

# Patient and Public Involvement: A Realist Review of the Implementation of the 2010-2015 Health and Social Care Integration Policy in England

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## INTRODUCTION

Patient and public involvement (PPI) in healthcare has become an increasingly important aspect of European health systems [1]; [2]; [3] and a fundamental aspect of sustainable healthcare [4]. In this section, the researcher will clarify the conceptual meaning of health and social care integration, patients and public involvement and justify the basis for this research. Also, questions that will guide the review will be raised in line with the objectives of the study.

PPI in health and social care policy making is the product of continuous development and the feature of the national health system in the UK. [5]. In the effort to improve the quality, effectiveness and efficiency of the health and social care services provided to patients in England, several health and

social care Acts have been launched. The patients charter (1995), the local government and public involvement Act (2007) and more recently Health and Social Care Act (2012) and Five Year forward Plan (2014) all emphasis on patients and the public being more involved in the decision making processes on regarding delivery of services within the NHS [6].

As the practice of patients and public involvement (PPI) in healthcare integration continues to progress globally with the UK in the forefront, the international research evidence base underpinning this activity remains partial and lacks coherence [7]. This situation has prompted many studies aimed at providing evidence base for PPI in health and social services.

## CONCEPTUAL CLARIFICATIONS

### Health and Social Care Integration

The meaning attached to the term, health and social care integration varies based on the context, organisation and professional groups making use of the term. Hence, integration of health and social care means different things to different people. [8]. A research group, [9] found around 175 definitions of integrated care in literature. This variation in the definition of integrated care could be because of the different perspectives and backgrounds of the scholars. Most of the definitions looked at health and social care integration as bringing together inputs, delivery, management and the organisation of services in the way that could lead to improved access to health and social care, better quality healthcare, user satisfaction and efficiency [10]. This definition presupposes that the ultimate aim of integration is to provide improved health

and social care services to patients. Many of the authors that explored the meaning of health and social care integration tend to agree with [11] definition. For instance, [12] agreed that the central aim of integration is to improve patient care and experiences through improved coordination. The National Audit Office (NAO), England (2017) sees integration as placing of patients at the centre of the design and delivery of care in order to achieve better healthcare outcomes, satisfaction and make patients to get value for their money. All these definitions have one thing in common - integration is patient-centred. However, these definitions failed to point out the involvement of patients in the management of their own care. It appears that the definition by the Chartered Institute of Public Finance and Accountancy, [13] is more comprehensive and captures the need for patients to be

given the opportunity to reason together with the healthcare professionals that manage their health and social care needs. On the other hand, it could also be argued that [14] definition is as well incomplete because it failed to bring the public into the picture. Hence, the researcher suggests that any definition of health and social care integration should be woven around patients and the need for the team or individual healthcare professionals to work together with the patients under their care and the understand the health needs of patients and meet up with public expectations.

Some scholars have tried to differentiate between integration and integrated care. For instance, [15] stated that integration is the combined set of methods and processes that seek to bring about improved coordination of care while integrated care is an organising principles for care delivery aimed at achieving improved patient care through better coordination of services. There are different perspectives on what integrated care stands for. For instance, many national governments use the process-based definition which looks at integrated care as “a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors” [16], and where the application of these multi-pronged efforts to promote integration produces benefits for people, the result can be called integrated care [17]. The aim of this methods and models is to improve the quality of care and quality of life, increase consumer satisfaction and system efficiency for the population by cutting across multiple services, providers and settings [18]. So, the process-based definition of integrated care is based on quality of care co-ordination as a continuous process in the improvement of the quality of health care provided to the people, and therefore distinguishes between integration which is “the process by which professionals and organisations come together; and integrated care understood as the

outcome experienced by service users”. [19]. This definition, however, fails to assign specific meaning to integrated care as it describes the term as a set of interconnecting processes and makes it difficult for the end user to identify which of these interconnected process to blame if the arrangement fails to satisfy his/her health needs [20].

Then, there is the user-led definition: “My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes” (National voices, 2013). This definition which is currently used by the Government of England as a guide to frame the integrated care strategies for the citizens emanated from the people themselves after several years of consultations with the a group that was recognised as patients representatives (National Voices). This definition emphasises the importance of the population and individual needs in design, implementation and evaluation of integrated care plans [21]. The Government of England applies this definition as a narrative for cross-governmental efforts [22]. It is, however, not as important as the process-based definition that gave birth to it.

Also, important is a health system-based definition which is commonly used by WHO Regional Office for Europe. The health system-based definition looks at integrated health service delivery as a way that is followed to strengthen people-centred health systems through the promotion of the comprehensive delivery of quality services throughout the life time of healthcare service users, and is designed to meet the different needs of the people and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. [23]. This approach requires effective management to make it result oriented and proper use of resources based on best available evidence and requires feedbacks from health and social care users to be used to continuously improve performance and to tackle causes of ill

health and to promote well-being of people through collective through actions. [24].

Central to the three definitions is the idea that integrated care should be based on the needs of individuals, their families and communities [25]. There is enough evidence that the view that discussion on the needs of individuals and families should be the central focus of integrated care [26]. This is necessary because health and social care is designed for the serve the people. This is not just because a user-centred vision for care delivery overcomes the tendency to choose structural or organisationally-based solutions, but also because it provides a compelling argument for making use of integrated care and, therefore, how success might be measured [27]. The distinction between integration and integrated care is vital because any conceptual confusion in the use of the terms could lead to poor healthcare policy formation. It will suffice to understand integrated care as the creation of a more joined-up care experience for people with both health and social care needs [28] and integration as should be allowed to stand for any arrangement made in the healthcare system improve the coordination of care.

In the context of the UK, health and social care integration refers to closing up the separation created by the 1948 settlement which put NHS to provide at the national level, a free at the point treatment for those who registered with it, with local authorities maintaining the responsibility for a means-tested social care system (Department of Health, 2015). Prior to the introduction of the 2010-2015 health and social care integration in England, health and social care were financed and administered and accessed separately [29]. The bridging of this divide is necessary because people now live longer, and more people develop complex, long term medical condition, hence, it has become important that NHS services work in partnership with each other and social care to ensure the population get the quality healthcare they need to live well.

(Department of Health and Social Care, 2018).

However, it is argued that this arrangement cannot serve patients satisfactorily, and by bringing the two services closer together, patient can become the central focus on how care is organised and the delayed discharges and emergency hospital admissions that characterised the separation of health and social care can be reduced to save cost by cutting down on emergency hospital admissions [30]. This argument informed the development of the 2010-2015 health and social care integration policy. The new policy aimed at achieving better and improved health and social care. This new policy became necessary as a result of the failure of previous health and social care policies in England [31]. For instance, the National Health Service Act of 1977 encourage the corporation of health authorities to corporate with local authorities and the 1999 Health Act allowed NHS to pool budgets, but these policies did not achieve the desired results. Also, the Health and Social Care Act, 2012 was passed to encourage integrated working, and the Care Act 2014 aimed at promoting healthcare integration but whether these initiatives achieved the intended goals remains uncertain [32].

Some patches of successful integration have been achieved throughout England in some areas like Integrated Care Pioneers launched in 2014 [33]. National Audit Office report in 2017 highlights some early integration successes but whether this success could be improved and sustained to deliver improved service is arguable. [34] argues that while some level of success in integrating health and social care has been achieved, it has failed to deliver to the people the right type of care that meets the health needs of the people. The reported failures of the various and past health and social care policies indicate that healthcare policy initiatives are often not given adequate consideration before their implementation [35]. It appears that the failure of health and social care policies in the UK as reported in literature is because these policies are mere rhetoric,

or it be because patient and public involvement in the planning and implementation of such policies has not been sufficient. In support of this view, [36] stated that experts in healthcare quality agree that safe and effective care can only be achieved when patients are present, powerful and involved at all levels.

Existing literature on patient and public involvement (PPI) in health and social care policy making and implementation covers different areas including the distinction between involvement and participation, the meaning of the term 'public' in the discussion of public involvement [37], the role of PPI in health and social care integration [38], the extent, quality and impact of PPI in primary care research reports evidence [39], preferences for individual and collective involvement in England [40], key elements of patients and public involvement in hospital policy making [41], the impact of patients and staff experience on service improvement [42], the impact of PPI in health policy making and healthcare delivery, and formulating recommendations for good PPI practice [43], [44] as well as the impact of involving patients and public in research [45].

However, in the discussion of these issues, authors varied on the conceptual meaning of the term, PPI, with the democratic and ideological rationale for PPI remaining a source of concern to an instrumental or consequentialist rationale [46]. An aspect of PPI that seems to have been understudied is the implementation of the 2010-2015 health and social care integration policy in England, which is a policy expected to have direct impact on the health and well being of patients. Only little attention has been paid to the study of the outcomes of the implementation of the policy, how patients are involved and the extent of involvement. For instance, many studies that investigated PPI in health and social care services did not connect them to the 2010-2015 health and social care integration policy [47]; [48]; [49]. Yet, this is an important policy that the process of its implementation could determine the

impact the policy will have on the health and social care services the NHS provide healthcare users.

It is against this background that the researcher undertakes to review the implementation of the 2010-2015 health and social care integration policy with a view to finding out the extent of public and patient involvement in the implementation of the policy.

#### **Patients and Public Involvement**

Patient and public involvement (PPI) in the context of this study means giving patients and the public the opportunity to be part of the plans and processes involved in the delivery of health and social care services. It is a deliberate activation of patient that relates to different aspect of healthcare such as self-care, patient education, decision-making and development [50]. PPI describes how patients are involved at different stages of the design, development, planning, and utilisation of healthcare [51]. Patient involvement is often justified on the ground that there are many variables that affect the health of patients and some of these variables are best understood by the patients and can only be utilised by the health and social care professionals if such factors or variable are disclosed to them by the patients. Such factors could be psychological, social, religious or even economic.

Patient involvement is underpinned by the argument that no decision about a patient should be taken without the patient (Department of Health; 2012). However, patients are not medical professionals and could be said to lack the professional knowledge needed to take decision about their own treatment but it could be argued that their contributions are vital to enable the professionals make the right decisions on the health and social care needs of the patients.

Related to patient involvement is public involvement. [52] defined public involvement as the "Ways in which members of the public can apply their priorities to the evaluation, development, organisation and delivery of health

services". Members of the public can at one time or the other become patient. This suggests that the public also have experience of what it means to be a patient. By implication, the voices of the public should be taken into account if the healthcare professionals must know the areas patients need improvement on health and social care services provided to them. [53] defined public involvement as the involvement of members of the public in making important decisions about health services and policy at local or national level. This differentiates public involvement from patient involvement which is limited to the involvement of individual patients together with health professionals in making decisions relating to their own health care [54].

Arguably, there is a difference between patient involvement and public involvement in health and social care. Some scholars attempted differentiating the two terms. For instance, [55] defined public involvement as "the involvement of members of the public in strategic decisions about health services and policy at local or national level", and patient involvement as a term used to refer more specifically to "the involvement of individual patients, together with health professionals, in making decisions about their own health care". These definitions did not capture 'collective' involvement which is also an important form of involvement.

PPI is patient-centred service and an effort to introduce the involvement of service users in health and social care decision making. It is referred to variously as 'user involvement', 'service user involvement' or 'lay involvement' and 'engagement' in healthcare services [56]. However, there could be slight

#### THEORETICAL FRAMEWORK

This study was anchored on the critical theory of [61]. Habermas critical theory explores reality from three different perspectives. First is the objective perspective. This perspective views all the natural, social and subjective item/theme as a subject matter. The second perspective is the subjective. The

differences between the various terms used to refer to PPI but whatever term used to describe PPI, retains the patient-centred focus of PPI. The distinction between the terms, patient involvement and public involvement is, however, not central to achieving improved health and social care services since a patient can become a member of the public when discharged from hospital and vice versa. On this premise, the terms are used in this study in an inclusive way [57] to mean patients, caregivers, and other community members affected by health care services provided by the National Health Service, England and the health policies of the Government.

The theoretical foundation for including patients and the public in decision making is that it contributes to the legitimacy of public health care systems within public institution [58]. PPI has also been advocated as a way of making healthcare system to be more responsive to people's health needs [59]. Involving patients and the public in health and social care has been tried in different areas in the process of health policy implementation such as health service planning and delivery, health research and priority-setting [60]. Despite this interest in PPI, sound empirical evidence for its impact or outcomes on healthcare policy has remained underdeveloped and difficult to ascertain (Nolte & RAND Europe, 2016). However, evidence exists that indicate that PPI plays developmental role such as enhancing awareness, understanding and competencies among lay participants of healthcare decision-making but the evidence on whether PPI improves decision making and policy in relation to processes and/or outcomes, is not well documented (Nolte & RAND Europe, 2016).

subjective perspective takes into consideration the inner world of feelings, ideas, opinions and attitudes; and the third is the social world which does not really exist but is constructed through human interactions and accepted as legitimate [62]; [63]. None of this perspective contradicts each other but

instead, they are complimentary and supplementary [64]. The interconnection between the objective, the subjective and the social domain explained by the critical theory of Habermas suggest that there should be an interplay between the health professionals working with NHS and the patients as well as the public in the implementation of health and social care policies in order to deliver a more effective and quality health care to health service users. This is vital because the goal of health care system is to achieve a well-organised, safe and holistic patient care, and this can only happen if there is an interaction between the varied distinctive disciplinary knowledge of professionals that work to achieve quality and patients together with the public that are framed within an existing system and/or structure [65].

The critical theory of Habermas suffices to explain the relationship between the healthcare professionals working with NHS and their patients together with the public because in relation to health care services, the different perspectives of the theory reveal vital personal factor that can help healthcare professionals and service providers to meet the health needs of the population of England.

#### **Rational for the Study**

Studies that investigated the involvement of patients and the public in implementation of the 2010-2015 health and social care policy in England provide small amount of empirical evidence, and are well reported [67] with methodological weakness and often they do not explore the factors surrounding PPI as a complex intervention [68]. Moreover, most of the studies that explored PPI lack evidence on outcomes and impact and as well seem to be observational evaluations which little or no attempts were made to establish links between PPI and the context it takes place and how it functions [69] as well as the difference PPI makes in healthcare policy implementation [70]. This study was aimed at addressing this gap in evidence. In addition, as a staff of NHS, England, working at the primary care level, the researcher has come in contact with

several patients. Many of the patients complain of their views not being taken into consideration when formulating health policies made to improve on the quality of the services they get. They appear to be a general outcry amongst patients that they are not given the chance to make their contributions before health policies are formulated, yet the policies are designed for their benefit. However, these claims are not usually substantiated by the service users. In contrast, the NHS, England, being part of the United Kingdom (UK) health systems claim that patients are put at the heart of everything the government does, not just as beneficiaries of care, but as participants in shared decision-making [71]. But [72] argues that it is not clear whether the statements that patients are put at the centre of decisions affecting their own health and social care are mere rhetoric or a reality. This study, therefore, is necessary to establish whether the 2010-2015 health and social care policy in England takes the views and ideas of patients and the public into consideration in the implementation of the policy. It is also necessary to explore literature in this area in order to see how patients and the public are involved by NHS in the formulation and implementation of the policy, and make recommendations on how the participation of patients and the public in health and social care planning and delivery could improve the quality of the health and social care services provided to the population of England.

#### **Study Context**

The setting of this study was England, and data gathering for the study was based on literature that captured PPI in primary care, mental health, hospital, and tertiary care. England is one of the major component units of the United Kingdom, and occupies more than half of the island of Great Britain [73]. England does not again exist as a political unit unlike Scotland, Wales, and Northern Ireland that have some degree of independence in domestic matters.

England has great rivers and small streams. The fertile land of the people supports the practice of agriculture, and

this has helped to support a growing agricultural economy for many years. In the early 19<sup>th</sup> century, England became the centre of global industrial revolution, and within a short period after the emergence of industrial revolution, it became the most industrialised country. Resources drawn from cities like Manchester, Birmingham, and Liverpool were used to convert raw materials to finished manufactured products for export to other countries of the world, while London, which was the capital city became one of the major cities and the centre of political, economic and cultural network that went beyond England shores [74]. England is bounded in the north by Scotland, West by the Irish Sea, South by Atlantic Ocean, and on the East by the North Sea. The peoples' language is the English Language which is today the world lingua franca.

England functions like a welfare State in the area of health. The health of the people receives priority attention with primary care services provided to the population by the National Health Service (NHS).

### **Purpose and objectives**

#### **Purpose Statement**

The purpose of this review is to assess the involvement of patients and the public in the implementation of the 2010-

#### **Research Design**

The researcher reviewed both qualitative and quantitative studies that were directly related to health/social care integration and PPI. The literature reviewed were mostly empirical studies that were evidence-based, meta-analysis and survey research method. The review of studies that were methodologically diverse was considered necessary because reviewing studies that used meta-analysis alone will not produce robust evidence in a study of a phenomenon like PPI and integrated health and social care policy. Relying on studies that used only systematic review and meta-analysis will lead to leaving out many relevant studies that used other methods and which the results produced were based on the experience of health care users and health

2015 health and social care integration policy.

### **Objectives**

The objectives of the study are as follows:

1. To find out whether patients and the public were involved in the implementation of health and social care integration policy in England.
2. To identify the ways patients and the public were involved in the implementation of health and social care integration policy in England.
3. To ascertain the extent patients and the public were involved in the implementation of health and social care policy in England.

### **Research Questions**

1. Were patients and the public involved in the implementation of health and social care policy in England?
2. If so, how were patients and the public involved in the implementation of health and social care policy in England?
3. What extent were patients and the public involved in the implementation of health and social care policy in England?

### **METHODOLOGY**

and social care professionals. The review method employed was realist review.

#### **Methods**

The study was underpinned by realist review utilising qualitative and quantitative data. Realist review is a research method for synthesising research which has an explanatory rather than judgemental focus [75]. Realist review is used to explain why complex programme fail in particular context and setting [76]. This review strategy which is to some extent new was considered suitable for this study because the literature on health care management and policy intervention is epistemologically complex and methodologically diverse, and this explains why the researcher argues that realist review is suitable for this study. The use of realist review for

the study informed the inclusion of studies that used different designs across the hierarchy of evidence, and outcomes that are most applicable to UK NHS context. This study is therefore, a realist review because it was not protocol-driven as is the case with systematic review [47].

#### **Information Source and Search Strategy**

To search for relevant literature for the study, the researcher conducted electronic database search in CINHAL,

PubMed, British Nursing Index and online books. Different search terms such as involvement, PPI, patient and public participation, engagement, health policy, integration, social care and health policy, health and social care integration or strategies for integration, PPI in health and social care integration or interventions were used to source relevant articles, user, etc (see Table 1):

**Table 1: Search Terms**

S1	S2	S3	S4
Patient*	Health*	Involve*	Empower*
User*	NHS	Participa*	Experience*
Carer*	'NHS'	Collaboration*	Develop*
Caregiver*		Engage*	Change*
Public*		Consult*	Redesign*
Citizen*			Impact*
Client*			Outcome*
Consumer*			Decision making
Lay			Policy making
Stakeholder*			Health planning
Representative*			Health priorities
Famil*			Survivor

Studies that were not relevant to this review were excluded. This was done by first screening the abstracts and titles of the several and varied studies that the search initially produced. To identify the relevant studies, Boolean operators were used to sieve the abstracts and titles. This was followed by full text screening of articles which the titles and the abstracts indicated they met the inclusion criteria. By combining Boolean operators AND, OR and NOT, the researcher was able to narrow down the search. [7]. Each of the terms was first combined with OR and then combined together with AND. Articles excluded by the Boolean terms were excluded [3].

Also, critical appraisal skill programme (CASP) checklist for evaluating systematic review was used to critique and assess both the selected quantitative and qualitative studies for inclusion and exclusion. Qualitative and quantitative studies included where those done between 2005-2018, and the results produced were clear, addressed either PPI

or health and social care integration or both and which considered all important outcomes, (CASP, UK., 2017).

To determine the suitability of any qualitative study for inclusion, the researcher based the selection on clarity of the aim of the research, the appropriateness of the research design to address the research question, method employed for data collection, ethical issues, rigourousity of data analysis and the value of the study to practice and policy-making. The search techniques of truncation and phrase searching were also used [8].

#### **Inclusion and Exclusion Criteria**

Search results in CINAHL, PubMed search and Cochrane Data Base yielded a total of 1124 studies. 230 studies out of the yielded results were selected. Most of the papers were not found relevant for this study because their contents were not directly related to health and social care integration policy and PPI involvement in health and social care decision making. That is, they veered off from the central



focus of this study, and as a result, more studies were rejected. The researcher was left with 120 studies after duplications were removed. .

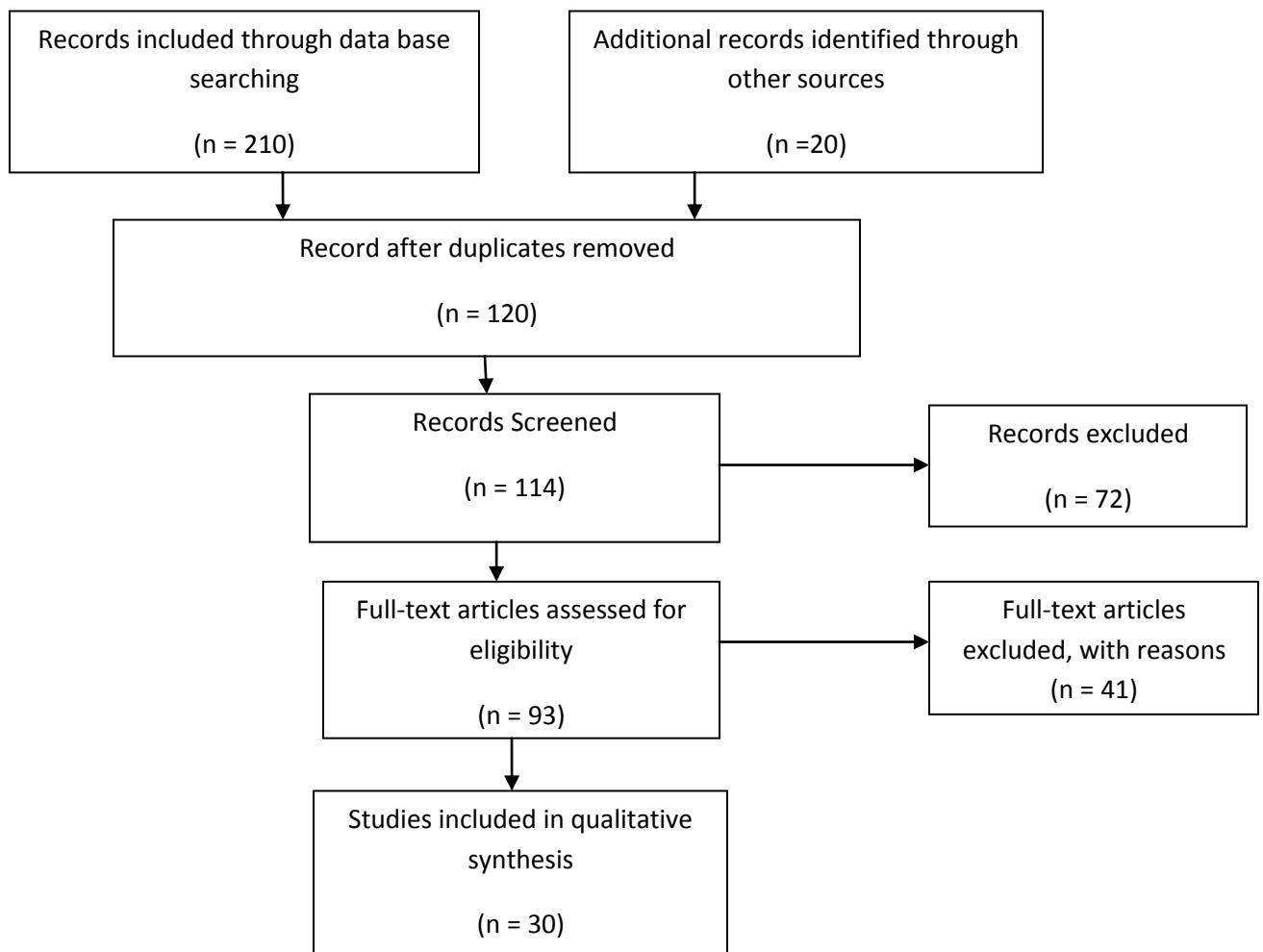
In addition, titles and abstracts of studies were screened by the researcher, and after which studies that were not relevant were removed to include publications that were relevant to the study. Where the abstract did not clearly indicate the focus of the study and where the abstract was brief or omitted, the full text of the study was obtained.

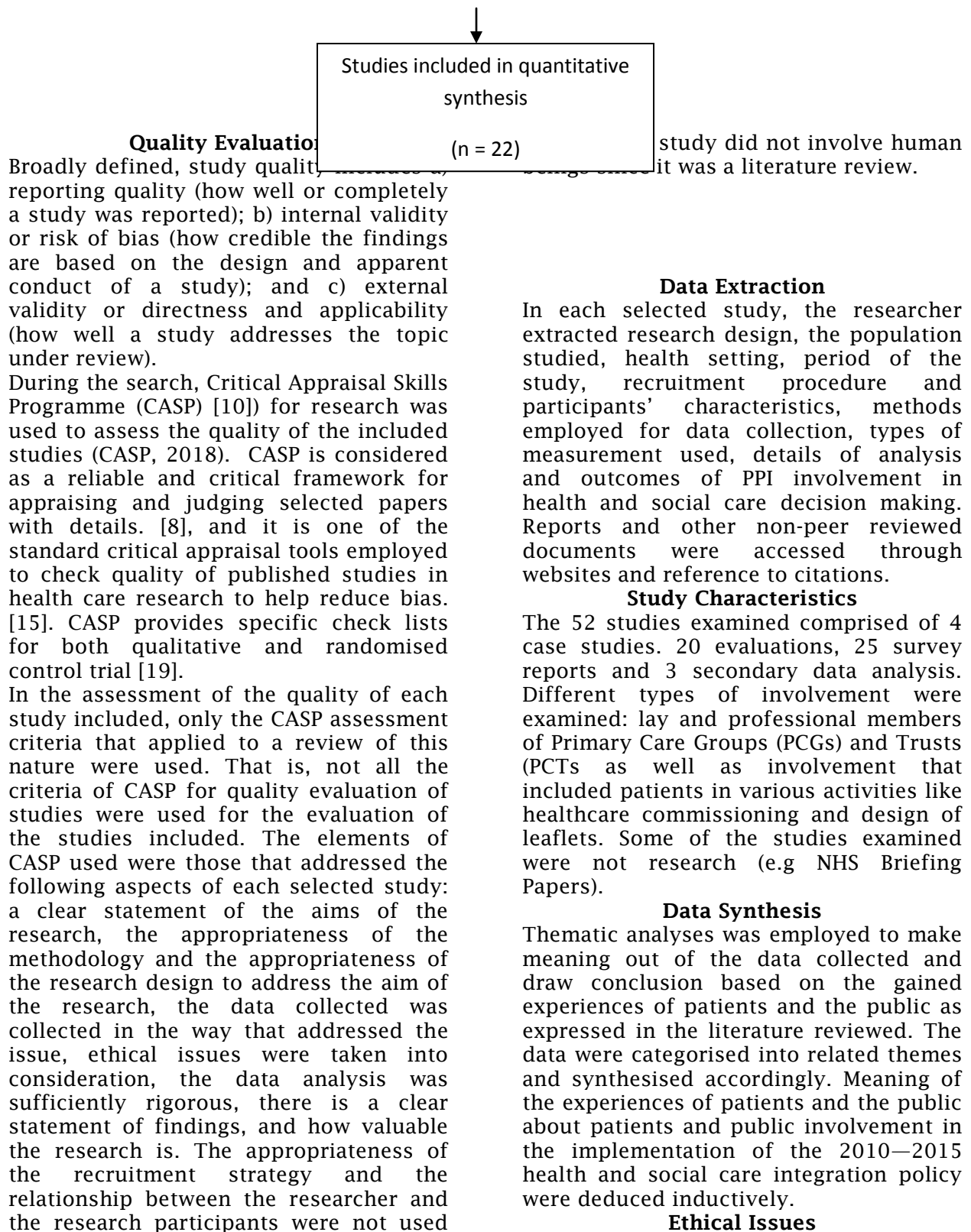
The inclusion strategy was designed to capture all literature that was related to PPI activity in the implementation of the 2010-2015 health and social care integration policy. All studies that indicated patients and public involvement in working out health and social care services were also included. To search for

studies that met these inclusion criteria, the search strategies were wide and diverse [12]. This was done to reduce the risk of publication bias. However, the researcher ensured that only studies which the results were evidence-based were included in the review and synthesis of the studies. Only articles published in English Language were included.

All think piece articles and editorials and articles without full texts were excluded to ensure that only scholarly articles that provided evidence of patients and public involvement in health and social care services were included. This was done to ensure that the result of the study was evidence based. The included and excluded studies in the review were summarised in a flow diagramme (see Figure 1):

**Figure 1:** PRISMA FLOW DIAGRAM





The study did not involve the collection of primary data. This is because it is a realist review. When primary data are not used for a study, it does not require ethical approval [34].

### **Were patients and the public involved in the implementation of health and social care policy in England?**

Studies on PPI in the literature reviewed varied from empirical research to narrative inquiry. [5] did a systematic narrative inquiry on the PPI which the author titled "From tokenism to empowerment: progressing patient and public involvement in healthcare improvement." The author examined literature from selected narrative review. [12] noted that repeated calls have been made to better involve patients and the public and place them at the heart of healthcare.

This, according to the author has become urgent because of serious clinical and service failings in the UK and beyond, and this underscores the importance of addressing this problem. [8] argued that despite the support PPI receives in the UK and internationally, progress in this area has been slow and limited and mostly focused on the lowest levels of involvement. These statements suggest that patients and the public have been involved in the implementation of health and social care policy in England.

Evidence in literature indicates that patients play important roles when they are involved in healthcare system. Such roles include helping to reach an accurate diagnosis, choosing an appropriate treatment, management strategy, ensuring treatment is properly adhered to and helping in monitoring, identifying adverse and side effects as well as acting upon them. [17]; [18]. Involvement also helps in improving patients choice, self-care and shared decision making as well as contributing to research partnership and to make changes in service delivery and patients outcomes [34]; [35]; [36]. The reviewed literature also shows that the processes followed in PPI enhance democratic principles and accountability [39]. It was also revealed that in reality, the implementation of PPI is complex and

this makes the evidence of the impact of PPI to be difficult to ascertain [44]. This suboptimal evidence of impact makes it difficult to predict the impact of PPI on health and social care quality of service and makes people to criticise PPI on the basis of exclusivity and tokenism [1]; [2]; [3].

A systematic review on the impact and outcomes of patient and public involvement had on UK NHS healthcare services conducted by [13] found several impacts of PPI on NHS healthcare services. The studies reviewed by the authors found impact on practice which includes service planning and development, information development and distribution, and changing cultures In service planning, PPI made inputs on new healthcare buildings and environment, location and access to service, reorganisation of existing services, improved dialogue between health professionals and patients and patients and other patients [47]. In information development and distribution, PPI were found involved in producing leaflets, creating awareness, and contributing to developing training sessions for service users and health professionals. In the culture of practice, health professional's attitudes, beliefs and values about PPI were found to be positive. However, it was not clear how much input services users actually had in the re-shaping of services.

Also, PPI contributions were usually not clearly described in the studies reviewed. A study of a Mental Health Trust that involved some of its patients in influencing decisions on the planning of buildings and the quality of the environment through a series of 'user panels' and a trust wide 'user and carer quality group' indicated that there were no clear indications of PPI contributions but in the redesign of cancer centre, a Cancer Partnership Project (collaborative service improvement groups consisting of NHS staff and service users) described successful user involvement [16]. On the reorganisation of the existing services, [28] reported that patients and public involvement in NHS decision making resulted in improved booking system,

consideration of the cultural needs of patients and reduced waiting times.

[31] case study for the head and neck cancer service at Luton and Dunstable Hospital also investigated the impact the experience of patients and staff will have on service improvement. Patients were given opportunity to work together with staff and co-design group to discuss points which were raised and how to improve on them. About 43 improvements at a head and neck service at one hospital was reported as the direct result of patients' involvement in the first Experience Based Design (EBD) pilot in the NHS [54]. Improvements were reported in performance, safety and governance, and improved experiences for the patients and staff as well as improved dialogue between health professionals and patients. The narrative method by patients which was employed for data collection is a good method of collecting data on actual experiences of patients and areas of improvements on patient's health care services.

#### **How were patients and the public involved in the implementation of health and social care policy in England?**

Patients and the public were involved in health and social care in planning, policy making, healthcare commissioning and governance and health healthcare research. Also, patients and the public were also involved in health and social care decision making by way of consultation and partnership and collaboration. Evidence in literature indicates that patients were consulted during health and social care policy formulation and even in the process of implementation. For instance research carried out by [45], found that patients and the public were involved in health and social care in England at various levels of healthcare planning and decision making beginning with consultation to partnership and shared leadership. However, the extent of involvement at these levels did give them enough power or decision-making authority but at the higher level of the continuum, patients served as active partners in setting

agenda and making decisions on health issues [65].

[66] examined the approaches Boards were using to involve patients and public in healthcare decision making in England. The study employed interview method to gather data, and reported the actual words of the interviewee. This method produced reliable results because the interviewees had provided details of the approaches used by primary care groups/trusts (PCG/Ts) to establish relationship with primary care users. The study found that PCG/Ts developed relationship with social groups, housing department, and voluntary sector but took consultation as a way of gathering direct opinions on the services the board rendered. The board regarded the opinions of service users as a piece of advice which it is not compelled to consider in its decision making process [59]. The implication of this approach was that the board treated public voice as subordinate [11]. Patients and the public lacked any active voice in choosing the issues to be considered [34].

Another way the board involved the public in decision making was by way of giving information to the public on its decisions [29]. The board did not consider the issue of representative as primary. In this regard, the public was merely considered as consumers of healthcare services. Also through dialogue, public views were accurately captured but the board looked at the views as less important [71]. The opinions of care users therefore, had no influence on the decisions of the boards and therefore, did not help to improve the quality of services primary healthcare organisations in England rendered to patients.

In contrast, [23] systematic review revealed that PPI on NHS healthcare services positively influenced health and social care services in the areas of planning and development, information development and distribution, and changing cultures. However, it was not clear how much input services users actually had in the re-shaping of services [20]. The authors described details of how each step ranging from setting up an advisory group, selection of studies, and

development of search terms to data synthesis was followed. The method was robust and provided results that showed enough evidence of PPI involvement and outcomes in health and social care decision making.

Similarly, [27] carried out a study on experience-based co-design involving patients and health professionals. The study findings were similar to previous research in the area that established that collaboration between service users and healthcare professionals resulted in fast access to reliable health advice, effective treatment delivered by trusted professionals, involvement in decisions, respect for preferences, clear and comprehensible information and support for self-care, and attention to physical and environmental needs [75]. Experience-based co-design (EBCD) methodology used for the study allowed patients with experiential knowledge to work together with experts in their field, thereby allowing the two knowledge systems to enrich one another [56].

In another study, [43] investigated the acceptability, perceived benefits and risks of PPI in health care policy. The authors used Delphi survey of Belgium stakeholders in healthcare and found that the stakeholders were open to PPI coverage in health care policy, and that the benefits of PPI is greater than the risks. However, they preferred consultation with citizens or patients to involvement at specific stages within the existing decision-making structure.

[48] investigated how organisations can help patients and professional to collaborate in order to improve quality of healthcare in the UK. The researchers engaged in a four year ethnographic study used CLAHRC North West London as the setting. They used multidisciplinary teams, patients as team members, patients co-designing interventions with healthcare professionals through collaboration to train participants to make sense of how involvement can be used to improve the quality of healthcare. Observations and the results from the interviews indicate that patients were active participants and regarded their selves as partners in healthcare

improvement [15], thus supporting the evidence that involving patients and the public in health and social care policy implementation can lead to improved health and social care services [28]. However, the improvement in healthcare decision making that is attributed to PPI services could be because all the participants according to the researchers had professional knowledge of participation in PPI initiatives and this may have influenced their easy adaptation [43].

In addition, [25] examined the role of PPI in three healthcare organisations. The study revealed that representatives of public were not certain about the role PPI plays in the organisations they studied. This confusion about PPI role in the organisations studied was attributed to poor knowledge of the research participants on the potential contributions of PPI in health and social care. This confusion was said to be the result of the failure of NHS to provide adequate information to the representatives that could make them comprehend what their functions should be. Where PPI role is not clearly understood by patients and the public, it will be difficult to achieve the main goal of involvement which according to [35] is to improve the health and the experience of services for patients, their relatives, carers, users of health and social care services and the wider public. The study also found that managers of healthcare organisations do not regard PPI as important because this group lacks the professional knowledge and experience to make decisions that health professionals will accept [62]. The view of health professionals in this case makes a lot of meaning partly because the argument can always be made that professionals are better informed on health and social care while the public are perhaps making decisions, or putting their views across based on insufficient information [67]. In the area of healthcare commissioning and governance, patients and the public were also found to be involved in the commissioning process.

Evidence in literature indicated that patients and the public were recruited by

researchers to take part in the research that were aimed at improving health and social care services in England. Involvement of patients and the members of the public have become a priority in conducting research on PPI. In support of this assertion, [13] reported that patient and public involvement (PPI) in research is acknowledged as best practice and presently, it is an important requirement to get funding from many funders globally, including the UK. The major argument for PPI in research is that it leads to better quality research through the impacts it has on the identification of appropriate research priorities, study marketing and research design [21]. For example, patients and the public were involved in the research carried out by [47]; [48]; [49]. PPI involvement in research is important to user needs and is therefore more likely to have beneficial impacts [32]. It is also argued that the public has the right to participate in a study or research funded with tax payers money [70]. This is important because research on PPI in health and social care without involving patients and the public is as good as treating somebody that is ill without asking the person questions that will help in the diagnosis of the illness. Patients and the public are the end users of health and social care services and therefore, their involvement in any study on PPI is important in order to gain insight that will help in preparing the research instrument.

[67] method was embedded within an existing NIHR funded programme of implementation research, 'Action to Support Practices Implementing Research Evidence' (ASPIRE). The ASPIRE PPI Panel was made up of nine people from different ethnic, occupational and social backgrounds and mainly collective lay experience in commissioning and governance of healthcare, national clinical audits, patient advocacy, and National Health Service leaders' management development and community development. [56]. The PPI panel was made up of experienced people in their various areas healthcare commissioning. The participants contributed to the design, conduct and interpretation of

findings for consensus study. The researchers used modified RAND consensus process [37] comprising four face-to-face meetings and completion of two online surveys. [38].

Findings from the study showed that there is presently limited scientific evidence of impact of PPI on health and social care in England. Based on the consistent policy interest in PPI in research, limited scientific evidence on the impact of PPI in health and social care represents a clear knowledge gap [49].

It was also found that PPI range from consultation to genuine involvement and coproduction. [50] also noted that PPI is reported inconsistently across studies. The authors, therefore, recommended that a standardised approach to reporting PPI is needed to improve understanding of how PPI adds value to research and underpin future evidence synthesis.

#### **What extent were patients and the public involved in the implementation of health and social care policy in England?**

The NHS, England has evolved several strategies and health and social care plans aimed at patients and public participation in health and social care services. One of such recent strategy was the Sustainability and Transformation Plans (STPs). STPs refer to plans made for the future of Health and social care services in England [2]. However, the author argues that patients and the public have been largely absent in the process. This could be because there was no enough time available to develop the plan, and because NHS bodies had given instruction to leaders not to allow the draft of STPs to be seen by the public. [2]. This approach could be said to be a deliberate attempt by the NHS national bodies to exclude the members of the public and patients from contributing to the development and implementation of STPs. In support of this view, Alderwick, et al reported the question asked by an interviewee asking themselves in a STP meeting 'Where are the real people in this?' However, even if real people, that is, patients and the public were present in the meeting, [3] argues that being consulted on plans that

have been already made does not seem to be a meaningful form of participation.

The study, though discussed PPI in STPs in a convincing manner and pointed out that the involvement of patients and the public in the whole processes of the plan and implementation, and consulted several and current grey literature, it lacked evidence of methodological rigour. This is a serious shortcoming in scientific research on a subject that is expected to provide empirical evidence that could be depended upon to make necessary changes in the way health and social care services could be improved for the benefit of the stakeholders. However, the currency and wide range of the literature reviewed make the conclusion made by the authors useful for practice.

[9] study with the setting in England captured the various words, theories, and approaches used by various scholars and organisations to discuss PPI. Words such as consultation, engagement, participation, partnership or co-production have been commonly used by desperate social movements, policies and practice to describe patients and public involvement in healthcare system [55]. These words sometimes were used to indicate the extent of involvement - greater or lesser level of involvement, power or influence in decision processes within an organisation [57]. This suggests that patients and the public were involved in health and social care decision making, but again, the extent of involvement is limited. The review further showed that evidence exist that involving patients and the public in the implementation of health and social care policies can make important contributions that could improve health and social care delivery in England. Patients and the public can contribute in helping to make accurate diagnosis of diseases, improving patient choice, self-care and shared decision-making, research partnerships and changes to service delivery and patient outcomes. PPI is seen as an important way of enhancing democratic principles and accountability in the health and social care system. [8].

In addition [31], also found that PPI in health and social care in England takes

place at various levels of healthcare planning and decision making beginning with consultation to partnership and shared leadership. But according to the authors, the extent of involvement of patients at the lower level of the continuum does not give them enough power or decision-making authority but at the higher level of the continuum, patients serve as active partners in setting agenda and making decisions on health issues [23]. Although this could be regarded as an improvement on what the situation was at the early stage of PPI [57], the contributions of the patients at the lower level of the continuum are not utilised and patients that are consulted and allowed to be part of the decision making at the higher level of the continuum may not have the same medical problems with their counterpart that are consulted at the higher level. This makes the participation of patient in health and social care decision to be one-sided and partial with the likelihood of producing one-sided and partial results that will not lead to a complete transformation of the NHS health services. Hence, desired improvement on health and social care services that could have been achieved with PPI might still remain unattainable.

[32] described their study as a narrative systematic review. This is an accepted method, particularly as the authors explained that it was a systematic review. Systematic review is a sound research method in nursing science but the authors did not show any evidence of methodological rigour. The inclusive and exclusive criteria were not explained and even the method of data extraction and data evaluation were also not stated. These are important steps in a systematic review that cannot be ignored if a robust result that can be applied in practice must emerge. However, the study reveals a research gap when it noted that evidence of the impact of PPI from the literature reviewed is not clear. Subsequent researchers could carry out further investigation on the impact of PPI on health and social care system and the healthcare service users.

The conclusion, the study emphasised the need to re-examine the methods and approaches for PPI in all aspects of healthcare and in healthcare improvement. It notes that the main goal of involvement is partnership working but current involvement practices at a national and local level often involve a few group of individuals in involvement activities, with little consideration given to including a broader demographic of the population.

[3] carried out a survey research on the level and quality of service user involvement in clinical audit. The overall results indicate that service users involvement has been at a more local, ad hoc and consultation levels and a few were user led. A respondent concluded that clinical audit liaison group is usually considered too technical to attract patient involvement. However, one respondent reported with an example of where care had been improved due to user involvement. The researcher used a robust method involving a cross sectional survey of 40 respondents comprising service users. The questionnaire was developed based on the result of a semi-structured interview. This methodological approach provided sufficient evidence to make the results of the study useful for evidence based nursing practice.

According to [35], involvement takes place at the individual level (e.g. healthcare professional-patient consultation, or at the collective level as is the case in policy making such as policy making, service commissioning and in allocation of resources. In this two levels identified, the contributions of patients can be passive, active or exists in the form of collaboration (partnership) [35]. The author gave Expert Patients' Programme as an example of the individual level of involvement. This programme is a training programme that helps people living with long term chronic condition to develop skills that will enable them to better manage their condition. [46] [47] argued that involvement at the collective level is the same as inviting patients and the public to attend meetings and be a board member. In most cases, the part this form

of involvement will play and the meaning of such involvement are not well defined or not defined at all [34]. Patients, carers and the public are also involved in NICE decision making like deciding which treatments to recommend [24]. However, such involvement could just become a tokenistic gesture [66].

Moreover, direct involvement through representatives selected from members of organised groups cannot be taken to be a true representative of patients and the public since majority of the patients and the public are not members of any organised group, and therefore, the views of the representatives cannot be said to represent the views of the majority [27]. Most patients would want healthcare providers to take their views and lived experiences into consideration, but this is not usually possible because only few of them are chosen to represent the patients [51].

Dating back to 1969, Arnstein described eight rungs on a ladder of citizen participation. At the bottom two rungs of the ladder, those holding power make effort to 'educate' or 'cure' participants' Rungs 3 and 4 progress to the levels of tokenism, where participants hear and are heard but they lack the power to guarantee that their views will be taken into account by those with power; at rung 5, participants have some degree of influence but tokenism remains clear; at rung 6, there is a higher level of tokenism because participants are given the opportunity to advise but those in authority still have the right to decide; at rung 7-8, participants have more decision-making power - partnership enables participants to negotiate and engage with decision makers; at the apex of the ladder, participants obtain the majority of decision making and managerial power.

The method that [31] employed was robust enough to produce evidence that could be of practical value in transforming PPI in health and social care in England. The study setting was England and data were collected from thirty members of an organisation concerned with improving the services patients and their carers get. The participants were



contacted through email asking them what patients, carers and public involvement meant to them; they were as well asked to ask patients and carers what it means to them to be involved in decision making about NHS services [11] “All the responses from patients and carers were from white British individuals” [17]. However, though the responses came from ethnically diverse areas, the exclusion of people from other races who might have as well been British citizens might have denied the researchers of the opportunity to obtain a more balanced view from the non-British races that were also registered members of NHS, England.

In another study by [8] the authors found that although the policy of involving patients and the public in health and social care services receives support from the UK Government, the success of the implementation has been patchy and slow and mostly concentrated at the lowest level of involvement - making consultation the norm instead of collaboration. Other researchers [12]; [13]; [14] that investigated PPI in the UK health system shared the same view.

However, a number of studies carried out in the UK indicated that patients are active participant in the implementation of health and social care policies. For instance, [23] investigated how organisations can help patients and professional to collaborate in order to improve quality of healthcare in the UK.. The researchers used ethnographic method and found that patients participate in co-designing interventions with healthcare professionals through collaboration. The authors reported improvement in healthcare services in the organisations studied. This finding provides supporting evidence that involving patients and the public in health and social care policy implementation can lead to improved health and social care services [43]. However, the evidence provided by this study cannot be holistically attributed to PPI because as noted by the authors, all the participants in the study had professional knowledge of participation in PPI initiatives. But it thus suggests that

if patient are educated on what should be their roles in improving health and social care services, their involvement in the processes of policy making and healthcare delivery can lead to improved healthcare services in England.

However, it can be inferred that the involvement of patients and the public in health and social care decision making in England was a limited one which might not give them the power to influence health policy to the extent that could lead to much improvement in the quality of the treatment and services targeted by the NHS was expected to provide for them.

### **Findings**

Several studies have been conducted on PPI in the UK and Health and social care integration. Many of the studies were carried out in England. [30] studied patient’s involvement in clinical audit. The study aimed at establishing the effectiveness of involving patients in clinical audit and service improvement. Setting of the study was Sheffield South West Primary Care Trust. Panel interview was used to gather data. The research was published in 2008 and this makes its findings relevant for improving PPI in healthcare services. Findings showed that patients can work in partnership with PCTs to improve the effectiveness of primary care services in England.

In another study, [7] investigated the need to shift from tokenism to empowerment in PPI. The study used selective narrative to explore existing literature. The study setting was the UK and published in 2016. This makes it current and its findings relevant for practice. Result from the study showed that patients and the public can be involved in health and social care services at different stages of health and social care implementation. Such involvement was found to be beneficial.

[55] used survey method to study the conditions that can support representative participation in health and social care policy implementation. Result showed that little is understood about the conditions that can support participation to make it legitimate.

[43] examined the extent of involvement of PPI in health and social care decision making. And the impact it makes. The

study was published in 2018 and its setting was England. It reviewed research project within the NIHR School of Primary Care Research. Findings showed that reports on PPI in primary care research were inconsistent, and this inconsistency was present across research design and topics. Some good practices that make impact on the health of patients and the public were identified.

[36] study focussed on shift from rational to narrative dialogue of control of public involvement. The study was carried out in 2016 in England. It investigated how healthcare policy is translated into practice in three commissioning organisations. The population studied was older people. The study aimed at finding out how decision making can be used to reduce hospital admission for this category of people. Observational method was employed, and findings indicated that there was confusion amongst public representatives on their role and what they could contribute to the organisation. It was also found that management dominated control of the group.

[36] Patients and public care organisations used to establish relationship with patients and the public. Findings showed that the board preferred consultation to any other method, and it treated the views of patients and the public as a mere advice which it can do without. The study setting was England.

[8] explored theories, barriers and enablers of PPI in the UK. Systematic review and meta-analysis protocols were used as the research design and methods. The study found that there are conceptual differences in the use of 'citizens', 'consumers', 'lay person', 'service user' and these words are used to indicate the level of involvement. The study setting was UK.

[58] conducted a study to determine who wants to be involved in health and social care decision making in England and Sweden. The study was a comparative sectional study. It was found that more people in England wanted to be involved in taking decision concerning their own health than in Sweden.

[51] studied how patients and the public can be involved in health and social care

at a more strategic level. The study aim was to identify the conditions that can enhance actual involvement of patients and the public in healthcare decision making. The study setting was six Flemish hospitals in Belgium. A three-phased-mixed-method design with individual questionnaires, observation and focus group was used to gather data. Finding from the study showed that hospitals should involve patients and the public in the choice of topics in areas such as operational issues'; the stakeholders in PPI requires adequate preparation; stakeholders committee should have greater autonomy to take decision. The setting of the study was Belgium. The study combined quantitative and qualitative data, and this enabled triangulation.

[32] examined a research report on how NHS commissioners in charge of commissioning health and social care organisations can develop services to improve integration in order to make NHS more efficient in delivering health care services. The setting of the report was Nuthfield Trust. The study examined the role of commissioners in promoting integration. This was a case study.

[47] investigated PPI in implementation research. The study design was structured consensus process. A convenience sample panel comprising 9 experienced PPI and 2 researcher members were recruited to participate in the study. The study found strong support for the role of PPI in research.

[25] studied the impact of PPI intervention on health and social care in the UK. ASPIRE was used as the research design and method. Findings showed that PPI intervention helped to improve the quality of care NHS provided to patients.

Evidence from this present study shows that patients and the public in England have been involved in health and social care services in various ways. Many of the studies reviewed reported that PPI has been an age long policy in the UK and invariably in England. PPI was reported to have made important contributions in some areas of health and social care planning, shared decision making, diagnosis of diseases, choice of

treatment, adherence to treatment as well as contributing to research (e.g. [31]; [32]; [33]; [34]. These contributions are evidence that the involvement of patients and the public in health and social care services in England has been a continuous practice.

It was also found that in the implementation of the 2010-2015 health and social care integration policy, patients and the public were involved at different stages of the implementation of the policy. In the area of clinical audit, the researcher found that service users were involved more at local level, ad-hoc and consultation levels [45]. Clinical audit was usually considered as too technical to involve patients and the public.

This study also found that there were some areas where health and social care in England has been improved as a result of the involvement of patients and the

public. For instance, PPI led to the construction of new healthcare buildings and environment such as a new cancer centre, a centre for mental health and a sickle cell centre; a planned location for post-surgical ward and a new day area for patients in some healthcare organisations, improved access to transport and car parking [37]. Changes were also reported confirming that PPI resulted in changes to appointment system, reduced waiting times, better protection of personal information and hand held records as well as improved cleanliness and hygiene in wards [32]. However, most of the views of patients and the public were often not taken into consideration. The reason for this was that laymen (service) are not professionals and as a result, their contributions were considered as not good enough for the professionals in the area to work with.

#### DISCUSSION

With regard to research question one that sought to identify evidence in literature that suggests that patients and the public were involved in the implementation of the 2010-2015 health and social integration policy in England, it was found that patients and the public in England were to some extent involved in the implementation of the 2010-2015 health and social care integration policy. For instance, [3] noted that patients and the public had representatives that participated in making decision on health and social care services in England but they were not given enough power that could enable them to make enough contributions to positively influence the quality of health and social care services the citizens receive. However, it could be argued that the fact that patients and the public were represented in the discussion on PPI suggests that patients and the public were not totally denied the chance of contributing to the decisions made on health of health and social care services. The problem, however, was that health care professionals did not accept that this group had the professional knowledge that could make the professionals to accept and use their contributions [7]. There has also been a transition from an

era in which clinicians had the authority to judge the quality of their own work, toward an era promoting outcome measurement and accountability to patients, third-party funding bodies, and society [14]; [15]. This new era suggests that professionals no longer have monopoly of managing the health care of patients without the involvement of the patients and the public directly or indirectly. In the reviews of the papers on PPI and healthcare delivery, the results indicated that in many of the healthcare organisations where PPI were practiced, improvements in some areas were attributed to the involvement of patients and the public in the health care services or projects. There is therefore, evidence in literature that PPI was used in health and social care integration but the involvement were few. As noted by Nolte & RAND Europe (2016), PPI has been tried in different areas of health policy such as health service planning and delivery, health research and priority-setting. [39] found that patients and the public were involved at different levels of healthcare planning and decision making ranging from consultation to partnership and shared leadership, purchase and delivery. However, involvement was reported to be

limited to consultations instead of participation in health and social care decision making (e.g. [51]; [52]. The implication of mere consultation is that health care professionals and policy makers do not use the advice from patients and the public.

Research question two sought to know how patients and the public involvement were involved in health and social care in England. Many of the works reviewed indicated divergent views on patient and public involvement in the planning and implementation of the 2010-2015 health and social care policy. [37] stated that user involvement is now a priority in the planning of services in the UK including England and that service users were also involved in the design and distribution of patient and public information, training programmes and awareness campaigns. The authors also noted that health professionals and managerial bodies appear to be beginning to value service user involvement as evidenced. This might have become so because patients and the public now have a group that unite them and they now speak with one voice and put pressure on both the Government of England and healthcare organisations to involve them in taking decision on their own health [45]. For instance, patient centred care (PCC) has received greater attention in health care in recent years, and has become advocates for a more biopsychosocial and mutualistic approach whereby the patient's beliefs, goals, and perspectives are taken into account in the development of practice guidelines and delivery of health care [43].

Research question three sought to find out the extent patient and the public were involved in the implementation of health and social care policy in England. There were inconsistent reports on the extent of patients and public involvement in research. Some scholars argue that patients and public involvement in health and social care decision making is absent. For instance, the study by [32] revealed that that patients and the public haven been largely absent in the implementation of health and social care policy in England. However, this was a report

specific to a particular organisation the researcher investigated, and therefore, cannot be used to make a generalisation on the involvement of patients and the public in health and social care implementation process. [53] argued that the absence of PPI in the absence of PPI in the Sustainability and Transformation plan (STPs) could be because there was a short time to develop the plan and also because NHS directive to the leaders was not to disclose the draft of STPs to the public. However, this could be a conscious plan by NHS to make to put the public off from making any contribution on the basis of their non professional knowledge.

Also, [67] pointed out that the various terms such as consultation, engagement, participation, partnership or co-production used to describe PPI suggest the extent of involvement of PPI in decision making. The use of any of the terms could mean a greater or lesser involvement of patients and the public in health and social care decision making. For instance, 'participation' suggest a lesser involvement with the voice of patients and the public serving as a mere advice that NHS is at liberty to accept and use or reject without any apology. Thus, the various words other than involvement used to describe PPI means that patients and the public has limited power to take decision concerning their own health and well being. The term 'participation' also suggested limited power of patients and the public. It can, therefore, be concluded that patients and the public were not given enough powers by NHS to determine the type of treatment that is best to meet their health and social care needs.

Similarly, [57], there seem to be some kind of discriminatory practices by NHS based on the social and economic status of patients and the public. Those at the lower rung of the ladder have less decision making power while those at the upper rung of the ladder are given more power to decide on the type of treatment they want, and could even be allowed to participate actively in setting agenda on any health and social care issue.

In addition, [34] noted that PPI in health and social care in England is limited to some areas of healthcare services. For example, service users involvement is more often than not allowed on ad-hoc basis and at a local level. Perhaps, the local level is where the NHS and those with power feel they could always dominate the voices of the citizens without any noticeable reactions; and if PPI is used as an ad-hoc group, they will not be there in the all through the implementation chain to know how and what the NHS has done with their contribution. It can therefore, be concluded that PPI power to make decision on health and social issues were limited

As noted by [53], involvement takes place at the individual level and collective level. The author identified PPI at these levels as passive rather than active or end up as a mere collaboration [32]. This happens in areas like healthcare commissioning, and resource allocation [25]. Although NHS provides training for patients and the public to encourage both individual and collective involvement, it could be argued that such trainings are mere official window dressing since the contributions of patients and the public are often not taken into account the process of health and social care implementation. It is the opinion of the researcher that it seems the NHS is involved in the politic of healthcare maneuvering on the basis that if patients and the public are fully involved in health and social care decision making, they could undermine the authority and professional knowledge of the health care professionals who often do not see patients and the public as people with any health and social care knowledge.

Agreeably, PPI representatives are selected to be part of health and social care decision making body. But a handful of representative cannot be said to adequately represent the view of the entire population of England. Moreover, most of the time, it is those who have some axe to grind that are usually selected to represent, [24]. and this could be just a ploy by NHS and those with power to placate this set of people so that

NHS and the government can have their way. After all, government may not be happy to continue spending the huge amount of money that goes into the health and social care services provided to individuals since treatment by NHS is free at the point of service. If this is the case, it is important that the government should remember that NHS is funded with public money, so the tax payers that fund the services of NHS should be respected and their voice not only heard but allowed to count in health and social care decision making. .

### **Study strengths and limitations**

This study made use of multiple literature which include peer reviewed articles on PPI and health and social care integration. Most of the literature reviewed were grey literature that were not produced for commercial reasons, reports on health and social care services, briefing papers and well researched dissertations. This helped the researcher to ensure that data collected and used for this review were evidence based. The use of realist review enabled the researcher to make use of literature on PPI and health and social care which came from multiple sources such as CINAHL, PubMed and Cochrane Data Base, etc.

There were few studies that examined the involvement of patients and the public in the implementation of the 2010-2015 health and social care integration policy in England. This made the evidence on the involvement of patients and the public in the formulation and implementation of health and social care services scarce. However, the researcher was able to reduce the effect of this limitation on the result of the study by identifying and synthesising all the empirical studies carried out within the context of this study and the publications that directly correlate to the research questions. As a result, this limitation did not have much significant impact on the findings of the study.

### **Contribution to Knowledge**

This study makes both theoretical and practical contributions to knowledge.

#### **Theoretical contribution**

Theoretically, the review brings together the findings of current studies on the role of PPI in the implementation of the 2010-2015 health and social care integration policy in England. By bringing together these current evidences and synthesising them, the study provides new evidence-base for improving PPI in health and social care policy formulation and implementation.

#### **Practical contribution**

At practical level, the study findings can be applied by healthcare professional and non professionals within healthcare system to improve the quality of health and social care services in England. This has become more important at the time when new diseases and an ageing population is challenging the capacity of NHS England and other healthcare organisations to cope with the increasing health needs of the population.

#### **Implications for Service Practice and policy Making Implications for Practice**

The review results have implications for practice at national level. The results indicate that PPI involvement in health and social care policy implementation is widely recognised and accepted in England, but it is not put into practice. It appears that healthcare organisations in England are still experimenting on the involvement of healthcare users in

Integrated health and social care has helped to reduce the fragmentation that existed before the introduction of the approach. This is particularly relevant where separation between healthcare services and social care is leading to adverse effects on people's care experiences and outcomes. The major aim

#### **CONCLUSION**

healthcare services. There is therefore, the need for NHS England and other health and social care organisations to move beyond theory and rhetoric to implementation of PPI in healthcare decision making and delivery.

At clinical level, the lesson from this study implies that Clinical audits involving PPI in health services is an important practice because such involvement provides an opportunity for collaboration between organisations, and minimizes risk of mere consultation of service users. The situation where service users are only consulted and indirectly involved without the opportunity to take active part in health policy articulation and implementation needs to be redressed.

#### **Implication for Policy**

Policy goal fails if the policy is not well thought through and no policy can succeed without the views of those the policy is meant to serve. In healthcare, past health policy initiatives failed because the policy makers did not involve services users to contribute ideas on that works for them. This study makes it clear that in order to avoid future policy failure in healthcare, policy makers should involve the tax payers (patients and public) in healthcare planning and decision making.

of integrated care is the promotion of the health and wellbeing of the citizens. The approach has helped to improve the quality of care. However, the impact of PPI on the implementation of the 2010-2015 health and social care integration policy on the health of the citizens of England seems to be minimal.

#### **RECOMMENDATIONS**

Based on the findings of this review, the researcher recommends as follows:

- NHS and other healthcare organisations in England should give more opportunities to patients and the public to be actively involved in health and social care decision making at all levels

- Researchers in the field of health and social care should be more detailed in their description of the outcomes of patients and public involvement in healthcare decision making.
- PPI education should be integrated into any health and social care plans to equip service users with the skills and knowledge of

- effective PPI in health and social care decision making.
- Studies should report sufficient details about the process of involvement to enable patients and the public to understand what it means to be involved in health and social care decision making.
  - The definition of PPI should be standardised to avoid conceptual confusion

- Patients and the public should be actively involved at all stages of any review of health and social care policy.
- Healthcare workers should be educated to respect the opinions of patients and the public when it will not cause harm.

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