



The Value of Participation in Health and Social Care Services: A Rapid Evidence Synthesis

May 2017

The Value of Participation in Health and Social Care Services: A Rapid Evidence Synthesis

Author: Gail McMillan (Healthcare Improvement Scotland and Scottish Graduate School of Social Science)

This project was undertaken as part of the Scottish Graduate School of Social Sciences internship programme in partnership with Healthcare Improvement Scotland.

Correspondence can be made to Gail McMillan, University of Strathclyde, School of Psychological Sciences and Health, Graham Hills Building, 40 George Street, Glasgow, G1 1QE. Email: gail.mcmillan.2014@strath.ac.uk

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Published May 2017

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Summary

Public participation in health and social care has been highlighted as an effective method for delivering the key aims of health and social care policy to produce quality services which are safe, person-centred and effective. While there is evidence of the efficacy of participation in creating safe, person-centred and effective services in health and social care, a further aim of health and social care policy is to create sustainable services. The economic impact of participation in health and social care was investigated by conducting a rapid review of the literature from the past 5 years. The literature was evaluated by grouping together similar approaches to participation and examining the impact of these on economic and health outcomes. While there were mixed findings of the economic impact of participation, the findings largely demonstrated a positive economic impact of participation in health and social care. However, the evidence across the literature was of poor quality, making it difficult to determine the true economic impact of participation.

Introduction

Within this paper, the findings of a rapid literature review of the economic impact of participation in health and social care are reported. Participation is an umbrella term for any activity in which the public takes part in the organisation of health and social care¹⁻³. For this report, cases of public participation in the design and delivery of services were reviewed. As participation is a key activity in delivering the aims of several key health and social care policy documents, grasping the economic impact of participation will be significant in shaping policy and practice.

Background and aims

The key drivers within the Healthcare Quality Strategy for NHSScotland³ are providing care that is safe, effective and person-centred. It is increasingly recognised that public participation in health and social care is a valuable method in fulfilling the aims of the Healthcare Quality Strategy³ and achieving a realistic medicine approach which is fundamentally concerned with putting patients, carers and the public at the centre of every decision in healthcare, from individual decisions about appropriate care to the design and delivery of health and social care services⁴. Further to the Healthcare Quality Strategy for NHSScotland³ and Realising Realistic Medicine⁴, the Health and Social Care Delivery Plan⁵ and 2020 vision set out for health and social care in Scotland² have also highlighted the usefulness of participation in health and social care in achieving safe, person-centred and effective care. A fundamental aim of participation is to enable service users and professionals to work in partnership to meet agreed outcomes. This approach supports capacity-building in communities to manage health sustainably, meaning the burden on formal health and social care services is reduced. There is evidence that effective and high quality participation has benefits such as improving patient experience and reduced medication errors¹, however, involving the public requires resources such as funding and staff time. Therefore, in order for the Healthcare Quality Strategy to be sustainable, the economic impact of participation needs to be ascertained.

The aim of this report was to review literature which illustrated cases of the economic impact of public participation at an organisational level; that is, involvement in the planning, production and provision of services. Therefore, examples of participation and engagement at an individual level, such as shared decision-making and self-management were not included.

Methods

Due to time constraints, the review comprised a rapid literature search and evidence synthesis. The aim of the search was to identify evidence of the economic impact of different levels of participation in health and social care. A focused systematic search was conducted of peer-reviewed and grey literature rather than an exhaustive search. The search was conducted using electronic database searching (for example OvidSP), hand-searching (for example The Kings Fund website) and web-based searching. Due to the rapid nature of the review, inclusion of papers was limited to those which were available in English, presented quantitative data and where full text was available from the period of January 2012 to November 2016.

Search results included papers which reported economic outcomes such as costs, cost savings and returns of investment made when service users and the public were engaged in the design and delivery of health and social care services. Search terms such as 'co-production', 'experience based co-design', participation and 'user-led' were used and combined with terms such as 'impact', 'evaluation', 'economic' and 'cost-effectiveness'. The search also identified papers which reported the impact of engagement on health-related outcomes for which economic impact could be calculated. Both types of paper have been included in this review.

Synthesis framework and analysis

Narrative synthesis was conducted using the groupings and clusters method⁶ which entails categorising studies in a meaningful way and consolidating the findings. For this report, the literature was synthesised within a framework of participation⁷ which conceptualises seven levels of participation. 'Coercing' and 'educating' are forms of engagement that involve professionals doing something *to* the public. 'Informing', 'consulting' and 'engaging' involve more participation, but have a focus in doing things *for* the public. For example, consulting and engaging involves services which are designed and delivered by professionals, but give service users options to provide feedback and improve services. 'Co-designing' and 'co-producing' involve professionals working with the public. That is, interventions where professionals and lay people or service users worked together with a shared goal to design and deliver services as equal partners. An example of co-design would be the public working with professionals to design a new procedure while professionals deliver it. On the other hand, a service user delivering training is an example of co-production. Co-production is considered the top level of participation as it entails service users and communities holding equal power with service providers, where they are involved in producing a service or product. Further narrative synthesis techniques such as

examining moderators and subgroups were not possible due to poor methodological reporting. The robustness of the evidence was examined by using the Effective Public Health Practice Project (EPHPP) quality assessment tool⁸ and the Cochrane Collaboration risk of bias assessment⁹.

Findings

Co-production

This section will first present studies which included examples of co-production. Nine papers depicting 12 studies were identified which reported outcomes of using co-production^{10-12, 14-19}. Several applications of co-production were identified. This section will first discuss volunteering as an application of co-production. Six papers reported outcomes of volunteering, four in health care and two in social care. Three papers which identified peer support interventions will then be discussed. Lastly, three studies which discussed other applications of co-production will be examined.

Volunteering

An evaluation of volunteers in acute trusts between 2006 and 2008 found that volunteers contributed 79,128 hours of service with £58,000 a year spent on volunteers¹⁰. It has been estimated that for every £1 spent on volunteers' training and supervision, NHS trusts can expect a return of about £11, based on a band two salary on the 'Agenda for Change' salary scale^{10,11}. Further to this, volunteering has an estimated worth between £250,000 and £700,000 per year to the NHS, depending on the setting. Kings College Hospital Trust found that the estimated return of investment (ROI), depending on volunteer hours, was between £5.40 and £16.40 for every £1 spent¹². A speculative calculation of the quality-adjusted life year (QALY), gained by the investment in volunteers, resulted in an estimate of between £7,543 and £18,947 per QALY, making volunteering cost-effective based on the cost-effectiveness threshold of £20,000 per QALY gained for health interventions suggested by the National Institute for Health and Care Excellence (NICE)¹³. Although volunteering within NHS trusts would, therefore, seem cost-effective, a study examining the impact of volunteers across several NHS trusts on outcomes of delayed transfer of care, readmission rates, length of stay, number of falls, mood, anxiety, nutrition, hydration and patient experience, demonstrates mixed results¹⁴. There was limited evidence reported of improvements in mood, anxiety and hydration levels (although these were not consistent findings across all NHS Trusts included in the study) but no significant improvements in any of the other outcomes, some of which may have reduced costs.

Volunteering within social care has also shown cost benefits. There are a number of programmes aiming to increase the use of volunteers to reduce demand on healthcare services. The Shared Lives initiative places vulnerable adults with mental health issues or learning disabilities with volunteers in the community for permanent or short-term care¹⁵. The scheme has been calculated to provide between £8,000 and £26,000 net savings per year compared with usual care of residential care. The Living Well programme, where volunteers support capacity and network-building for older people, found there were 27% and 37% reductions in A&E use and non-elective admissions respectively, as well as 8% reduction in social care costs¹⁶. While the costs of Living Well were £130,000 per year, the savings based on the reduction of services would be £400,000 per year. The Partnership for Older People Projects (POPPs) involve older people volunteering to work in partnership with health boards and third sector organisations to develop services for older people (16). The projects resulted in reduction of overnight hospital stays by 47%, reduction in A&E presentation by 29% and reductions in referrals to outpatient service such as physiotherapy. Emergency hospital bed use was also reduced and it was estimated that for every £1 spent on the project, £1.60 was saved from the reduction in bed use alone. It was also reported that there would be a saving of £300 per person per year based on improved quality of life following decreases in anxiety and depression.

Peer support

The effectiveness of the Service User Network (SUN) was examined by comparing the need of psychiatric ward beds for members of the network, with the need for beds for patients receiving mentalisation-based therapy (MBT)¹⁷. There was a significant negative difference in bed use between 6 months pre and 6 months post joining SUN with a medium effect size, suggesting a positive impact on bed use. While there was no significant difference in bed-use at 6 months post-intervention between SUN and MBT, there was a significant difference at 12 months post-intervention suggesting that for long-term management, SUN was more effective than MBT at reducing bed use. However, conclusions drawn from these findings are limited. Due to the small sample size and skewed data in the SUN group, non-parametric statistical analysis was used. Although there was a statistically significant difference, the actual number of beds used was very low both pre and post, meaning it is difficult to gauge the impact of this finding. Also, frequency of SUN group attendance was not measured in either SUN group or MBT group. There was no difference when comparing 12 months pre and post-intervention for SUN users. Therefore the impact of using a peer support SUN compared to MBT is uncertain.

Case studies demonstrate a positive impact of peer support on economic outcomes. The British Lung Foundation initiated a peer support programme which resulted in participants feeling more confidence and control in managing their condition, in

addition to 42% and 57% decreases in both unplanned GP visits and hospital admissions respectively¹⁸. This resulted in a ROI between £3.43 and £9.36 for every £1 invested. Another review of a peer support self-management programme for people living with hepatitis C and HIV found that 49% of participants experienced better emotional wellbeing, and there was a 34% reduction in NHS services. A peer support programme for addiction, delivered through text messages in East Lancashire and West Kent found that of 169 service users using the Evie service in East Lancashire, none re-presented to structured treatment within a 6-month period. In West Kent, only 4% re-presented to structured treatment¹⁸. No other outcomes were captured reliably. A study of peer support for breastfeeding found that while costs for the peer support group (£3,276) were significantly higher than the control group (£2,725), the intervention group had reduced visits to primary care and the emergency room, and had significantly fewer prescriptions issued¹⁹. Due to a small sample size and a failure to report the monetary value of these reductions in services it is uncertain, however, whether the peer support group was cost-effective.

Other examples of co-production

A time-banking and flexicare support service in London where 500 members contribute time equating to £137,119 per year (based on the London Living Wage) was estimated to produce over £1 million in savings for formal mental health care and employability¹⁶. The social ROI was calculated as £5.75 for every £1 invested. A smoking cessation support service which began with participation from volunteers but became managed completely by the community was estimated to cost £1,737 including volunteer time, which was considered cost-effective in the USA¹⁹. The Expert Patient Programme (EPP) is a six-session self-management programme delivered by people with lived experience of a chronic health condition¹⁹. A pragmatic RCT found that the EPP group incurred patient costs of £1,912 over 6 months compared with £1,939 for the control group. This meant that the EPP was cost effective at the £20,000 per QALY gained threshold.

It appears that applications of co-production are cost-saving in health care. However, the majority of the above cited studies^{10-12, 14-16, 18} are unpublished case studies or cross-sectional surveys. The majority did not report enough information, such as participant characteristics and methodology, as well as a lack of follow-up data, and as such are poor quality with a high risk of bias. While one study found no benefit of volunteering, it was also poorly designed as a result of the use of unvalidated measures, high turnover of the patients who received support from volunteers and sampling bias¹⁴. While the study conducted on the effectiveness of the SUN had a comparison group and long-term follow-up, there was a very small sample size and a limited number of people who required bed use in a ward, meaning changes may not be meaningful differences¹⁷. There was also no control group, making it difficult to

determine whether changes were due to natural improvements over time. The poor quality means that only limited conclusions can be drawn about the financial impact. The EPP study used a pragmatic RCT design, had good quality reporting and conducted a cost-effectiveness analysis based on QALY, making its findings of positive financial impact more credible¹⁹. Nevertheless, overall, these are promising findings of the financial impact of co-production on health care.

Co-production and co-design

Four studies were identified where interventions used had both elements of co-production and co-design. Interventions which use both co-production and co-design involve lay people and health professionals working together to shape services and implement them. An example of this is when patients, the community and health professionals work together to design and commission services. A group of patients whose care had been determined by the AF4Q community (a group of patients, doctors, carers and representatives of the community, who commission, design and deliver services) were compared with a national sample of patients²⁰. The study measured care co-ordination, patient satisfaction, provider interaction and support, and receipt of recommended diabetes care (cholesterol, A1c, eye-screening and circulation). Patients within AF4Q communities reported better interpersonal relationships with their healthcare providers. AF4Q communities also had significantly better diabetes care with improvements of 1.5% in cholesterol, 3.9% in eye screening and 5.3% in blood pressure at 6-month follow-up. Overall, 12 of 14 AF4Q communities showed some improvement in diabetes indicators.

A number of studies report on the impact of using both co-production and co-design to improve mental health outcomes. One study reported the effectiveness of a computerised CBT programme (CCBT) commissioned by a user-led mental health service²¹. There was a 53.6% reduction in patients who met criteria for depression or anxiety after taking part in the CCBT. It appears that the impact of service user-led commissioned CCBT had a positive impact, while CCBT has been found to be cost-effective compared to treatment as usual^{22,23}.

Consumer-operated support services (COSS) are another example of using both co-production and co-design as service users are directly responsible for the design, management and delivery of services. The literature search found a study investigating the effectiveness of using community mental health services (CMHS) compared with CMHS and COSS together²⁴. This study found that over 8 months participants in the CMHS with COSS group experienced decreases in self-efficacy and social integration with slight increases in personal empowerment, while those in the CMHS-only condition experienced enhanced self-efficacy, personal

empowerment and social integration. As the combined CMHS-COSS group incurred more costs and led to poorer outcomes, it was not cost-effective.

A third study reported an experience based co-design (EBCD) project where patients also helped implement changes²⁵. EBCD involves service users giving experiential feedback about a service or product from start to finish and then working with health professionals to design changes, while the health professionals usually implement the changes. Patients in the Betts psychiatric ward helped conduct EBCD to improve the experience of both patients and staff which resulted in formal complaints falling from 13 in 19 months to no complaints in the 23 months following EBCD. This suggests that valuable staff time would not be taken up by complaints leading to a more efficient service. However, no formal analysis was done and, therefore, conclusions are speculative.

A fourth case study of a support service where service users were involved in the design and delivery of support reported that each service user contributed approximately 6 hours of support a week – overall 252 hours of support²⁶. It was reported that of 42 service users, 38% believe that without the support they would have been hospitalised or required crisis treatment. Three members also reported that after receiving crisis treatment, they believe that recovery would not have been possible without the support.

There were four studies which indicated a positive economic impact of both co-production and co-design on health care^{20, 21, 25, 26} but these were of poor to medium quality with high risk of bias. One study indicated a negative impact in health outcomes meaning it had a negative economic impact²⁴. This study provided good quality evidence with low risk of bias as it was a randomised controlled trial with minimal confounding variables such as age or gender and statistical analysis was based on actual treatment received as opposed to just intention to treat²⁴. Of the studies which reported participant characteristics, participants appear to be mostly white, female, between the ages of 36–55 and well educated, meaning that the above findings may only apply to people who meet these characteristics. While there were encouraging findings, the methodological limitations and mixed results mean the results of the financial impact of co-production and co-design are inconclusive.

Co-design

Two studies reported cost indicators of co-design projects^{27,28} and two reported health outcomes^{29,30}. The difference in costs of conducting EBCD and an accelerated (AEBCD) version were calculated²⁴. AEBCD re-uses footage from archives of trigger films but, other than this, has the same process as EBCD. This led to savings of up to 44% where average costs were £28,565 per trust compared with EBCD where average costs £50,761 per trust. However, the longer term

savings and impact of using either EBCD or AEBCD to design services have never been reported. The establishment of the Esther group, a group of patients, carers and the community working with health professionals to plan and design services, was reported within a case study. The Esther group led to the number of overall unnecessary days in hospital to fall from 1,113 in 1999 to 62 in 2011²⁸. Furthermore, the number of hospital days for heart patients was reduced by 1,000 within 2 years. Waiting times to see neurologists and gastroenterologists were both reduced to 14 days in 2003, having previously taken 62 days and 48 days respectively. Hospital admissions were reduced from 9,300 in 1998 to 7,300 in 2003. The cost of the Esther project was reported at £170,741 in 2011. However, the savings made from the decrease in services were not reported and so no return of investment or cost-benefit calculation was conducted.

A self-management programme co-designed both by clinicians and people with lived experience of mental health showed improvements in health outcomes²⁹. It was reported that 56% of participants had clinically meaningful improvement. There were significant decreases in depression and anxiety at 6-month follow-up, and 39% of participants were considered recovered. Health status, quality of life and self-management skills were significantly improved at follow-up from before completing the course. While this study did not report cost-effectiveness analysis, lay-led self-management which improves quality of life and confidence in self-management skills has been found to be cost-effective^{31, 32}. A co-designed patient scorecard to improve management of chronic obstructive pulmonary disease had a mixed impact on health outcomes³⁰. The outcome measures recorded to determine the effectiveness of the scorecard were confirmation of diagnoses by post-bronchodilator spirometry, smoking cessation advice given to smokers, annual review carried out within 18 months, receipt of a self-management plan, inhaler technique checked and recorded within 18 months, and referral for pulmonary rehabilitation for patients with Medical Research Council dyspnoea score of 3 or greater. Use of the scorecard significantly improved adherence to confirmation of diagnoses by spirometry, referral for pulmonary rehabilitation and receipt of a self-management plan. There were no differences in smoking cessation advice given or reviews carried out within 18 months between the two groups. Checking of inhaler technique between the control and intervention groups had to be abandoned as a quality indicator because of poor quality and quantity of recording. It can be assumed that the cost of designing and implementing the scorecard and the increased adherence to medical tests cost more than care as usual. The increase in referrals to self-management programmes and, therefore, improved health behaviours, may have made this cost-effective but the costs or savings were not reported and no other indicator was improved.

As with examples of co-production, and examples using both co-production and co-design, there are mixed results for the cost-effectiveness of co-design. The co-designed patient scorecard appeared to have neither a positive nor a negative impact³⁰. Of the two studies which showed a positive financial impact, one was very poor quality²⁸ and it is difficult to tell whether the co-design was the reason for improvement and of the other, there was no reports of costs²⁹. Another study simply showed that there is a more cost-effective way to conduct EBCD²⁷. Similar to the above reviewed literature, of the study which reported participant characteristics, most participants were white, female, with an average age of 50.

Engagement and consultation

The literature search identified a meta-analysis of effectiveness of community engagement interventions on health inequalities¹⁹: one project which involved aspects of both consultation and engagement³³ and one paper which used consultation³⁴. The meta-analysis¹⁹ provided robust evidence that community engagement interventions are effective at improving self-efficacy, health behaviours, health consequences and perceived social support in both individuals who engaged and communities as a whole. There was limited evidence that some intervention effects are sustained at follow-up, but effects were smaller than at post-intervention. The most effective interventions were single-component interventions, those conducted in non-community settings and those shorter in duration. Interventions were most effective for people of low socioeconomic status. Interventions in which skills were developed, or involved peers, the community, or education professionals were more effective when compared with interventions which only involved health professionals. These results are consistent with the finding that engagement projects, where community members delivered the intervention, were more effective than interventions which were community-designed but delivered by health professionals.

A cluster randomised trial was conducted in the Well London project, a community engagement initiative to encourage neighbourhoods to pull together to improve health and wellbeing³³. Consultations were held to determine the individual priorities of each community meaning the interventions varied, for example exercise groups or creating green spaces. The project primarily measured indices of health such as eating five portions of fruit and vegetables a day, taking 5x30 minutes of moderate-intensity exercise per week, and wellbeing and health activities. The project found that snacking on unhealthy foods was significantly lower in intervention neighbourhoods than controls. However, no other outcomes showed significant differences.

A consultation was conducted to identify preferred courses for social prescribing³⁴. Social prescribing is referral to non-clinical community services which provide social support through activities such as art and crafts. There were significant increases in self-efficacy and mental wellbeing after taking part in the social prescribing activities. Also, 38% of participants' symptoms of depression and 54% of participants' symptoms of anxiety reduced from severe to moderate or moderate to mild. The number of participants who scored within the clinical range of depression and anxiety was reduced by 17% and 16% respectively, statistically significant reductions. Based on these findings, social prescribing may reduce the need for formal mental health services, encourage recovery and prevent relapse in a cost-effective way. Therefore, it could be argued that consultation with the community led to a valuable service with positive outcomes.

Based on these studies, there is not enough evidence to determine the economic impact of consultation and engagement. The extent to which the social prescribing and engagement activities independently accounted for the changes in outcomes is unknown as a result of the designs used. In the social prescribing study, other factors such as medication were not measured and there was no comparison group. There would also need to be a follow-up to determine the long-term impact of both programmes. The evidence was of weak to moderate quality with high risk of bias.

Conclusion

Across levels of participation, there appeared generally to be a positive economic impact of participation on health and social care, although the evidence was mixed. While the majority of studies reported positive financial gains from using methods of participation in health and social care, the published and unpublished evidence on the financial impact of levels of participation in healthcare design and delivery appear to be inadequate to provide strong conclusions. Across the literature, the quality of study designs and reporting is hugely problematic. Of all the literature reviewed, there was a high risk of bias and overall low quality evidence meaning the causal relationship between outcomes and interventions cannot be determined, particularly long-term due to lack of follow-up data. This includes a lack of reporting on participant characteristics, while studies which did report this data included participants who were mainly white, female and between 36–55 years old. This means we do not know what methods and aspects of participation work for whom, in what circumstances or which provided the most cost benefits.

It is recommended that future research conducts RCTs to ascertain the true impact of participation, while proficient reporting of methodology and costs will allow the financial impact of participation to be determined. In saying this, there may be several reasons for the lack of good quality evidence within the literature. First of all, many of these projects are initiated from grass-roots organisations where the focus is on producing a service and where there may not be adequate knowledge or experience to conduct high quality evaluations. Within a clinical setting, patient data can be difficult to access while evaluations of participation often rely on busy clinicians and health professionals who do not have dedicated time and resources to produce a high quality assessment of impact, and then publish those findings. On that note, conducting RCTs are time-consuming and costly, especially with complex interventions, which may be why the literature lacks this kind of high quality evidence. Nevertheless, the limitations of this review must be taken into consideration. As a rapid review, the literature was not searched extensively, with limits on the past 5 years meaning the conclusions drawn here must be taken with caution.

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Edinburgh Office

Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

0131 623 4300

Glasgow Office

Delta House
50 West Nile Street
Glasgow
G1 2NP

0141 225 6999

ihub.scot