**A Critical Analysis of the Implementation of Service User involvement in Primary Care Research and Health Service Development using Normalization Process Theory:**

**Revised draft May 21st 2014**

**Authors**

\*Edel Tierney, Graduate Entry Medical School, University of Limerick, Ireland. T: 00 353 61 213372. F: 00 353 61 233778. E: edel.tierney@ul.ie

Rachel McEvoy, Health Service Executive, Galway, Ireland. E: Rachel.McEvoy@hse.ie

Mary O’Reilly-de Brún, Discipline of General Practice, National University of Ireland, Galway, Ireland. E: mary.oreillydebrun@nuigalway.ie

Tomas de Brún, Discipline of General Practice, National University of Ireland, Galway, Ireland. E: tomas.debrun@nuigalway.ie

Okonkwo, Ekaterina, Galway Migrant Service, Galway, Ireland. E: katyaokonkwo@hotmail.com

Michelle Rooney, Mayo Intercultural Action, Ireland. E: mbtrooney@ymail.com

Prof. Chris Dowrick, University of Liverpool, Primary Medical Care, Liverpool L69 3GL, United Kingdom. E: Cfd@liverpool.ac.uk

Prof. Ann Rogers, NIHR Collaboration for Leadership in Applied Health Research and Care, Wessex

 Faculty of Health Sciences, University of Southampton, United Kingdom. E: a.e.rogers@soton.ac.uk

Prof. Anne MacFarlane, Graduate Entry Medical School, Primary Health Care Research, University of Limerick, Ireland. E: anne.macfarlane@ul.ie

\*Corresponding author

**Sources of Funding**

This project was funded by the Health Research Board, Dublin, Ireland.

**Conflicts of Interest**

The authors declare no conflicts of interest.

**Abstract:**

Background: There have been recent important advances in conceptualizing and operationalizing involvement in health research and healthcare service development. However, problems persist in the field that impact on the scope for meaningful involvement to become a routine – normalised- way of working in primary care. In this review, we focus on current practice to critically interrogate factors known to be relevant for normalization – definition, enrolment, enactment and appraisal.

Method: Ours was a multidisciplinary, inter-agency team, with community representation. We searched EBSCO host for papers from 2007-2011 and engaged in an iterative, reflexive approach to sampling, appraising and analyzing the literature following the principles of a critical interpretive synthesis approach and using Normalization Process Theory.

Findings: Twenty-six papers were chosen from 289 papers, as a purposeful sample of work that is reported as service user involvement in the field. Few papers provided a clear working definition of service user involvement. The dominant identified rationale for enrolling service users in primary care projects was linked with policy imperatives for co-governance and emancipatory ideals. The majority of methodologies employed were standard health services research methods that do not qualify as research with service users. This indicates a lack of congruence between the stated aims and methods. Most studies only reported positive outcomes, raising questions about the balance or completeness of the published appraisals.

Conclusion: To improve normalisation of meaningful involvement in primary care, it is necessary to encourage explicit reporting of definitions, methodological innovation to enhance co-governance, and dissemination of research processes and findings.

Word count: 250/250

**Background**

The idea of involving patients and the public in healthcare has grown significantly in recent decades and is now enshrined in health policy across a range of international settings ([1-5](#_ENREF_1)).

Therefore, patient and public involvement (PPI) has increasingly become the focus of attention in health services research and health services development. Thompson et al. (2012) argue that these are overlapping categories whereby data generated by such research can inform and improve healthcare services. There are a number of models or frameworks that aim to conceptualise public and patient involvement (PPI). Gibson et al.’s ([7](#_ENREF_7)) recent work on conceptualisation of PPI provides a valuable overview of models and frameworks in the field, and provides new theoretical directions (that were previously absent) for an emancipatory concept of patient and public involvement in health services development. A systematic review by Brett et al. focused on the conceptualisation, measurement and impact of outcomes of PPI in health and social care research ([9](#_ENREF_9)).

However, conceptualisation and theorisation of PPI is not common in studies of PPI ([9](#_ENREF_9)). Furthermore, there have been recent important developments in the operationalisation of public and patient involvement in health research and health service development. Earlier literature in the field proposed that involvement could be captured through the use of conventional health service research methods such as surveys, in-depth interviews and general consultation ([10](#_ENREF_10)). It is now accepted that these methods, by themselves, do not facilitate meaningful involvement unless service users have contributed to research design. This emphasis on more extensive involvement is captured in the INVOLVE definition of involvement in health research and health service development as research ‘with’ or ‘by’ service users, rather than ‘to’, ‘about’ or ‘for’ service users (see [www.invo.org.uk)](http://www.invo.org.uk)).

There have been examples of concerted efforts to develop infrastructure and capacity to support meaningful collaborations and partnerships between academia, healthcare providers and patients in North America (see <http://pram.mcgill.ca/>) and the United Kingdom (see <http://piiaf.org.uk/>).

 However, problems persist in the field. Firstly, there is a problem of definition. There is still a wide range of terms used in the field, including patient involvement, patient engagement, patient participation, service user involvement, citizen engagement, community participation, community engagement, and public involvement ([11](#_ENREF_11)). Gallivan et al. argue that this can contribute to misunderstanding and misinterpretation of expectations, goals and outcomes by different groups of stakeholders, which poses barriers to achieving meaningful and successful outcomes in partnership work together ([12](#_ENREF_12)). We clarify our terminology in Box 1.

Secondly, there are many reasons why service users and health professionals get involved with service user involvement (SUI) projects. This presents the problem of enrolment in the field ([6](#_ENREF_6), [13-15](#_ENREF_13)). We do not know what factors motivate health professionals or service users to enrol in specific projects: Is it a question of personal motivation or is it a response (voluntary or involuntary) to policy directives? Are service users and health professionals enrolling with shared or differential motivations and definitions of involvement?

Thirdly, there is the problem of enactment. As above, standard conventional research methods can be mistakenly conflated with SUI ([16](#_ENREF_16)). It is important to know why a specific method is selected for a project and whether the selected methods are *congruent* or not with an intended level of involvement and working definitions of service user involvement in health research and/or health service development.

National and international literature reviews of the field have highlighted that it is very possible for healthcare professionals to be ‘engaged’ in numerous purported involvement activities with service users *without genuinely involving people* (particularly if the professionals continue to set and drive the agenda and make decisions about services and treatments without involving service users in a meaningful way) ([8](#_ENREF_8)), [17](#_ENREF_17)). This has implications for understanding the outcomes of SUI, which is the fourth problem – appraisal of SUI. While negative effects of SUI on research processes and subsequent health service outcomes have been reported ([9](#_ENREF_9), [18](#_ENREF_18), [19](#_ENREF_19)), there is growing evidence that participatory approaches to research that involve service users in a meaningful and sustained way can have positive impacts in terms of setting the research agenda, programme sustainability and advancement, the generation of systemic change ([17](#_ENREF_17), [20-22](#_ENREF_20)), and on service users themselves ([23](#_ENREF_23)) ([24](#_ENREF_24)) ([25](#_ENREF_25)) ([26](#_ENREF_26)). Therefore, we have to seriously and critically analyse any claims about outcomes based on SUI where, in fact, service user involvement did not occur or was so poorly enacted that it ought not to be claimed as genuine service user involvement.

Overall, our observation is that the four problems outlined above are problematic in and of themselves, but they are also barriers to the implementation of meaningful SUI as a routine way of working in healthcare research and healthcare service settings, i.e., as a normalised practice. The problems are about the definition, enrolment, enactment and appraisal of SUI, and these resonate with the four constructs of Normalization Process Theory (NPT) ([27](#_ENREF_27)) (see Table 1). This is a contemporary social theory that can be used to understand and investigate the normalisation of innovation in healthcare ([28](#_ENREF_28)).

The aim of this review is to critically interrogate the conditions for the implementation of SUI in both primary care research and health service development projects in order to make recommendations that will enhance chances of its normalisation. We focus on a sample of original published empirical work that is reported as SUI in the primary care literature to rigorously examine the way definition, enrolment, enactment and appraisal are reported vis-à-vis each other.

**Methods**

The methodological approach for conducting this review followed the broad precepts of a critical interpretive synthesis (CIS) ([29](#_ENREF_29)). We employed an inductive and iterative approach using the research question as a compass during the review process. We sought a purposeful sample of papers, integrated quantitative and qualitative data, and aimed for a more fundamental critique of literature (rather than a summary). While we adopted an inductive approach at the outset of the review process, given our interest in implementation and normalisation, we used NPT as a heuristic device to synthesise emergent findings and draw out key recommendations.

The research team constituted academics, health authority personnel, clinicians and community organisation representatives, all of whom have experience of using participatory research approaches.

We searched EBSCO host for original primary care papers about research and health service development projects that were identified by relevant search terms between 2007 and 2011 (see Figure 1 for description of search terms).

The first stages of the review involved an iterative reflexive approach to searching and sampling the literature using a series of identification, sampling and appraisal steps as per the CIS methodology. Each of these stages of the review was led by the first author with substantial input, independent reviewing of abstracts and development of sampling parameters by the second and last author, and consultation with the other authors. The thematic analysis and subsequent synthesis of findings was led by the first and last author in consultation with all other authors, using a combination of data analysis clinics, project meetings and email correspondence.

We identified 289 abstracts at the outset, which resulted in 234 abstracts after duplicates were removed. From this, 78 empirical abstracts were identified, and using iteratively developed sampling parameters, we excluded conventional qualitative research studies and selected a final purposive sample of 26 papers for inclusion in the review (see Figure 1).

Not all papers included in the review involved service users in a meaningful way as per the definition espoused by INVOLVE, but we included them on the basis that they were identified in the literature as SUI. Our search terms therefore represented ‘current practice’ reported in peer-reviewed published literature. They were included because they contained at least some data about definition or enrolment or enactment or appraisal of SUI. For example, the work was presented as SUI in the introduction section against the policy background of SUI, or the work reported revealed proximity between data generation and healthcare service outcomes, which we considered relevant to understanding the impact and appraisal of SUI.

Table 2 provides an overview of the final set of sampling parameters and the numbers of papers reviewed per parameter. Following Dixon Woods ([29](#_ENREF_29)), and using checklists developed by others, ([30](#_ENREF_30), [31](#_ENREF_31)) we conducted a quality appraisal exercise on these 26 papers with an emphasis on the *relevance* of the paper to our review. All were deemed appropriate for inclusion in the review.

For the data extraction process we used a modified version of the Critical Appraisal Tool (CAT) ([32](#_ENREF_32)). Our process and working definitions for the synthesis are shown in Box 2. First order constructs were drawn from the information extracted during the critical appraisal process, and were informed by the items on the amended CAT ([32](#_ENREF_32)) (see Table 3, Column 1). All papers, qualitative and quantitative, were appraised by the same method.

These first order constructs informed the development of our second order constructs through interpretation and collation of themes from first order constructs (see Table 3, Columns 3 and 4).

Whilst we were reviewing our second order constructs and the data contained therein, we were exploring the evidence from across all studies in the review to integrate this data into a synthesising argument. Given our noted link between the practice of SUI and NPT’s constructs, we developed a synthesising argument around the theory’s four constructs of Coherence, Cognitive Participation Collective Action and Reflexive Monitoring (Table 3 shows how the data from each paper informed this final synthesis).

By mapping our first and second order constructs onto these synthesising NPT constructs in a sequential manner, we were representing the network of synthetic constructs and explaining the relationships between them with the aim of providing a more insightful formalised and generalisable way of understanding a phenomenon([29](#_ENREF_29)) - in this case the phenomenon of Service User Involvement in Primary Care Research and Health Service Development. Therefore, the synthesising constructs of NPT were informed by data from across the second order constructs (which were developed from thematic analysis and interpretation of first order constructs).

In the main, the second order constructs which most informed the final stage of our synthesis and conclusions were partnership and collaboration, roles and responsibilities and power and control (See Table 4 below).

The other themes generally described standard information about the conduct of the research typically contained in an academic write-up of a peer-reviewed paper, but they did not reveal anything specific about the topic of service user involvement itself. For example, all accounts of Ethical Practice referred to standard procedures of applying and receiving ethical approval. There were no data about specific ethical considerations that had to be taken into account to support/enhance the service user involvement dimension, for example, the development of training or mentoring to enhance service users’ capacity for co-working and co-governance.

Our findings are reported under the headings of definition, enrolment, enactment and appraisal below.

**Findings**

The majority of papers were from the UK (n=11). Four were from Ireland, three from the US, two from Australia and one each from Brazil, Canada, Finland, Germany, Sweden and The Netherlands.

*Definition*

Only six papers included a definition of service user involvement ([33-38](#_ENREF_33)). All six definitions focused on the notion of SUI as involving partnership, collaboration, and notions of ownership and empowerment for service users. Thus, we inferred that in each case the researchers were indicating strong aspirations for meaningful service user involvement. In the other papers, while authors didn’t provide an explicit definition, many stated that their project had been designed in response to policy imperatives to re-balance power and control between those planning or delivering health services, and those who use the health services.

There were no data in any paper about whether definitions within or across stakeholder groups differed, so we could not determine if the definitions were shared or not by those involved in the work.

*Enrolment*

Several papers reported that the rationale for creating partnerships and collaborations was specifically to reform aspects of healthcare delivery by drawing on the experiences and perspectives of service users in research projects ([39-44](#_ENREF_39)). O’Reilly et al.’s aim ([40](#_ENREF_40)) was to gather drug users’ perspectives on how they are treated by services, and to assess drug users’ views of health services in order to change services. There were examples of collaborations that were initiated to improve clinical consultations, specifically, studies about shared decision-making (SDM) which aimed to improve adherence, satisfaction with treatment, and clinical outcomes ([45](#_ENREF_45)). Other studies enrolled patients in SDM for depression treatment ([36](#_ENREF_36)), and for the treatment of depression in patients with cancer ([42](#_ENREF_42)), and for cardiovascular risk management ([39](#_ENREF_39)).

Other partnerships and collaborations were initiated for the purposes of iterative testing and refinement of clinical tools with providers and patients ([46](#_ENREF_46)). For example, Goodrich et al. ([46](#_ENREF_46)) sought patient input into the development of an Internet-mediated walking programme to develop and evaluate an online interface and to monitor participant progress in the programme.

Partnership in healthcare service development was addressed by Peconi et al. ([47](#_ENREF_47)) in scoping activities that brought together key players and stakeholders in emergency and unscheduled care, strengthening commitment to the proposed research and development network. This was reported to be the first time in Wales that these groups were brought together across the emergency care system, to focus on research issues in this way.

Across studies overall, the key reported rationale for enrolment in research and health service developments was to bring the service user perspective to the work in hand. This is consistent with a vision of primary health care as one that stretches the boundaries of relationships beyond formal agencies and professionals, to include community representatives as collaborators to influence healthcare delivery, healthcare decisions and research ([48](#_ENREF_48)). However, what is missing are data on *who* initiated the collaborations, and data about *what* strategies, if any, were employed to facilitate meaningful collaboration, as well as critical reflections on the nature of the partnerships or collaborations.

*Enactment*

Service users reportedly held a diverse set of roles and responsibilities across the studies reviewed. The most common one was being asked to comment on study materials/proposed interventions, and often there is evidence of some changes to the projects as a result of their input. However, as reported above, despite the fact that most papers’ explicit or implicit definitions indicated strong aspirations for meaningful service user involvement, standard methodologies such as interviews and focus groups were generally employed ([35](#_ENREF_35), [43](#_ENREF_43), [45](#_ENREF_45), [47](#_ENREF_47), [49-54](#_ENREF_49)).

There were some examples of innovative methods that enabled more meaningful involvement and these were studies that were designed at the outset as participatory health research projects([33](#_ENREF_33), [40](#_ENREF_40), [41](#_ENREF_41), [44](#_ENREF_44), [50](#_ENREF_50), [52](#_ENREF_52), [55](#_ENREF_55)). Here, there was evidence of stronger congruence between the aims of sharing power and control and practicing emancipatory principles, and the methods employed. For example, de Brún and Du Vivier conducted a participatory learning and action (PLA) research study with homeless men to design an intervention using PLA timelines (designed to elicit accounts of life journeys and stories of personal breakthroughs). A visual representation of the meta-analysis of their experiences was presented in a PLA matrix chart ([44](#_ENREF_44)). Interestingly, participants *and* researchers generated data together on the topic of interest, shared each others’ experiences and perspectives, and completed a co-analysis together. In the Alexander study, emancipatory actions during the research process supported ethnically diverse women to regain control of their healthcare and maintain equality over the course of five successive focus group meetings and in their subsequent interactions with primary care clinicians ([33](#_ENREF_33)).

Furthermore, in several of these participatory studies it was evident that service users had sustained involvement in the project, with changing roles as per the project progression. Lindenmeyer et al. reported that service users shaped the direction of their work at the outset, and also assisted with recruitment, the development of questionnaires, analysis and dissemination activities ([50](#_ENREF_50)). However, even where such efforts were made, an explanation of how a participatory research process can lead to empowerment or other similar positive health service outcomes was lacking, which begs the following questions: What actually happens in the research process that leads to these outcomes, and in what ways can researchers elucidate or report these processes?

Finally, it was interesting to note that in the majority of papers reviewed participants are referred to as ‘patients’, which perhaps reflects notions of the ‘expert patient’, i.e., that patients have expertise by virtue of their experience of a particular condition or illness or health service utilisation. In other cases, rather than using the term ‘patient’, the authors used terminology that emphasised the individual’s or group’s socio-demographic identity, e.g., men ([51](#_ENREF_51)), women ([33](#_ENREF_33)), or older people ([43](#_ENREF_43)). Whether this difference in terminology is indicative of researchers’ attitudes toward the service user, which in turn may be reflective of power differentials within research or service development initiatives, is hard to say, but it may be worthy of further examination.

*Appraisal*

Authors’ appraisals of their work were mostly positive. The most consistent claim made was that service users offered a unique and practical expertise that added credibility to the work with positive impacts on service delivery of research. Many authors reported that SUI added real-world connection to their research ([43](#_ENREF_43), [47](#_ENREF_47), [51](#_ENREF_51), [52](#_ENREF_52)), and changed the mind-sets of researchers ([50](#_ENREF_50)).

There were reported benefits for service users. For example, confidence and self-knowledge increased ([33](#_ENREF_33)), confidence in making healthcare decisions increased ([33](#_ENREF_33), [56](#_ENREF_56)), a sense of power increased ([33](#_ENREF_33), [56](#_ENREF_56)), and participants learned how to speak up and talk back ([33](#_ENREF_33), [56](#_ENREF_56)). Equality in the research process led to positive interactions ([33](#_ENREF_33)) and equality of interaction ([50](#_ENREF_50)). Interestingly, only one paper([40](#_ENREF_40)) provided data from service users directly to support these claims.

In contrast, negative outcomes were rarely reported, for example whether there had been frustrations, power struggles or disengagement by either the service users or healthcare workers/researchers. Few studies explored the problems or challenges of participation, including passive consumer roles and tokenism. A notable exception was Radermacher et al. ([38](#_ENREF_38)) who provided a critical analysis of the powerlessness of people with disabilities in the face of organisational structures and culture.

**Discussion**

In this review, we focused on documented problems in the field of involvement in primary healthcare research and healthcare service development projects – problems of definition, enrolment, enactment and appraisal. We have critically interrogated conditions for implementation of meaningful involvement in primary care in primary healthcare research and health services development projects.

Our findings confirm rather than resolve the problem of definition. Only six papers in our sample provided an explicit definition to convey the meaning of the work they were doing. The definitions provided were typically in the introduction section, with references to existing literature. There were no empirical data about how different stakeholder groups involved in the project defined involvement. This limited the scope for our intended analysis of issues of definition vis-à-vis enrolment, enactment and appraisal within individual projects, and diminishes the scope for strong coherence in the field.

In terms of enrolment, based on these available data we see an emphasis on policy imperatives to involve service users in primary care in order to share power and control. There is a sense that those involved in research and healthcare delivery projects believe it is right that they engage with stakeholders in order to follow policy imperatives, but less evidence that they believe it is worthwhile and valuable as *a way of working*. It was interesting to contrast the rhetoric about sharing power and control with the apparent gravitation to high ideals about meaningful involvement with the enactment of SUI. Much of what is reported reflects standard practice in health service research and health service development projects rather than evidence of a body of specialised practice that is committed to realising such high ideals.

Notwithstanding the fact that there are ethical practices and scientific principles that are important across all kinds of research designs, we would argue that it is reasonable to expect to see *additional and/or creative* activities in this particular field. The purpose of such activities would be to enable service users to undertake roles and responsibilities that go beyond ‘having an input’. Service users would be enabled to create and participate in meaningful and ongoing partnerships and collaborations, which in turn would enhance the scope for sharing power and control. In this review there were papers that claimed to have these aims but did not employ suitable methodologies to achieve those goals. For example, most papers reported involvement at only one point in time, echoing findings reported elsewhere by Brett et al. who found that user-led or collaborative studies with users were more likely to demonstrate sustained involvement ([9](#_ENREF_9)).

There are valuable examples in our data set of the specific considerations that some researchers reported in their efforts to enact more meaningful participatory approaches. Alexander ([33](#_ENREF_33)) describes her investigator role as providing a forum where analysis, reformulation and recognition of emancipatory interests could be supported and encouraged, and she outlines the use of a participatory group methodology to create such a context for women in the research process to experience empowerment. De Brún and Du Vivier describe their decision to generate data and share *their* life stories and turning points with the homeless men with whom they were engaged ([44](#_ENREF_44)).

Our finding about enactment echoes previous work but we emphasise that a major finding from this review is that the balance of work in the field appears to be consultative rather than participatory ([21](#_ENREF_21)). Moreover, there are significant gaps in the field that make it challenging to progress the realisation of emancipatory ideals in this field ([7](#_ENREF_7)). For example, the gap in knowledge about whether stakeholders have shared or differential understandings of the work in hand is problematic. Such ambiguities can cause frustrations and misunderstandings which become barriers to meaningful involvement ([12](#_ENREF_12)). Worse, we know that repeated disappointments with research involvement among specific communities can accumulate, leading to research fatigue and resistance to partnerships and collaborations with university or health service personnel ([57-59](#_ENREF_57)). This in turn affects the appraisal and reported outcomes of SUI for research and health service development projects.

Therefore, to advance our understanding and practice it is important that issues of definition and expectations are made explicit so that appraisals of outcomes can be fair and meaningful. A recent review of the benefits of participatory research ([17](#_ENREF_17)) carefully identified and explicated key characteristics of participatory practice, which enabled compelling conclusions to be drawn about the positive impact of such research approaches. This kind of attention to framing the specifics of practice in the field is important for expanding its evidence base. In time it would be good to see an evidence base about different levels of involvement and their outcomes. Like Brett et al. ([9](#_ENREF_9)), we argue that poor reporting of impact acts ‘as a fog obscuring the real impact of PPI’ (p. 15).

Another key finding from this review is the observed emphasis in the papers on positive appraisal and impact. The exception in our review was Radermacher et al.’s critical analysis of the powerlessness of people with disabilities in the face of organisational structures and culture. It is interesting to note that the analysis of barriers to participation was not incidental or secondary to their research, but was in fact their stated objective ([38](#_ENREF_38)). This explicit attention to problems is unusual in our sample of literature, where the emphasis is on ideals and notions of only *good* practice because of/during service user involvement initiatives. Arguably, this more critical stance is as real and warrants further scrutiny, particularly given recent findings from the PIRICOM Review ([9](#_ENREF_9)) which reported negative impacts in terms of personal impact, skill levels and knowledge levels and users feeling overburdened, not listened to and marginalised.

***Methodological Critique***

This review was based on a search of one platform database only. Arguably, we could have included other platforms. However, EBSCO offers a suite of more than 300 full-text and secondary research databases, and our intention was not to conduct a comprehensive review of all published literature but to generate a purposeful sample that represented the range of practice in this field. Our iterative development of sampling parameters during the search phase was crucial for this.

Our critique of the literature is limited to single accounts of the studies in our review, which in turn are limited by the strict criteria for style and word count of academic journals. This may, of course, influence the nature of what is reported and may explain the emphasis on positive findings. We did not engage in chain referencing to identify additional papers about the studies in our sample, and this may have augmented or modified our analysis. However, we did note that during our search there were no obvious examples of related papers; had there been, we would have included them. We only included grey literature from an Irish context and not from an international setting, and we do accept that there are additional and extended accounts of service user involvement in practice in reports and other documentation that may have provided detail missing from academic journal articles. However, we had a specific interest in reviewing literature that had been through peer review and had therefore been accepted by our peers as a form of service user involvement and representative of work in the field. Our review is influenced by our background as participatory researchers and our national contexts. We have endeavoured to be open and reflexive about that throughout the work and in this article.

Finally, this review is limited to papers published up to 2011. We acknowledge that there are relevant recent additions to the literature that have further enhanced our knowledge about co-productions of knowledge with expert laity ([60](#_ENREF_60)), experiential expertise ([61](#_ENREF_61)) and positive contributions to research, e.g., acquisition of new skills, knowledge and experience ([60](#_ENREF_60)). The GRIPP checklist for reporting the practice of PPI ([62](#_ENREF_62)) is another valuable addition and, indeed, there are similar findings across our two studies. However, the additional contribution this review makes is its focus on analysing current *practice* to understand *implementation* of SUI in health research and health services development, and to make recommendations that will improve practice and the chances of *normalisation.* Our use of NPT was appropriate for these aims. It helped us to ‘think through’ complex data and inter-related macro, meso and micro level issues because we could organise them conceptually under NPT’s four constructs which enhances understanding ([28](#_ENREF_28)).

***Directions for Future Research and Practice***

It would be valuable to seek answers to the questions of definition, enrolment, enactment and appraisal by prospectively conducting multi-perspectival fieldwork with stakeholders about their work together in specific projects. This would be a very effective way to explore shared and differential perspectives. We also recommend that primary care researchers publish an explicit account of their working definition of ‘service user involvement’, the process by which that was determined (i.e., whether it was in consultation with other stakeholders or not), and an explanation of their choice of methods in relation to that definition. Effectively, this practice should become part of the repertoire of practice and reporting procedures by researchers engaged in the field of service user involvement to augment the evidence base, encourage more methodological innovation and enable robust appraisals of work that is undertaken ([48](#_ENREF_48), [62](#_ENREF_62)).

**Conclusion**

Following Normalization Process Theory, the likelihood that service user involvement becomes a routine and normalised way of working in healthcare settings relies on the four problems of definition, enrolment, enactment and appraisal being resolved. It is necessary to encourage explicit reporting of definitions employed, methodological innovation to enhance co-governance, and dissemination of research processes as well as findings. This will augment the evidence base about current practice and improve normalisation of meaningful involvement.

**Word count excluding abstract and tables 4,565 (word limit 5000)**

**References**

1. Department of Health. Patient and public involvement in the NHS London: UK Department of Health1999.

2. Charles C, DeMaio S. Lay participation in health care decision-making: a conceptual framework. Journal of Health Politics, Policy and Law 1993;18(4):881-904.

3. Department of Health. Involving patients and the public in healthcare: response to the listening exercise. London: UK Department of Health2001.

4. Health Canada. Health Canada Toolkit for public involvement in decision making: Department of Health Ottowa Canada2000.

5. Neuwelt PM. Community participation in primary care: what does it mean 'in practice'? Journal of Primary Health Care. 2012;4(1):30-8.

6. HSE, DoHC. Strategy for service user involvement in the Irish Health Service 2008-2013. Dublin, Ireland: Health Services Executive and Department of Health and Children2008.

7. Gibson A, Britten N, Lynch J. Theoretical Directions for an Emancipatory Concept of Patient and Public Involvement. Health. 2012;16(5):531-47.

8. McEvoy R, Keenaghan C, Murray A. Service User Involvement in the Irish Health Service: A Review of Evidence. Dublin: Department of Health and Children and Health Service Executive2008.

9. Brett J, Staniszewska S, Mockford C, Seers K, Herron-Marx Sa, Bayliss H. The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research: Royal College of Nursing Research Institute (RCNRI)2010.

10. Arnstein SR. A Ladder Of Citizen Participation. Journal of the American Institute of Planners. 1969;35(4):216-24.

11. Buckland SH. Public Information Pack (PIP): How to get actively involved in NHS, public health and social care research. Eastleigh: INVOLVE2007.

12. Gallivan J, K. Kovacs Burns, Bellows M, Eigenseher C. The many faces of patient engagement. The Journal of Participatory Medicine Research. 2012;4(e32).

13. Brophy S. "Personal excellence" as a value for health professionals: a patient's perspective. International Journal of Health Care Quality Assurance Incorporating Leadership in Health Services. 2006;19(4-5):373-83.

14. WHO. Primary Health Care. Report of the international conference on primary health care. Geneva WHO1978.

15. Flynn J. People, Poverty and Participation. Dublin, Ireland: Combat Poverty Agency2009

16. Morrison C, Dearden A. Beyond tokenistic participation: Using representation artefacts to enable meaningful public participation in healthservice design. Health Policy. 2013;112(3):179-86.

17. Jagosh J, Macaulay AC, Pluye P, Salsberg JON, Bush PL, Henderson JIM, et al. Uncovering the benefits of participatory research: Implications of a realist review for health research and practice. Milbank Quarterly. 2012;90(2):311-46.

18. Bryant L, Beckett J. The Practicality and Acceptability of an Advocay Service in the Emergency Department for People Attending Following Self-Harm. Academic Unit of Psychiatry: University of Leeds, Leeds2006.

19. Boote J, Baird W, Beecroft C. Public involvement at the design stage of primary health research: A narrative review of case examples. Health Policy. 2010;95(1):10-23.

20. Faulkner A. Beyond our Expectations: A Report of the Experiences of Involving Service Users in Forensic Mental Health Research, National Programme on Forensic Mental Health R&D. London: Department of Health2006

21. Faulkner A. Changing Our Worlds: Examples of User-Controlled Research in Action. Eastleigh: INVOLVE2010

22. Abma TA, Broerse JEW. Patient participation as dialogue: setting research agendas. Health Expectations. 2010;13(2):160-73.

23. Macaulay AC, Commanda, L.E., Freeman, W.L., Gibson, N., McCbem, M.L., Robbins, C.M., & Twohig, P.L. for the north American Primary Care Research group Participatory research maximises community and lay involvement. BMJ 1999;319:774-8.

24. Beresford P. User Involvement in Research and Evaluation: Liberation or Regulation? Social Policy and Society. 2002;1(02):95-105.

25. Rhodes P, Nocon, A., Booth, M., Chowdrey, M.Y., Fabian, A., Lambert, N. Mohamed, F. & Walgrove, T. A service users’ research advisory group from the perspectives of both users and researchers. Health and Social Care in the Community. 2002;10:402-9.

26. Cotterell P, Harlow G, Morris C, Beresford P, Hanley B, Sargeant A, et al. Service user involvement in cancer care: the impact on service users. Health Expectations. 2011 Jun;14(2):159-69.

27. May C, Finch T. Implementing, embedding, and integrating practices: An outline of Normalization Process Theory. Sociology. 2009;43(3):535-54.

28. McEvoy R, Ballini L, Maltoni S, O'Donnell C, Mair F, MacFarlane A. A qualitative systematic review of studies using the normalization process theory to research implementation processes. Implementation Science. 2014;9(1):2.

29. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. BMC medical research methodology. 2006;6:35.

30. Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: Reviewing disparate data systematically. Qual Health Res. 2002 November 1, 2002;12(9):1284-99.

31. Jadad AR, Moore RA, Carroll D, Jenkinson C, Reynolds DJM, Gavaghan DJ, et al. Assessing the quality of reports of randomized clinical trials: Is blinding necessary? Controlled Clinical Trials. 1996;17(1):1-12.

32. Wright D, Foster C, Amir Z, Elliott J, Wilson R. Critical appraisal guidelines for assessing the quality and impact of user involvement in research. Health Expectations. 2010;13(4):359-68.

33. Alexander IM. Emancipatory actions displayed by multi-ethnic women: 'Regaining control of my health care' Journal of the American Academy of Nurse Practitioners. 2010;22(11):602-11.

34. Box G. Patient participation groups: the national picture. Quality in Primary Care. 2009;17(4):291-7.

35. Frank C, Asp M, Fridlund B, Baigi A. Questionnaire for patient participation in emergency departments: development and psychometric testing. Journal of Advanced Nursing. 2011;67(3):643-51.

36. Loh A, Leonhart R, Wills CE, Simon D, Härter M. The impact of patient participation on adherence and clinical outcome in primary care of depression. Patient Education & Counseling. 2007;65(1):69-78.

37. McEvoy R, MacFarlane A. Community participation in primary care in Ireland: the need for implementation research. Primary Health Care Research & Development 2012;14(2):126-30.

38. Radermacher H, Sonn C, Keys C, Duckett P. Disability and participation: It's about us but still without us! Journal of Community & Applied Social Psychology. 2010;20(5):333-46.

39. Koelewijn-van Loon MS, van der Weijden T, Ronda G, van Steenkiste B, Winkens B, Elwyn G, et al. Improving lifestyle and risk perception through patient involvement in nurse-led cardiovascular risk management: A cluster-randomized controlled trial in primary care. Preventive Medicine. 2010;50(1–2):35-44.

40. O'Reilly F, Reaper E, Redmond T. "We're people too." Views of drugs users on health services. Dublin: UISCE, Mountjoy Street Family Practice, Participation and Practice of Rights Project2005.

41. Heidemann ITSB, Almeida MCP. Friere's dialogic concept enables family health program teams to incorporate health promotion. Public Health Nursing. 2011;28(2):159-67.

42. Hodges L, Butcher I, Kleiboer A, McHugh G, Murray G, Walker J, et al. Patient and general practitioner preferences for the treatment of depression in patients with cancer: How, who, and where? Journal of Psychosomatic Research. 2009;67(5):399-402.

43. Iliffe S, Kharicha K, Harari D, Swift C, Goodman C, Manthorpe J. User involvement in the development of a health promotion technology for older people: findings from the SWISH project. Health Soc Care Comm. 2010;18(2):147-59.

44. de Brun T, Du Vivier E. Own Goals and Penalties: a Study of the Needs of Socially-excluded Males in Dublin Inner City Dublin Inner City Partnership and Dublin City Council2008.

45. Emmett CL, Murphy DJ, Patel RR, Fahey T, Jones C, Ricketts IW, et al. Decision-making about mode of delivery after previous caesarean section: development and piloting of two computer-based decision aids. Health Expectations. 2007;10(2):161-72.

46. Goodrich D, Buis L, Janney A, Ditty M, Krause C, Zheng K, et al. Integrating an internet-mediated walking program into family medicine clinical practice: a pilot feasibility study. BMC Medical Informatics and Decision Making. 2011;11(1):47.

47. Peconi J, Snooks H, Edwards A. Thematic Research network for emergency and UnScheduled Treatment (TRUST): scoping the potential. BMC Emergency Medicine. 2008;8(1):2.

48. Beard TC, Redmond SR. Declaration of Alma-Ata. The Lancet. 1979;313(8109):217-8.

49. Kuosmanen L, Jakobsson T, Hyttinen J, Koivunen M, VÃ¤limÃ¤ki M. Usability evaluation of a web-based patient information system for individuals with severe mental health problems. Journal of Advanced Nursing.66(12):2701-10.

50. Lindenmeyer A, Hearnshaw H, Sturt J, Ormerod R, Aitchison G. Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: a qualitative case study. Health Expectations. [Article]. 2007;10(3):268-77.

51. Linnell S, James S. Involving men in targeted primary health care: men's health MOTs. Community Practitioner. 2010;83(5):31-4.

52. Lowes L, Robling MR, Bennert K, Crawley C, Hambly H, Hawthorne K, et al. Involving lay and professional stakeholders in the development of a research intervention for the DEPICTED Study. Health Expectations. 2011 Sep;14(3):250-60.

53. Shipman C, Hotopf M, Richardson A, Murray S, Koffman J, Harding R, et al. The views of patients with advanced cancer regarding participation in serial questionnaire studies. Palliative Medicine. 2008 December 1, 2008;22(8):913-20.

54. Lowes L, Robling MR, Bennert K, Crawley C, Hambly H, Hawthorne K, et al. Involving lay and professional stakeholders in the development of a research intervention for the DEPICTED Study. Health Expectations.14(3):250-60.

55. MacFarlane A, Dzebisova Z, Karapish D, Kovacevic B, Ogbebor F, Okonkwo E. Arranging and negotiating the use of informal interpreters in general practice consultations: Experiences of refugees and asylum seekers in the west of Ireland. Soc Sci Med. 2009;69(2):210-4.

56. Slade SC, Molloy E, Keating JL. `Listen to me, tell me': a qualitative study of partnership in care for people with non-specific chronic low back pain. Clinical Rehabilitation. 2009 March 1, 2009;23(3):270-80.

57. Johnson MRD. Engaging communities and users. In: Nazaroo JYE, editor. Health and Social Research in Multiethnic Societies. London: Routledge; 2006.

58. Feldman A, Frese C, Yousif T. Research Development and Critical Interculturalism: A Study on the Participation of Refugees and Asylum Seekers in Research and Development Based Initiatives. Dublin: Social Science Research Centre, University College Dublin2002.

59. Kennedy P, deBrun T, O'ReillydeBrun M, MacFarlane A. An exploration of evidence-based policy in Ireland: health and social inclusion. Evidence and Policy: A Journal of Research, Debate and Practice. 2010;6(2):255-68.

60. Gillard S, Simons L, Turner K, Lucock M, Edwards C. Patient and public involvement in the coproduction of knowledge reflection on the analysis of qualitative data in a mental health study. Qual Health Res. 2012;22(8):1126-37.

61. Thompson J, Bissell P, Cooper C, Armitage CJa, Barber R. Credibility and the ‘professionalized’ lay expert: Reflections on the dilemmas and opportunities of public involvement in health research. Health 2012;16(602):1-17.

62. Staniszewska S, Brett J, Mockford C, R. B. The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. International Journal Technol Assess Health Care. 2011;27(4).

63. Noblit GW, Hare RD. Meta-ethnography: Synthesizing Qualitative Studies: Sage Publications; 1988.

64. Britten N, Campbell R, Pope C, Donovan J, Morgan M, Pill R. Using meta ethnography to synthesise qualitative research: a worked example. J Health Serv Res Policy 2002;7(4):209-15.

65. Malpass A, Shaw A, Sharp D, Walter F, Feder G, Ridd M, et al. “Medication career” or “Moral career”? The two sides of managing antidepressants: A meta-ethnography of patients' experience of antidepressants. Soc Sci Med. 2009;68(1):154-68.

66. Ross S, Barton J, Read J. Staff in-service training on post-stroke psychological and communication issues. International Journal of Therapy & Rehabilitation. 2009;16(6):342-9.

67. Richardson J, Letts L, Chan D, Stratford P, Hand C, Price D, et al. Rehabilitation in a primary care setting for persons with chronic illness – a randomized controlled trial. Primary Health Care Research & Development. 2010;11(04):382-95.

68. Sullivan-Marx EM, Mangione KK, Ackerson T, Sidorov I, Maislin G, Volpe SL, et al. Recruitment and retention strategies among older african american women enrolled in an exercise study at a PACE program. The Gerontologist. 2011 June 1, 2011;51(suppl 1):S73-S81.

69. Holland R, Brooksby I, Lenaghan E, Ashton K, Hay L, Smith R, et al. Effectiveness of visits from community pharmacists for patients with heart failure: HeartMed randomised controlled trial. BMJ. 2007 2007-05-24 00:00:00;334(7603):1098.

70. Frank C, Asp M, Dahlberg K. Patient participation in emergency care–A phenomenographic study based on patients’ lived experience. International emergency nursing. 2009;17(1):15-22.

**Box 1: Terminology: Service User Involvement**

In this paper we employ the term Service User Involvement (SUI) because this is the terminology employed by the Health Service Executive (HSE) in Ireland in its Strategy for Service User Involvement 2008 ([6](#_ENREF_6)), and the research reported here is designed to inform our national policy context as well as informing international debates. In the Irish context, the term SUI refers to ‘a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ ([3](#_ENREF_3), [6](#_ENREF_6)). The term SUI was chosen from a variety of options (e.g., engagement, public participation and community participation)([4](#_ENREF_4), [5](#_ENREF_5), [8](#_ENREF_8)) as a workable rather than ‘perfect’ definition.

 **Table 1: SUI and Normalization process Theory (NPT)(**[**27**](#_ENREF_27)**)**

|  |  |  |
| --- | --- | --- |
| **Question re SUI**  | **Problems in the practice of SUI** | **NPT construct** |
| How is service user involvement defined?  | Definition  | Coherence  |
| Why do stakeholders get involved?  | Enrolment  | Cognitive Participation  |
| What methods are used? | Enactment  | Collective Action  |
| What are the outcomes? | Appraisal  | Reflexive Monitoring  |

**Table 2: Sample of 26 papers included in the critical review categorised by six sampling parameters**

|  |
| --- |
| n=8 - SUI studies explicitly reporting experience of ‘doing service user involvement’ and/or studies that demonstrate high-level involvement using participatory methodologies.  |
| n=3 - Qualitative and quantitative health services research (HSR) studies that focus on the perspective or experiences of service users, with more of an emphasis than other HSR studies on reporting outcomes or actions taken as a result of their input.  |
| n=5 - Qualitative and quantitative health services research studies on the theme of SUI and/or patient participation. |
| n=2 - Studies with a focus on shared decision-making, including studies that analyse patient/practitioner consultations in which there is shared decision-making. |
| n=4 - Randomised controlled trials where the intervention component has some evidence of patient involvement, e.g., learning skills for self-management, participation in mentoring or coaching. |
| n=4 - Irish papers (including grey literature) focusing on user involvement in primary care in the Irish context, as recommended by our research team to ensure our review (a) had relevance to the national policy context and (b) was inclusive of studies with participatory methodologies, which were under-represented at one point in the sampling process.  |

**Box 2: Our working definition of 1st, 2nd and 3rd order constructs (drawing on work of** [**63-65**](#_ENREF_63)**)**

|  |  |  |
| --- | --- | --- |
| First order constructs  | Information extracted during the critical appraisal process of reviewing the evidence in the literature for Service User Involvement in Primary Care Research and Health Service Development. | Interpretations of what the literature tells us about Service User Involvement in Primary Care Research and Health Service Development. |
| Second order constructs | Interpretation and collation of themes from 1st order constructs. | Interpretations of interpretations of what the literature tells us about Service User Involvement in Primary Care Research and Health Service Development. |
| Third order constructs  | The views and interpretation of the synthesis team expressed in terms of themes and key concepts and mapped onto four NPT constructs | Interpretations of interpretations of interpretations of what the literature tells us about Service User Involvement in Primary Care Research and Health Service Development. |

**Table 3: Translation to inform 1st order, 2nd order and 3rd order constructs and their arrangement in temporal sequence**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **First order constructs informed by CAT Wright et al.** | **Studies**  | **Second order constructs – emergent inductive themes**  | **Studies** | **Third order constructs following NPT (**[**27**](#_ENREF_27)**) May and Finch 2009**  | **Studies** (References in bold indicate quantitative papers) |
| **1. Socio-political context or drivers**  | ([52](#_ENREF_52)) ([33](#_ENREF_33), [49](#_ENREF_49), [66](#_ENREF_66)) **(**[**34**](#_ENREF_34)**,** [**50**](#_ENREF_50)**)** **(**[**36**](#_ENREF_36)**,** [**39**](#_ENREF_39)**) (**[**67**](#_ENREF_67)**)** ([42](#_ENREF_42)) **(**[**35**](#_ENREF_35)**)** ([41](#_ENREF_41)) ([68](#_ENREF_68)) ([47](#_ENREF_47)) ([46](#_ENREF_46)) ([45](#_ENREF_45), [53](#_ENREF_53)) ([69](#_ENREF_69)) ([38](#_ENREF_38), [56](#_ENREF_56))  | **1.Control and Power**  | ([33-35](#_ENREF_33), [41](#_ENREF_41), [45](#_ENREF_45), [46](#_ENREF_46)) **(**[**38**](#_ENREF_38)**,** [**43**](#_ENREF_43)**,** [**50**](#_ENREF_50)**,** [**52**](#_ENREF_52)**,** [**69**](#_ENREF_69)**)** ([56](#_ENREF_56), [68](#_ENREF_68)) ([37](#_ENREF_37), [40](#_ENREF_40), [44](#_ENREF_44), [55](#_ENREF_55)) | **1.Definition**  | 40, 41, 42, 43, 44, 4555, 50([33](#_ENREF_33), [34](#_ENREF_34), [70](#_ENREF_70)) **(**[**36**](#_ENREF_36)**)** ([37](#_ENREF_37)) ([38](#_ENREF_38)) ([51](#_ENREF_51)) ([43](#_ENREF_43)) |
| 2. **Definition of service user involvement** | **(**[**35**](#_ENREF_35)**) (**[**34**](#_ENREF_34)**,** [**36**](#_ENREF_36)**,** [**38**](#_ENREF_38)**)** | **2. Dialogue and communication** | ([33](#_ENREF_33), [41](#_ENREF_41), [45](#_ENREF_45)) ([39](#_ENREF_39), [43](#_ENREF_43), [69](#_ENREF_69)) **(**[**36**](#_ENREF_36)**,** [**49-53**](#_ENREF_49)**,** [**56**](#_ENREF_56)**,** [**66-68**](#_ENREF_66)**)**  | **2. Enrolment**  | **(**[**39**](#_ENREF_39)**)** ([40](#_ENREF_40), [41](#_ENREF_41)) ([42](#_ENREF_42)) ([43](#_ENREF_43), [44](#_ENREF_44)) ([46](#_ENREF_46)) ([47](#_ENREF_47)) |
| 3. **Level of SUI** | ([33](#_ENREF_33), [49](#_ENREF_49), [52](#_ENREF_52), [66](#_ENREF_66))([42](#_ENREF_42)) **(**[**34**](#_ENREF_34)**,** [**36**](#_ENREF_36)**,** [**39**](#_ENREF_39)**,** [**50**](#_ENREF_50)**,** [**67**](#_ENREF_67)**,** [**68**](#_ENREF_68)**)** ([47](#_ENREF_47)) ([46](#_ENREF_46)) ([45](#_ENREF_45), [53](#_ENREF_53)) ([69](#_ENREF_69))([56](#_ENREF_56)) ([38](#_ENREF_38))  | **3. Ethical Practice** | ([33](#_ENREF_33), [35](#_ENREF_35), [41](#_ENREF_41), [45](#_ENREF_45)) ([42](#_ENREF_42)) **(**[**39**](#_ENREF_39)**,** [**43**](#_ENREF_43)**,** [**69**](#_ENREF_69)**)** *(*[*36*](#_ENREF_36)*,* [*49-53*](#_ENREF_49)*,* [*56*](#_ENREF_56)*,* [*67*](#_ENREF_67)*,* [*68*](#_ENREF_68)*)*  | **3. Enactment**  | ([33](#_ENREF_33), [52](#_ENREF_52)) ([47](#_ENREF_47)) **(**[**35**](#_ENREF_35)**)** ([43](#_ENREF_43), [45](#_ENREF_45)) ([47](#_ENREF_47), [50](#_ENREF_50), [51](#_ENREF_51)) **(**[**49**](#_ENREF_49)**,** [**52**](#_ENREF_52)**,** [**53**](#_ENREF_53)**)** ([40](#_ENREF_40)) ([41](#_ENREF_41), [44](#_ENREF_44)) ([50](#_ENREF_50)) ([36](#_ENREF_36), [55](#_ENREF_55))([42](#_ENREF_42)) ([45](#_ENREF_45)) **(**[**39**](#_ENREF_39)**)**  |
| **4. Recruitment** | ([33](#_ENREF_33), [41](#_ENREF_41), [49](#_ENREF_49), [52](#_ENREF_52), [66](#_ENREF_66)) **(**[**35**](#_ENREF_35)**)** ([42](#_ENREF_42)) **(**[**39**](#_ENREF_39)**,** [**67**](#_ENREF_67)**) (**[**36**](#_ENREF_36)**)** ([34](#_ENREF_34), [50](#_ENREF_50), [68](#_ENREF_68)) ([47](#_ENREF_47)) ([46](#_ENREF_46)) ([53](#_ENREF_53)) ([45](#_ENREF_45)) ([69](#_ENREF_69)) ([56](#_ENREF_56)) ([38](#_ENREF_38))  | **4. Methods** | ([33-35](#_ENREF_33), [41](#_ENREF_41), [45](#_ENREF_45), [46](#_ENREF_46)) ([42](#_ENREF_42)) **(**[**39**](#_ENREF_39)**,** [**43**](#_ENREF_43)**,** [**69**](#_ENREF_69)**) (**[**36**](#_ENREF_36)**,** [**47**](#_ENREF_47)**,** [**49-52**](#_ENREF_49)**)** ([38](#_ENREF_38)) **(**[**67**](#_ENREF_67)**)** ([53](#_ENREF_53), [56](#_ENREF_56), [66](#_ENREF_66)) ([68](#_ENREF_68))  | **4. Appraisal**  | ([33](#_ENREF_33), [43](#_ENREF_43), [51](#_ENREF_51), [52](#_ENREF_52)) ([47](#_ENREF_47)) ([33](#_ENREF_33), [50](#_ENREF_50), [52](#_ENREF_52)) ([56](#_ENREF_56)) ([38](#_ENREF_38), [40](#_ENREF_40))  |
| **5. Training** | ([39](#_ENREF_39), [66](#_ENREF_66))([50](#_ENREF_50)) ([69](#_ENREF_69))  | **5. Partnership and Collaboration**Data for this construct was extracted from Theme 1 Socio-political context or driversTheme 2 DefinitionTheme 3 Level of SUI | ([33](#_ENREF_33), [34](#_ENREF_34))([35](#_ENREF_35), [41](#_ENREF_41), [45](#_ENREF_45), [46](#_ENREF_46)) ([42](#_ENREF_42)) **(**[**39**](#_ENREF_39)**,** [**43**](#_ENREF_43)**,** [**69**](#_ENREF_69)**)** ([36](#_ENREF_36), [47](#_ENREF_47), [50-52](#_ENREF_50))([38](#_ENREF_38)) **(**[**67**](#_ENREF_67)**)** ([56](#_ENREF_56), [68](#_ENREF_68)) ([44](#_ENREF_44)) ([37](#_ENREF_37), [40](#_ENREF_40), [55](#_ENREF_55)) |  |  |
| **6. Ethics** | ([33](#_ENREF_33), [49](#_ENREF_49), [52](#_ENREF_52))([35](#_ENREF_35), [41](#_ENREF_41))([42](#_ENREF_42)) ([67](#_ENREF_67)) **(**[**39**](#_ENREF_39)**) (**[**36**](#_ENREF_36)**,** [**46**](#_ENREF_46)**,** [**50**](#_ENREF_50)**,** [**68**](#_ENREF_68)**)** ([45](#_ENREF_45), [53](#_ENREF_53)) ([69](#_ENREF_69)) ([56](#_ENREF_56))  | **6. Roles and Responsibilities** | ([33](#_ENREF_33)) **(**[**34**](#_ENREF_34)**,** [**35**](#_ENREF_35)**,** [**41**](#_ENREF_41)**,** [**45**](#_ENREF_45)**,** [**46**](#_ENREF_46)**)** ([42](#_ENREF_42)) **(**[**39**](#_ENREF_39)**,** [**43**](#_ENREF_43)**,** [**69**](#_ENREF_69)**) (**[**49**](#_ENREF_49)**)** ([38](#_ENREF_38), [47](#_ENREF_47), [50-52](#_ENREF_50)) ([56](#_ENREF_56), [66](#_ENREF_66)) ([68](#_ENREF_68)) ([44](#_ENREF_44)) ([37](#_ENREF_37), [55](#_ENREF_55)) ([40](#_ENREF_40)) |  |  |
| 7**.Methodological considerations** | ([33](#_ENREF_33), [49](#_ENREF_49), [52](#_ENREF_52))([35](#_ENREF_35), [41](#_ENREF_41))([42](#_ENREF_42)) **(**[**67**](#_ENREF_67)**) (**[**36**](#_ENREF_36)**,** [**39**](#_ENREF_39)**,** [**50**](#_ENREF_50)**)** **(**[**34**](#_ENREF_34)**,** [**68**](#_ENREF_68)**)** ([47](#_ENREF_47)) ([46](#_ENREF_46), [53](#_ENREF_53)) ([45](#_ENREF_45)) ([69](#_ENREF_69)) ([56](#_ENREF_56)) ([38](#_ENREF_38))  | **7. \*\*Standard practice** | ([33](#_ENREF_33), [35](#_ENREF_35), [41](#_ENREF_41), [45](#_ENREF_45), [46](#_ENREF_46)) ([39](#_ENREF_39), [42](#_ENREF_42), [43](#_ENREF_43), [69](#_ENREF_69)) **(**[**49**](#_ENREF_49)**)** ([36](#_ENREF_36), [50](#_ENREF_50), [51](#_ENREF_51))([52](#_ENREF_52), [67](#_ENREF_67))([53](#_ENREF_53), [66](#_ENREF_66)) ([56](#_ENREF_56)) |  |  |
| **8. Dissemination** |  | **8. Other** | **(**[**34**](#_ENREF_34)**,** [**35**](#_ENREF_35)**,** [**41**](#_ENREF_41)**,** [**45**](#_ENREF_45)**,** [**46**](#_ENREF_46)**)** **(**[**39**](#_ENREF_39)**,** [**43**](#_ENREF_43)**,** [**69**](#_ENREF_69)**) (**[**49**](#_ENREF_49)**)** ([36](#_ENREF_36), [50](#_ENREF_50), [51](#_ENREF_51))([47](#_ENREF_47), [52](#_ENREF_52)) ([38](#_ENREF_38)) **(**[**67**](#_ENREF_67)**)** ([66](#_ENREF_66)) ([53](#_ENREF_53)) ([56](#_ENREF_56), [68](#_ENREF_68))  |  |  |
| **9. Impact of SUI** | ([33](#_ENREF_33), [49](#_ENREF_49), [52](#_ENREF_52))([35](#_ENREF_35), [41](#_ENREF_41))([42](#_ENREF_42)) **(**[**67**](#_ENREF_67)**)** ([36](#_ENREF_36), [39](#_ENREF_39), [50](#_ENREF_50)) **(**[**34**](#_ENREF_34)**)**([68](#_ENREF_68)) ([47](#_ENREF_47)) ([46](#_ENREF_46)) ([53](#_ENREF_53)) ([45](#_ENREF_45)) ([69](#_ENREF_69)) ([56](#_ENREF_56)) ([38](#_ENREF_38))  |  |  |  |  |
| 10.  **Evaluation of SUI** | ([52](#_ENREF_52), [66](#_ENREF_66)) ([33](#_ENREF_33), [49](#_ENREF_49))([41](#_ENREF_41)) **(**[**35**](#_ENREF_35)**)** ([42](#_ENREF_42)) **(**[**67**](#_ENREF_67)**) (**[**39**](#_ENREF_39)**) (**[**36**](#_ENREF_36)**,** [**50**](#_ENREF_50)**)**  |  |  |  |  |
| **11. Other**  | ([47](#_ENREF_47), [68](#_ENREF_68)) ([46](#_ENREF_46)) ([53](#_ENREF_53)) ([45](#_ENREF_45)) ([69](#_ENREF_69)) ([56](#_ENREF_56)) ([38](#_ENREF_38))  |  |  |  |  |

**Table 4: Description of 2nd order constructs - Partnership and Collaboration, Roles and Responsibilities, and Control and Power – informing the 3rd order constructs**

|  |  |
| --- | --- |
| **Theme name** | **Theme content** |
| **Partnership and Collaboration**Subthemes * Collaboration in healthcare delivery
* Collaboration in clinical consultation
* Collaboration in research
 | The data in this theme relate to partnerships and collaborations for research and healthcare projects. Data refer to the working relationship and style of working involved in partnerships and collaborations. Data also refer to working in a specialised way or with specialised roles within partnerships and collaborations. The data in this theme relate to where collaboration has happened and there is evidence of what happens when collaboration and partnership is in place. Data that describe partnership with service providers, partnership between systems (socio-political systems, health systems), communities and individuals were also included here. Data were included if they describe system-level changes that are required for partnership and collaboration to occur. |
| **Roles and Responsibilities**Subthemes* Diverse research roles
* The ‘expert patient’ role
* Roles in clinical interventions
 | The data in this theme refer to particular roles or responsibilities that were defined and described in the research paper. The focus is on actions and interactions by stakeholders in the research. These data relate more specifically to practice rather than rhetoric.  |
| **Control and Power**Subthemes* The rhetoric of SUI
* Issues of equity and human rights
* Empowering research methods
 | Data coded in this theme refer to issues of service user control, or lack of, in healthcare settings or healthcare research. Emancipatory methods used in research studies or in clinical collaborations to readdress the balance of power are described. The process and implications of rebalancing power and regaining power are also discussed. Data also include references to equality in healthcare relationships and the levers and barriers to equity. The role that research can play in this power dynamic is more explicitly discussed. Examples include data where research brings about changed mindsets, surrenders power, or realigns control and power in relationships.  |

**Figure Legend**

Figure 1: Sampling and selection process for papers included in the critical review