Journal of Public Health | pp. 1–12 | doi:10.1093/pubmed/fdz126

Identifying evidence of effectiveness in the co-creation of research: a systematic review and meta-analysis of the international healthcare literature

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ABSTRACT

Background To investigate and address the evidence gap on the effectiveness of co-creation/production in international health research.

Methods An initial systematic search of previous reviews published by 22 July 2017 in Medline, Embase, PsycINFO, Scopus and Web of Science. We extracted reported aims, elements and outcomes of co-creation/production from 50 reviews; however, reviews rarely tested effectiveness against intended outcomes. We therefore checked the reference lists in 13 included systematic reviews that cited quantitative studies involving the public/patients in the design and/or implementation of research projects to conduct meta-analyses on their effectiveness using standardized mean difference (SMD).

Results Twenty-six primary studies were included, showing moderate positive effects for community functions (SMD = 0.56, 95%CI = 0.29–0.84, $n = 11$) and small positive effects for physical health (SMD = 0.25, 95%CI = 0.07–0.42, $n = 9$), health-promoting behaviour (SMD = 0.14, 95%CI = 0.03–0.26, $n = 11$), self-efficacy (SMD = 0.34, 95%CI = 0.01–0.67, $n = 3$) and health service access/receipt (SMD = 0.36, 95%CI = 0.21–0.52, $n = 12$). Non-academic stakeholders that co-created more than one research stage showed significantly favourable mental health outcomes. However, co-creation was rarely extended to later stages (evaluation/dissemination), with few studies specifically with ethnic minority groups.

Conclusions The co-creation of research may improve several health-related outcomes and public health more broadly, but research is lacking on its longer term effects.

Keywords co-creation, co-design, co-production, ethnicity, health, meta-analysis, systematic review

Introduction

The co-creation, co-production or co-design of research is broadly defined as 'the collaborative generation of knowledge by academics working alongside stakeholders from other sectors' (p. 393),[1] including service users, carers, practitioners and commissioners. The main purpose is to devolve control so that particularly service users, but also community members, can be more active in the design of the services they receive. Co-creation principles have been evident in policy development and administration of public, private and

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non-governmental services.[2] In health and social sciences, these principles are promoted as non-academic stakeholders are perceived to possess more experience-near forms of knowledge and to ensure that programmes are relevant to their priorities and needs.[1–4] It is not always clear, however, which mechanisms are optimal for successful co-creation or which outcomes matter most to the intended beneficiaries.

Some groups are under-represented in health research, including ethnic minority people.[5,6] Co-creation with socially excluded groups is likely to require a different type of engagement and more time and resources to overcome barriers and address specific needs. However, given the social distance between such groups and the research community and the health inequalities facing these groups, co-creation may be particularly important and productive, if not essential if research is to offer direct benefits. Co-creation principles may determine not only what is researched, but how power is shared and knowledge generated.[1–4]

This article reports on a systematic review and meta-analysis of co-creation in international healthcare literature. With the number of emerging projects in this field in health research alone, a comprehensive synthesis of the international evidence base seems timely. Prior related systematic reviews have been restricted to one geographical context,[7] focused on health services rather than research[8] or barriers and facilitators to research participation rather than co-creation *per se*.[5] We identified relevant primary studies to uniquely pool the effects of co-creation research projects—addressing a notable gap in the evidence base[9]—and linked effects to key process elements.

Methods

We followed PRISMA guidelines and a protocol was registered on PROSPERO: CRD42017071294.

Searches and screening process

A structured search strategy was implemented (Supplementary Material 1) in

- MEDLINE
- Embase
- PsycINFO
- Scopus
- Web of Science.

Searches were completed by K.H. and K.R. up to 22 July 2017, testing searches iteratively to capture all populations and a targeted search for research with racial and ethnic minority groups.

Titles and abstracts were screened by two reviewers (K.H. and K.R.) in EndNote and full texts examined (with authors contacted if papers were unavailable). Any differences in reviewers' decisions were resolved by discussion or consultation with a third reviewer (K.B.).

Eligibility criteria

Study design

Initially, we included reviews of research (systematic or non-systematic literature reviews) with no limitations on research methods. When subsequently extracting primary studies, we only included those with sufficient post-treatment or post-exposure data or estimations available for quantitative pooling (i.e. experimental designs including randomized control trials (RCTs), quasi-experimental and pre-post evaluations; all relevant observational studies such as cohort, case-control, cross-sectional).

Sector/domain

We included research literature of co-creation approaches applicable to health policy and health service research (e.g. public health or community interventions) relating to any health conditions or diseases in adult populations. We excluded co-creation with only adolescents and children, because structural differences between child and adult health services, including regulations on the involvement of parents and carers in children's care, mean that the form of co-creation substantially varies across these settings (see e.g. [10]). All geographical contexts were included.

Theoretical framework

Alongside others who employ the term 'co-creation' to describe creative and collaborative activities to improve human experience—potentially leading to innovation—[1,9,11] we privileged 'co-creation' as an umbrella term for this particular review to describe the involvement of non-academic stakeholders in research. However, the terms 'co-creation', 'co-production' and 'co-design' are often used interchangeably although each relates to different processes,[2] and all three descriptors were retained in the search strategy to capture their different roots and how definitions and applications may vary depending on the profession, discipline, stakeholder group or setting.[2]

References were included if they sufficiently described non-academic stakeholders' co-creation with researchers in the design and/or implementation of the research project and reported an outcome (e.g. clinical, social or educational). We excluded 'co-creation approaches' that failed to involve non-academic stakeholders in research, e.g. where patients were neither invited to help with the design nor the implementation of the research, or that lacked a substantive research or

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evaluation element altogether (such as community-based projects not extending in scope beyond deliberations on patients' decision-making or selection of some pre-defined/healthcare service-driven treatment options).

Publication status, date and language

We included articles in peer-reviewed journals and publications on recognized platforms such as government or university websites, but excluded theses, book chapters and conference papers. No restrictions were put on date of publication or the timescales considered. We only included English language publications.

Data extraction and risk of bias assessment

Data extraction was undertaken by two reviewers (K.H. and K.R.) with a form piloted and amended as necessary. We used the Cochrane's tool for assessing risk of bias in RCTs and the Risk Of Bias In Non-randomised Studies of Interventions (ROBINS-I) tool for the other studies. Two reviewers (K.H. and J.K.) independently assessed each study to reach domain-based decisions.

Data synthesis

A thematic synthesis[12] of the reported aims, process elements and outcomes across included reviews was initially undertaken. While meta-analyses were not originally considered due to insufficient reporting of raw data and/or individual study level effect estimates in reviews, we assessed the reference lists of systematic reviews citing relevant primary studies. In cases where a protocol of a relevant study was cited, we tracked and replaced this with any subsequent primary research publication.

However, even at primary study level, there was considerable heterogeneity in study design, interventions and types of outcomes. We therefore adapted O'Mara-Eves *et al.*'s[13] broad classification scheme to conduct meta-analyses for the following categories:

- Physical health (e.g. body mass index, blood pressure, sexually transmitted infections and mortality).
- Mental health (e.g. emotional well-being, depression and post-traumatic disorder).
- Health promoting behaviour (e.g. healthy eating, physical activity, smoking cessation, medication use and family planning).
- Self-efficacy of participants (e.g. in smoking and diabetes management).
- Community or social functions (e.g. collective agency, social support and networks).
- Health service access or receipt (e.g. coverage of services, cancer screening, pap test and antenatal care).

We conducted subgroup analyses of co-creation with ethnic minority people and involvement of non-academic stakeholders in one versus more than one research stage (i.e. in the design, implementation, evaluation and/or dissemination), while sensitivity analyses of RCTs versus non-randomized studies and studies with lower risk of bias versus studies in which > 50% of domains had 'high'/'unclear' risk (Cochrane's tool for RCTs) and 'critical'/'serious' risk/'no information' (ROBINS-I tool for non-randomized studies), respectively.

Random effects meta-analyses, to account for heterogeneity, were conducted by K.H. in Comprehensive Meta-Analysis 3.3. We prioritized raw data to calculate the average standardized mean difference (SMD), but when sufficient data were unavailable we extracted summary estimates (unadjusted rather than adjusted to avoid potential confounding by the inclusion of different variables across studies). We interpreted SMDs < 0.40 as a small, 0.40–0.70 a moderate and >0.70 a large effect.[14] We used a verified formula[13,15] to convert any binary outcome data to the SMD, with continuous outcomes providing greater power.[15]

Some positive effects benefitted the intervention group (e.g. cancer screening), whereas other apparently 'positive' effects in forest plots would represent more adverse consequences for the intervention (e.g. mortality). We followed standard conventions[15] for reversing in sign estimates relating to the latter type of outcome measures so that an indicated positive effect in these was also synonymous with beneficial changes associated with the intervention (e.g. decreased rather than increased mortality).

Between-group and within-group heterogeneity were assessed through Cochran's Q with P values < 0.05 indicating significant heterogeneity and the I_2 statistic with a $\geq$50% cutoff for 'substantial' within-group heterogeneity.[14]

Following Cochrane guidelines, assessments of publication bias through funnel plot generation and Egger's test of small-study effects (in Stata 14.1) were only performed on meta-analyses with a minimum of 10 studies included.[14,16]

Finally, we identified process elements in studies that demonstrated positive results.

Results

Synthesis of previous reviews

Titles and abstracts of 2814 records were assessed, followed by 320 full texts of which 50 reviews were included[1,4,5,17–63]

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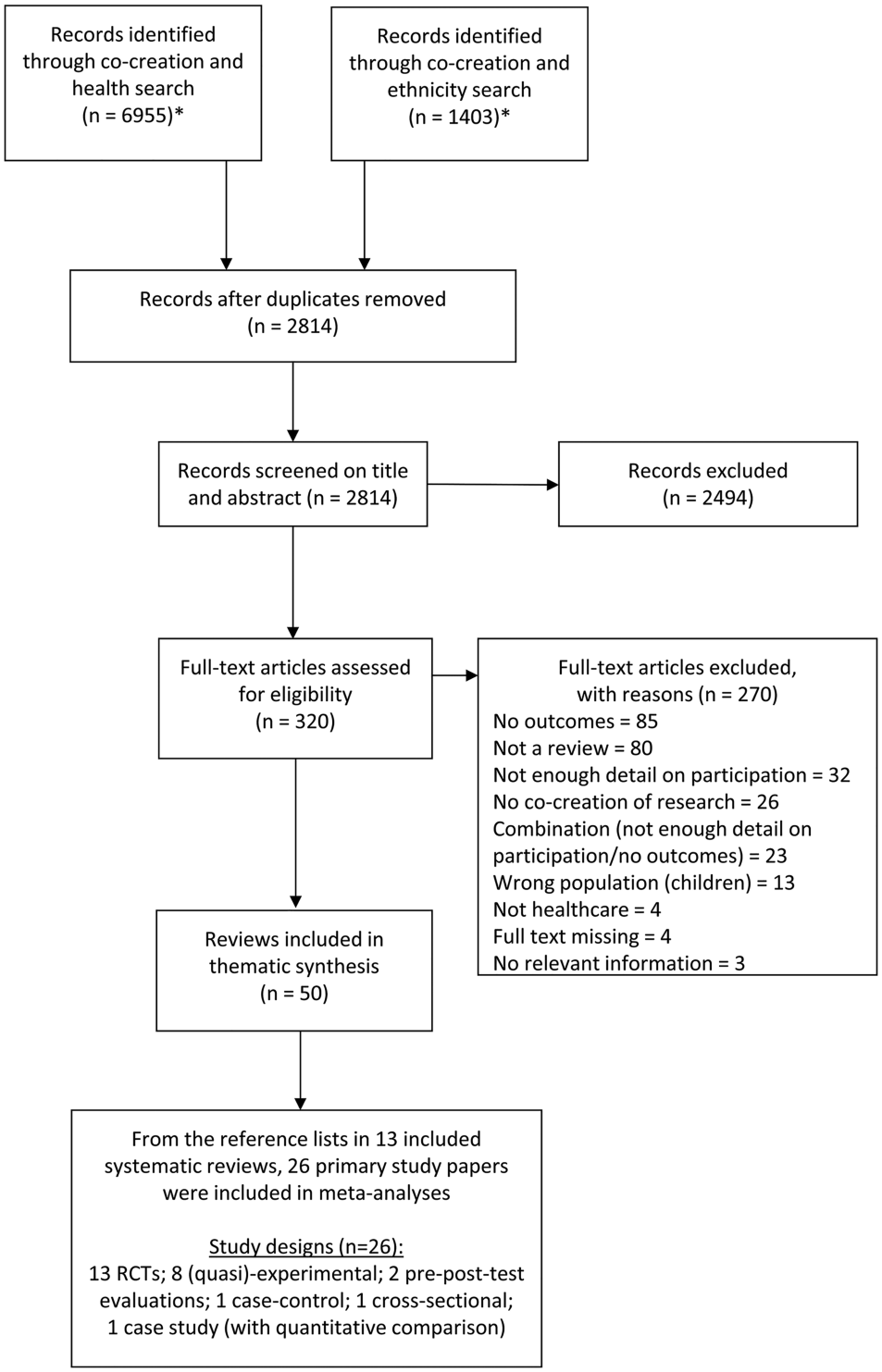

Fig. 1 Flow diagram of searches and screening.

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(Fig. 1 and Supplementary Material 2). Reviews contained quantitative and qualitative studies, while the most reviewed approach was Community-Based Participatory Research (32%).[20,22,26,30,43,46–49,53–55,57,60–62] Multiple geographical settings were covered, but 36% of reviews had a specific US focus[18–20,22,26,28,38,41–44,48,53–55,57,60,61] (Supplementary Material 3).

In the prevalence chart (Fig. 2), some reviews paid attention to multiple themes within their reported aims, elements and outcomes, so that the total percentage within each is >100%. Figure 2 shows that seven aims of co-creation were identified. The most widely represented was 'to validate or enable more reliable research' (62%),[1,4,5,19,20,24,26–30,33,35,37–39,43–45,47,49–52,54–57,59,60,62] including to reduce dropout rates or increase participants' engagement and make long-term goals more sustainable. The most common process element was to 'focus on equality, empowerment and measures of power-sharing' (54%).[4,21,22,28,29,32–36,38–41,44,45,47–51,53,56,58,59,61,63] There were seven outcomes, with 'health literacy promotion and behaviour change' the most frequently reported (56%).[4,17,19–21,27–30,32,34–37,40,42–44,48,52–56,58,59,61,63] However, the vast majority of reviews did not provide sufficient access to quantifiable data to enable meaningful assessments and pooling of effects.

Meta-analyses

Overview of included primary studies

To investigate effectiveness, it was necessary to check the reference lists of the 13 included systematic reviews with quantitative data reporting on the co-creation of research with service users and community members.[5,17,23,28–31,34,49–52,62] This directed us to 26 primary study papers of relevance for meta-analyses.[64–89] Fifty percent of the studies were RCTs,[65,66,68,69,74,75,79,82–85,87,89] while the remaining were (quasi)-experimental or observational studies (see Fig. 1 and Supplementary Material 4 for the full breakdown). Seven studies (26.92%)[64,66,68,69,73,79,80] reported on ethnic minority groups. All of these were conducted in the USA, including three reporting on African American people,[64,68,69] two on Hispanic populations,[66,79] and two with Vietnamese American people.[73,80] Furthermore, the table in Supplementary Material 5 illustrates that service users and community members were more involved in co-designing research projects (92.31%)[64–66,68–71,73–89] than implementing or delivering the interventions (76.92%).[66,67,69–73,75,76,78–82,84–89] However, their involvement was not typically extended to later research stages (evaluation = 11.54%[76,87,89]; dissemination = 19.23%).[69,76,78,80,89]

Results of meta-analyses

Figure 3 shows the forest plots of the main meta-analyses, while Supplementary Material 6 provides more detailed statistics. Co-creation appears particularly beneficial at the social or community level with moderately positive effects (SMD = 0.56, 95% CI 0.29–0.84, n = 11). A small but significantly positive effect was also identified at the systems level for health service access or receipt (SMD = 0.36, 95% CI 0.21–0.52, n = 12) and at the individual level for physical health (SMD = 0.25, 95% CI 0.07–0.42, n = 9), health-promoting behaviour (SMD = 0.14, 95% CI 0.03–0.26, n = 11) and self-efficacy (SMD = 0.34, 95% CI 0.01–0.67, n = 3). For individual mental health outcomes, the result was non-significant (SMD = 0.12, 95% CI −0.02–0.25, n = 6).

Marked heterogeneity was detected for all main meta-analyses (see Supplementary Material 6, including all subgroup and sensitivity analyses). Supplementary Material 6 shows significantly higher effects for ethnic minority people than a more general population for community functions and self-efficacy, but lower for physical health. When the public/patients were involved in co-creating more than one research stage, effects were altered to significantly higher for mental health (SMD = 0.18, 95% CI 0.12–0.24, n = 3). Study design only affected self-efficacy, with significantly lower effects in two RCTs vs. one quasi-experimental study. Based on risk of bias assessments (Supplementary material 7), effects were higher in studies with lower risks of bias for certain outcomes—albeit including few studies. This was the case for health promotion and community functions in RCTs and physical health in other study types.

However, longer term impacts were seldom evaluated/reported and could not be synthesized. Some authors suggested that systematic, longitudinal evaluations were hindered by simultaneous resource demands posed by highly intensive public engagement activities.[28,54,55,58]

Egger's test indicated no significant small-study effects for the two outcome measures with a minimum of 10 unique studies (health-promoting behaviour: P = 0.42; health service access/receipt: P = 0.55; funnel plots shown in Supplementary Material 8).

Process elements of effective co-creation projects

Inspecting the forest plots (Fig. 3) gives an indication of significant positive findings of individual studies. We focused on process elements that these projects—with a significantly positive effect on at least one outcome—had incorporated to, potentially, generate the positive effects (Table 1). The most frequently cited elements were

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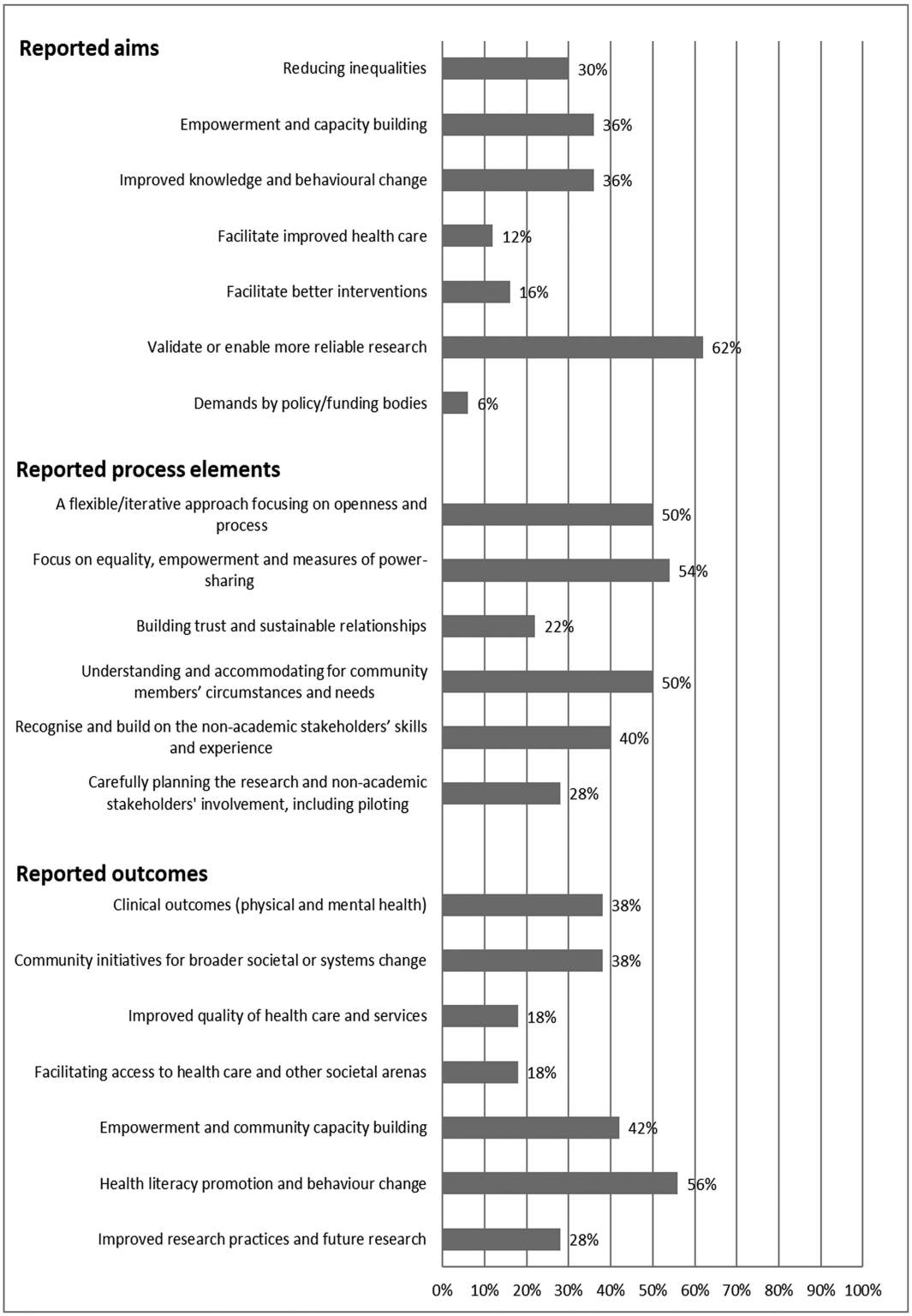

Fig. 2 Reported aims, process elements and outcomes of co-creation (from reviews).

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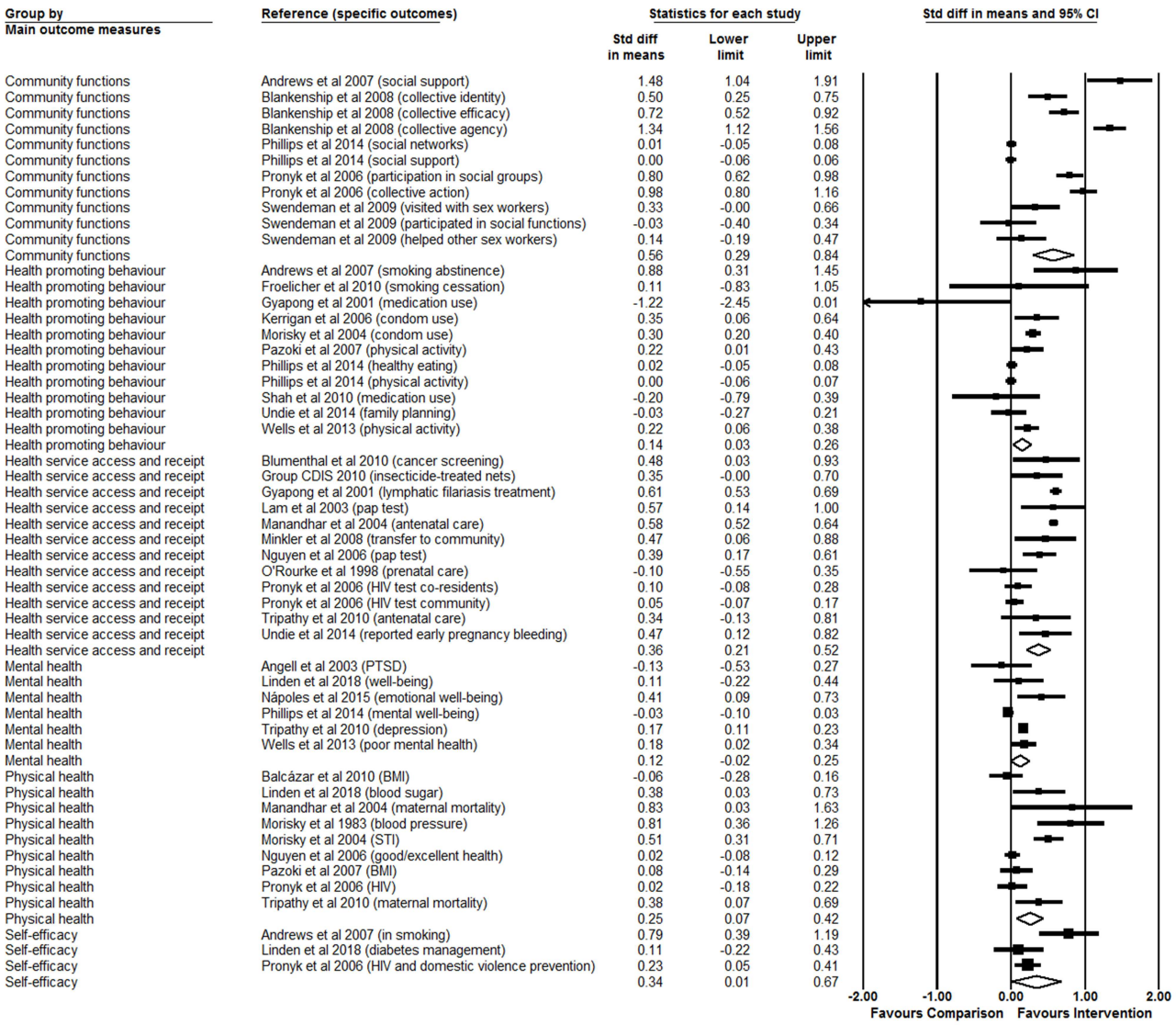

Fig. 3 Forest plot of the effects of co-creation of research on health-related outcomes.

accommodating for co-creation partners' needs and priorities (88.89%),[64,68,71,73–80,82,84,87–89] building on their skills (77.78%),[67,71–73,75,76,78–80,82,84,87–89] adopting an iterative approach of openness and process allowing for continuous amendments (72.22%)[68,71,75–80,82,84,87–89] and measures of equality, empowerment and power-sharing (50%).[64,67,68,74,76,78,80,82,84]

Discussion

Main finding of this study

This systematic review and meta-analysis included 50 reviews and 26 primary studies. Our findings suggested that co-creation of research may improve immediate health-related outcomes from individual to systems levels, including physical health, health-promoting behaviour, self-efficacy, health service access or receipt, while particularly stronger community relations. A significant result for individual mental health outcomes was also shown for studies with participants co-creating more than one research stage. However, co-creation was rarely extended to later stages (evaluation/dissemination).

The accommodation of needs and priorities and incorporation of skills were the most frequently adopted process elements in effective projects. However, multiple elements were identified with an overarching theme of empowerment, transparency, accommodation and enablement. Some degree of overlaps should be expected, so that, for example, initiatives that focused on empowerment were likely to produce stronger relationships between partners.

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Table 1 Cited process elements of co-creation interventions with a significantly positive effect on at least one outcome in our meta-analyses

Reference	*Piloting of study*	*Accommodating needs*	*Building on skills*	*Focus on empowerment*	*Trusting relationships*	*Iterative approach*
Andrews et al 2007[64]	◊	◊		◊		
Blankenship et al 2008[67]			◊	◊		
Blumenthal et al 2010[68]	◊	◊		◊		◊
Gyapong et al 2001[71]		◊	◊			◊
Kerrigan et al 2006[72]			◊			
Lam et al 2003[73]		◊	◊			
Linden et al 2018[74]		◊		◊		
Manandhar et al 2004[75]	◊	◊	◊			◊
Minkler et al 2008[76]		◊	◊	◊	◊	◊
Morisky et al 1983[77]		◊				◊
Morisky et al 2004[78]		◊	◊	◊		◊
Nápoles et al 2015[79]		◊	◊			◊
Nguyen et al 2006[80]		◊	◊	◊	◊	◊
Pazoki et al 2007[82]		◊	◊	◊		◊
Pronyk et al 2006[84]	◊	◊	◊	◊	◊	◊
Tripathy et al 2010[87]		◊	◊			◊
Undie et al 2014[88]		◊	◊			◊
Wells et al 2013[89]		◊	◊			◊

What is already known on this topic

Evidence from previous reviews suggested that co-creation practices may require flexibility and process orientation to accommodate for varied needs, particularly with vulnerable groups. Time and resources need to be made available to facilitate sufficiently engaging public engagement initiatives and rapport, while avoiding tokenistic approaches.[28,54,55,58,90] However, resource demands may compromise the scientific rigour and generalizability through inconsistent operationalizations across approaches and reporting standards. There is currently a lack of validated evaluation tools,[91] with a few emerging such as the Guidance for Reporting Involvement of Patients and the Public (GRIPP) checklist[92] and the PRoblem, Objective, Design, Co-creators, end-Users, Evaluation and Scalability (PRODUCES) guidelines.[9] It may be too early to expect these to have been adequately filtered into research, although a recent systematic review of reporting in patient and public involvement in surgical research used the GRIPP-checklist.[93]

There was also little detail on co-creation with ethnic minority populations, mainly skewed towards more established ethnic minority populations in the USA (e.g. African American people). A recent systematic review[6] (published after our cutoff date for inclusion of reviews) confirmed that despite increasing support for involving ethnic minority groups in research, their involvement is either limited or its extent or nature insufficiently reported.

What this study adds

We believe our study addresses an important gap in health research,[9] demonstrating average effects of co-creation research projects with potential broader applications to public health. Previous reviews have not comprehensively pooled the evidence to establish whether co-creation research has positive effects on health-related outcomes—including how they may be generated, for which outcomes and for whom—and potential effect magnitudes.[9] Our contribution is, to our knowledge, the first systematic review on co-creation in international health research with a more rigorous statistical approach incorporating meta-analyses and investigating effectiveness related to several health-related outcomes, while linking effects to process elements. A meta-analysis from 2013[13] considered all types of community engagement to reduce health inequalities; however, it did not clarify the extent to which these related to research. Our analyses also explored possible explanations for heterogeneity, although we still recognize the potential for confounding by the design and implementation of a multitude of co-creation approaches, interventions and outcomes.

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Limitations of this study

There are some limitations. Firstly, we excluded non-English language articles, grey literature and co-creation with younger people and children, while further evidence may have been identified through a supplementary search for primary studies (our meta-analyses were restricted to studies cited in systematic reviews). Secondly, the RCT is frequently regarded as the 'gold standard' of effectiveness studies.[14] Yet, the interactive nature and context and resource contingency of certain co-creation work mean that other study designs such as observational studies might yield complementary value to the more controlled conditions of RCTs, so were not excluded. As various practices and views exist on whether to include different study designs in the same meta-analysis,[94] we conducted sensitivity analyses by RCTs compared to other study designs and risk of bias within both respective study categories (notably, retrospective designs such as cross-sectional[67] and case–control[81] studies tended to score high on risk of bias; Supplementary Material 7). The sensitivity analyses revealed little evidence of influence of either study design or risk of bias (Supplementary Material 6). Thirdly, it is difficult to ascertain the exact extent to which identified effects are 'purely' a result of research being co-created or were affected by available resources and constitutive ingredients shaping multiple intervention and comparison conditions (Supplementary Material 4). Although we compared co-creation through only one research stage versus more than one stages, future primary studies should emphasize interventions in which co-creation is the only difference between the intervention and comparison conditions to isolate the effects of co-creation *per se*. Moreover, there should be more attention to the longer term feasibility of co-creation. Reviews reported that the most common aim was a broad, high-level, aim to improve overall standards of research; however, the most commonly identified outcomes were more immediately observable at post-intervention (e.g. health promotion). This likely reflects preference for more 'straightforward' outcomes but could also indicate that co-creation's innate value is assumed to 'speak for itself', or is a research expectation, rather than researchers believing in its potential to genuinely improve health practices and public health more broadly or reduce wider inequalities. Improved research may indirectly benefit the community through more inclusive and better implemented practices; however, the lack of longer term evaluations precluded any definitive conclusions. Finally, we were unable to perform a more robust comparison of specific co-creation approaches due to the limited evidence within each approach and authors' imprecise and varied definitions. Future research could develop and apply standardized definitions and reporting frameworks to improve comparability and consistency in this field.

Supplementary data

Supplementary data are available at the *Journal of Public Health* online.

Acknowledgements

None.

Funding

The research reported in this article takes part of the emerging work of the Synergi Collaborative Centre, which is a 5-year national initiative to build a knowledge hub on ethnic inequalities and multiple disadvantage in severe mental illness in the UK. The Centre has been funded by the Lankelly Chase Foundation. The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Conflict of interests

None.

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