

Public Engagement in Health: A Literature Review

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Public Engagement in Health: A Literature Review

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Section One: Introduction

Context for the Review

Patient and public involvement is now at the forefront of the UK policy agenda, enshrined in legislation, and expected to be a core consideration in both the design and delivery of health and social care services. Despite the championing of more holistic measures that place patient experience and engagement at the core, debate continues regarding the way in which patients and the public can be *effectively* engaged, and the means by which this should be carried out. Healthwatch England commissioned a review of literature and research relating to public engagement in both service improvement and service transformation, focussing particularly on the outcomes and effectiveness of engagement across the fields of health and social care. The specification called for outputs that can guide next steps, and enable Healthwatch England to develop a case for effective engagement activity. To this end, SERIO, an applied socioeconomic research unit at the University of Plymouth, designed a robust research approach in order to generate a review that will ensure Healthwatch England gain an advanced understanding of the breadth of existing research and evidence available. In highlighting best practice, and the real and tangible benefits of public engagement, the review is intended as something which can be utilised to inform subsequent decision-making, and to pave the way for effective patient and public involvement. This report outlines the main findings of the review conducted by SERIO of a wide breadth of available literature and research.

Scope of the Review

This review was driven by the need to capture and condense a very large number of information sources on an extensive topic within a set time period. SERIO, being situated within the University of Plymouth, has unbridled access to a wide range of academic literature sources, as well as a variety of library and information specialists. As such, the scope of the review was widened to cover an expanse of academic outputs. Resultant academic literature was blended together with a wide range of grey literature sources, legal cases, and reports from key players within the field of public engagement in healthcare, ensuring a comprehensive balance of robust, quality information, with information that is both useful and applicable. Existing systematic reviews, meta-analyses and literature reviews were studied, summarised and combined with new and innovative cases in the field of public engagement, as well as a wealth of best practice and impact evaluation literature. This broad and all-encompassing approach optimized the retrieval of relevant materials, ensuring the targeted search that was conducted captured both research and non-research items.

Review Structure

The review begins with an outline of the methodology employed by SERIO, detailing the databases used, the search strategy adopted, and the selection criteria applied. This methodology section offers a summary description of the resultant body of evidence which has informed the review.

The main body of the review is structured according to key research themes explored over the course of the information search, as detailed below:

- An introductory section which discusses literature on the subject of public engagement in health and social care, addresses what works in public engagement, and highlights emergent issues in the field
- A section outlining best practice in public engagement in health and social care, with reference to outputs from key players in the field, and the inclusion of guideline extracts
- A review of available evidence on the impact of public engagement in health and social care
- Some cautionary notes on the dangers of getting public engagement in health and social care wrong, and the associated consequences
- A section addressing social stratification in the field of public engagement in health and social care
- And, finally, a concluding section which offers a summary of findings, and some notes on the limitations of the review, as well as the potential implications for future research

This review includes three appendices, one of which illustrates a search strategy typical of those which have been applied to the range of databases used in order to access research items. Also included is a copy of the call for evidence distributed by SERIO. A further appendix provides a list of purposefully selected information sources, all of which have been deemed particularly noteworthy for the purposes of this review. These include a list of existing systematic reviews/ meta-analyses/ literature reviews; a selection of public engagement in health case studies; a number of recent and relevant legal cases; and articles pertaining to the measurement and evaluation of public engagement impact, all of which may be of special interest to Healthwatch.

The final section contains a complete bibliography, which includes all references that met exacting selection criteria and informed the review. The bibliography encompasses a wide range of academic references, together with a selection of grey literature sources, and reports from relevant key bodies operating in the field.

Section Two: Review Methodology

Developing and Refining the Review Strategy

The review began with the development of a search strategy, something which was conducted as an iterative process, building upon test searches and assessments made by the team. Having developed an exhaustive list of index terms, ensuring synonyms and variants were accounted for, the research team executed various combinations of these search terms, narrowing the search as appropriate in order to drill down to the most relevant and applicable literature, and tailoring the search as appropriate to accommodate the different features and operating processes of each individual database utilised.

Sources Used

Bearing in mind the scope of the review, as set out by Healthwatch in the specification, a wide range of resources and databases was used in the search. Acknowledging that many relevant documents would not be indexed in academic databases, the search strategy included grey literature sources and legal databases to reflect this. This optimized the retrieval of relevant materials, and ensured a targeted search which captured both research and non-research items, incorporating a comprehensive blend of robust research, grey literature and legal cases. A number of academic databases were included in the search, all of which have been listed below:

- AMED (EBSCO) The Allied & Complementary Medicine Database
- Child Development & Adolescent Studies
- CINAHL Plus with Full Text
- Dentistry & Oral Sciences Source
- SocINDEX
- EMBASE
- MEDLINE (Ovid)
- PsycINFO
- PubMed Central
- Social Care Online
- BMJ
- Taylor & Francis Online

Additionally, government and sectoral outputs were retrieved via general internet browsing using a broad range of search terms and combinations in order to access the most relevant materials; through the use of databases such as OpenGrey and Trip; and by targeting key evidence libraries

such as those offered by INVOLVE. Evidence from grey literature contributed to providing greater granularity as to what works, how and why. Legal cases were retrieved via searches through databases Westlaw and Lexis Library, using the appropriate search terms and filters, as well as through general internet searching.

Screening and Selecting for Inclusion

The next phase involved the review and refinement of search results, selecting and appraising results for inclusion in the final review via the gradual application of filters, and the creation of exclusion criteria. Results were initially captured from 2000 onwards, before narrowing the focus to the time period 2014-2018. Occasionally, exceptions to this rule were made, to accommodate articles of particular interest uncovered elsewhere. Articles were also restricted to the English language, before also being refined to cover only modern developed countries. For academic databases, results were restricted to published articles and duplicates were removed. The final list of articles, which just exceeded 200 following screening for relevance and quality, was later reduced to 154, through the retention only of those articles deemed most relevant. Grey literature and legal cases were collated and selected according to relevance, with the most recent outputs from recognised bodies prioritised.

Call for Evidence

During the course of the research, SERIO distributed a call for evidence to a number of relevant bodies, and via social media channels. This was a notice to networks of organisations who may have commissioned research that SERIO was unaware of, and provided an opportunity for them to forward relevant materials which met set selection criteria for inclusion in the review. Submissions were invited across the following themes, in order to contribute to particular elements of the review for which results were less forthcoming:

- Quantitative data measuring the benefits of public engagement in health
- Longitudinal studies addressing the lasting impact of effective public engagement in health
- Costs and consequences of poorly executed public engagement (including legal cases)
- Any social stratification identified in public engagement activities
- Examples of best practice in public engagement in health and social care

Extracting and Synthesizing Results

Once the search strategy was fully executed, and all exclusion criteria applied, the process of extracting and synthesising data began. Data deemed relevant was extracted from the collated information sources, with results grouped together based on the outcomes under examination. At

this stage, it was possible to identify information sources that are particularly relevant to Healthwatch's aims, and these have been highlighted separately in an appendix.

Results were synthesised, bringing together findings from the wide range of data sources explored over the course of the research. Results from academic outputs, grey literature, and any additional sources were blended, with all evidence combined in order to inform this review.

Section Three: What Works Best in Public Engagement in Health?

In recent years, there has been a heightened focus on patient and public engagement in health. Funders more often call for it as a prerequisite for investment; it is frequently highlighted in best practice professional standards frameworks; it is enshrined in NHS legislation for the planning, development and delivery of new services; and the desire to use it as a means by which to shape the health system is gaining traction. A recent NHS report asserted that 'Making progress on our priorities and addressing the challenges the NHS faces over the next two years cannot be done without genuine involvement of patients and communities (2017: 34), and the Five Year Forward View sets out a mission to heighten public involvement in NHS processes. However, the extent to which a solid and credible evidence base as to its benefits has been effectively gathered is in question. Many sources have tended towards rhetoric and relied on anecdotal evidence, often utilising informally gathered sources of data and falling short of clearly demonstrating impact. In measuring and demonstrating the impact and tangible benefits that patient and public involvement can precipitate, one can strengthen the case for its wider adoption across the board. And that impact may be seen in a number of areas, including on the service end-user; on the researchers seeking the public contribution; on the services areas in line for improvement; and also on the communities in which those services operate. Public engagement is increasingly seen as a means by which to empower patients, allowing them to become more active partners in their own healthcare, and effecting change on the healthcare services which they are in receipt of.

The case for public engagement is an attractive proposition. Indeed, it is widely accepted that public engagement has the potential to be a widely transformative practice. Nass et al. (2012) state that 'Proponents of involving the public in healthcare research argue that, not only is it the public's moral and democratic right to participate in healthcare research, but that, even more importantly, lay members might also provide insights that could lead to new discoveries' (2012: 10). 'Moreover, there is a general consensus that involving the public in healthcare research introduces a higher level of accountability and transparency to medical research, and generates research that is more relevant to patients' (Ibid). However, there are calls more recently for this approach to become more inclusive and meaningful, and do so in a way that does not replicate existing health inequalities. Ocloo and Matthews (2016) believe that current PPI models are too narrow, and that equality and diversity is not sufficiently addressed. They also note that models which enable power and decision-making to be more equitable shared with patients and the public are desirable (Ibid).

The means by which patient engagement can occur are manifold, although Bagnall et al. (2015) assert that dominant modes to date have been asset-based approaches, co-production, volunteering and support. Brunton et al. (2017) describe three overarching models of effective

engagement which either: utilise peer-led delivery; employ varying degrees of collaboration between communities and health services; or build on empowerment philosophies. Andreassen (2018) outlines three models of democratic consultation – advisory bodies of service users (common in Norway); panels of the general public (common to the UK); and a third emergent model where citizens are engaged as workers in service providing organisations, a model which involves co-production. More recently, reports of public engagement via online and social media means are being highlighted, an area which is rapidly expanding (Veale et al., 2015; O’ Connor et al, 2016). But some uncertainty still remains about why and how to do public involvement well, and particularly about how to evaluate its impact, something which Ocloo and Matthews (2016) state exposes PPI to criticisms of tokenism and exclusivity. Snape et al. (2014) have also commented on the presence of tokenism, and state that demonstrating impact is further complicated by tokenistic practice. Neech et al. (2018) have also expressed concerns around tokenism, and around ill thought through schemes for engagement. They note the need to involve people in a way that is meaningful and not just as distant and removed providers of feedback to those responsible for shaping and delivering services, as well as the need to gain an advanced understanding of the reasons why people choose to engage in the first place.

Khodyakov et al. (2017) discuss results which highlight the presence of a perceived discrepancy between what is most desirable and what is potentially most effective, something which is made yet more difficult in the absence of reliable evaluation data about what is, in fact, most effective. Furthermore, Macdonald and Taylor-Gooby (2014) note that practitioners’ and volunteers’ expressed motivations and views on the aims goals and expectations tied into PPI often diverge. Rifkin (2014) has also highlighted the issue around definitions of ‘community’ and ‘participation’, noting that this makes it difficult to measure impact. With a view to standardising definitions in their work, the ISPOR Patient Centered Special Interest Group also ascertained, through a review of literature, that numerous definitions of patient engagement and patient centeredness from multiple stakeholders are aimed at involving the patient in research and health care decision-making (Hanna et al., 2016). Additionally, Boswell (2018) notes that one must be sensitive to context and accept the need for a nuanced and reflexive approach to deal with the ambiguities and tensions that go hand-in-hand with the field of public engagement. Boswell also cautions against the appeal of a one-size-fits-all approach to public engagement (Ibid).

Martin et al. (2018: 34) assert their finding that ‘those responsible for public involvement in large-scale transformation efforts should consider not only what they can do to maximize opportunities for involvement, but also whether some approaches inadvertently work against active and inclusive involvement beyond a small, selective group.’ Findings are based on a study of two health service transformation programmes which incorporated extensive public engagement, and suggested that

'the policy imperative to involve the public appears to hasten a very particular realization of public involvement' (Ibid: 33). Researchers highlighted the need for a cultural shift, by describing how professionals express concern over the process of involving the public in all aspects, and the public that were involved feeling restricted and only conveying those views which they felt would be acceptable and influential, omitting views which they felt were in opposition. Al-Tannir et al. (2017) have reported how some physicians and nurses reported believing that improving healthcare outcomes via the utilisation of patient engagement was actually not important or not extremely important. Following their study of primary care practices, Han et al. note also note that 'In all likelihood, achieving true patient- and family-centeredness will require a cultural shift in how we think about patients as partners in, rather than solely as recipients of, care. Practices must gain more experience in involving patients and families as partners and using their input for improvement and must also be exposed to more examples of the benefits of this involvement' (2013: 373). Carmichael et al. (2016) describe how one in five staff have reported never having recruited someone into a mental health research study, believing this to be a concern given NHS priorities around improving patient outcomes. Results showed that lacking confidence and data protection concerns were factors in their consideration. Also, difficulties around ethical approval have been cited by Staley as a barrier to engagement with the public (2006). On a related note, Mantovani et al. (2017) discuss the importance of those seeking patient and public involvement being equipped with bespoke communication skills so that they be deftly talk to participants about potentially sensitive issues.

Recent offerings have called for the process of public engagement to be normalised. As asserted by Healthwatch, '...as people's willingness to share their experiences with Healthwatch grows, so does the appetite of professionals to listen' (2016: 9). And 'This openness is extremely positive, but if services are to truly deliver what people want from health and care, it must become the norm for them to be involved early in the decision making process' (Ibid). Along similar lines, Han et al. (2013) call for patient feedback and patient involvement to be made a core requirement in order to qualify for the title of being 'patient-centred' in the first place (2013). Also, Tierney et al. (2016) suggest that public engagement becoming the normalised way of working in primary care is the end goal. To this end, Tierney et al. believe the explicit reporting of definitions; methodological innovation to enhance co-governance; and ample dissemination of findings to be of greatest importance.

In their 2016/ 2017 annual report, Healthwatch note it has 'seen some truly inspirational stories of people taking action to help make a difference. There have also been some outstanding examples of services listening to what people want and using their feedback to improve care. There are positive signs of a growing desire amongst professionals to understand and act on the views of communities. However, many services still do not understand how to achieve this consistently in

practice' (Ibid). This is echoed by Han et al., who describe how 'A lack of resources and knowledge about successful models of patient and family involvement activities limited implementation (2013: 272). Han has also noted that '...practices that valued patient and family involvement often used multiple approaches to achieve it. These practices went beyond patient surveys to gather additional input by other methods and had processes in place to act upon the feedback. They saw patient involvement as a core strategy for improving performance on quality, cost, and experience metrics' (2013: 372). The optimal level of involvement by patients and the public is also often called into question. Ocloo and Matthews (2016) criticise that although there appears to be a very supportive policy context, progress towards a greater level of involvement is often patchy and slow, and is, according to the authors, often concentrated at the lowest possible levels of engagement.

According to Shimmin et al '...evidence of the relative impact of public involvement in health research is still limited and weak at this time, primarily due to poor reporting, with many studies only providing partial information and a lack of consistency in terminology' (2017: 545). Manafo et al. point to a key limitation being the lack of available evaluation data on the success and extent in which patients are engaged. They note that 'Limited evaluative evidence may hinder future uptake of patient and public engagement in prioritization and decision-making exercises' (2018: 12). In their notion of evaluation, the authors include 'the patient perspective about how, when, and why they are engaged', and note that the views of the public/patients, researchers, policy-makers, and organizations, out to be gathered using validated evaluation tools. Holmes et al. (2018) have also called for a heightened focus on the study and evaluation of the actual patient engagement methods themselves, in order to enhance understanding on the topic and add to the body of knowledge on PPI, filling gaps on evidencing impact and illustrating which modes of operation in PPI yield the most meaningful and effectual input from the public. Brunton et al. (2015) also note that whilst evidence of involvement in the design and delivery of interventions is easily found, there is little evidence of involvement in evaluation. Additionally, Cyril et al. (2015) note the importance of developing innovative approaches for more rigorous measurement of the impact of community engagement.

Boivin et al. assert that 'A growing number of evaluation tools are available to support patient and public engagement in research and health system decision making. However, the scientific rigour with which such evaluation tools are developed could be improved, as well as the level of patient and public engagement in their design and reporting' (2018: 1). In measuring impact, Amann et al. (2018) describe how important it is to demonstrate that impact on both patients' and healthcare professionals' experiences, whilst Collins et al. (2018) caution that the time and effort involved in the creation of effective engagement impact assessment plans is considerable. Edelman and Barron (2016) contend that PPI should not be evaluated as an intervention but as a part of the

research process. They call for us to revisit the values and purposes of patient and public involvement, and to develop common goals in our efforts (Ibid).

What is clear from the available research is that the need for more robust and consistent ways in which we can measure the impact of PPI is ever more pressing, and that making that practice of measurement and evaluation a permanent fixture in all PPI efforts will be an essential component, should the PPI movement wish to continue gaining traction. More advanced and robust means of measuring and evidencing impact will allow for the story of patient and public involvement to be told, focussing not just on capturing the patient voice, but on relating back to the patient where impact has been realised; a more reciprocal model of healthcare and patient contribution. Li et al. (2015) have written on the importance of accountability and transparency, noting how crucial responding to the public is in this two-way system of public engagement. They describe how ‘the act of “responding” highlights the public's expectation to be informed about how their input has been used in health policy decision-making. It is considered the element that closes the loop between what the public has said, what the government has heard, and the interpretation of what was said’ (2015: 19).

Section Four: Best Practice in Public Engagement in Health

Over the course of the review, a wealth of recommendations and guidelines for best practice emerged. This section addresses some of this advice, in order to provide a comprehensive view from experts in the field of the kinds of suggestions being reported in order to enhance the future public engagement experience.

Jennings et al. (2018) describe the way in which public participation is becoming increasingly prevalent, but note that this is often in the pre-funding phases, and that there is much advantage to be gained by making public participation part of the analysis phase as well. They put forward a best practice framework for collaborative data analysis (CDA), instructing on how best to incorporate input from the public throughout the later stages, making it part of the project life cycle. A preparation phase marks the beginning phase, with a co-production phase to follow, and an application phase complete with reflective learning at the end. Jennings et al.'s best practice framework illustrates the way in which modern research is pushing for a more iterative level of engagement with participants, taking their views on board throughout the process, and not just in a tokenistic fashion at the outset. Jennings et al. developed their framework having assessed available evidence and examined the characteristics of successful involvement, before then developing, piloting and refining their own suggested approach. This more inclusive approach which sees the patient take on more of a collaborative role throughout the process is one which is also advocated by others in recent times.

Bagley et al. set out a number of essential prerequisites for effective PPI – the need to effectively plan for PPI, something which includes the successful identification of appropriate participants and the managing of their expectations; supporting PPI on an ongoing basis; and finally recording and evaluating the impact of PPI, an element which the authors, as do many others, agree has not been optimally recorded formally to date (2016: 9-10). Bagley et al. assert the need for adequate evaluation tools from the dual perspectives of both the public and the health team in order to ensure public contributors are being adequately supported; to evidence clearly when and where PPI happened; and to accurately record the impact it had in enabling ease of funder feedback (Ibid).

Gluck et al. have described their approach to PPI in the context of ageing and brain health research, putting forward strategies they feel could be implemented by others in order to foster successful public engagement. They describe how their level of PPI requires a 'longterm commitment of time and effort to build trust and partnerships with local community organizations and community members' (2018: 81). This longer-term approach, seeing PPI through to a point at

which those members of the public who got involved become ambassadors, is one which can bring about greater effects in the longer term. Through targeted recruitment efforts and communication via trusted community leaders, and building trust through long term relationships, the health team are, in their own words, 'cultivating research participants as ambassadors' (Ibid: 78), an approach which is to be encouraged for effective and lasting impact from public engagement in health.

Devonport et al. (2018: 155) are critical of a lack of focus on the interpersonal dynamics of partnership working. They reference Copeland's assertion that there is a need to be clear about roles, boundaries and how these relate together, and to culture more widely; Ballatt and Campling's description of a level of cooperation which promotes kindness, hence reducing anxiety and defensiveness amongst those taking part; and Gutteridge and Dobbins conclusion that the time required for effective partnership working is often considerably underestimated. These interpersonal elements, focussing on roles and relationships and how they ought to be developed over time feed into to success or failure of public engagement measures, and warrant careful consideration and planning in the implementation of any PPI measures.

Devonport et al. (Ibid) also discuss the need to focus on perceptions of power imbalance among lay people and professionals. They convey how training PPI contributors is sometimes suggested, but is not a decision to be taken lightly, and one which can have a negative effect. They also note how removing training and opting for a more informal induction is still something which brought about an effect on perceptions of power imbalance. The authors express a pressing need to 'think more proactively about relational aspects and power dynamics' (Ibid). Locock et al. (2017) also reflect on forms of power and capital wielded, encouraging those planning PPI activities to reflect on the power balances present in their own PI efforts.

Holmes et al. (2018) have acknowledged the challenges around research consensus on what works best in public engagement in health, noting that there is a tendency amongst some to ignore the challenges which lay and professional collaboration oft give rise to. Whilst acknowledging the positive and promising momentum present in the field of PPI, and asserting its potential to improve the relevance and quality of work, Holmes et al. call for an increased focus, not just on the practical elements of PPI, but also on issues such as credibility, legitimacy and power when looking to incorporate public input. The authors suggest that all projects engaging in PPI would benefit from the utilisation of a similar framework from which to operate, one which would allow for the anticipation and mitigation of challenges and barriers from an early stage in the project.

Li et al. discuss the importance of demonstrating accountability and transparency, and responding to the public to signal use. They consider the act of responding to the public a means by which to

acknowledge the public's expectation to be told of the impact their input has had on policy measures. It is, what they describe as 'the element that closes the loop between what the public has said, what the government has heard, and the interpretation of what was said' (2015: 19), and an element which warrants consideration for the upholding of good practice in public engagement.

Mantovani et al., (2017) talk about the need for those acting as researchers (in the context of community well-being champions) to be equipped with bespoke communication skills, so that they are able and qualified to talk appropriately about sensitive health issues which they are seeking to investigate.

A number of additional recommendations for best practice came forward from the research uncovered by this review. The following suggestions are some of those discovered through the review of literature, many of which will be project specific. Rashid et al. (2017) suggest improving the recruitment of guideline group chairs; widening evidence reviews to include patient preference studies; adapting guidance presentation to highlight patient preference points; and providing clearer instructions on how patient organisations can submit their intelligence to further enhance PPI. Pennel et al. (2017) suggest engaging a broad array of community stakeholders and members in a meaningful manner through the community health needs assessment planning process. Mockford et al. (2016) call for clarification on the requirements for NHS Trust approval, and a simplification to the system of financial reimbursement for lay co-researchers. Moule et al. (2016) favour a clear underpinning philosophy and having support mechanisms in place to support devolved models. Dalton et al. (2016) suggest that guidance which sets out the stages of reconfiguration and opportunities for participant input could be a helpful practical framework for engagement activity in the future. They also describe how engagement that started early was most likely to succeed, especially when led and supported by clinicians, and when the engagement offered opportunities for genuine interaction (Ibid). Renedo et al. suggest that 'Creating enabling environments is important if we are to allow new forms of knowledge – and improvements in patient care that might result – to emerge from the burgeoning patient participation initiatives within healthcare services' (2018: 791). Snape et al. (2014) comment on the importance of team cohesion and availability of appropriate resources, alongside clear guidance, models of good practice and measurable standard, as a recipe for success. Ng (2018) has described how new and novel technologies, telemedicine and social media are tools to be availed of that can be utilised to significantly improve patient engagement in particular contexts, a sentiment echoed by INVOLVE (2014), who described a growing body of research which is incorporating PPI through social media techniques, allowing people at distance to participate; enabling wider reach and consequently higher response rates; and facilitating discussions on research in online fora. It is a novel and modern method of engaging the public, and one which ought to be utilised. Although it does

present some new challenges, for which researchers need to be trained. Challenges exist around the resource required to manage such engagement and moderate platforms; only reaching people who are already engaged to an extent; and also the fact that you may be missing those who are digitally excluded, and potentially most in need.

The following extract from Neech et al. provides context to their two key recommendations which have been included below. 'User representatives in this study, involved in a UK mental health service, wanted to help people in a similar position and give something back to those that helped them. As people started involvement activities, such as interviewing staff, they gained confidence and felt part of something that was making a difference. After being supported by staff to explore opportunities, representatives become more independent and some moved to different, sometimes salaried, roles. Some representatives did not feel valued or supported. Staff often controlled opportunities, and many users missed out on being involved' (2018: 327).

Key recommendations for the implementation of effective engagement (Ibid):

- Staff need to understand and receive training on involvement. The definition of involvement should be agreed by users and staff together, and outcomes of involvement activities must be fed-back to users on a regular basis.
- There should be dedicated involvement workers in services, to support individuals and integrate involvement into the system. It is important to consider how to make involvement accessible to more mental health service users.

The National Institute for Health and Care Excellence (2017) has published a standard comprised of four quality statements, which are listed below, requiring that members of the local community:

- Are involved in setting priorities for health and wellbeing initiatives
- Are involved in monitoring and evaluating health and wellbeing initiatives as soon as the priorities are agreed
- Are involved in identifying the skills, knowledge, networks, relationships and facilities available to health and wellbeing initiatives
- And are actively recruited to take on peer and lay roles for health and wellbeing initiatives

The National Involvement Partnership has developed the 4Pi national involvement standards: principles (respect, equality); purpose (potential and limits of change); presence (at all decision-making levels); process (engagement, communication, support, practical issues); and impact (ethos/culture, policy/practice, delivery, outputs/outcomes, diversity and equality of opportunity, PPI

experience). Similarly, INVOLVE published a PPI values and principles framework emphasising respect, support, transparency, responsiveness, fairness of opportunity and accountability.

Healthwatch England has set out five public engagement principles to ensure that the public voice is effectively heard (Ibid: 34):

- Set out the case for change so people understand the current situation and why things may need to be done differently.
- Involve people from the start in coming up with potential solutions.
- Understand who in your community will be affected by your proposals and find out what they think.
- Give people enough time to consider your plans and provide feedback.
- Explain how you used people's feedback, the difference it made to the plans and how the impact of the changes will be monitored.

Harden et al. (2015) offer the following insight, after their evidence review commissioned by NICE, regarding barriers and facilitators of public engagement:

- Planning and resources (or lack of) can impact upon community engagement
- Effective community engagement is hindered where there is a lack of clarity and transparency about the goals of the engagement, competing agendas across stakeholders within partnerships, a lack of dedicated staff and resources, and limited timelines for building trust or achieving the scope or depth of the community engagement.
- Effective community engagement is enhanced where there is planned rather than ad-hoc community engagement strategy and methods, clarity of community engagement goals and transparency of process, mechanisms for joint decision-making and a transactional and reciprocal process between communities and engaging organisations, strong partnerships and networks, and time, effort and resources invested to build relationships and trust.
- Further training in methods of community engagement and coproduction and other skills is essential for both community members and professionals, as well as mentoring and ongoing support for community members.

- A lack of capacity of both community members and organisations is a limit on effective community engagement, as is the difficulty in engaging specific groups within the community.
- Using community organisations with good reach, being flexible in methods of engagement, and using outreach or advocacy can overcome the latter difficulty.
- Barriers such as poor communications, cultural or language barriers, untimely events and a lack of support to attend, or lack of appropriate venues for engagement events can adversely affect community engagement. However, early and consistent advertising of community engagement opportunities through multiple channels, use of plain language and provision for non-English speakers, appropriate timing of events and providing support to involvement (such as transport or childcare) can overcome the barriers to involvement.
- The review noted a lack of mixed methods studies which integrated process and outcomes; the predominance of qualitative evaluations; and the fact that methodological rigour could be improved.
- Community engagement still appears to be a somewhat experimental and ad hoc process rather than a planned and purposeful activity with a rationale given for the choice of strategy or approach.
- Evaluations of community engagement too tend to be retrospective and occur at the end of the process rather than formative and running alongside the engagement process so that early problems can be picked up and rectified.
- There was very little generally in the studies about the costs of engagement, about the setting up of processes, or the investment of time or other resources in the preparation of structures, processes or mechanisms of engagement. Further related gaps are how engaging agencies recorded, tracked, or analysed collected information/data from the community engagement activities and how this information/data was fed back into decision-making processes and the subsequent impact they had on, for example, programme design or service delivery.

With much criticism mounted against the evaluative processes present in public participation processes, there is a clear need for some agreed standards to improve this process. Dalton et al. (2016) have asserted that future evaluation and more explicit reporting on the subject of

engagement and its impact are required. Abelson et al. (2016) are critical of the presence of only rudimentary tools in support of PPI evaluation. Their study represents a collaboration of researchers and practitioners in the co-design of an evaluation tool to be used in the health setting. Phillips et al. (2016) also criticise the lack of reliable and valid tools available, but note that the dyadic Observing Patient Involvement in Decision Making (dyadic-OPTION) tool shows the greatest promise for measuring core PPI components. Phillips et al. call for further study into potential measurement strategies as part of a continuous improvement process. Staniszewska et al. (2017) also contend that the reporting of PPI in research papers has tended to be inconsistent and partial. They aimed to develop reporting guidelines for PPI in order to improve the quality of the PPI evidence base going forward. They discuss GRIPP2-LF and GRIPP2-SF, which they describe as representing ‘the first international evidence-based, consensus-informed guidance for reporting patient and public involvement in research. Both versions of GRIPP2 aim to improve the quality, transparency and consistency of the international PPI evidence base, to ensure PPI practice is based on the best evidence.’

The National Institute for Health Research (2014) has produced a handbook for researchers on PPI in health and social care. It outlines how evaluating PPI can help to:

- Identify what works (or not), for whom and in what circumstances identify how the involvement impacted on the research process
- Celebrate success – recognising the achievements of your research team and your patients and the public
- Generate evidence and share learning of the value of PPI; could your PPI activities inspire others and help evidence the impact of PPI on the research process?
- Improve the planning of future projects - evaluating what worked and what didn't will help you identify how to plan future projects.

Wilson et al. have written about the ‘20 years’ experience of attempts to embed PPI in UK health research’ (2018:105), noting how the UK has led the way with its significant policy drive. In their realist evaluation of how embedded public involvement actually is in mainstream health research in England, Wilson et al. (Ibid: 98) describe how developing true reciprocal working relationships and embedding patient and public involvement is in fact contingent upon a number of variables. They note the importance of the following criteria:

- The purpose of patient and public involvement being clear
- Public contributors reflecting research end-beneficiaries

- Researchers understanding the value of patient and public involvement
- Patient and public involvement opportunities being provided throughout the research and ongoing evaluation of patient and public involvement

Wilson et al. also noted a number of key contested areas, concluding that patient and public involvement can indeed be well-integrated within research, but that there is a strong need for policy makers to 'take account of tensions that must be navigated in balancing moral and methodological imperatives' (Ibid). The contested areas identified by Wilson et al. are listed below:

- Whether to measure patient and public involvement impact
- Seeking public contributors to maintain a balance between being research-aware and an outsider standpoint seen as 'authentically' lay
- Scaling-up patient and public involvement embedded within a research infrastructure rather than risk token presence
- Whether patient and public involvement can have a place within basic science

Comments from Wilson et al. on PPI priorities are included below:

'The NIHR commissioned a review of the state of PPI in research which informed the INVOLVE decision to focus on three priorities. The first priority is to encourage more diversity, equity and inclusion. The second is to develop support, capacity building and learning and development for both public contributors and the research community. The third is community, network and partnership building. These priorities can be informed by the RAPPORT findings which also shed light on key areas of debate for policy makers to consider. These include maintaining a balance between the moral and methodological imperatives in evaluating PPI; seeking the most appropriate public contributors and how best to harness PPI skills and relationships developed over time; ensuring adequate resources and scale in PPI to support research whilst avoiding impersonally 'industrializing' PPI activities and finally, enabling optimal PPI contributions at all stages of research without adversely affecting research outcomes. Tensions are to be expected in PPI, but working through them in partnership can fuel novel research synergies' (Wilson et al., 2018: 105).

Nass et al. (2012) distinguish between minimal public involvement; consultation; collaboration; and control, with control having the greatest level of engagement where the public drive the research project. Based on a review of best practice, Nass et al. (2012: 8-9) conclude the following on how best to approach public engagement with regards to topic generation:

- Public engagements should use a theory-based approach

- Researchers and moderators should be skilled in using and interpreting social science methods
- The engagement process should use more than one method to elicit sufficiently diverse viewpoints and appropriate detail
- The process should also involve researchers who are skilled in translating the information received from the public into a research project
- The use of data from health experience research is encouraged to provide sufficient detail of the patient experience, combined with systematic CER reviews to avoid the duplication of research, and a health disparities analysis to ensure that the needs of underserved populations are addressed
- The process should also involve researchers who are skilled in translating the information received from the public into a research project

Manafó et al. (2018: 8) writing on the Canadian approach, have put forward three recommendations with respect to public engagement in health:

- Clarify the terminology of patient engagement in health research to illuminate expectations and understanding for patients, researchers, clinicians and policy-makers.
- Implement a predefined, validated framework to support and evaluate patient engagement in research.
- Support development of evaluation frameworks and tools, and collection of robust evaluation data to measure near, intermediate and long-term outcomes.

In a recent review of PPI engagement principles, and in recognition of the fact that consensus on how best to incorporate the public voice is lacking, Baines and Regen de Bere (2017: 334) addressed how to optimise PPI, identifying its essential and desirable principles collated via a systematic review of literature on the topic. Results were based on what the authors ascertained were the resounding principles of PPI, and which ones in particular are of considerable importance to effectively carry out the process.

Essential

- Work in equal partnerships built on mutual trust, respect and transparency.
- Share information, good practice, negative experiences, knowledge and power.
- Communicate and inform regularly, clearly and inclusively. Do not rely on one method of communication; this is unlikely to be suitable for all those involved—be creative.
- Listen, assess and respond to the information shared. Regularly update people involved. Do not collect information and then ignore it. This is disrespectful and tokenistic.

- Support and prepare everyone involved before, during and after any working together initiative. This includes offering relevant training, information, practical, emotional and financial support.
- Acknowledge, reward and value everyone involved. Celebrate good practice.
- Accommodate individual and collective needs to ensure inclusivity.
- Evaluate throughout your working together initiative to identify best practice and areas that can be improved.
- Tailor your working together approach, materials, training and evaluations provided to match your purpose, aim, local context and individual choices of people involved.

Desirable

- Commit to working together on a personal, organisational and long-term basis. Do not involve sporadically, be consistent.
- Resource and invest: Effective working together takes time, money and resources. Be prepared to invest time and effort in working together; it will nearly always take longer than you think.
- Empower all members involved. Be proactive in your approach. Do not expect people to come to you. Go out into relevant communities, get involved.

NICE (2016) has identified four future research areas, all of which are in line with priorities identified in this review. The four research areas are listed below.

- Effectiveness and cost effectiveness.
- Evaluation frameworks and logic models.
Which evaluation frameworks and logic models can be used to evaluate the impact of community engagement on health and wellbeing?
- Collaborations and partnerships. What are the components of collaborations and partnerships between people, local communities (including community representatives, such as peers) and organisations that lead to improved health and wellbeing?
- Social media. How effective are online social media and networks at improving health and wellbeing and reducing health inequalities

The NHS (2016) has produced a guide for local areas developing Sustainability and Transformation Plans. It notes that, 'To succeed, STPs will need to be developed with, and based upon, the needs of local patients and communities and engage clinicians and other care professionals, staff and wider partners such as local government. And we cannot develop care

coordinated and centred around the needs of patients and users without understanding what communities want and without our partners in local government. That is why we need robust local engagement plans as part of the STP process' (2016: 4-5). STPs are now expected to demonstrate how they have been engaging patients and the public; evidence and publish their plans for wider future engagement; and present insight into the needs and views of patients which have been uncovered. STPs hold responsibility for ensuring they are not exposed to potential legal challenge through effectively and adequately involving the public in the 'exercise of their statutory functions' (Ibid: 6). Failure to do so would result in unavoidable costs to the NHS.

In light of all of these requirements, NHS guidelines stress the importance of an ongoing dialogue with those to be engaged, as well as maximising efficiency and effectiveness through the harnessing of existing networks. They suggest 'establishing citizen summits or panels, participatory events, or strengthening the roles of lay peers and champions' as potential avenues to explore in order to effectively engage lay people (Ibid: 7). Choosing the appropriate engagement method dependent on the individual circumstances of the proposed change and relevant audience, the ongoing development of engagement plans as proposals evolve, and working in a coordinated manner with all relevant parties form additional recommendations.

Substantial changes require public consultation, and service change must be evidence based, with that evidence made publically available. Guidelines note that it is important that 'consultation is approached in a way that is genuinely open to influence' (Ibid: 12).

The optimum level and duration of engagement also requires consideration, and NHS guidelines note that, as a general rule, 'the greater the extent of changes and number of people affected, the greater the level of activity that is likely to be necessary to achieve an appropriate and proportionate level of public involvement' (Ibid: 10).

Guidelines suggest that 'Particular emphasis should be given to engagement with people who are less frequently heard and who experience the greatest inequalities in health outcomes' (Ibid: 7).

Guidelines also suggest that STPs should be able to document engagement during every stage, from planning right through to implementation, and ought to engage with organisations such as Healthwatch in order to gain understanding on 'what matters to local people and how services might be improved' (Ibid: 8). Documenting the approach and maintaining an audit trail is of paramount importance, bearing in mind how this will 'strengthen proposals, highlight likely areas of concern, and provide evidence in the event of subsequent challenge' (Ibid: 10).

The guidelines offer four key consultation guiding principles (Ibid: 11), as listed below:

- Consultation must take place when the proposal is still at a formative stage.
- Sufficient reasons must be put forward for the proposal to allow for intelligent consideration and response.
- Adequate time must be given for consideration and response.
- The product of consultation must be conscientiously taken into account.

The NHS (2017) has also produced statutory guidance for clinical commissioning groups and NHS England with respect to PPI in commissioning health and care. The guidance provides direction on how to embed PPI in their work, and offers ten key actions (the principles of participation) for CCGs and NHS England, which are listed below:

- Reach out to people rather than expecting them to come to you and ask them how they want to be involved, avoiding assumptions.
- Promote equality and diversity and encourage and respect different beliefs and opinions.
- Proactively seek participation from people who experience health inequalities and poor health outcomes.
- Value people's lived experience and use all the strengths and talents that people bring to the table, working towards shared goals and aiming for constructive and productive conversations.
- Provide clear and easy to understand information and seek to facilitate involvement by all, recognising that everyone has different needs. This includes working with advocacy services and other partners where necessary.
- Take time to plan and budget for participation and start involving people as early as possible.
- Be open, honest and transparent in the way you work; tell people about the evidence base for decisions, and be clear about resource limitations and other relevant constraints. Where information has to be kept confidential, explain why
- Invest in partnerships, have an ongoing dialogue and avoid tokenism; provide information, support, training and the right kind of leadership so everyone can work, learn and improve together.
- Review experience (positive and negative) and learn from it to continuously improve how people are involved.
- Recognise, record and celebrate people's contributions and give feedback on the results of involvement; show people how they are valued.

Devonport et al. (2018) have offered a number of critical reflections and recommendations on the PPI process, noting that they are not currently covered by existing PPI guidelines. They suggest

that a greater focus must be placed on understanding and thinking proactively about relational aspects and power dynamics in order to facilitate success. These follow a reflective account of PPI in obesity and binge eating research, and have been listed below:

- Attain clarity of PPI purpose and resolve differences in aims and priorities
- Support relevant disclosure whilst managing risk and safety, balanced alongside the ethical principles of respecting patient autonomy and confidentiality
- From the earliest planning phase pay attention to relational dynamics, particularly perceived power and to the methods used to communicate so that tacit mixed messages are minimized
- Create opportunities to share and establish 'difference' as a valued component of the research process
- Acknowledge constraints and limitations so these can be addressed

These recommendations, together with those described earlier, all serve to create a collection of useful learning points, which collectively can inform a model of best practice with respect to PPI. By combining recommendations across the differing arenas of health and social care, one can create a toolkit that is widely applicable, fosters effective public engagement, and protects against the widely documented pit falls within the field of PPI.

Section Five: Evidence of the Impact of Public Engagement in Health

Traditionally, much criticism has been levied regarding the lack of a cohesive body of evidence in support of public engagement. Some have described the evidential support for the current legislative and policy drive for heightened community engagement as lacking. Edelman and Barron (2016) have asserted how developing an evidence base around the impact of public involvement in health research has been problematic, with a tendency to rely on rhetoric as to its benefits. Similarly, Staley (2009: 8) notes that 'The vast majority of the evidence of impact is based on the views of researchers and members of the public who have worked together on a research project,' much of which is often collected informally. Conklin et al. (2015), too, note that despite the growing body of work on public involvement, impact evidence is scarce, limiting the ability to draw firm conclusions about the most appropriate and effective engagement activities. In a similar vein, Rifkin (2014) notes that the evidential link between community participation and improved health status is not strong, something which constitutes a barrier for those wishing to promote community participation. Brittin et al. (2015) have called for further work to be carried out in order to integrate community perspectives through planning and design processes, and for a greater level of evaluation of the longer-term impacts of such efforts in order to enhance the available evidence base.

In light of this debate, considerable interest has been growing in recent years around the gathering of an evidence base to demonstrate the value that patient involvement in health research can give rise to. Pinning down the associated benefits, and conclusively evidencing them, is now seen as imperative in order to advance the public engagement agenda in a meaningful and effective way. Despite the negative views of the evidence base put forward by academics in the field, there is some empirical evidence available which does illustrate the benefits of public involvement in health research. Edelman and Barron (2016) note that public involvement in research has indeed been shown to 'improve the quality, relevance and ethical conduct of research' (209), and Bath and Wakerman (2015) assert that there is, in fact, a small but substantial body of evidence which indicates that community participation is indeed associated with heightened health outcomes. In the recent years which this review has chosen to focus on (2014-2018), there has been considerable progress made, and advances in the development of an evidence base which can be utilised to progress the public engagement mission have been observed. The following section sets out research which has been uncovered over the course of this literature review, in order to present some of the evidence which is bridging the gap in establishing a link between public engagement and positive health outcomes across a range of measures. Whilst it is clear from earlier sections that the means by which impact is measured and evaluated needs addressing, this has not precluded the gathering of existing evidential support for public engagement in health.

As methods for patient and public engagement and consultation become more sophisticated, and with an increased awareness of the need to document engagement processes and evidence impact, we are now transitioning to a state where a more solid and credible evidence base is beginning to emerge. A number of systematic reviews have been conducted in recent years, looking to extract evidence of areas where the impact of public engagement has been effectively recorded. Additionally, there have been meta-analyses and literature reviews addressing the same. The all-encompassing literature review presented here, which sought to include all such pre-existing reviews, together with academic outputs and grey literature, presents a selection of the more robust analyses that have been carried out in recent years. As can be seen from those that have been included, the evidence base for effective community engagement, and the wider impacts it can be seen to have, is mounting.

In their review of local Healthwatch reports (2015), Healthwatch gathered the views of more than 11,000 patients, enabling them to articulate a cohesive view of the insight that Healthwatch gathers nationally. Outputs from this level of engagement demonstrate the way in which the patient voice can be captured and used to influence service provision, allowing the possibility of tailoring services to adequately meet the true needs of the end-users. This engagement approach allows Healthwatch to address issues articulated through the patient voice on patients' behalf. In their 2016/ 2017 annual report, Healthwatch noted having gathered the views of 341,000 people over the course of the year, something which fed into service improvement nationally, and 'demonstrated the impact that a strong public voice can have' (2017: 8).

The Health Research Authority and INVOLVE (2016) have surmised, through a review of available existing literature and related evidence, that PPI throughout the course of a study can in fact make research more ethical by making it more relevant; helping to define what participants consider acceptable; improving the process of gaining informed consent; enhancing the research participant experience; and improving the communication of research findings to participants and the public.

INVOLVE also commissioned a review of academic Research Excellence Framework (REF) case study submissions, showcasing twelve examples where PPI in research was reported in the REF 2014 Medical and Health Sciences category (Faulkner, 2016). Cases included in the review describe a wide range of methods and subject areas, and demonstrate the many ways in which PPI is being integrated into academic, peer-reviewed research at the highest level. Peer led self-help groups and citizen research groups contributing to service development and improvement; user-controlled research feeding into the optimisation of person-centred support in social care; a stroke patient and family group contributing to the design of a national survey; mental health service users operating as researchers resulting in changes in mental health policy and practice;

and work with people with learning disabilities as expert witnesses and co-producers of knowledge to inform policy and practice from just some of those included in this review, further contributing to the evidence base for public engagement.

A recent review of examples where PPI has been integrated into funding applications has highlighted the many contributions PPI can make in this context (INVOLVE, 2013). An example includes patient contributions leading to the development of new research questions in Parkinson's disease medication research. Patients were also seen to influence outcome measures, leading to the addition of a wellbeing measure, and also to influence practical arrangements in their care, resulting in new care plans being developed. Another example cited in this review noted how working with cancer survivors had the effects of changing the attitudes of the researchers and the way in which the team functioned. A further example noted the importance of the patient voice in designing the way in which patient data was captured, and in the practical design of the study in question.

A further review conducted by INVOLVE addressed the impact of PPI on research quality. A number of emergent themes were identified. All six authors felt that PPI had enhanced the relevance of both the research questions and the topic, and that they had contributed in a meaningful way to the design of the research. Data collection processes were also found to be improved on the back of participant inputs. Additionally, patients were described as having played an important role in the interpretation and refinement of findings. The contribution public involvement could make to implementation and impact was also discussed, with one author feeling this was an untapped area, and another noting that the debate on public involvement ought to move from one around impact on rigour to one which addresses the impact agenda more widely. A link was also made between the quality of relationships formed over the course of the user-involved research and the quality of the research itself.

In her study of user-controller research, a more demanding level of user engagement, Faulkner (2010) screened studies for inclusion before selecting seven to explore in-depth. Much benefit and impact was reported in this review, from enhancements to access, trust, skills and credibility, right through to making change happen and improving research quality. That impact was felt across service users, the research itself, on services, and directly on policy. Tangible outputs which could be utilised to effect change in the wider communities of service users were created, and many were in a position to make use of relationships with powerful allies to bring about change and have an impact. Faulkner describes how some projects included in the exploration found themselves in a position to have an impact on national policy.

A selection of NICE reviews published in 2015 provide a wealth of evidence in support of public engagement and the wide reaching impact it can have. In Evidence Review 1, Brunton et al. (2015) describe the high level of community engagement in the design and delivery of interventions. Findings indicated that 'The majority of outcomes showed beneficial effects or positive trends for a range of health behaviours, clinical measures, health/social status, self-efficacy, and knowledge, attitudes or intentions' (2015: 60). Whilst the authors asserted that the synthesis of evidence seems to suggest that 'a higher extent of community engagement reports more beneficial effects and positive trends across outcomes,' they do caution that 'this must be tempered by the overall moderate to high risk of bias operating in this set of studies' (2015: 60).

Evidence Review 2 also proved promising, with community-led or community collaboration projects which 'design, deliver and evaluate health interventions' found to be associated with 'larger behavioural outcomes' (Brunton et al., 2015: 82). Results also showed that where 'coalitions, collaborations and partnerships with community members include the use of bidirectional communication, collective decision making and training support for intervention provision, a higher extent of community engagement across the project's design, delivery and evaluation' was found to be present. Additionally, projects with a low extent of engagement were found to be aligned with lower reported effects (Ibid).

In addition to larger scale studies carried out by key bodies operating in the field of public engagement in health, this review has uncovered a number of studies which evidence the impact of public engagement in health. A selection of these has been included below:

A study by Luhr et al. (2018) highlighted the benefits of facilitating patient engagement in the context of a self-management care programme. 'The factors that facilitate patient participation – respect, engagement, opportunities to share and learn, sufficient time and adequate information – can strengthen the patients' own resources to engage and take responsibility for their own healthcare' (Luhr et al., 2018). This article from Luhr offers some insight into the considerable impact public engagement can have on the self. Impact on the end-user is but one facet of the impact which public engagement can give rise to, but an important one to note.

The PRISM trial comparing treatments for Paget's disease of the bone worked alongside service users and carers, something which researchers reported as aiding the process of recruitment, the quality of the applicants and the retention of recruits, all of which was seen to enhance the quality of the trial data (Langston et al., 2005).

In their study of primary care practices, Han et al. note that 'Practices with higher levels of patient and family involvement saw a connection between improved involvement and improved care for individual patients' (2013: 371). They also state that '...robust patient involvement in every aspect of the practice, including designing effective patient engagement strategies, positively affected the way in which patients and families interacted with physicians and staff, supporting stronger relationships and enabling patients to feel more empowered to become active partners in their care (Ibid).

Ghisoni et al. (2017), in their study of user-led mental health research, demonstrated how participants can help with setting the research agenda at the outset, with findings illustrating how two user-generated research priorities were successfully identified. Nass et al. (2012) have also identified a number of studies where patient involvement eliciting the public voice has led to consensus development and the generation of research topics and priorities which are of utmost importance to patients. A variety of methods were employed across the studies referenced, and health areas covered include ulcerative colitis, urinary incontinence, chronic pain in older adults, and quality of life issues in rural breast cancer survivors. They note that 'Experience with patient involvement in research has shown that engaging the public early in the design of studies, ideally at the planning stage, leads to better results' (2012: 10).

Bias et al. (2017) have written on the impact of community input in community health needs assessments (CHNAs), noting that community participation was found to have an impact on finalised priorities. They concluded that community participation is a key factor in identifying unique health needs and ought to be incorporated as an important part of the assessment process. They note that CHNAs that do not seek adequate public input may not translate into plans which accurately seek to address the most pressing and immediate health concerns.

In their study of engaging patients with heart failure into the design of health system interventions, Newhouse et al. (2017) reported how patients validated the study design, measures and outcomes, and were also seen to identify one area that ought to be added to the study protocol. Yet another example of the participant setting the research agenda, and highlighting something which might otherwise have been missed. The authors concluded that patient engagement in the conceptualization of research is in fact an essential component in order to guide patient-centered studies.

In their study of the impact of patient and public involvement on service users, researchers and communities, Brett et al. (2014) identified a number of positive impacts which enhanced the quality and appropriateness of research. The authors reported impacts across all stages of research,

including the development of user-focused research objectives; development of user-relevant research questions; development of user-friendly information, questionnaires and interview schedules; more appropriate recruitment strategies for studies; consumer-focused interpretation of data; and enhanced implementation and dissemination of study results. The authors do, however, despite uncovering evidence, that this evidence is not as strong as is ideal, and need enhancing in future.

Grumbach et al. (2017) has written on the merits of the San Francisco Health Improvement Partnership (SFHIP), noting that its model of emphasizing community engagement accomplished many of its foals to create a health- and health equity-promoting environment. The SFHIP model includes a wide range of diverse stakeholders, including ethnic-based community health equity coalitions; the local public health department; hospitals and health systems; a health sciences university; a school district; the faith community; and others sectors. It seeks to translate evidence into policy change via its unique collective community engagement focussed approach. Impacts were recorded in reducing sugar sweetened beverage consumption; regulating retail alcohol sales to reduce alcohol-related violence; and eliminating disparities in children's oral health.

Baldwin et al. (2018), in their systematic review on the impacts of older people's patient and public involvement in health and social care research, identified a number of benefits for older co-researchers, including psychological and social benefits; new learning; and activism and career opportunities. Benefits to academic researchers encompassed new learning and shared workloads. Positive impacts on research quality and impact were also observed (as were negative impacts), and the benefits to participants and the community were further identified. According to the authors, critical to the success of such efforts are the building of relationships; breaking down barriers; and facilitating communication.

In another study uncovered in this review, South et al. (2016) conclude that PPI can be of great benefit to clinical studies, and a variety of different approaches should be considered. Looking at ten case studies, the authors assess models and impact of patient and public involvement in studies carried out by the Medical Research Council Clinical Trials Unit at University College London. Impact were recorded via improvements the research question; study design; communication with potential participants; study recruitment; confidence to carry out or complete a study; interpretation and communication of results; and influence on future research. They further assert that employing multiple models of PPI may in fact increase the potential impacts of PPI in the field of clinical research.

Bolton et al. (2016) have concluded that community organising is a strong and a promising model for the facilitation of community engagement in health. Through their study of community organizing and community health, as applied to an early intervention project in south London, the authors conclude that mothers who took part perceived their involvement as bringing about co-production and community control, and that mothers also experienced reductions in distress and increases in social capital, another means of community engagement seen to bring about positive advantages for the self.

Laurance et al. (2014) present four cases studies from across the globe that highlight the potential for heightened patient engagement to improve health outcomes as well as reduce costs, while also simultaneously extending, into communities, the reach of treatment and diagnostic programs. The authors examine an online mental health community in the United Kingdom; a genetic screening program in the United Arab Emirates; a World Health Organization checklist for new mothers; and a hospital-based patient engagement initiative in the United States. According to the authors, evidence suggests that a greater level of public engagement from patients, families, providers, systems and policy makers could bring about more effective and appropriate healthcare using fewer resources.

As can be seen from the above descriptions, there is a growing body of evidence in recent years which is contributing to a more solid and credible evidence base. This will only continue to grow, and as evaluation techniques become better integrated into process of public engagement, more robust impact evidence will begin to emerge, leaving behind the need for rhetoric and anecdotal evidence, and clearly evidencing further what this review indicates is the reality of huge potential for public engagement to have a great impact in the field of health and social care.

Section Six: The Dangers of Getting Public Engagement Wrong

With a legislative basis in health systems for patient and public engagement, and a policy agenda which champions collaborative working, as well as effective involvement and engagement in decisions about healthcare, the means by which community engagement can be optimally realised is ever more pressing. The statutory nature of public engagement in the field of health service reform brings with it an additional pressure faced by those responsible for the design and delivery of healthcare services, owing to the potential for legal challenges to be mounted if patient and public engagement is not adequately implemented. Included below are some examples of where legal challenges have been undertaken on the basis of an alleged failure to adhere to the legislated consultation process, and an inadequate presence of patient and public engagement. Further detail on all cases noted may be viewed in Appendix Three in the *Legal Cases* section.

In the 2018 case of **R (Hutchinson & Anor) v Secretary of State for Health and Social Care & Anor**, the contention was raised that the proposed Accountable Care Organisation model was to be introduced with only very limited public engagement. It was this lack of public consultation which informed the basis of the legal challenge at the time. Additionally, we saw in the 2018 case of **R (on the application of British Homeopathic Association) v National Health Service Commissioning Board** how crucial it is to get the public consultation process right, with the British Homeopathic Association claiming the consultation document was needlessly complex and misrepresentative, and accusing the NHS Commissioning Board of ‘manipulating the consultation process and making decisions about healthcare services without genuine patient engagement.’ Whilst both unsuccessful in their challenges, these cases highlight the dangers of a failure to adhere to policies of best practice with respect to public engagement in health, and the ways in which one can become exposed to legal challenge without a steadfast and incontestable engagement approach in place. To avoid the threat of legal recourse, there is no room for ambiguity in one’s adherence to legislated consultation processes, and conforming to engagement best practice is of paramount importance.

In a recent successful challenge, we saw in the 2018 case of **R (on the application Of Lyn Buckingham) v NHS Corby Clinical Commissioning Board**, how the high court quashed a proposed service reconfiguration in Corby which would have seen an Urgent Care Centre in the region downgraded. The judge ruled that patients and the public had not been sufficiently involved in the Clinical Commissioning Group’s consideration of its proposals, again highlighting how vitally important it is for those delivering healthcare to get patient and public involvement right. Dorset CCG faced a similar judicial review in their 2018 case **Defend Dorset NHS campaign group v NHS Dorset Clinical Commissioning Board**. This was over their consultation process, but the

challenge mounted was unsuccessful. What is common amongst all cases, regardless of outcome, is that they bring with them considerable costs to the NHS; costs which are best avoided through adherence to robust and incontestable public engagement and consultation practices.

Section Seven: Social Stratification in Public Engagement in Health

With great diversity across the NHS patient population, the need to consider the inclusion and representation of all user groups in patient engagement efforts is of paramount importance. Shimmin et al. call for a more inclusive model of patient and public engagement, noting that patient engagement ‘continues to essentialize the identity of “patient” as a homogenous group, denying the reality that individuals’ economic, political, cultural, subjective and experiential lives intersect in intricate and multifarious ways’ (2017: 539). Shimmin et al. caution that in failing to account for the different social groups, and the systems of oppression and domination they are often subject to, we ‘risk excluding the involvement of individuals who often carry the greatest burden of illness — the very voices traditionally less heard in health research’ (Ibid: 540). They call for additional measures and metrics to be included in the engagement process and its ongoing evaluation, so that pre-existing health inequities are not simply reproduced in efforts of engagement (Ibid). Further acknowledging the need for more inclusive community engagement strategies, De Freitas and Martin (2015) have highlighted the importance of a ‘proactive approach providing minorities and other marginalised groups with opportunities and incentives that attract, retain and enable them to build and release capacity through involvement’ (2015: 31). The authors suggest that, in policy terms, ‘both health authorities and civil society organisations have a role in creating ‘hybrid’ spaces that promote the substantive inclusion of marginalised groups in healthcare decision-making’ (Ibid). De Freitas and Martin assert that to exclude minority groups from the field of health participation may actually weaken the ‘transformative potential of public participation’ (Ibid). Furthermore, Fredriksson et al. caution on the need to take account of variation in the desire to actually be involved across the patient population, and the implications that this may have for the preservation of equity. So, it is not merely accounting for the characteristics of the patient population which warrants consideration, but also the individual participation preferences which individual pockets of that population may hold (2017). Whilst some may wish to participate, others may require alternate approaches in order to foster engagement. Fleming et al. (2017) point to the challenge of reconciling pressure to direct care towards patients who are engaged, with the knowledge that low levels of patient engagement can be the result of difficult socioeconomic conditions. They note that providers made effort in their assessments of patient engagement to not just look at the more explicit indicators of engagement, but also to seek out the more subtle and intuitive indications of engagement for patients who are marginalized. This research highlights the complexity of assessing engagement and ensuring one does not replicate inequity. Building on community engagement and driving towards the accessing of underrepresented groups will require providers being attuned to the engagement preferences and habits of marginalised groups.

A review of literature has shown that community engagement practices do have a role to play in addressing inequity in health systems. Bagnall et al. (2015) describe how community engagement and empowerment are oft linked to strategies which deal with health inequalities. In their review of barriers to, and facilitators of, community engagement practices, Bagnall et al. report a high volume of evidence from public engagement initiatives which were targeting health inequalities via socioeconomically deprived areas and groups, and also via groups deemed hard to reach. According to results, 'Community level outcomes (e.g. improved housing) and wellbeing outcomes (e.g. improved self-esteem) were most commonly addressed, and community mobilisation/ action and community partnerships/ coalitions were the types of community engagement most commonly employed' (Bagnall et al., 2015: 98). Unertl et al. (2016) describe how the application of community based participatory research approaches can bring with it significant benefits, most notably in the engagement of populations that are known to be underserved by healthcare systems. Similarly, Cyril et al. (2015) describe their findings which indicate that community engagement models can bring about improved health and health behaviours among disadvantaged populations if they are appropriately designed and implemented through effective consultation with, and participation by, the community. O'Mara-Eves et al. (2015), in their meta-analysis of the effectiveness of community engagement in public health interventions for disadvantaged groups concluded that there is a solid evidence base that community engagement interventions have a positive impact on a range of health outcomes across various conditions. Despite encouraging results with respect to health inequity, there are gaps in research and literature with respect to women and disadvantaged groups. In their systematic review and meta-analysis of community engagement for health via coalitions, collaborations and partnerships, Stokes et al. (2015) specifically noted that very few studies which targeted women only or disadvantaged groups were identified. Similarly, Bagnall et al. (2015: 98) highlighted a 'lack of initiatives found in rural settings, and the lack of evidence on cultural adaptation, groups at risk of health inequalities due to religion/ culture or lack of education', suggesting that it may be beneficial to explore community engagement practice in amongst these social groups.

Research does indicate the need to be mindful of power and trust dynamics, and the way in which engagement efforts may impact upon different societal groups and demographics in variable ways. For instance, a positive outcome with respect to this tendency may be seen in Bharmal et al. (2014), which suggests that efforts to heighten community engagement in research have been seen to be associated with a decrease in distrust in health research, particularly when looking at the African American participants that contributed to the analysis.

In a study of public engagement with respect to the LGBT community, Anonymous (2017) concluded that a more inclusive focus on patient engagement for all patient demographics is critical in ensuring the upholding of care quality and in reducing risks to healthcare. The author

calls for a greater depth of understanding of diverse populations, in order to enable healthcare professionals to better serve their patient population. Central to these findings is the need for continual examination and updating of policies and practice in order to eliminate barriers to engagement, regardless of sexual orientation, gender identity or transgender status.

Watters et al. (2016) write of a need for healthcare practitioners to develop their levels of cultural competence so that they may effectively engage patients in their care and reduce the health disparities which have been identified in ethnic minority populations. They argue that cultural competence and patient engagement are inextricably linked. The authors also call for demographic data to be used in order to engage patients in a culturally competent way. Kamaraju et al. (2016) also call for a greater need for culturally competent breast health education in community outreach for engaging women facing multiple barriers.

Additional calls have been made for greater recognition of the contribution to be made by those who are non-native speakers. 'We know little about patients who do not speak English as a first language. Such patients may be particularly vulnerable to patient safety incidents and unable to access existing feedback mechanisms. Further studies of patient safety in general and patient reporting more specifically should include patients who do not speak English' (Wright et al., 2016: 193).

NHS guidelines include a number of recommendations relevant to CCGs and NHS England with respect to health inequalities in patient and public participation (2016). These have been summarised below:

- Use a flexible range of methods to hear and engage with potentially excluded groups, or there is a risk that participation will reinforce inequalities in access to services and in health outcomes. For instance, digital engagement may exclude certain groups, and enable others.
- A planned approach will maximise involvement from different groups and reduce the risk that participation activities will engage the same groups and individuals.
- Ensure equitable access to public participation opportunities regardless of a person's cultural, linguistic or religious background, or communication and accessibility needs. A holistic approach should be taken which recognises people's lived experience and the range of barriers they experience.
- Identify and address the participation needs of those who share more than one protected characteristic, or those that experience hidden discrimination, or are part of an 'invisible minority' group.
- Make sure disabled people have access to information that they can understand, and to any communication support they might need. External stakeholders have highlighted the importance of ensuring that opportunities for people to participate in primary care commissioning are accessible to people with communication support needs.

- Connect with existing patient, service users and voluntary sector organisations to reach in to and develop relationships with diverse communities, and especially with people whose voices can be harder to hear.
- Auditing and monitoring participation of equalities protected groups, for example in events and formal governance roles, supports commissioners to manage and improve performance in involving a more reflective range of people.
- Commissioners should review the available insight for evidence of experiences of different patient groups. This can highlight where there may be potential issues that should be followed up with local insight gathering and that therefore may need to be a particular focus of the commissioning engagement activity.

Section Eight: Conclusion

Summary of Main Findings

- Academic debate on the credibility of the existing public engagement evidence continues, with concerns around tokenism and the use of anecdotal evidence.
- As public engagement policies and processes have become more sophisticated, and understandings of the need to document engagement approaches and assess the impact of engagement have grown, a more robust and reliable evidence base in support of public engagement has been emerging.
- Clarity of terminology, and of expectations from all those involved are of paramount importance, with divergence in motivations, aims, goals and expectations of those being engaged and those doing the engaging sometimes reported.
- Whilst public and patient engagement is becoming increasingly pressing and, indeed, more prevalent, modern writing is now calling for more of a life-cycle approach to engagement, incorporating the patient voice and input throughout the entire process, and not just in a tokenistic fashion at the outset.
- Consensus on the optimal modes of PPI application remains elusive, and is an ongoing source of debate.
- A growing body of research is evidencing how community engagement at an early stage can result in patients and the public successfully contribute to setting the research agenda and identifying research priorities.
- Authors report a tendency to ignore some of the challenges around lay and professional collaboration, and suggest that all patient-oriented projects could benefit from adopting a similar framework to guide PPI, anticipating and mitigating challenges from the outset.
- Optimal and formal evaluation and recording of PPI impact on the end-user, the service, and the community has been lacking over the years. Research suggests these processes need considerable tightening up through the consistent application of best practice by those seeking to incorporate PPI into their programmes.
- Incorporating the study of the public engagements themselves into the process of PPI utilisation is to be encouraged, in order to enhance the existing body of knowledge on what produces the greatest level of impact, and effects the most considerable level of change.
- A greater focus on relational aspects of PPI and the power dynamics of relationships present therein is to be welcomed in any future guidelines.
- Patient and professional views on engagement are sometimes found to be incongruous. There is a need to ensure that the value of patient engagement is understood, accepted and valued in practice by professionals and lay people.
- In order to effectively engage all social groups and reduce disparities, the link between the cultural competence of researchers/ practitioners and public engagement must be acknowledged.

- In order for optimal public engagement to become normalized in the health system, explicit reporting of definitions and processes is called for.
- Guidance on articulating the outcomes of patient involvement would be of benefit to PPI practice.
- The potential risk of exposure to legal challenges is considerable in the absence of adherence to policies of best practice in public engagement in health. Legal challenges have, and will continue to be, mounted in cases where public consultation processes are deemed inadequate, bringing with them considerable costs to the NHS.
- Public engagement strategy and evaluation needs to take account of diversity in the patient population, ensuring appropriate measures and metrics are included in these processes. Failure to do so runs the risk of excluding those who are traditionally underrepresented and typically most in need and, in essence, reproducing existing health inequities.
- It is not just the diversity of the patient population which one must account for in engagement strategies, but also the particular participation preferences that individual pockets of that population may hold. Whilst some may wish to participate, others may require alternate approaches in order to foster engagement.
- A review of literature has shown that community engagement practices do have a role to play in addressing inequity in health systems. However, there is a need for continual review of policies and processes in order to ensure community engagement practice is culturally aware and inclusive at all times, and also that healthcare workers are sufficiently culturally competent to manage such inclusive practice and diverse patient populations.

Review Limitations

This review was broad in scope, and sought to condense results from a great many information sources within a set time period. As such, delving deeper into outputs was not always possible. However, the review does present an overview of a wide array of topics, and establishes a more recent contribution to the growing evidence base for public engagement in health.

Implications for Future Research

This review has highlighted and confirmed the relevance of NICE's four areas for future research, particularly with respect to the need to refine evaluative processes within the field of public engagement in health.

Section Nine: Appendices

Appendix 1: Search Strategy Sample

1. ('community engagement' or 'engag\$ communit\$' or 'civic engagement' or 'public engagement' or 'engag\$ public' or 'engag\$ people' or 'patient engagement' or 'engag\$ patients' or 'user engagement' or 'engag\$ users' or 'customer engagement' or 'engag\$ customers' or 'client engagement' or 'engag\$ clients' or 'beneficiary engagement' or 'engag\$ beneficiaries' or 'engag\$ individuals').m_titl.
2. ('community involvement' or 'involv\$ communit\$' or 'civic involvement' or 'public involvement' or 'involv\$ public' or 'involv\$ people' or 'patient involvement' or 'involv\$ patients' or 'user involvement' or 'involv\$ users' or 'customer involvement' or 'involv\$ customers' or 'client involvement' or 'involv\$ clients' or 'beneficiary involvement' or 'involv\$ beneficiaries' or 'involv\$ individuals').m_titl.
3. ('community participation' or 'civic participation' or 'public participation' or 'patient participation' or 'user participation' or 'customer participation' or 'client participation' or 'beneficiary participation' or 'individual participation').m_titl.
4. ('community contribution' or 'civic contribution' or 'public contribution' or 'patient contribution' or 'user contribution' or 'customer contribution' or 'client contribution' or 'beneficiary contribution' or 'individual contribution').m_titl.
5. ('community input' or 'civic input' or 'public input' or 'patient input' or 'user input' or 'customer input' or 'client input' or 'beneficiary input' or 'individual input').m_titl.
6. ('community influence' or 'civic influence' or 'public influence' or 'patient influence' or 'user influence' or 'customer influence' or 'client influence' or 'beneficiary influence' or 'individual influence').m_titl.
7. ('community role' or 'civic role' or 'public role' or 'patient role' or 'user role' or 'customer role' or 'client role' or 'beneficiary role' or 'individual role').m_titl.
8. ('community feedback' or 'civic feedback' or 'public feedback' or 'patient feedback' or 'user feedback' or 'customer feedback' or 'client feedback' or 'beneficiary feedback' or 'individual feedback').m_titl.
9. ('community opinion' or 'civic opinion' or 'public opinion' or 'patient opinion' or 'user opinion' or 'customer opinion' or 'client opinion' or 'beneficiary opinion' or 'individual opinion').m_titl.
10. ('community view' or 'civic opinion' or 'public opinion' or 'patient opinion' or 'user opinion' or 'customer opinion' or 'client opinion' or 'beneficiary opinion' or 'individual opinion').m_titl.
11. ('community voice' or 'civic voice' or 'public voice' or 'patient voice' or 'user voice' or 'customer voice' or 'client voice' or 'beneficiary voice' or 'individual voice').m_titl.
12. ('community consultation' or 'civic consultation' or 'public consultation' or 'patient consultation' or 'user consultation' or 'customer consultation' or 'client consultation' or 'beneficiary consultation' or 'individual consultation').m_titl.
13. ('community response' or 'civic response' or 'public response' or 'patient response' or 'user response' or 'customer response' or 'client response' or 'beneficiary response' or 'individual response').m_titl.

14. ('community knowledge' or 'civic knowledge' or 'public knowledge' or 'patient knowledge' or 'user knowledge' or 'customer knowledge' or 'client knowledge' or 'beneficiary knowledge' or 'individual knowledge').m_titl.
15. ('community understanding' or 'civic understanding' or 'public understanding' or 'patient understanding' or 'user understanding' or 'customer understanding' or 'client understanding' or 'beneficiary understanding' or 'individual understanding').m_titl.
16. ('community interaction' or 'civic interaction' or 'public interaction' or 'patient interaction' or 'user interaction' or 'customer interaction' or 'client interaction' or 'beneficiary interaction' or 'individual interaction').m_titl.
17. PPI.m_titl.
18. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19. (health or 'social care' or healthcare or 'health research' or medicine or medical or physi\$ or psycho\$ or 'mental health').m_titl.
20. 18 and 19
21. limit 20 to yr="2014 -Current"
22. limit 21 to english language
23. limit 22 to human
24. remove duplicates from 23

Appendix 2: Call for Evidence

CALL FOR EVIDENCE: PUBLIC ENGAGEMENT IN HEALTH

DEADLINE: 10 OCTOBER 2018

WHAT ARE WE LOOKING FOR?

We are seeking evidence relating to public engagement in health and social care. We are particularly interested in research which relates to the following areas of consideration:

- Quantitative data measuring the benefits of public engagement in health
- Longitudinal studies addressing the lasting impact of effective public engagement in health
- The costs and consequences of poorly executed public engagement in health (may include legal cases)
- Any social stratification identified in public engagement activities
- Examples of best practice in public engagement in health and social care

WHAT IS IT FOR?

The evidence will be used to inform a literature review focussing on the outcomes and effectiveness of public engagement across the fields of health and social care, in order to guide next steps and help develop a case for effective engagement activity.

CRITERIA FOR SUBMISSION AND REVIEW

We will select submissions for review and potential inclusion in our research using the following criteria:

- Submissions must be in the form of an authored report or research paper.
- Submissions must have been completed in the past 10 years (2008-2018), and should include author details (individuals, groups, organisations, etc.).
- Submissions must relate to developed countries only.
- Submissions must meet an accepted quality threshold.
- Submissions must be fully GDPR compliant.

PLEASE NOTE: Evidence can only be reviewed for inclusion in this research if submitted via the channel specified below.

SUBMISSIONS

Please submit relevant responses, using the subject title 'Call for Evidence Return (Engagement)' to:

serio@plymouth.ac.uk

Appendix 3: Sources of Special Interest

Systematic Reviews/ Meta-Analyses/ Literature Reviews

Baldwin, J. N. et al. (2018) Impacts of older people's patient and public involvement in health and social care research: a systematic review, *Age and Ageing*. afy092.

DOI: <https://doi.org/10.1093/ageing/afy092>

Brunton, G., et al. (2017). "Narratives of community engagement: a systematic review-derived conceptual framework for public health interventions." *BMC public health* 17(1): 944.

DOI: <https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-017-4958-4>

Phillips NM, Street M, Haesler E (2016) A systematic review of reliable and valid tools for the measurement of patient participation in healthcare *BMJ Qual Saf* 2016;25:110-117.

DOI: <http://dx.doi.org/10.1136/bmjqs-2015-004357>

Dalton, J., et al. (2016). "Service user engagement in health service reconfiguration: a rapid evidence synthesis." *Journal of Health Services & Research Policy* 21(3): 195-205.

DOI: <https://doi.org/10.1177/1355819615623305>

Brett, J., et al. (2014). "Mapping the impact of patient and public involvement on health and social care research: a systematic review." *Health expectations: an international journal of public participation in health care and health policy* 17(5): 637-650.

DOI: <http://dx.doi.org/10.1111/j.1369-7625.2012.00795.x>

Brett, J. et al. (2014). "A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities." *The patient* July.

DOI: <http://dx.doi.org/10.1007/s40271-014-0065-0>

Staley K. (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*, Eastleigh: INVOLVE.

http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf

O'Mara-Eves, A., et al. (2015). "The effectiveness of community engagement in public health interventions for disadvantaged groups: a meta-analysis." *BMC public health* 15: 129.

DOI: <http://dx.doi.org/10.1186/s12889-015-1352-y>

Health Research Authority / INVOLVE (2016), *Impact of public involvement on ethical aspects of research*.

<http://www.invo.org.uk/posttypepublication/impact-of-public-involvement-on-the-ethical-aspects-of-research/>

Faulkner, A. (2016) *Twelve examples of patient and public involvement in research reported in the Research Excellence Framework (REF) 2014 Medical and Health Sciences impact case studies: annotated summary*. Southampton: INVOLVE.

<http://www.invo.org.uk/wp-content/uploads/2016/01/REF-2014-public-involvement-impact-case-studies-Annotated-Summary.pdf>

INVOLVE (2013) Examples of public involvement in research funding applications. INVOLVE, Eastleigh.

http://www.invo.org.uk/wp-content/uploads/2014/10/INVOLVEExploringPublicInvolvementInResearchFundingApplications_linksSept14FINAL.pdf

INVOLVE (2013) Exploring the impact of public involvement on the quality of research: examples, Eastleigh: INVOLVE.

http://www.invo.org.uk/wp-content/uploads/2014/11/INVOLVEExploringImpactQualityResearchExamples_updated-July-2014.pdf

Faulkner, A. (2010) Changing our Worlds: Examples of user-controlled research in action. INVOLVE, Eastleigh.

<http://www.invo.org.uk/wp-content/uploads/2011/09/INVOLVEChangingourworlds2010.pdf>

Brunton, G., J. Caird, G. Stokes, C. Stansfield, D. Kneale, M. Richardson and J. Thomas (2015) Review 1 - Community engagement for health via coalitions, collaborations and partnerships: A systematic review. UCL: EPPI-Centre.

<https://www.nice.org.uk/guidance/ng44/evidence/evidence-review-1-community-engagement-2015-brunton-pdf-2368403677>

Brunton, G., J. Caird, D. Kneale, J. Thomas and M. Richardson (2015) Review 2 - Community engagement for health via coalitions, collaborations and partnerships: A systematic review and meta-analysis. UCL: EPPI-Centre.

<https://www.nice.org.uk/guidance/ng44/evidence/evidence-review-2-community-engagement-2015-brunton-pdf-2368403678>

Stokes, G., M. Richardson, G. Brunton, M. Khatwa, J. Thomas (2015) Review 3 - Community engagement for health via coalitions, collaborations and partnerships (on-line social media and social networks): A systematic review and meta-analysis. UCL: EPPI-Centre.

<https://www.nice.org.uk/guidance/ng44/evidence/evidence-review-3-community-engagement-2015-stokes-pdf-2368403679>

Bagnall, A.-M., J. South, J. Trigwell, K. Kinsella, J. White, A. Harden (2015) National Institute for Health and Care Excellence Review 4: Community engagement – approaches to improve health: map of the literature on current and emerging community engagement policy and practice in the UK. Leeds: Leeds Beckett University.

<https://www.nice.org.uk/guidance/ng44/documents/evidence-review-4>

Harden, A., K. Sheridan, A. McKeown, I. Dan-Ogosi, A.-M. Bagnall (2015) Review 5: Evidence review of barriers to, and facilitators of, community engagement approaches and practices in the UK. London: Institute for Health and Human Development, University of East London.

<https://www.nice.org.uk/guidance/ng44/evidence/evidence-review-5-community-engagement-barriers-and-facilitators-pdf-2368403681>

Case Studies

Bolton, M., et al. (2016). "Community organizing and community health: piloting an innovative approach to community engagement applied to an early intervention project in south London." *Journal of public health (Oxford, England)* 38(1): 115-121.

DOI: <https://doi.org/10.1093/pubmed/fdv017>

Laurance, J., et al. (2014). "Patient engagement: Four case studies that highlight the potential for improved health outcomes and reduced costs." *Health Affairs* 33(9): 1627-1634.

DOI: <http://dx.doi.org/10.1377/hlthaff.2014.0375>

Ghisoni M., et al. (2017) "Priority setting in research: user led mental health research." *Research Involvement and Engagement* 3:4.

DOI: <http://dx.doi.org/10.1186/s40900-016-0054-7>

Nass, P., S. Levine and Y. Clyde (2012) *Methods for Involving Patients in Topic Generation for Patient-Centered Comparative Effectiveness Research: An International Perspective*. Washington: PCORI.

<https://www.pcori.org/assets/Methods-for-Involving-Patients-in-Topic-Generation-for-Patient-Centered-Comparative-Effectiveness-Research-%E2%80%93-An-International-Perspective.pdf>

Grumbach, K., et al. (2017). "Achieving Health Equity Through Community Engagement in Translating Evidence to Policy: The San Francisco Health Improvement Partnership, 2010-2016." *Preventing chronic disease* 14: E27.

DOI: <http://dx.doi.org/10.5888/pcd14.160469>

Luhr, K., et al. (2018). "Patient participation during and after a self-management programme in primary healthcare - The experience of patients with chronic obstructive pulmonary disease or chronic heart failure." *Patient Education and Counseling* 101(6): 1137-1142.

DOI: <http://dx.doi.org/10.1016/j.pec.2017.12.020>

Newhouse, R. P., et al. (2017). "Engaging patients with heart failure into the design of health system interventions: Impact on research methods." *Geriatric nursing (New York, N.Y.)* 38(4): 342-346.

DOI: <http://dx.doi.org/10.1016/j.gerinurse.2016.12.012>

South, A., et al. (2016). "Models and impact of patient and public involvement in studies carried out by the Medical Research Council Clinical Trials Unit at University College London: Findings from ten case studies." *Trials* 17 (1) (no pagination)(376).

DOI: <http://dx.doi.org/10.1186/s13063-016-1488-9>

Legal Cases

2018 case of R (Hutchinson & Anor) v Secretary of State for Health and Social Care & Anor

Contention: That the Accountable Care Organisation model was to be introduced with only very limited public engagement informed the basis of a legal challenge at the time.

<http://www.bailii.org/ew/cases/EWHC/Admin/2018/1698.html>

2018 case of R (on the application of British Homeopathic Association) v National Health Service Commissioning Board

Contention: The British Homeopathic Association claiming the consultation document was needlessly complex and misrepresentative, and accusing the NHS Commissioning Board of ‘manipulating the consultation process and making decisions about healthcare services without genuine patient engagement.’

<https://www.britishhomeopathic.org/media-centre/bhas-brave-legal-bid-overturn-nhs-decision-homeopathy-fails/>

2018 case of R (on the application of Lyn Buckingham) v NHS Corby Clinical Commissioning Board

Contention: That patients and the public had not been sufficiently involved in Corby Clinical Commissioning Group’s consideration of its proposals.

<https://www.dacbeachcroft.com/en/gb/articles/2018/september/high-court-quashes-proposed-service-reconfiguration-in-corby/>

2018 case of Defend Dorset NHS campaign group v NHS Dorset Clinical Commissioning Board

Contention: That the consultation process in the proposed reorganisation of services was not correctly adhered to.

<https://www.dorsetccg.nhs.uk/dorset-ccg-wins-judicial-review-high-court-dismisses-all-claims-bought-by-a-local-resident/>

Impact Assessment Methods

A Public Involvement Impact Assessment Framework

Collins, M., et al. (2018). "Using the public involvement impact assessment framework to assess the impact of public involvement in a mental health research context: A reflective case study." *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy*.

DOI: <https://onlinelibrary.wiley.com/doi/abs/10.1111/hex.12688>

GRIPP2 Reporting Checklists

Staniszewska, S. et al. (2017). "GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research." *BMJ*. 358. j3453. 10.1136/bmj.j3453.

https://www.researchgate.net/publication/318874929_GRIPP2_reporting_checklists_Tools_to_improve_reporting_of_patient_and_public_involvement_in_research

'GRIPP2- LF and GRIPP2- SF represent the first international evidence- based, consensus- informed guidance for reporting patient and public involvement in research.'

Public and Patient Engagement Evaluation Tool

Abelson, J., et al. (2016). "Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool." *Health Expectations* 19(4): 817-827.

DOI: <https://doi.org/10.1111/hex.12378>

Evaluating Community Engagement

South, J. and G. Phillips (2014). "Evaluating community engagement as part of the public health system." *Journal of epidemiology and community health* 68(7): 692-696.

DOI: <http://dx.doi.org/10.1136/jech-2013-203742>

Evaluation Tools

Boivin, A., et al. (2018). "Patient and public engagement in research and health system decision making: A systematic review of evaluation tools." *Health Expect.* 2018 Jul 30.

DOI: <http://dx.doi.org/10.1111/hex.12804>

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Abelson, J. (2018). "Patient engagement in health technology assessment: what constitutes 'meaningful' and how we might get there." *Journal of Health Services Research & Policy* 23(2): 69-71.

Abelson, J., et al. (2016). "Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool." *Health Expectations* 19(4): 817-827.

Aizenberg, L. (2014). "Facilitating Indigenous women's community participation in healthcare: A critical review from the social capital theory." *Health Sociology Review* 23(2): 91-101.

Alameda, L., et al. (2016). "Assertive outreach for "difficult to engage" patients: A useful tool for a subgroup of patients in specialized early psychosis intervention programs." *Psychiatry Research* 239: 212-219.

Alonzo, D. (2016). "Suicidal individuals and mental health treatment: a novel approach to engagement." *Community Mental Health Journal* 52(5): 527-533.

Al-Tannir, M., et al. (2017). "Patient experiences of engagement with care plans and healthcare professionals' perceptions of that engagement." *BMC health services research* 17(1): 853.

Amann, J., et al. (2018). "How healthcare professionals experience patient participation in designing healthcare services and products. A qualitative study in the field of spinal cord injury in Switzerland." *Patient Education and Counseling* 101(8): 1452-1459.

Andreassen, T. A. (2018). "From democratic consultation to user-employment: shifting institutional embedding of citizen involvement in health and social care." *Journal of Social Policy* 47(1): 99-117.

Andrews L., Allen H., Sheppard A. Z., Baylis G., and Wainwright T.W., (2015) More than just ticking a box...how patient and public involvement improved the research design and funding application for a project to evaluate a cycling intervention for hip osteoarthritis, *Research Involvement and Engagement*, 1:13.

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