A selection of systematic reviews for Researchers, Services and Commissioners

ARC KSS Co-production theme | May 2021

Co-production: a selection of systematic reviews

In this document we present a selection of reviews that use co-production in a meaningful way. We hope this helps provide ideas for gaps in the literature, designing studies and getting a flavour of what is already 'out there'. We have started with reviews focused on capturing or evaluating outcome measures and then focused on three areas where there are recognised challenges to co-production of research and services: social care for people with cognitive impairment living in the community; end of life care; and children and young people. The reviews cover a range of settings and include examples where digital technology has been used.

Dr Nadia Brookes, Dr Vanessa Abrahamson and Lisa Richardson

n.k.brookes@kent.ac.uk | v.j.abrahamson@kent.ac.uk| l.j.richardson-29@kent.ac.uk

May 2021

Contents

Measuring co-production and capturing outcomes (alphabetical order)

	Aim	Type of systematic review, method & studies included	Study overview and the main strengths/limits
(Clarke et al. 2017)	To identify and appraise reported outcomes of co-production as an intervention to improve quality of services in acute healthcare settings.	**Rapid evidence synthesis**: 6 databases (Medline, CINAHL, Web of Science, Embase, HMIC, Cochrane); grey literature (SCIE, Proquest Dissertation and Theses, EThOS, OpenGrey); 3 journals; and citation tracking of five key papers. Jan 2005-Jan 2016. **Main inclusion criteria**: studies reporting patient (adults), staff or organisational outcomes associated with using co-production in an acute healthcare setting (emergency departments, acute inpatient and some outpatient facilities e.g. medical, trauma). **Analysis**: standard data extraction and data synthesis which entailed grouping studies by findings viewed as answering the same research questions or addressing the same aspects of a target phenomenon. **11 studies:** one feasibility randomised controlled trial, three process evaluations and seven qualitative studies. Countries: Canada, England, New Zealand, Australia and the Netherlands. Five of the settings were inpatient and outpatient oncology services.	**Background**: short review of co-production. The review was undertaken to inform a study about acute stroke care and rehabilitation. **Findings/discussion**: Most papers focused on the *processes* used to understand and co-design within services rather than evaluating *outcomes*; the exception being the feasibility RCT (also the only study to use a validated outcome measure). Most studies used descriptive qualitative approaches to evaluate changes in services or explore participant's experiences, but these lacked detailed description. Despite different use of terminology (e.g. participatory, creative design) most papers demonstrated patient, carer and staff working together to improve services. Outcomes were divided into involvement in the process; generating ideas and suggestions for changes; tangible change in services and impact on patient or carer experiences. Table 1 describes types of outcome with helpful examples. Main barriers: lack of support, resources or managerial authority to bring about changes; ensuring patients could attend meetings and recruiting/retaining them; constraints on staff time. Difficult to set up and implement co-production approaches in busy acute settings 'where no formal, practical and financial provision is made for staff, patient and carer involvement on a sustained basis' (p10). Implementation of improvements, evidence of impact and sustainability were not well reported. Only one study reported a (limited) cost analysis which led to the conclusion that there is a 'lack of rigorous evaluation of effectiveness and cost-effectiveness of co-produced interventions in the acute healthcare sector at both the service and system levels' (p10). **Strengths**: comprehensive review; the included studies provide helpful examples of co-production in a range of acute settings. **Limits:** not much guidance on how to capture impact, embed sustainability or measure cost effectiveness.
(Hoekstra et al. 2020)	Describe a review of reviews focusing on four key domains of research	**Review of reviews** using PRISMA guidelines. Twelve electronic databases of which four health databases (Medline, Embase, CINAHL, PsycInfo) were searched from inception to January 2018 and updated in April 2018.	**Background**: the project consists of a series of literature reviews conducted across six Canadian universities, exploring unique aspects of different types of research partnership approaches, predominantly in the health sciences. **Findings**: Tables 5-7 provide detailed breakdown of each category:

| | partnerships: principles, strategies, outcomes and impacts. | **Main inclusion criteria**: reviews that focused on the following concepts: partnership research, participatory research, knowledge translation and knowledge transfer and specifically how partnerships work and the outcomes or impacts.

Analysis: methodological appraisal tool and three rounds of direct content analysis to extract principles, strategies, outcomes and impacts. Included a Consensus Panel of stakeholders.

86 reviews: majority (83%) were published between 2012-18. First authors were mainly from the United States (n = 36), Canada (n = 17), UK (n = 14) and Australia (n = 9). The main research areas were population health, health services and health and social sciences. | *Principles* were distilled into six sub-categories: (1) relationship between researchers and stakeholders (e.g. based on trust, credibility, respect, dignity and transparency) (2) co-production of knowledge; (3) meaningful stakeholder engagement (e.g. flexible and creative); (4) capacity-building, support and resources; (5) communication between researchers and stakeholders; and (6) ethical issues of collaborative research activities.

Strategies were also grouped into categories that included the relationship (and communication) between researchers and stakeholders; capacity-building, support and resources; stakeholder engagement in planning, conducting and dissemination of the research, and its application.

Outcomes and impacts were synthesised into five subcategories that related to researchers and stakeholders, the relationship between them (and the broader community), and the research process. Two-thirds were classified beneficial outcomes/impacts and included the research partnership creating high quality research; stakeholders experiencing personal benefits and/or increased capacity, knowledge and skills; and the research partnership leading to system changes or action. However, each of these was only identified in 10-15% of studies.

Discussion: most useful were comments on gaps in the literature which included:
- limited understanding of which principles and strategies were successful in which contexts and under what circumstances
- mainly focused on perceived/self-reported outcomes and impacts, and failing to differentiate between the two concepts
- the reasons for negative outcomes/impacts e.g. failed partnerships, poor co-production processes, a combination or other influences.
- variation in terminology and/or the lack of reporting on details of the research partnerships processes.

Strengths: very comprehensive description of all stages and outcomes of the review with helpful tables; lots of further information available on the study website

Limits: descriptive and limited discussion but the study limitations section is very thorough. |
| (Marsilio et al. 2021) | To identify the methods, tools and metrics used to evaluate health co-produced | **Systematic review** using PRISMA guidelines: 6 databases (Scopus, Web of Science, Psych INFO, PubMed, Cochrane and CINAHL) searched 1987 to Nov 2020.

Main inclusion criteria: studies focused on evaluating co-production. Search terms for co-production combined with those for health and | **Background**: discusses co-production at the individual and collective level (to enhance community resilience in the context of covid-19). Suggests there is evidence linking co-production to specific single dimensions (e.g. perceived service quality) but not to 'the impacts of coproduction on the different stakeholders involved and its sustainability over time' (p2).

Findings: outcomes were mainly investigated through qualitative methods and from the lay or provider perspective. Marked lack of attention to informal caregiver or |

	services, according to each stakeholder.	public sector AND evaluation, impact, outcome, indicator or measure. **Analysis**: methods, tools and metrics used were initially coded using a particular framework. Outcomes classified according to the actors affected by co-production: provider, professionals, lay and community. For quant/mixed methods papers, picked out what measures or metrics were used and who they related to. **203 articles** (health n=161, public, n=42) were included in the analysis. Of the health studies, 50% were UK based and 61% of the papers focused on long-term conditions. About half of the articles were qualitative, the rest were equally divided between quantitative and mixed methods.	professionals' perspective. Thorough account of the quant measures and metrics used for each category (e.g. providers) and Figure 4, analytical components framework, provides a helpful summary. **Discussion**: suggests a 'fragmented picture' regarding study design, approaches, methods and tools (how co-production is measured) and specific metrics (what is measured) (p18). Less than a quarter of the studies were based on longitudinal or cross-sectional design so little comparison of outcomes for different actors, against pre- and post- benchmarks or over time (sustainability). Argues that preponderance of qualitative research misses important contribution of quantitative or mixed method approaches. Concludes that the findings 'offer a blueprint multidimensional quantitative performance measurement system' that can inform the evaluation of co-production (p20). **Strengths**: comprehensive search strategy, well presented and useful framework with suggestions for further research. **Limits:** we know with complex interventions it is difficult to elucidate what aspect led to which outcome or why and the review does not really elucidate underpinning mechanisms as to why a particular approach to co-production, in a specific context led to which outcomes.
(Pirinen 2016)	Explores the prerequisites of co-design for services by identifying barriers and enablers to co-design activities occurring across organisations that are developing services.	**Methods:** Not a review, but based on interviews with stakeholders from 6 research driven co-design projects focused on collaborative service development, specifically projects focused on technology, healthcare and education (based in Finland). **Selection criteria for case studies:** focus on cross-organisational service development, use of design methods, and access to project data. **Analysis:** focused on methods, processes and impacts of co-design. Content driven analysis, looking for perceived barriers and enablers.	**Background:** brief overview of how health and social care services have begun adopting collaborative service design approaches and role in innovation. Focus is on co-design as facilitation of collaboration. More detailed overview of research from organisation studies and design, which emphasises that organisational hierarchy and culture are the main barriers to co-design. Shared user focus, openness and experimental approaches are cited as main enablers. **Findings:** 20 barrier-enabler couples are presented, these focus around 5 themes: 1. collaboration- finding a common ground, 2. Organisation- creating commitment, 3. Process- being integrated, 4. Implementation- making an impact, 5. Methods- becoming a practice. **Discussion:** The findings highlight selection of co-design methods as important, as well as skilled facilitation and the role of a 'change agent'. **Strengths:** Outlines approaches for impactful co-design, thus enabling person's undertaking co-design projects to focus their efforts in getting in right **Limits:** does not consider participatory design with users of health and social care services. Relies on subjective experiences of participants who are advocates of co-design.

Involving older adults in research and/or technology design

	Aim	Type of systematic review, method & studies included	Study overview and the main strengths/limits
(Boulton, Horne and Todd 2020)	To identify the extent to which older adults have been involved in the **design, delivery, implementation** and promotion of primary prevention interventions to promote **physical activity**.	**Review** influenced by the principles of realist synthesis. CINAHL, Embase, HMIC, MEDLINE, PsychINFO, Social Policy and Practice and the SSCI. Up to Jan 2019 (no date restrictions). **Main inclusion criteria**: original research; older adults, 50+; community dwelling; involvement in design, delivery, implementation or promotion of interventions. **Analysis**: used a mixture of quality appraisal tools and narrative synthesis. Included reviewing the extent of involvement in the intervention. **10 studies** with broad range of methods including participatory (3), cohort study (2), RCT (1) and various others but no exclusively qualitative designs. Countries: eight from USA, one each from UK and Sweden.	**Background**: overview of evidence on programmes promoting physical activity (PA) amongst older adults and why involving them in all aspects of these interventions could contribute towards better outcomes. **Findings**: unsurprisingly, the *nature of involvement* varied widely and was categorised as consultation, co-operation, co-learning, collaboration, peer leadership and mentoring (Table 4); each category is reported on. Reported benefits of the PA programme related to PA *adherence and engagement* (Table 5) and were cross referenced to the style of involvement. For example, four studies described peer leadership or mentoring and reported that participants continued to engage in activity at longer-term follow-up stages. Similarly, involving people in the iterative process to identify barriers and facilitators to PA appeared to produce practical solutions with high levels of consensus. **Discussion**: all studies reported positive relationships between older adults' involvement and increased levels of satisfaction, participation, or measures of physical Health but it was difficult to identify the reasons why. Discusses the lack detailed description of participatory involvement resulting in limited evidence on outcomes. Concludes that 'participatory research methodologies demand systematic, regular critical reflection on actions taken and their relationship to the outcomes achieved' (p340). **Strengths**: part of a PhD so if of interest, the thesis will provide further details. **Limits:** Another vague conclusion that 'there is some value in the involvement of older adults at various levels of intervention development' (p342) but it is not possible to ascertain any specifics. It says it is realist informed but this is not evident despite linking the nature of involvement with outcomes (suggesting a nod at context and outcomes, but not exploring mechanisms). However, it does lend itself to a realist evaluation!
(Hopwood et al. 2018)	To identify key components of existing **internet-based**	**Systematic review** searched CINAHL, Cochrane Library, EMBASE, MEDLINE, PsycINFO and Web of Science; articles published Jan 1990 - Apr 2018.	**Background:** overview of the impact of being a carer for a person with dementia, including at end of life; reasons for the poor uptake of interventions; and the rationale for internet-based interventions. **Findings:** identified 5 key components of interventions: *peer support* from fellow carers, either on-line or privately (e.g. email); *contact with a professional* (often an

	interventions designed to support family carers of people with **dementia**; consider the evidence of effectiveness of these interventions; and develop an understanding of which components are most valued by carers.	**Main inclusion criteria**: digital interventions delivered via the internet, fully described and aimed at informal carers. **Analysis**: CASP quality appraisal tool and their own data extraction tool. Narrative synthesis with thematic analysis. **40 studies** comprising 31 different interventions. Nine 9 RCTs, 7 quasi-experimental studies, 4 qualitative and 20 mixed or other methods. Study characteristics are in a supplementary file.	occupational therapist) to provide personalised practical advice and emotional support; *provision of information*, mostly as part of a multi-component intervention; *decision making support*; and *psychological support*. Barriers included internet literacy and where interventions were not personalised, carers found this frustrating and their needs were not met. **Discussion**: overall quality of the studies was low and many different outcome measures were used, making interpretation and generalisability of the effectiveness findings difficult. Some multiple-component interventions showed promise in reducing stress, anxiety, and depressive symptoms for carers with the usual caveat that the limited number of high-quality RCTs and the multiple-component nature of many interventions made it difficult to ascertain which aspects of an intervention were effective. Additionally, many studies had high levels of dropouts and/or carers made limited use of some of the components of the intervention. Issues around privacy and security were highlighted, reflected in the contrast of public versus private messaging approaches, given the sensitivity of what was discussed. **Strengths:** the follow up article (Davies et al. 2019) is excellent and we have included this in our co-production guide. **Limits:** as the authors noted, many of the studies were feasibility and pilot studies, so they were unable to draw definitive conclusions surrounding effectiveness and acceptability. Other limitations are noted above.
(Merkel and Kucharski 2019)	To examine what different forms of **participatory design** (PD) exist in the field of **gerontechnology** and how these can be categorised.	**Systematic review** using PRISMA guidelines. Databases: APA Search, GeroLit, PubMed, and Web of Science. Google scholar for grey literature and tracking references. 2012-2017. **Main inclusion criteria**: interventions targeting older people (60+yrs) as (future) users of a technological artefact (search terms included technology development, assistive device) and involving a participatory approach (e.g. co-production). **Analysis**: standard data extraction using their own template; classified studies based on the phase of the research or design process. **26 studies:** reported on technology, sample and method (but not country). A broad range of approaches and instruments used to develop and design a variety of technologies.	**Background:** short overview of participation; why modern technologies (e.g. assisted living technologies, telecare) have the have the potential to support active and healthy aging. Technology divided into software (e.g. smartphone applications) or interfaces and hardware devices (e.g. touchscreen or robot). **Findings**: categorised into three groups: studies that used already existing technology with the aim of finding new ways of use; studies designing completely new technologies for and with older persons, as co-producers and co-designers, either starting from scratch or with an initial idea; and studies focused on testing and/or modifying existing products. **Discussion**: focused on thinking through the aims of participatory research – *who* is involved (e.g. patient, carer, care home staff), how to include socially disadvantaged groups, and how to ensure participants are representative of those who will use the device; *when* (divided into four stages - idea generation/conceptualisation, device (re-) design, prototype testing, and diffusion); and *how* technology users are incorporated into the innovation process. Notably, none of the studies included an evaluation of the process asking co-designers if they were satisfied with the outcomes and process!

			Strengths: if you are planning a participatory approach to technology this review provides will help you think through the issues and provides useful references. **Limits:** largely descriptive and limited search (2012-17). Studies had very different remits.
(Rai et al. 2019)	Aimed to evaluate current approaches, and create best practice guidelines for involving people with **dementia** in developing **technology based interventions**.	**Systematic review:** searched EMBASE, PsycINFO, MEDLINE, CINAHL and Web of Science. Studies published between 2000-2019. **Main inclusion criteria**: diagnosis of dementia and involved in developing a technology-based intervention. Search terms in 3 categories: dementia, technology, and involvement in development (codesign, participatory research, user participatory development). **21 studies**: 14 were purely qualitative; 6 were mixed methods, of which 1 combined qualitative and a controlled trial; only 1 purely quantitative study. **Analysis**: created their own data extraction tool and quality was assessed using CASP guidelines. Narrative synthesis.	**Background**: short review about involving end users in developing technology. **Findings**: Wide variety of technology-based interventions, including communication aids, music tools, devices to support activities of daily living, reminder systems, and tracking devices. Studies were described by phase of involvement (development, feasibility & piloting, evaluation and implementation), as outlined by the Medical Research Council framework and the Centre for eHealth Research roadmap. **Discussion**: Benefits for participants included the 'empowering effects of involvement that were evident in increased feelings of well-being, being able to voice opinions, learning a new skill through the use of technology, and an enhanced sense of control' (p9). Interesting finding that once a piece of technology had been developed into a more refined version, the involvement of people with dementia shifted towards the participants becoming the objects of study. Additionally, no studies involved the participation of people with dementia in the implementation phase. Most studies concluded that it was necessary and feasible to involve people with dementia, with the right prerequisites in place, and that it was a positive research experience for participants. The 'Summary of best practice guidance' (Box 2) provides helpful albeit common sense suggestions. **Strengths**: Useful logic model on optimising the involvement of people with dementia (Figure 3). Helpful to divide by phase of involvement. **Limits**: the authors regard the preponderance of qualitative studies as a limit. The 'long-term outcomes' in the logic model are rather a leap of faith.
(Schilling and Gerhardus 2017)	To support scientists intending to involve older people in health research by systematically identifying and describing studies involving older people and	**Literature review:** PubMed, CINAHL and Cochrane Library, 2007-Jul 2017; manually searched reference lists of the nine retrieved articles and other relevant sources; citation tracking from Google scholar. **Main inclusion criteria**: active patient involvement in research; at least one old age-related condition; English, German, French and Spanish language. Wide range of terms for participation including co-research but not co-production. Criteria (Table 1) and search terms (Figure 1) are very clear.	**Background:** short review of the continuum of PPI and study rationale. **Findings**: starts with a description of aims, methods and stages of involvement (only two studies involved people in all stages of research); recruitment strategies; level of participation and roles; setting (four were conducted in a familiar environment); and ethical approval. Table 2 summarises this information. More useful are the findings around *challenges and facilitators of PPI* (Table 3 is very helpful) which were grouped into seven categories: diversity, communication, location, relationship, timing, continuity and support. Two strategies were identified to increase *diversity*: the use of wide networks when recruiting, and the use of separate PPI activities for people with different conditions and experiences.

	analysing associated **facilitators** and **challenges**.	**Analysis**: developed their own data extraction form. No quality assessment. Narrative synthesis: the main categories aligned (deductively) with the research questions. Subcategories for 'challenges' and 'facilitators' were created inductively based on the data. **9 articles** representing 10 studies: all conducted in the UK. Eight focused on people with dementia and one on people with frailty.	Strategies to enhance *communication* included ensuring accessibility of information, adapting information to the group, securing knowledge through refreshments and summaries, use of meaningful and non-suggestive task, setting a pace that is appropriate for all participants and the use of visualisations. There is a short discussion of location, timing and relationship building, in relation to people with dementia. None of the studies explicitly presented methods for the involvement of people in nursing homes, or with mobility, hearing or visual impairments. **Discussion:** discusses *selection bias* and ideas to be more inclusive of those with stigmatising conditions. One paper recommended prudent language and careful reflection on how potential participants could be approached. Short discussion around *ethics* and ensuring consent is monitored and reviewed over the duration of the project. This also related to *continuity* for long projects and *flexibility* of involvement to accommodate individual need. **Strengths:** provides food for thought, whether PPI or co-production, on how best to involve a wide range of people and to ensure it is a positive experience. **Limits:** mainly descriptive and the focus is PPI. However, the information is relevant, particularly suggested strategies which can be followed up in more detail by accessing the full PhD on which this review is based.
(Sumner et al. 2020)	To evaluate the effects and experiences of **co-designed technology** that support older adults to age in place.	**Systematic review:** PRISMA guidelines. Searched MEDLINE, EMBASE, CINAHL, Web of Science, Scopus, OpenGrey, and Business Source Premier, 2009-2019. **Main inclusion criteria**: combination of MeSH terms and keywords on the themes: older adults, community setting, and co-design. Key journals were hand searched. **Analysis**: Cochrane risk of bias tool was used to assess the quality of studies. Studies that included health and well-being outcomes were synthesised narratively. Facilitators/ barriers to co-design were extracted and organised using a co-design framework (Pirinen, 2016). Reported outcome measures were too diverse for a meta-analyses. **Studies**: 34 projects, 43 articles. Projects were largely from Europe (n = 28) and the rest from	**Background:** basic overview of co-design and technology. **Findings**: The intensity and method of involvement varied greatly. Twenty projects targeted older people's general needs or concerns and an additional 14 targeted specific medical conditions/problems. Technological solutions included robots, online applications and software, smart televisions, computer games for exercise, global positioning solutions, smart home systems, and design of care pathways. Solutions mostly targeted older adults as individuals (n = 30) rather than group applications (n = 4). **Discussion**: Helpful section on the barriers and facilitators to co-design - the most frequently reported were divided into three areas related to *relationships and trust building*, *stakeholder knowledge building*, and *methods and skill in co-design*. Figure 3 provides a helpful summary. The diversity of methods used made it hard to compare across studies and identify which approaches were effective. Concluded that the impact of co-designed technology for aging in place 'remains unclear' (p10).

		Australia (n = 4), USA (n = 1) and Canada (n = 1). Five RCTs.	**Strengths**: using a co-design framework which divided involvement into 5 domains (collaboration, origination, processes, implementation and methods) was helpful. Table 2, study characteristics is well presented (compared to many other reviews).
			Limits: no major limits but we could quibble that it was unclear what the study designs were other than the five RCTs.

End of life care and frail/seriously ill

	Aim	Type of systematic review, method & studies included	Study overview and the main strengths/limits
(Chambers et al. 2019)	To examine the evidence regarding patient/carer involvement in **palliative care research** and identify the facilitators, barriers, impacts and gaps in the evidence base.	**Qualitative evidence synthesis**: 11 databases, websites & palliative care organisations searched up to Mar 2018 (no start date). **Main inclusion criteria**: palliative care research or setting; any evidence on the effects of involvement on process or outcome; Western populations; & adults. Search terms included Involv* OR Engag* OR Participat* OR Co-produc* OR Collaborat* OR Partnership working. **Analysis**: integrative review approach and thematic analysis (coding framework developed inductively). **93 records** included reflecting **60 studies**. Characteristics are provided as supplemental material.	**Background**: briefly covers why patient involvement in research has a shorter history compared to other disciplines and is regarded as more complex and challenging. **Findings:** eight themes, mainly describing facilitators and barriers to effective patient and carer involvement: definitions/roles, values/principles, organisations/culture, training/support, networking/groups, perspectives/diversity, relationships/communication and emotions/impact. The perceived vulnerability of patients/carers by professionals was frequently cited as a barrier to involvement. Nicely summarised in Figure 2 and Table 3 with key learning points. Evidence gaps were found in non-cancer populations and collaborative/user-led involvement. **Discussion:** the range of issues reported from differing perspectives suggested a greater power imbalance between patients/carers and professionals than in other fields, and a resulting amplification of the complexities. When involvement was carried out effectively, there were positive benefits for all concerned in addition to improving the relevance and quality of the research. **Strengths:** comprehensive and detailed review with particularly thorough data extraction and evaluation which used two quality assessments tools to provide ratings. Patients/carers were involved at several stages of the review. **Limits:** conflates PPIE and co-production but this reflects unclear definitions of involvement (and palliative care) in the literature.
(Ludwig et al. 2020)	To synthesise the evidence on the engagement of **frail and/or seriously ill** (FSI) patients as research partners across the research cycle.	**Systematic review**: using PRISMA guidelines, searched MEDLINE, EMBASE, CINAHL, and PsycINFO databases from journal inception to April 2019. **Main inclusion criteria**: All studies of any design if they included frail and/or seriously ill patients as research partners. Search terms included participation, involvement, collaboration and empowerment (but not co-production). **Analysis**: studies were appraised with a Mixed Methods Appraisal Tool and ranked as having low,	**Background**: overview of patient engagement continuum, including co-production, and definition of frailty. **Findings:** provided a thorough description of patient characteristics; most studies included people with cancer (60%). *Barriers* were divided into system, team, researcher and patient level factors and included: lack of time and resources, discontinuity in contribution, lack of clarity around roles and expectations, and concerns for wellbeing. *Facilitators* included: trust and mutual respect, structural accessibility, flexibility in timing and methods of engagement and attention to comfort.

		moderate, or high quality. Engagement in research was extracted on four components: a) stages of the research cycle; b) the level of engagement in decision-making; c) barriers and facilitators to engagement; d) the described impacts of engaging FSI patients. **30 studies** included, most published 2015-19. Twenty used qualitative methods (and most were rated as high quality), 2 were quantitative and 8 were mixed methods; 18 studies were UK based.	Perceived impacts for *patients* included renewed personal sense of agency and emotional/peer support while benefits for *researchers* included sensitisation to the experience of illness and an increased appreciation of the benefits of patient engagement. Impacts were also divided by patient, research and researchers. Table 5 provides a helpful summary. **Discussion:** brief but highlights the need to 'confront' (p17) clinicians and caregivers' reticence to over-burden FSI people which can lead to active and passive gatekeeping to engagement. Also discussed discontinuation due to illness. Concluded that research developed and implemented with patients was 'deemed more suitable, relevant and reflective of patients' priorities' (p1). **Strengths**: the conceptual framework for engaging FSI patients (divided into level of engagement at different stages of the research cycle and level of involvement in decision making) was evidence based and clearly presented (see Table 1). Barriers and facilitators to participation were thoroughly described (see Figure 3 for a great visual representation). An excellent example of how to do a systematic review and why it takes so long! **Limits:** as they acknowledged, the use of terminology across studies lacked clarity. Interesting they did not use co-production in their search terms but did refer to it in the introduction.
(Ludwig et al. 2021)	To identify the **ethical considerations** related to engaging frail and seriously ill (FSI) patients as partners in research.	**Sub-analysis of the above systematic review** **Main inclusion criteria**: studies that reported on ethical considerations associated with engaging FSI patients as partners in research. **Analysis**: deductive content analysis, data were categorised according to the ethical principles of autonomy, non-maleficence, beneficence, and justice. **25 studies** included, as above.	**Background**: overview of moral and ethical arguments for patient engagement based on the above systematic review. **Findings:** common ethical considerations reported in relation to the principles were: *Autonomy* - promoting desired level of involvement, addressing relational and intellectual power, facilitating knowledge and understanding of research; *Non-maleficence* – protection from financial burden, physical and emotional suffering; *Beneficence* – putting things right for others, showing value-added, and supporting patients; and *Justice* – achieving appropriate representation, mutual respect for contributions, and distributing risks and benefits. **Discussion**: highlights the importance of researchers considering the 'purpose of partnering with patients, roles, anticipated outcomes (beneficial/harmful)' and how these may develop during the project (p8). Discusses informed consent in the context of, for example, dementia and the potential impact of relational power differences. Touches on lack of diversity. Interesting comments around the conflation of FSI patients with other stakeholders (e.g. patients no longer receiving treatment, carers) when

			reporting the outcomes of partnering with patients. Concludes that FSI patients must be offered the opportunity to partner in research.
			Strengths: clearly written and presented. Table 1 presents ethical principles and themes in a digestible format.
			Limits: the authors acknowledge criticisms of the approach to categorising ethical issues as reductionist but argue the advantages outweigh.

Children and young people

	Aim	Type of systematic review, method & studies included	Study overview and the main strengths/limits
(Bradbury-Jones, Isham and Taylor 2018)	To explore ethical & methodological issues in carrying out participatory research with **vulnerable children and young people** (CYP)	**Qualitative review**: carried out Sep-Oct 2017, searched 6 databases, 2000 onwards plus hand searching. **Main inclusion criteria**: research carried out with children or led by children. Included papers that reported on empirical studies and contained a substantial critical or reflective element. Vulnerable defined as CYP in care and/or experienced abuse, neglect or violence; physical disability or learning disability; mental health; LGBTQ. **Analysis**: inductive, thematic analysis of each article, & across all included articles **13 studies** included from Australia, Canada, Finland, India, Papua New Guinea, South Africa, Sri Lanka, UK (x3) & USA. Only 2 include young children (age 8+).	**Background**: useful discussion on the history, terminology and challenges of participatory research with vulnerable/marginalised CYP. **Findings:** three themes: empowerment as a reason to undertake participatory research and/or the process having positive outcomes; the power relationship between adult researchers and CYP; and the need for inclusive, adaptable research designs and methods to enable CYP to participate. **Discussion**: findings supported the view that participatory research provides an opportunity to strengthen links between young people, policies and practices but acknowledged that 'empowerment is nebulous and over-used and… risks over-simplification' (drawing on Foucault). **Conclusion**: provided an analysis of the conceptual complexities and contradictions of participatory research with CYP, particularly regarding power, empowerment & voice. **Strengths**: provides excellent rationale for using this approach. **Limits**: only 3 UK studies; limited guidance on the practicalities of implementation.
(Brunn, Brunner and Mutsch 2021)	To embed a systematic literature assessment coproduced with stakeholders in the **nightlife setting** in a structured stakeholder dialogue.	**Systematic review** using PRISMA guidelines. Searched EBSCO Medline, Embase, PsyIndex, PsycInfo, 2012-2016; reviews and gray literature sources from 1990-2016 in English, German, French, Spanish, or Italian; topic-based websites. **Main inclusion criteria**: young people, 18–35 years; nightlife setting (social activity and entertainment); interventions targeting recreational drug and/or alcohol use in nightlife. **Analysis**: assessment of quality using standard tools for systematic reviews (AMSTAR) or observational studies (STROBE). Narrative data synthesis.	**Background**: association between nightlife participation and recreational alcohol and drug use; subsequent problems; specific to Switzerland. **Findings**: interventions were grouped according to their starting point (before the party, at the party or after the party) and the type of strategy (individual-centred, environmental or structural. **Discussion**: brief and related to the topic, not the process of knowledge co-creation. **Strengths**: a thorough review and Figure 2 provides a helpful framework. **Limits**: at first glance, this paper suggested a systematic review carried out with young people but in fact stakeholder involvement referred to community-based experts in the field of addiction prevention and did not include young people, even in a half-day 'stakeholder dialogue' event! We have included it because it is a good example of a review that could have been so much enhanced by entering into dialogue with those it appertains to.

| (Honingh, Bondarouk and Brandsen 2020) | To establish what research has been conducted on co-production in **primary schools**, and to what extent there is evidence of effectiveness. | **Systematic** review, 3 steps to search strategy. Databases: Web of Science & Education Resource Information Centre, 2007-16. Keywords included co-production, involvement, engagement, partnership and participation AND education/ school.

Main inclusion criteria: explicit focus on the relationship between co-producers & service providers; barriers/facilitators to parental involvement; governance issues. Children 4–12yrs.

Analysis: data extraction included theoretical orientation, mode of co-production, organisational barriers & facilitators, & teachers/parent relations.

122 studies: 71 USA; 8 UK; the rest from multiple other 'developed' countries. Majority were empirical (66%) or conceptual (24%) papers, the rest were reviews or policy discussions. | **Background**: the theory (why actively involving parents should be beneficial) and evidence for co-production in schools. Divides into goals – acquisition of knowledge and socialisation.

Findings/discussion: papers divided into three types:

Conceptual papers: focused on theoretical reflections on the assumptions underlying co-production and the diverse interpretations of parental activities in school.

Policy papers: marked differences between countries in terms of how co-production was embedded in policy debates, mentions contribution of school governance policy in the UK.

Empirical papers: About 70% of papers discussed parent/teacher relationships; nearly 20% involved teacher training. Some were specific to minorities or low socioeconomic status. Divided into
- *antecedents of co-production* in primary schools: inconclusive regarding the mechanisms contributing to better academic achievements and effective parental involvement;
- *parent-teacher relationship* such as teachers having negative attitudes;
- *training teachers* to improve their skills in building school–parent partnerships;
- *effects of co-production:* the majority tried to measure knowledge acquisition but programme aims were too diverse to compare;
- studies supporting the engagement of parents from specific *socioeconomic and demographic groups* by, for example, providing parents with the necessary knowledge, skills and confidence with mostly positive outcomes.

Conclusion: a lot of unknowns and lack of transferability. Co-production appeared to improve knowledge acquisition but effects on socialisation were unclear.

Strengths: brings together different strands of the literature and raises interesting conceptual and practical issues.

Limits: literature only until 2016 and mainly USA studies. |
| (Larsson et al. 2018) | To systematically map recent research involving children and young people in the development of **interventions targeting** issues of **health and** | **Interpretative scoping literature review** based on Arksey & O'Malley: seven databases, reference lists, a manual search in key journals & contact with existing networks. Carried out Dec 2014, updated April 2015 & again in Dec 2017. Articles published 2000-17.

Main inclusion criteria: CYP under the age of 25yrs. | **Background**: differentiates between nonparticipation, consultative participation, and collaborative participation (CYP as experts, partnership based on trust & shared decisions). Study aimed to map the level of participation in each study according to Shier's (2001) Pathways to Participation Model.

Findings: divided into three areas:
- *General characteristics* of the included articles: divided into support for lifestyle changes and support in managing illness and disease, see Figure 2;
- *Methodological characteristics*: most used interviews/focus groups but also more innovative methods e.g. video recordings, photographs, drawings and texts; |

	well-being.	**Analysis**: included studies were judged overall based on a) quantitative aspects of participation (i.e. number of activities or stages that included CYP) & b) qualitative aspects i.e. to what extent such involvement was based on reciprocity concerning influence, power and decision-making). **41 studies** included from wide range of countries (UK x7). 21 were conducted in North & Central America, 15 in Europe. Actual age range: 3-25yrs.	- *CYP's level of participation* in the development of interventions: Figure 3 rates articles according to level of participation - only three were rated at the highest level 5; seven as level 4; and 28 as level 3. **Discussion**: considers the gap between aspirations and actual level of participation. Specific feature of level 5 studies was that CYP were co-researchers in all parts of the development process and methods used enabled CYP to be active participants and express themselves in different formats (i.e. not just talking). **Conclusion**: Studies need to carefully describe the methods used in the collaboration with CYP and to use models, such as Shier's, in their description of how CYP were involved. **Strengths**: comprehensive and robust literature search. Shier's (2001) model provides useful framework (it is worth looking up). Lists which studies used what innovative methods and whether they were tested for feasibility. **Limits**: will not help with the practicalities of implementation but does link to useful studies that do.
(Liverpool et al. 2020)	To identify modes of delivery used to engage CYP in **digital mental health** (MH) interventions; explore barriers and facilitators for using and implementing Digital health interventions (DHIs).	**Systematic review and meta-analyses** using PRISMA guidelines. Cochrane Library, EMBASE, MEDLINE & PsycINFO (date limits unclear but up to Dec 2018); 3 key concepts "child and adolescent mental health," "digital intervention," and "engagement." **Main inclusion criteria**: CYP with mean age of <25yrs; any study design; DHI targeting an MH symptom; explored the development or testing of a DHI resulting in data on adherence, acceptability, or barriers/facilitators. **Analysis**: articles were quality assessed using the mixed methods appraisal tool (MMAT) & data were extracted to address the review aims. Data aggregation & synthesis was conducted as descriptive numerical summaries & narrative synthesis. **83 studies** included from USA & Canada (37%); Australia & New Zealand (28%); Europe (25%); Asia (8%); Brazil (1%). Included studies published 2001-18 (59 between 2013-18, 15 published in 2018).	**Background**: rationale for increasing use of DHIs with CYP with MH issues, benefits of DHIs, limitations to current research (e.g. how CYP experience DHIs). **Descriptive findings:** 71 interventions were identified with cognitive behavioural therapy being the most common (47%) and combinations of interventions (30%). 46% of articles targeted CYP suffering from affective disorders. Broad range of digital modes to deliver interventions: most commonly website interventions (n=43) and games/ computer assisted interventions (n=23). Retention rates were reported in 67 articles and 56 of these had a retention rate of at least 70%. **Narrative themes**: divided into *intervention-specific* influences (suitability, usability, acceptability); *person-specific* barriers and facilitators to behaviour change (sense of connectedness, motivation and perceived usefulness of the intervention). **Discussion**: developed the above themes, for example, the importance of a sense of connectedness with peers (and challenges due to safeguarding), professionals (connecting with a trusted individual) and self-connectedness (sharing experiences in a way which mitigates stigma or shame). A little on 'persuasive design methods', or incentives to encourage CYP to engage. **Conclusion**: future studies should explore the impact of new modes of delivery to promote a sense of connectedness in DHIs in CYP; importance of co-design to circumvent potential barriers.

			Strengths: extremely thorough review with helpful narrative as well as descriptive summaries. Figure 2, framework of factors influencing engagement in DHIs is helpful. **Limits**: very diverse studies so hard to glean which aspects of a DHI were best suited to whom, why or in what context.
(Reed et al. 2020)	To understand the types & underlying theories & processes for co-production in **school-based health interventions** with students aged 11–16.	**Thematic synthesis**: 5 databases, citation tracking, consultation with an expert international panel. co-production, 1986-2018. **Main inclusion criteria**: involved students in developing the intervention, was conducted in schools, & included problem-setting/solving; age 11-16yrs. **Analysis**: data extraction included theoretical underpinning, problem-setting and solving processes undertaken and resulting health promotion activity adoption and implementation. Quality rating with EPPI Centre health promotion review criteria. NVivo used to code stakeholder experiences. **22 studies** (30 papers) reported on types of co-production and theories of change. Nine of these were case studies on a single school. 12 studies from USA, 5 from UK, the rest mixed. **18 studies** (23 papers) reporting on stakeholder experiences (RQ2).	**Background**: discussed limitations in the evaluation of school-based interventions to promote adolescent health and the mixed/limited effectiveness often reported. Reviewed drivers for co-production with CYP including the 'new sociology of childhood'. **Findings/discussion**: *Types of co-production*: three categories were identified: external, which focused on generating capacity outside the school by increasing facilitators' knowledge of co-production processes; individual-level, which involved upskilling students as researchers or group leaders; and system-level capacity-building, which involved developing structural capacity through Research Action Groups with multiple stakeholders. *Stakeholder experiences*: were categorised into themes around acceptability (how stakeholders received co-production); feasibility (stakeholders' thoughts on how co-production interacted with context); and decision-making (views on developing and delivering co-produced health activities) which were found in all co-production types and expressed by all stakeholders apart from students. Constraining forces were both subtle, as facilitators manoeuvred students to more 'acceptable' ideas, and transparent, when school decision-makers refused student ideas, albeit due to valid barriers. **Conclusion**: the review helped elucidate the processes necessary to activate the underpinning theory of change and support the reporting of co-production. It also demonstrated key areas of acceptability, feasibility and decision-making. **Strengths**: a huge review, clear reporting on theory, process frameworks and outcomes. Theory explained using understandable terminology. **Limits**: the usual caveats that studies were not comparable and often limited in their description of co-production, and limited evidence that co-production was effective.

References

Boulton, E. R., Horne, M. and Todd, C. (2020). Involving older adults in developing physical activity interventions to promote engagement: a literature review. *Journal of Population Ageing*, 13(3), 325-345. https://link.springer.com/article/10.1007/s12062-019-09247-5

Bradbury-Jones, C., Isham, L. and Taylor, J. (2018). The complexities and contradictions in participatory research with vulnerable children and young people: A qualitative systematic review. *Social Science & Medicine*, 215, 80-91. https://www.sciencedirect.com/science/article/pii/S0277953618304702

Brunn, J., Brunner, S. and Mutsch, M. (2021). Preventive Interventions for Young Adults in Nightlife: Coproduction for a Systematic Literature Assessment Followed by a Stakeholder Dialogue Process. *European Addiction Research*, 1-15. https://www.karger.com/Article/PDF/511191

Chambers, E., Gardiner, C., Thompson, J. and Seymour, J. (2019). Patient and carer involvement in palliative care research: an integrative qualitative evidence synthesis review. *Palliative Medicine*, 33(8), 969-984. https://journals.sagepub.com/doi/pdf/10.1177/0269216319858247

Clarke, D., Jones, F., Harris, R., Robert, G. and Collaborative Rehabilitation Environments in Acute Stroke (CREATE) team (2017). What outcomes are associated with developing and implementing co-produced interventions in acute healthcare settings? A rapid evidence synthesis. *BMJ Open*, 7(7), e014650-2016-014650. https://bmjopen.bmj.com/content/7/7/e014650

Davies, N., Hopwood, J., Walker, N., Ross, J., Iliffe, S., Walters, K. and Rait, G. (2019). Designing and developing a co-produced theoretical and evidence-based online support for family caregivers of people with dementia at the end of life. *BMC Palliative Care*, 18(1), 1-16. https://link.springer.com/article/10.1186/s12904-019-0455-0

Hoekstra, F. et al. (2020). A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: a first step in synthesising the research partnership literature. *Health Research Policy and Systems*, 18, 1-23. https://link.springer.com/content/pdf/10.1186/s12961-020-0544-9.pdf

Honingh, M., Bondarouk, E. and Brandsen, T. (2020). Co-production in primary schools: A systematic literature review. *International Review of Administrative Sciences*, 86(2), 222-239. https://journals.sagepub.com/doi/pdf/10.1177/0020852318769143

Hopwood, J., Rait, G., Walters, K., Iliffe, S., Ross, J. and Davies, N. (2018). A systematic review of digital interventions aimed at supporting family carers of people with dementia. *J Med Internet Res*, 20(6), e216. https://www.jmir.org/2018/6/e216

Larsson, I., Staland-Nyman, C., Svedberg, P., Nygren, J. M. and Carlsson, M. (2018). Children and young people's participation in developing interventions in health and well-being: a scoping review. *BMC Health Services Research*, 18(1), 1-20. https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-3219-2

Liverpool, S., Mota, C. P., Sales, C. M., Čuš, A., Carletto, S., Hancheva, C., Sousa, S., Cerón, S. C., Moreno-Peral, P. and Pietrabissa, G. (2020). Engaging children and young people in digital mental health interventions: systematic review of modes of delivery, facilitators, and barriers. *Journal of Medical Internet Research*, 22(6), e16317. https://www.jmir.org/2020/6/e16317/

Ludwig, C., Graham, I. D., Gifford, W., Lavoie, J. and Stacey, D. (2020). Partnering with frail or seriously ill patients in research: a systematic review. *Research Involvement and Engagement*, 6(1), 1-22. https://link.springer.com/article/10.1186/s40900-020-00225-2

Ludwig, C., Graham, I. D., Lavoie, J., Gifford, W. and Stacey, D. (2021). Ethical considerations for engaging frail and seriously ill patients as partners in research: sub-analysis of a systematic review. *Research Involvement and Engagement*, 7(1), 1-12. https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-021-00254-5

Marsilio, M., Fusco, F., Gheduzzi, E. and Guglielmetti, C. (2021). Co-Production Performance Evaluation in Healthcare. A Systematic Review of Methods, Tools and Metrics. *International Journal of Environmental Research and Public Health*, 18(7), 3336. https://www.mdpi.com/1660-4601/18/7/3336

Merkel, S. and Kucharski, A. (2019). Participatory Design in Gerontechnology: a systematic literature review. *The Gerontologist*, 59(1), e16-e25. https://academic.oup.com/gerontologist/article/59/1/e16/4999719

Pirinen, A. (2016). The barriers and enablers of co-design for services. *International Journal of Design*, 10(3), 27-42. https://acris.aalto.fi/ws/portalfiles/portal/11469459/2575_9446_5_PB.pdf

Rai, H. K., Cavalcanti Barroso, A., Yates, L., Schneider, J. and Orrell, M. (2019). Improving the involvement of people with dementia in developing Technology–Based interventions: A narrative synthesis review and best practice guidelines. *Journal of Medical Internet Research*, 22(12), e17531. https://nottingham-repository.worktribe.com/preview/4121912/preprint-17531-accepted.pdf

Reed, H., Couturiaux, D., Davis, M., Edwards, A., Janes, E., Kim, H. S., Melendez-Torres, G., Murphy, S., Rotevatn, T. A. and Smith, J. (2020). Co-production as an Emerging Methodology for Developing School-Based Health Interventions with Students Aged 11–16: Systematic Review of Intervention Types, Theories and Processes and Thematic Synthesis of Stakeholders' Experiences. *Prevention Science*, 1-17. https://link.springer.com/article/10.1007/s11121-020-01182-8

Schilling, I. and Gerhardus, A. (2017). Methods for involving older people in health research—a review of the literature. *International Journal of Environmental Research and Public Health*, 14(12), 1476. IJERPH | Free Full-Text | Methods for Involving Older People in Health Research—A Review of the Literature (mdpi.com)

Sumner, J., Chong, L. S., Bundele, A. and Lim, Y. W. (2020). Co-designing technology for ageing in place: a systematic review. *The Gerontologist*. https://academic.oup.com/gerontologist/advance-article-pdf/doi/10.1093/geront/gnaa064/33496555/gnaa064.pdf