**Table 1. Characteristics of included systematic reviews**

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| **Author, year** | **Aim of review (as quoted)** | **Time frame of searches and date range of included studies** | **Population** | **Number of included studies (number in full review if different)**  **Sample size**  **Number of unique included studies** | **Included study design and data collection method** | **Subject of research participation** | **Location** | **Amstar score and category** |
| Crane, 2017 (24) | The objective of this systematic review was to examine ethical issues surrounding research with **children and adolescents from their perspective as participants**. | Time frame: Dates not listed.  Range: 2003 - 2014 | Children and adolescents, majority with physical or mental illness. | 9 studies  (23 in full review)  N = 6326  Unique studies: 8 of 9 | Qualitative: 4  Quantitative: 3  Mixed methods: 2  Methods: interviews, focus groups | Any phase vaccine trials | Sweden: 2  USA: 7 | 5, medium |
| Dhalla, 2013 (26) | The objective of this review article is to review **barriers to participation in** **actual preventative HIV vaccine trials**. | Time frame: Cochrane Database for Systematic Reviews (no date), Medline (1950-2012)/Pubmed (no date), Embase (1980-2012), Google Scholar (no date). Range: 1994 - 2010.  Range: 1995 -2012. | Adults.  8 studies involving low risk adults  12 studies involving ‘higher risk’ adults (e.g. intravenous drug users, gay men, sex workers) | 20 studies  N = 18033  Unique studies: 8 of 20 | Qualitative: Not reported.  Quantitative: Not reported.  Methods: Focus groups, questionnaires, mixed methods, spontaneous reporting | Any phase HIV vaccine trials | Canada: 1  Kenya: 1  Spain: 1  Tanzania: 2  Thailand: 4  UK: 1  USA: 8  Multiple countries: 1  Not reported: 1 | 7, medium |
| Dhalla, 2014 (27) | The objective of this review article is to better understand **motivators to participation in actual preventive HIV vaccine trials** in terms of perceived social and personal benefits to such participation, as construed at these levels. | Time frame: Dates not listed.  Range: 1997 - 2011. | Adults.  9 studies involving low risk adults  5 studies involving ‘higher risk’ adults (e.g. intravenous drug users, gay men, sex workers)  6 studies involving a mix of high and low risk adults  1 studies unknown risk. | 21 studies    N = 32825  Unique studies: 11 of 21 | Qualitative: Not reported.  Quantitative: Not reported.  Methods: Questionnaires, interviews, telephone hotline and focus groups. | Any phase HIV vaccine trials | Canada: 1  Italy: 1  Spain: 1  Tanzania: 2  Thailand: 6  UK: 1  USA: 6  Multiple countries: 3 | 6, medium |
| Fayter, 2007 (10) | Our aim was to undertake a systematic review of the relevant literature relating to the **barriers, modifiers, and benefits involved in participating in** **RCTs of cancer therapies** as perceived by health care providers and patients. | Time frame: 1996 to 2004.  Range: 1996 - 2004. | Patients (adults and children) diagnosed with various cancers | 37 studies (56 in full review)  N = 25788 (plus an unreported number from 4 studies)  Unique studies: 23 of 37 | Qualitative: Not reported.  Quantitative: Not reported.  Methods: Surveys, focus groups, chart review, case controlled studies | Randomised controlled trials (excluding solely phase I or II) | Australia: 3  Canada: 1  Denmark: 1  Finland: 1  Italy: 1  Netherlands: 1  Sweden: 1  UK: 12  USA: 15  Multiple countries: 1 | 8, high |
| Fisher, 2011 (21) | This review takes a different focus and considers the **reasons that parents accept or decline an invitation to enrol children of any age in clinical research**. | Time frame: SCOPUS - 1960 to Feb 2010; Web of Knowledge - 1971 to Feb 2010.  Range: 2001 - 2011. | Parents/caregivers of children invited to take part in research.  Two thirds of studies involved children with life-limiting or life-threatening conditions including cancer and diabetes. | 16 studies  N = 365 (plus an unreported number from one study)  Unique studies: 10 of 16 | Qualitative: 16  Quantitative: 0  Methods: Interviews, focus groups, ethnography, content analysis of websites. | 14 trials, 2 unclear | Canada: 1  Gambia: 1  Malawi: 1  UK: 4  USA: 9 | 7, medium |
| Forcina, 2018 (25) | We aimed to conduct a systematic review of studies limited to AYA patients which assessed **attitudes and beliefs that influence cancer CT enrolment** to prioritize areas for future study and intervention | Time frame:  Inception to May 2017.  Range: 2009 - 2016. | Adolescent and young adult cancer patients aged 15-39 years. | 6 studies  N = 754  Unique studies: 4 of 6 | Qualitative: Not reported.  Quantitative: Not reported.  Methods: semi-structured interviews, questionnaires/surveys | Cancer clinical trials | USA: 1  Not reported: 5 | 6, medium |
| Gad, 2018 (28) | We conducted a literature review to determine (1) **the factors that influence *[cancer]* patients' decisions to enter a phase 1 trial,** (2) patients' perceptions of the information they receive when they are invited to participate in a phase 1 trial, and (3) relatives perceptions of the information given to patients. | Time frame: Inception to April 2017.  Range: 1995 – 2014. | Adult patients diagnosed with various cancers. | 15 studies (37 in full review)  N = 1313  Unique studies: 10 of 15 | Qualitative: 4  Quantitative: 11  Methods: interviews, questionnaires, focus groups | Phase 1 trials | Canada: 1  Italy: 1  Japan: 2  UK: 3  USA: 8 | 10, high |
| Glover, 2015 (29) | To our knowledge there have been no reviews that specifically focus on **barriers or facilitators for** **Indigenous peoples’ participation in RCTs**. This paper aims to address that knowledge gap by presenting the findings of a systematic review of the literature on challenges and facilitators of participation in health RCTs among Indigenous people from New Zealand, Australia, Canada and United States. | Time frame: Inception to March 2012.  Date range: 1994 - 2011. | 5 studies with indigenous or aboriginal Australians, 4 studies with First Nation participants, 6 studies with Maori participants, 31 studies with Native Americans or Alaskan Natives  The majority (N = 11) focused on cancer, 7 on diabetes, 6 on substance abuse and 22 on other conditions/factors | 46 studies  N = not reported.  Unique studies: 45 of 46 | Qualitative: Not reported.  Quantitative: Not reported.  Methods: Not reported. | Randomised controlled trials. | Australia: 5  Canada: 4  New Zealand: 6  USA: 31 | 5, medium |
| Grand, 2012 (30) | This review examines the relationship between the obstacles to **participation in cancer clinical trials** and accrual, **focusing wherever possible on clinical trials in Radiation Oncology.** | Time frame: 1984 to 2009.  Range: 1983 - 2007. | Patients diagnosed with various cancers. | 20 studies (31 in full review)  N = 13681  Unique studies: 15 of 20 | Qualitative: Not reported  Quantitative: Not reported  Methods: Questionnaires, interviews, surveys, review of patient/trial records, focus groups | Oncology clinical trials | Not reported. | 5, medium |
| Gregersen, 2019 (23) | To systematically review and thematically synthesise the **experiences of patients and relatives when they have to decide whether or not to participate in a clinical oncology trial** and to provide knowledge about the decision-making process. | Time frame: Dates not listed.  Range: 2000 – 2016. | Adult patients with advanced cancer. | 11 studies  N = 203  Unique studies: 4 of 11 | Qualitative: 11  Quantitative: 0  Methods: Interviews, focus groups | Clinical trials | USA: 6  UK: 3  Japan: 1  Sweden: 1 | 5, medium |
| Hughes-Morley, 2015 (20) | Our aims in undertaking this review were firstly to systematically identify relevant qualitative studies describing **factors affecting recruitment of participants into depression trials**; and secondly to perform a meta-synthesis to identify common themes that describe factors affecting recruitment in to depression trials, to develop a conceptual framework of factors influencing the decision to participate in depression trials. | Time frame: ASSIA 1987 to April 2013; CINAHL - 1937 to April 2013; Embase 1974 to April 2013; Medline 1946 to March 2013; PsychInfo 1806 to April 2013.  Range: 2007 - 2012. | Patients with depression. | 4 studies (15 in full review)  N = 1034  Unique studies: 4 of 4 | Qualitative: 4  Quantitative: 0  Methods: questionnaire, interviews, focus groups | Randomised controlled trials | UK: 3  Multiple countries: 1 | 9, high |
| Liljas, 2017 (36) | This systematic review aimed to identify facilitators, barriers and strategies for **engaging ‘hard to reach’ older people in research on health promotion**; the oldest old (≥80 years), older people from black and minority ethnic groups (BME) and older people living in deprived areas | Time frame: 1990 to 2014.  Range: 1996 - 2014 | 18 studies of BME older people (aged over 50 years), 3 studies with oldest old patients (80 years and over), and two studies of older people in deprived areas. | 23 studies  N = not reported  Unique studies: 23 of 23 | Qualitative: 12  Quantitative: 10  Mixed methods: 1  Methods: Surveys, questionnaires, interviews, focus groups | Not reported. Studies focused on health promotion. | Canada: 1  New Zealand: 1  UK: 4  USA: 17 | 7, medium |
| Limkakeng, 2013a (31) | We carried out a systematic review of literature published between 1985–2009 to understand **Chinese patients’ motivations and concerns to participate in clinical trials**. | Timeframe: 1985 to 2009.  Range: 2004 - 2008. | Chinese adults between 18 years and 85 years.  1 study relating to HIV vaccine trials and 1 relating to cancer, 3 studies non-specific | 5 studies  N = 645  Unique studies: 5 of 5 | Qualitative: 3  Quantitative: 2  Methods: surveys, interviews. | Clinical trials | USA: 3  China: 1  Singapore: 1 | 8, high |
| Limkakeng, 2013b (38) | The objective of this study, then, was to conduct a systematic review and metasummary to evaluate what values, attitudes, or beliefs on the part of **potential or actual research participants with emergent medical conditions influence participation in research.** | Time frame: Inception to 2011.  Range: 2000 - 2009. | Adult patients aged over 18 years.  5 studies focused on suspected myocardial infarction patients, 3 on stroke patients, 1 on sudden cardiac near-death survivors and 5 on other emergency patients. | 14 studies  N = 4003 (plus one study unclear)  Unique studies: 12 of 14 | Qualitative: 6  Quantitative (survey): 8  Mixed methods: 3  Methods: Surveys, interviews | Not reported. | Primarily conducted in American and Western European contexts. Number not reported. | 7, medium |
| Martinsen, 2016 (39) | The aim of the current report was to perform a systematic review of the current literature on participation motives, response rates, and recruitment strategies in **research bronchoscopy studies with an emphasis on studies including COPD patients.** | Time frame: Dates not listed.  Range: 1998 - 2013. | Patients with HIV, bronchoscopy patients, smokers, children with or without cystic fibrosis and parents | 6 studies (7 in full review)  N = 455  Unique studies: 6 of 6 | Qualitative: Not reported  Quantitative: Not reported  Methods: Interviews and questionnaires, focus groups, surveys | Not reported. | The Netherlands: 1  UK: 3  USA: 1  Multiple countries: 1 | 5, medium |
| McCann, 2007 (32) | The aim of this review was to draw together qualitative and quantitative studies reporting **patients' experiences of trial recruitment and participation** to provide a broad based overview of the literature. | Time frame: 1996 to 2005.  Range: 1982 - 2005. | Demographic data largely not reported. Range of trials including HIV, cancer, neonatal and myocardial infarction. | 32 studies  N = 6068  Unique studies: 21 of 32 | Qualitative: 12  Quantitative: 12  Mixed methods: 3  Systematic reviews: 5  Methods: Interviews, questionnaires | Phase III trials | Denmark: 2  Europe: 1  Isreal: 1  UK: 13  USA: 9  The Netherlands: 1  Multiple countries: 5 | 4, medium |
| McCann, 2013 (33) | Update of 2007 review – no new objective stated. | Time frame: September 2005 to December 2010.  Range: 2006 - 2010 | Patients with a variety of conditions including cancer, epilepsy, stroke and pre-term labour. One paper discussed interviews with parents of children with leukaemia and two studies involved pregnant women or parents. | 11 studies (12 in full review)  N = 290  Unique studies: 9 of 11 | Qualitative: Not reported  Quantitative: Not reported  Methods: Interviews, focus groups, observations | Randomised controlled trials. | Australia: 1  Denmark: 1  UK: 7  USA: 1  Multiple countries: 1 | 7, medium |
| Nalubega, 2015 (19) | This review aimed to synthesize and present the best available evidence in relation to **HIV research participation in sub-Saharan Africa**, based on the views and experiences of research participants. | Time frame: Inception to July 2013. Updated in September 2014.  Range: 2004 -2014. | All current or former adult HIV research participants from sub-Saharan African countries. 16 studies only involved women. | 21 studies  N = not reported  Unique studies: 18 of 21 | Qualitative: 21  Quantitative: 0  Methods: focus groups, interviews, participant observation | Not reported. | Kenya: 1  Malawi: 1  South Africa: 12  Tanzania: 4  Zimbabwe: 1  Multiple countries: 2 | 9, high |
| Nielsen, 2019 (22) | The aim of this study was to examine cancer patients’ perceptions of factors that may influence their **decisions on participation in phase I–III clinical drug trials.** | Time frame: 2010 to 2016.  Range: 2010 - 2013. | Adult cancer patients. | 9 studies  N = 236  Unique studies: 3 of 9 | Qualitative: 9  Quantitative: 0  Methods: Interviews, questionnaires | Cancer clinical drug trials | USA: 7  Japan: 1  Sweden: 1 | 5, medium |
| Nievaard, 2004 (41) | To assess the factors that may **influence a patient's consent to participate in a clinical trial.** | Time frame: 1980 to April 2002.  Range: 1984 - 2002. | Adult patients, 14 with cancer patients. 5 with HIV patients, 6 from other patient groups and 5 did not report the patient group. | 30 studies  N = not reported.  Unique studies: 19 of 30 | Qualitative: Not reported.  Quantitative: Not reported  Methods: Not reported. | 6 randomised controlled trials, others not reported. | Australia: 3  USA: 14  Western Europe: 13 | 5, medium |
| Nobile, 2013 (40) | The aim of this article is to review the literature addressing **actual and apparently healthy** **participants’ reasons to enrol in biobank studies** in order to see if some motives are unduly influencing the decision to participate. | Time frame: Inception to Jan to Feb 2012.  Range: 2006 - 2012. | Healthy adult participants  4 studies involved just women. | 13 studies  N = 1762  Unique studies: 12 of 13 | Qualitative: 9  Quantitative: 4  Methods: interviews, focus groups and surveys | Not reported. | Australia: 2  Europe: 1  UK: 3  USA: 7 | 5, medium |
| Prescott, 1999 (34) | To assemble and classify a comprehensive bibliography of **factors limiting the quality, number and progress of RCTs**. To collate and report the findings, identifying areas where firm conclusions can be drawn, and identifying areas where further research is required. | Time frame: 1986 to March 1996.  Range: 1986 - 1996. | Majority of studies involved cancer patients (N = 9), two studies concerning child health involved parents/caregivers. | 22 studies (27 studies in chapter)  N = 15295  Unique studies: 19 of 22 | Qualitative: Not reported.  Quantitative: Not reported.  Surveys, trial data, questionnaires, structured interviews | Clinical trials, not Phase I or Phase II. | Australia: 1  Canada: 1  France: 3  The Netherlands: 1  UK: 5  USA: 11 | 8, high |
| Quay, 2017 (35) | The aim was to identify barriers and facilitators to **recruitment of South Asians to health research studies** and associated strategies to improve participation. | Time frame: January 2004 to April 2016.  Range: 2004 -2016. | South Asian patients. Majority of studies involved patients with a condition e.g. asthma or diabetes | 10 studies (15 in full review)  N = 3139  Unique studies: 8 of 10 | Qualitative: 9  Quantitative: 6  Methods: surveys, interviews, focus groups, literature reviews | 10 randomised controlled trials | Australia: 1  India: 1  UK: 7  USA: 1 | 8, high |
| Tromp, 2016 (42) | This systematic review attempts to answer the following research question: **What are motivating and discouraging factors for children and their parents to decide to participate in clinical drug research**? | Time frame: Inception to March 2013. Updated August 2014.  Range: 1997 - 2013 | 26 studies involved parents or caregivers/guardians, 5 involved children and 11 involved both. Included children aged between 6 and 21.  Diverse research population but many involved oncology patients (11 studies).  39 studies involved people who had consented, 24 involved people who had dissented. 29 studies involved treatments with prospect of direct benefit. | 42 studies  N = 5500  Unique studies: 33 of 42 | Qualitative: 16  Quantitative: 26  Methods: questionnaires, registry analysis, focus group, interviews | Not reported. | Not reported. | 7, medium |
| Van der Zande, 2018 (37) | The objective of our paper was therefore to identify and systematically review all articles regarding **pregnant women’s reasons to participate in clinical research** | Time frame: Dates not listed.  Range: 2013 - 2016. | Pregnant/previously pregnant women. | 30 studies  N = 7905, plus an unreported number from 1 study  Unique studies: 28 of 30 | Quantitative: Not reported.  Qualitative:  Not reported.  Methods: Interviews, focus groups, questionnaires, surveys, analysis of records. | Observational studies and randomised controlled trials | UK: 10  USA: 7  Canada: 5  Australia: 2  China: 1  Ghana: 1  Ireland: 1  Italy: 1  Netherlands: 1  Pakistan: 1 | 5, medium |
| Woodall, 2010 (43) | We therefore aimed to review the current literature on the nature of **barriers to participation across different mental health studies** **with a focus on whether there are specific gender, age and ethnicity related barriers** | Time frame: 1990 to 2008.  Range 1992 - 2008. | Adult participants.  5 schizophrenia studies, 5 depression studies, 6 dementia studies and 5 where the illness was not specified. | 16 studies (49 in full review)  N = 2033, plus an unreported number from 9 studies  Unique studies: 15 of 16 | Qualitative: Not reported.  Quantitative: Not reported.  Methods: surveys, interviews, recruitment | Not reported. | Australia: 1  Canada: 1  Germany: 1  Mexico: 1  Switzerland: 1  UK: 1  USA: 10 | 6, medium |