivers' health is
23 recognised (12), adding to previously noted psychosocial benefits (13).

24 In order to inform targeted interventions to promote PA to specific populations, the prevalence first
25 needs to be identified to acquire accurate estimates of current PA levels and correlates need to be

known. Correlates can either be non-modifiable (e.g. sex, age, ethnicity), allowing for the identification of those groups in need of intervention, or modifiable (e.g. motivation, access to equipment, physical environment), identifying variables that can be manipulated to increase PA. To date, no attempt has been made to collate the literature on the prevalence of PA and correlates in informal carers within the UK. It is crucial to focus on UK-based evidence, rather than high income countries generally, due to the different caring pathways, as well as the social and political contexts, between countries.

A preliminary search for existing systematic reviews and/or scoping reviews on the topic found that within the UK there are limited research syntheses available on this topic, although there is more research in this area in the US and Canada (14-22). A protocol has been published for a UK scoping review looking at PA in people with young-onset dementia and their carers (23), although at the time of writing the full review has not been published. No other systematic review has been published or registered with Prospero or Cochrane, which specifically focuses on prevalence of PA in informal carers in the UK or correlates (i.e. barriers and facilitators) to PA in informal carers in the UK.

The aim of the current systematic review is to provide a greater understanding of the prevalence of PA of informal carers in the UK and the barriers and facilitators to PA of informal carers in the UK. Following the PICO framework (24), this systematic review aims to synthesize existing knowledge, identify gaps in the literature and provide recommendations for future research.

This review aims to answer the following research questions:

1. What is the prevalence of physical activity in informal carers in the UK?
2. What are the barriers and facilitators to physical activity in informal carers in the UK?

Methods

This systematic review was conducted according to the recommendations in the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) statement (25).

This article incorporates the results from two separate systematic reviews on the prevalence of physical activity in informal carers in the UK (see Prospero Registration CRD42020162032) and the barriers and facilitators to physical activity in informal carers in the UK (see Prospero Registration CRD42020167742).

Search strategy

The search was conducted on PubMed, SPORTDiscus, PsycInfo and CINAHL from inception until 17/07/20, for articles written in English. The search terms (Title / Abstract) were ('Carer' OR 'caregiver' OR 'family member' OR 'informal carer') AND ('physical activity'). Additionally, grey literature was searched in Open Grey. The search term "physical activity of carers" was used to identify grey literature because this was identified as the most relevant term in the exploratory and database searches. In addition, reference lists of all relevant studies, reviews and reports were hand-searched by two reviewers (JH and NK) to identify additional literature. There were no restrictions on study design or date. Where potentially relevant review protocols had been published, but not the final reviews, authors were contacted by email to assess whether any data had been collected that were relevant to the current systematic reviews. In all cases, the authors replied to the initial email, so follow-up was not required.

Study selection

Titles and abstracts were screened by two reviewers (NK, JH) for eligibility against the inclusion / exclusion criteria. Any disagreements were solved by consensus, or by the decision of a third

reviewer (JV) where necessary. The researchers were inclusive at this stage and, if uncertain about the relevance of a publication, it was retained. The full text was obtained for all the records that potentially met the inclusion criteria (based on the title and abstract / summary only). Full text screening was conducted by three reviewers (JV, NK, JH) for eligibility against the inclusion / exclusion criteria.

Inclusion criteria: Studies were included if they met all the following criteria:

1. Published in English
2. Relate to informal carers of any age, caring for individuals with any condition requiring care (excluding parenthood / bereaved carers)
3. Relate to carers in the UK
4. Relate to any type of physical activity of informal carers
5. Report on levels (either self-reported or objective) of physical activity of informal carers and/or on barriers / facilitators to physical activity of informal carers

Exclusion criteria: Studies were excluded if they met any of the following criteria:

1. Relate to professional (paid) carers
2. Relate to parenthood (unless caring for a child suffering from a condition requiring care beyond a normal parenting role)
3. Relate to bereaved carers no longer performing a caring role

Data extraction

The following data were extracted by one reviewer (JH) and checked by a second reviewer (MT) with 100% agreement: authors, year of study/report, aim/purpose, type of paper (e.g. journal article, annual evaluation report etc), geographical area, study population (e.g. age of carers and condition

of individuals being cared for), sample size, study design, and key findings that relate to the systematic review questions.

Critical appraisal

Each of the included studies were appraised using the appropriate Critical Appraisal Skills Programme (CASP) checklist (26) by one reviewer (JH), and these were verified by two other reviewers (MT, JV). The CASP checklists were selected because they are specific to health-related research, provide a high level of detail and cover the appropriate methodologies for this review. The appropriate tools in this case were the CASP Checklist for qualitative research and the CASP Checklist for cohort studies.

Results

The literature search yielded 2606 results (CINAHL n = 1108; PsycInfo n=782; PubMed n=447; SPORTDiscus n=269), of which 906 were removed as duplicates, resulting in 1700 studies remaining. Additionally, a search on Open Grey yielded 2 results. The titles / abstracts of these were screened separately for the two systematic reviews.

Review 1: Prevalence of physical activity

The title / abstract screening resulted in the removal of 1655 results, with 47 going through to full text review. Of these, none were eligible for inclusion. Reasons for exclusion are given in Figure 1, and include not being based in the UK, not being related to informal carers, not being related to PA, and not providing a measure of the prevalence of PA in carers.

Review 2: Barriers and facilitators to physical activity

The title / abstract screening resulted in the removal of 1686 results, with 16 going through to full text review. Of these, only three studies were eligible for inclusion. Reasons for exclusion are given in Figure 1, and include not being based in the UK, not being related to carer PA, and not providing an indication of barriers or facilitators to PA in carers.

The extracted data for the included studies are given in Table 1. These three studies included carers of individuals with multiple sclerosis and dementia, with the carers of those with multiple sclerosis being younger on average (mean age 52) than those with Alzheimer's specifically (aged 64-84) or dementia of any type (mean age 71). Barriers to physical activity included increasing aging, not wanting to leave the caree alone, the caree being unable to take part in activities, health conditions, fatigue, lack of time, and difficulties in changing routine for the caree. Facilitators included an appreciation of the benefits of engaging in exercise, previous participation in activities, group activities with similar people, and having some free time.

The studies were critically appraised using either the CASP Checklist (26) for qualitative research or the CASP Checklist for cohort studies, and were all determined to be valid, appropriately designed, ethical, rigorous, and with clear and valuable results (see Appendices A, B and C).

Discussion

Prevalence of PA

No studies reported on the actual prevalence of PA in carers. However, one qualitative study identified does contribute to our understanding of the situation. Nabbout et al. (2019) (27) found that 50% of carers report an impact on leisure, 50% report an impact on daily activities, and 75% report an impact on physical functioning. However, it is not clear which of these categories directly relates to physical activity, which could fall into any of these. It should also be noted that the sample size for UK participants (n=4) is very small and relates to a very specific population of carers for children with Dravet syndrome. Nevertheless, this fits with research by Carers UK (4) which suggests

that the majority of carers are unable to engage in as much physical exercise that they would like to due to the impact of caring.

Barriers

Whilst the study by Forbes et al. (2007) (28) didn't directly consider barriers to physical activity, it did identify that carers experience specific health problems (physical functioning, bodily pain, reduced energy, bad back, anxiety, tiredness, insomnia, depression, shortness of breath), which could be barriers to PA, and are in fact identified by Malthouse et al.'s (2014) study as a barrier to PA for carers (29). This fits with the finding of Nabbout et al. (2019) that 75% of carers report an impact on physical functioning (27), as well as with similar findings in the literature (4-6, 9). Furthermore, Forbes et al. (2007) suggest that carers providing more care activities (i.e. providing specific help to patient in terms of washing, eating / drinking, lifting / moving, toileting, dressing) show a higher impact of caring on these health issues (28). It should be noted that this study relates only to carers of individuals with multiple sclerosis.

Malthouse et al. (2014) and Farina et al. (2020) identified several specific barriers to PA for carers, which include perception of aging (not wanting to push themselves physically), not wanting to leave their caree alone / leaving them for too long, their caree being unsafe to take part in activities (e.g. bike rides) or unable to participate socially in group activities, health conditions causing pain / risk of falling, feeling tired / lacking energy due to the PA associated with caring, lack of time due to caring role, difficulties in changing routine for their caree, and their own PA being inhibited through supporting the caree being active (29, 30). Malthouse et al.'s (2014) study only involved a small sample of spousal carers of individuals with Alzheimer's disease, so it must be recognised that the barriers to PA for other groups of carers may differ (29). Farina et al.'s study included a slightly larger sample, but, again, only considered carers of individuals with dementia (30).

Facilitators

Malthouse et al. (2014) also identify several specific facilitators to PA for carers, which include an appreciation of the benefits of engaging in exercise (e.g. mood, weight, flexibility, slowing deterioration), previous participation in activities (e.g. walking groups, dog walking), group activities with similar people who understand Alzheimer's, and having some free time (29). Again, this study only involved spousal carers of individuals with Alzheimer's disease, so the facilitators to PA for other groups of carers need to be considered.

Limitations

Although the CASP appraisals of the included studies were generally positive, there are some limitations to these studies, particularly with regards to sampling. The sample studied by Forbes et al., although large (n=257), included only carers of individuals with multiple sclerosis identified by seven neurological services, excluding those not known to these services (who are likely to be carers of patients with milder disease impact). Malthouse and Fox's qualitative study included only five spousal carers of people with Alzheimer's disease from one memory clinic. The people with Alzheimer's disease were all taking part in drugs trials, indicating that they were likely to be more active and have fewer comorbidities than their age-matched peers. They were also a volunteer sample and may not be representative of the population of people with Alzheimer's disease. Finally, Farina et al.'s qualitative study included only 15 carers of people with dementia from the South East of England, primarily through self-referral. Additionally, because those with dementia were required to have the capacity to consent to the study, the study only included carers of people with mild to moderate dementia, excluding those caring for people with more severe dementia. Furthermore, the researchers in both qualitative studies have not critically examined their own role in the formulation of the research question or data collection.

It is clear that the UK literature within the focus of this review is limited. There are no studies investigating the prevalence of PA in informal carers in the UK, and only three studies providing information on the barriers and facilitators to PA in informal carers in the UK. Those studies that do exist focus primarily on patients with particular conditions and often consider the PA of carers as a secondary objective. Further research is required to objectively evaluate the PA levels of informal carers in the UK and their barriers and facilitators to PA, utilising a large and wide-ranging sample of carers caring for individuals with varying conditions (including physical and mental health related) and level of need, with a focus on the carer rather than the patient-group.

Conclusion

It is clear that there is a paucity of research into the prevalence of, and barriers and facilitators to, PA in informal carers in the UK. The search process did reveal a much higher level of research internationally, particularly in the US, Canada and Australia. The authors are, therefore, currently undertaking two international reviews on these topics to investigate these areas more widely. It was also apparent that many studies focus primarily on patients / carees with a specific condition, with the health / activity level of the carer being a secondary outcome. This review highlights the need for more research focusing primarily on informal carers, caring for individuals with a range of conditions.

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Table 1. Descriptive characteristics of included studies: Barriers and facilitators to physical activity

Authors	Year	Aim	Type of paper	Geographical area	Study population	Sample	Study design	Key findings
Forbes A, While A, Mathes L (28)	2007	Explore the contribution of carer characteristics, activities and disease impact to care burden and health in multiple sclerosis caregivers	Journal article	England	Carers of individuals with multiple sclerosis	257 carers (154 male, 103 female; mean age 52)	Quantitative survey	Carers experience specific health problems (physical functioning, bodily pain, reduced energy, bad back, anxiety, tiredness, insomnia, depression, shortness of breath) which could be barriers to PA. Carers providing more care activities (providing specific help to patient – washing, eating/drinking, lifting / moving, toileting, dressing) show a higher impact of caring on these health issues.
Malthouse R, Fox F (29)	2014	Improve understanding about barriers / facilitators to PA for people with Alzheimer's and their spouse carers	Journal article	England	Individuals with Alzheimer's disease and their spouse carers	5 patient-carer dyads (gender of the carer / caree is not stated; ages ranged from 64-84)	Qualitative interviews	Barriers to PA for carers included perception of aging (not wanting to push themselves physically), not wanting to leave their spouse alone, spouse being unsafe to take part in activities (bike rides) or unable to participate socially in group activities, health conditions causing pain / risk of falling, feeling tired / lacking energy due to the PA associated with caring, lack of time due to caring role, difficulties in changing routine for their spouse; facilitators to PA included an appreciation of the benefits of engaging in exercise (mood, weight, flexibility, slowing deterioration),

								previous participation in activities (e.g. walking groups, dog walking), group activities with similar people who understand Alzheimer's, having some free time
Farina N, Williams A, Clarke K, Hughes LJ, Thomas S, Lowry RG, Banerjee S (30)	2020	Explore the barriers, motivators and facilitators toward physical activity of people with dementia and their carers living in England; understand the similarities and differences in themes discussed between the two groups.	Journal article	England	Individuals with dementia and their carers	15 patient-carer dyads (mean age of carers 71; 5 male, 10 female; 12 spouses to the person with dementia, 2 sons / daughters)	Qualitative interviews	Barriers to PA for carers included physical health (increasing age, reduced energy, fear of overexertion - tiredness / pain), time (finding time in daily routine due to other activities and duties) and caring role (unable to do as much or do things on their own as they used to - not wanting to leave the person with dementia on their own at all / for too long, supporting person with dementia being active inhibits own physical activity). Carers did not identify any facilitators of PA.

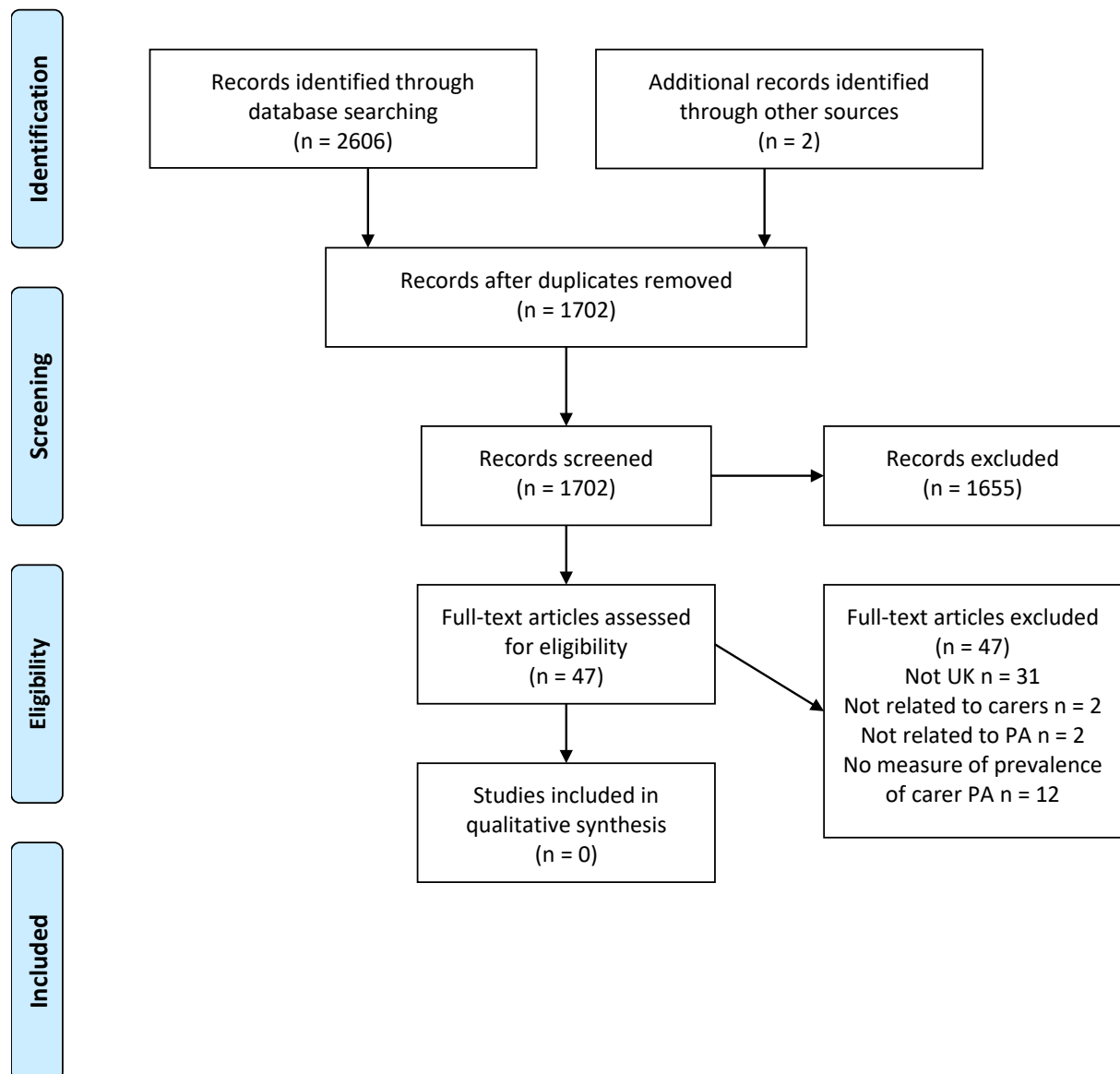


Figure 1. PRISMA flowchart of included studies: Prevalence of physical activity

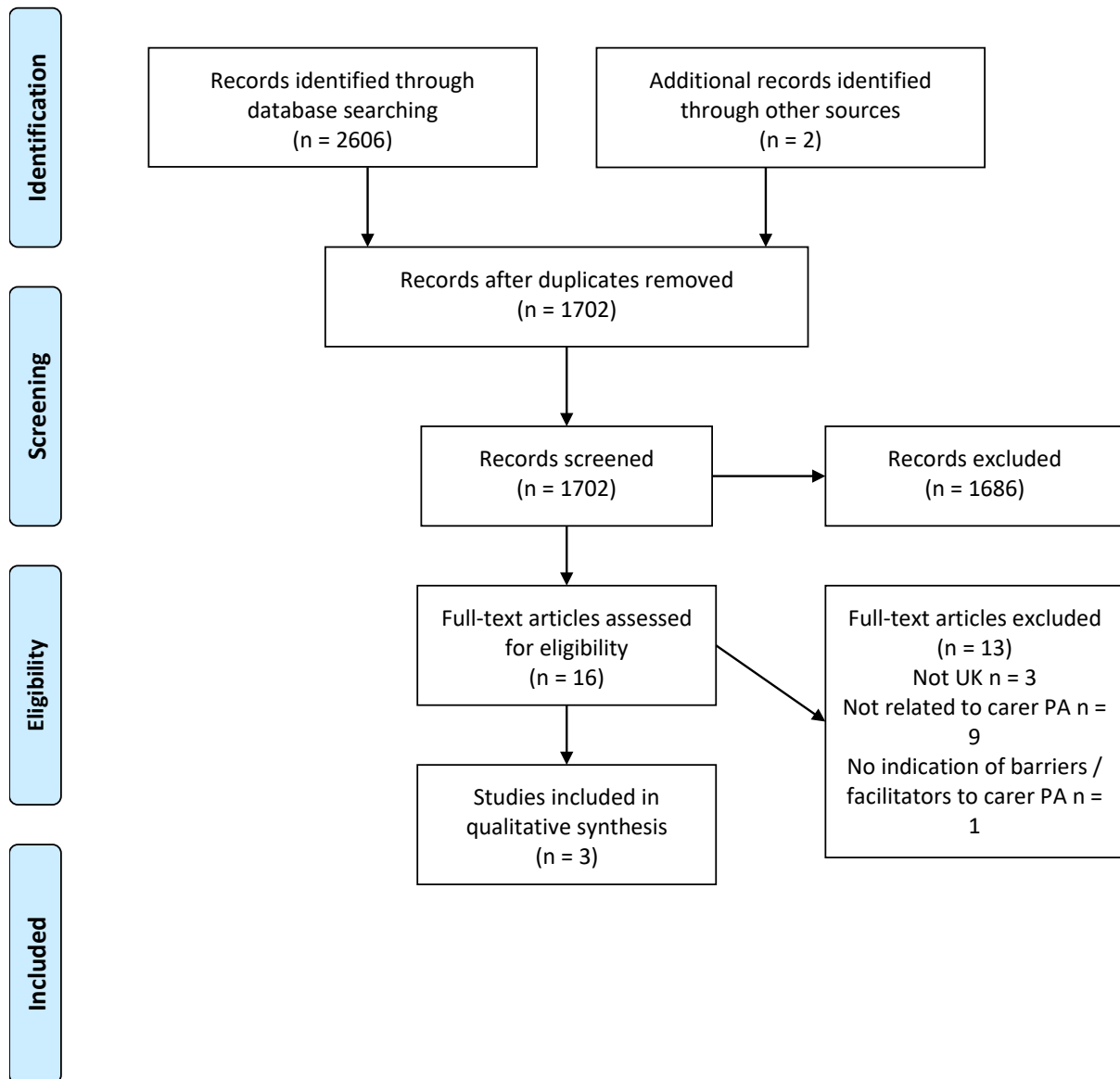


Figure 2. PRISMA flowchart of included studies: Barriers and facilitators to physical activity