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# Accessing participatory research impact and legacy: developing the evidence base for participatory approaches in health research

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## ABSTRACT

Action research has been characterised as systematic enquiry into practice, undertaken by those involved, with the aim changing and improving that practice: an approach designed to have impact. Whilst much has been written about the process and practice of 'researching', historically 'impact' has been somewhat taken for granted. In recent years, however, the impact of all forms of research has become the focus of interest with many funding bodies now demanding that researchers not only articulate the prospective impact of their work, but what kinds of evidence will be proffered to demonstrate that impact. This has raised questions for action researchers, not about whether their work has an impact, but what form that impact takes, how it is recognised and by whom. This paper focuses on difficulties researchers find in both articulating the impact of participatory research and demonstrating links between such forms of research and impact. We draw on discussions about the notion of impact with authors that have self-reported and published their work as participatory. These discussions revealed that not only were there difficulties in clarifying the participatory dimension of their research but that whilst authors were able to discuss particular impacts of their work, articulating and evidencing that impact was often absent from their published papers. This paper offers insights into some of issues and barriers those who undertake participatory research face in explicating, for the external audience (and indeed sometimes for ourselves), the impact of this action-based form of enquiry.

## Background

In recent years there has been a move towards recognising the importance of more participatory approaches to health research that include the views of those whose work or lives are the focus of research. In many countries throughout the world, the participation of relevant stakeholders, such as patients and the public, in the co-creation of knowledge, is central to health research policy. In the UK, for example, the National Institute for Health Research (NIHR) states that, 'involving patients and members of the public in research can lead to better research, clearer outcomes, and faster uptake of new evidence' (NIHR accessed 4 April 2016). In Australia, the shared vision of the National Health and Medical Research Council (NH&MRC) and the Consumers Health Forum of Australia is for, 'consumers and researchers [to work] in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind' (NH&MRC Accessed 4 April 2016). In Canada, the Canadian Institutes of Health Research (CIHR) has established a Framework for Citizen Engagement, recognising that there is a desire to 'develop tools that will

assist all of the funding agencies to engage the public effectively' (CIHR Accessed 4 April 2016). In the USA, the National Institute of Health (NIH) has established a Council of Public Representatives which advises the NIH Director on issues related to public participation in NIH activities, outreach efforts, and other matters of public interest (NIH Accessed April 2016). In addition, the Patient Protection and Affordable Care Act states that the Patient-Centred Outcomes Research Institute will have public representatives on the Board, as well as on expert advisory panels, which will identify research priorities and establish a shared research agenda for outcomes research in the USA (<https://www.dpc.senate.gov/healthreformbill/healthbill04.pdf> Accessed 4 April 2016). In the UK, the policy objective of the NIHR to engage the public and patients in the research process, termed Patient and Public Involvement (PPI) was first predominantly understood as a consultation approach with key drivers being improved recruitment into studies and improved dissemination (NIHR Accessed 4 April 2016). INVOLVE, the organisation funded by the NIHR to support involvement in NHS presents a broader understanding of the process of involvement:

research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants (INVOLVE <https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2>).

This more embedded notion of involvement, known as public involvement (PI), is part of the continuum of more engaged approaches to research that seek to make changes, particular with those whose voices are seldom heard and could also include participatory research approaches.

The word participation can be applied to a broad range of engagement processes, from research that might involve the public merely as part of a research steering committee, or commenting on the content of a questionnaire, to approaches where the creation of and meaning making from research is initiated and led by those who would be directly affected by the study (Martin 2008; Tritter 2009). There is, however, a conceptually more radical form of participatory research, termed variously, but not exclusively, as community-based participatory research (CBPR), participatory health research (PHR) and participatory action research (PAR).<sup>1</sup> The fundamental difference between such participatory research (PR)<sup>2</sup> approaches and PI being that PI, whilst seeking engagement, is generally driven from an external, professional, standpoint with the purposes of enhancing current notions of science through engagement. Such research would not be termed 'participatory' as it does not have participation as its starting point for the research. Participatory research would, however, come under the umbrella of PI.

The underlying principles of PR involve a disruption to traditional notions of research as framed by distanced experts, those with research expertise but not embodied knowledge, embodied because it creates and depends on the specific circumstances of peoples' lived experiences (Liamputtong 2014, 324) and has, as the primary aim, the maximisation of the participation of those whose life or work is the subject of the research in all stages of the research process. The origins of this more radical approach are complex but its beginnings are closely connected with a critique of the raised positioning of objective, distanced expertise as a value base for mainline social sciences (Blumer 1969). Those engaged in PR are part of a shared engagement that brings them together in reflexive thinking and deliberation as part of a co-construction process. It is an approach to research that seeks to understand the world by trying to change it through collaborative and systematic reflection, 'communities of inquiry and action evolve and address questions and issues that are significant for those who participate as co-researchers' (Reason and Bradbury 2008, 1) PR approaches disturb the

way in which expertise is framed as an external product to recognising expertise and knowledge developed through experience.

This in turn necessitates a fundamental shift in the way research is designed, establishing the communicative discourse as central, rather than the implementation of method. Such approaches to research, described by Alfredo Molano in 1997 as the 'result of an atmosphere rarefied by the clash between clear-cut scientific explanations and a rough reality' (Swantz 2008, 31), work in very different ways from those supporting given processes for research.

### **The issue under consideration**

In tandem with the increased adoption of research approaches that move beyond collecting expert testimony to embedding the knowledge of those whose lives or work are the subject of the study as part of the research process, there has been an increased awareness of the need for applied research to go beyond being predominantly a tool for knowledge collection, i.e. for research to be more directly connected to a change process; to make a difference to communities; to have an impact. Widely discussed as the 'impact agenda' it can be seen across research funders in the UK (Research Council UK <https://www.rcuk.ac.uk/innovation/impacts>) as part of the periodic activity undertaken to assess the quality of research in universities in the United Kingdom known as the Research Excellence Framework (HEFCE et al. 2012) and in other English-speaking countries, for example within the work of the Patient- Centred Outcomes Research Institute (PCORI) an independent US non-profit, nongovernmental organisation authorised by Congress in 2010 (<https://www.pcori.org/about-us/what-we-do/what-drives-our-work>). Historically, loose connections have existed between research efforts and clinical practice (Haines and Donald 1998). Despite the considerable amount of money spent on clinical research as Bero et al. (1998) state, relatively little attention has been paid to ensuring that the findings of research are implemented in routine clinical practice. In recent years there has, however, been a focus on bridging the gap between what is known and action and implementation (research into practice) and, as Thomson (2015) suggests, action researchers might therefore

...be forgiven for thinking that, in this context, their moment in the sun had finally arrived. The idea that research might make a difference is integral to our field. However, this is not the case. The press for more 'useful' research has been accompanied by the elevation of particular research approaches (p 309).

Many authors/researchers have been turning their attention to the articulation of both the importance of capturing different forms of impact (Pain et al. 2016; Reed 2016), and pathways to recognising achieving that impact (Wallerstein et al. 2008; Cacari-Stone et al. 2014; Liamputtong 2014; Ramaswamy and Ozcan 2014; Greenhalgh et al. 2016) however, Greenhalgh and Fahy (2015), demonstrated how impact that occurs indirectly through non-linear mechanisms remains under-represented in published accounts of research evidence. The predominant routes whereby impact has traditionally been identified and the way it is measured, through metrics that track predetermined outcomes with specific time- frames for that measurement and articulation, does not fit well with certain types of changes we anticipate from participatory forms of research (Pain et al. 2016). As Greenhalgh and Fahy (2015) point out, whilst what they term 'co-creation models' have a high potential for societal impact, capturing the 'nonlinear chains and complex interdependencies of causation', necessitates a focus on processes as well as outcomes. In addition, there is currently a lack of clear criteria for what might be termed PR and what might be research that has strong

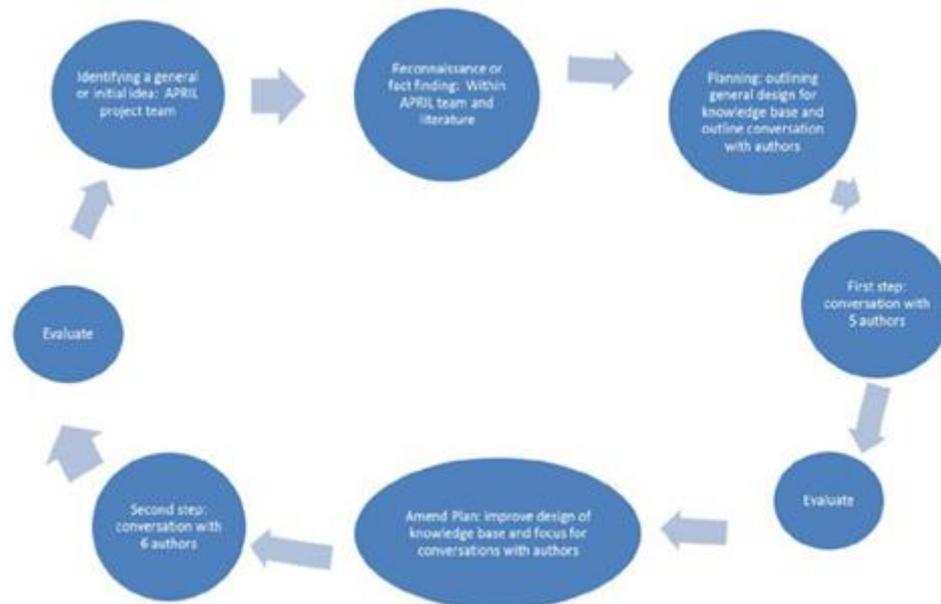
collaborations but where people participating in the research do not have central agency (PI). The wide and imprecise use of the term 'participatory' has led to difficulties in articulating expected impact from such research practices. It is rational to expect that research that has participatory practices at its centre is likely to have different types of impact on knowledge creation and learning compared with research where people/the public are asked to comment on aspects of research design. To date there has been no means of categorising research in a way that articulates both the depth of participatory practices and its relationship to possible impacts. The broader potential of learning, capacity and system change created through PR has not been systematically captured, acknowledged or valued (Trickett 2011; Cook 2012). This creates difficulties in relation to recognising linkages between participation and impact and building a body of knowledge to share and learn about impact.

This paper describes how a group of researchers and impact analysts, supported by IT specialists, set out to better understand how authors working in the participatory paradigm understood the notion of PR and its impact. The learning from conversations with 12 authors was used to develop an early prototype as the basis for progressing the shaping of an inter- active knowledgebase (IK) designed to both capture the participatory dimension of health research<sup>3</sup> and to develop understandings of the nature and impact of such approaches. The intention of this project was not to produce a hierarchy of participation, but to design a reflective framework for the variety of participatory engagements and associated impacts that could be used by researchers. The purpose of the IK was to act as an interactive space where researchers could lodge their research, articulating both the dimensions of participation, and its impact(s) for the following purposes: firstly, to enable researchers to locate research that was being termed participatory, secondly to have a clear view of what participation might look like in each case: thirdly, to illuminate impact and different forms of impact: fourthly, to provide the conditions to enable a future meta-analysis of whether and how different types of participation could be seen to have different effects on change mechanisms and impact, and finally, given that the IK would be populated by researchers themselves, its formation would be an ongoing opportunity for reflexive learning in relation to participation and impact by participatory researchers. It would also provide secondary data for the ongoing project of understanding whether the nature of participation in a project has an effect on outcomes and impact. The IK was not envisaged as a fixed entity designed by an external group of 'experts' but ultimately as a place formed and developed by those lodging their own work. The project received £30 000 funding from a joint initiative of Joint Information Systems Committee (JISC, an organisation set up by the Higher Education Funding bodies of England, Wales, Scotland and Northern Ireland to fund information technology investment in UK Universities), and the National Co-ordinating Centre for Public Engagement (NCCPE), funded by the four UK Funding Councils, Research Councils UK and the Wellcome Trust, to help inspire and support universities to engage with the public.

#### The project: accessing participatory research impact and legacy

The process of designing the prototype for an IK was developed through a set of conversations with a small group of authors. These were mainly based in the UK as we hoped to have direct conversations with as many authors as possible. The authors we approached had self-reported and published their work as being within the participatory paradigm. Exploring their work with them, discussing the nature of participation and impact, would be the central plank for shaping the prototype for the IK. The project was undertaken in four phases. The first phase was to establish the approach we might take to engaging with authors through sharing our own approaches and understandings amongst ourselves. Phase two involved direct discussions with six authors to reveal

more detail about where in the research process, and in what ways, they considered their research to be participatory, what the impact had been of the participatory process and where this had occurred. These discussions would provide data and frame the focus of our conversations more purposefully for phase three. Phase three involved conversations with a further set of six authors to evaluate, critique and develop the nascent framework for identifying the participatory profile and impact of projects as described by authors. Given the limited funding for the project, it was only feasible to work with 12 authors/papers in total.<sup>4</sup> Phase four was the designing of a prototype IK that could form the first step in beginning the process of creatively co-producing a fully interactive IK (Figure 1).



**Figure 1:** Design of APRIL project

**Table 1.** Prompts for articulating dimensions for participation.

co-option	token representatives are chosen but have no real input or power in the research process compliance outsiders decide the research agenda and direct the process, with tasks assigned to participants
consultation	local opinions are asked for, but outside researchers conduct the work and decide on a course of action
co-operation	local people work together with outside researchers to determine priorities, with responsibility remaining with outsiders for directing the process
co-learning	local people and outsiders share their knowledge in order to create new understanding and work together to form action plans, with outsiders providing facilitation
collective action	local people set their own agenda and mobilise to carry out research in the absence of outside initiators and facilitators

Phase one: the accessing participatory research impact and legacy (APRIL) team began by mining our own understandings of participatory approaches to research and impact as the basis for shaping our proposed conversations with authors. The rather unusual terms for the funding of the APRIL project meant that members of the team were established from a national database, constructed by the NCCPE, of those interested in impact but who had not all worked together before. The team had not, therefore, been founded on a set of shared perspectives and understandings and so had varying types of experience and expertise which included participatory researchers, public engagement specialists, impact analysts and experts in IT/information particularly in open sources platforms. Discussions of what we understood by participatory illuminated the very nature of how the term participatory is understood in a range of ways by researchers in general. These critical conversations

within the newly developed team provided the basis for shaping the conversations we were about to have with authors about dimensions for participatory engagement.

The initial conversations with the authors were to be open discursive narratives about their papers, with prompts to help authors clarify the work in respect of dimensions for participation (drawn from the work of Cornwall and Jewkes 1995 and Cornwall 2008) (See Table 1)

The team then began to source published papers that had reported health research as participatory in nature. This search can be characterised as an initial scoping search for papers where the authors had, in the writing of the paper, articulated that they were discussing a participatory approach. Papers were identified from the following:

- Invonet Bibliographies of Public Involvement in NHS, Public Health and Social Care Research (INVOLVE 2010)
- Patient and Public Involvement in Health and Social Care Research: A Bibliography (Boote 2011)
- Papers identified through the Realist Review for Health Research and Practice (Jagosh et al. 2012)
- Authors' local networks

Finding papers proved more difficult than we had expected. Many papers identified by our search as potentially being participatory were, in reality, projects where the research had been shaped, designed and controlled by 'outsider' researchers who, whilst committed to improving the lives of those who were at the heart of the research, were essentially determining the parameters for, and controlling, their engagement in research. Papers that reported on purely qualitative research with good collaboration were, therefore, not included. Conducting a somewhat larger study, but one that also necessitated identifying truly participatory research, (Jagosh et al. 2012) noted that one difficulty in finding such papers was that the frameworks for publication within which the authors are writing do not encourage authors to describe the key elements that they were looking for. The initial set of papers was also checked against McTaggart's notion of authentic participation (i.e. 'ownership, that is responsible agency in the production of knowledge and improvement in practice'. 1997, 28) and the following questions, based on those used by Minkler and Wallerstein et al. (2003):

- Are dimensions between collaborators discussed?
- Are participation characteristics mentioned?
- Are dimensions and methods of the participatory process characterised?
- Have the participatory processes been linked to impact?

Of the first six papers, we had identified as falling into the criteria of participatory on the basis of author descriptions, on closer inspection only five of our six ultimately fitted the brief.

Phase Two: contact was made with the five authors. All readily agreed to contribute to the project, mainly on the basis that they could see a real benefit in developing a more open articulation of participatory dimensions in relation to research. Where possible discussions were in person, but for geographical reasons some were conducted over the telephone (2 out of the 5). These first discussions demonstrated that authors appeared to have few difficulties in describing the nature of participation in their narrative, but our conversations revealed confusion about the difference between research where patients and the public were invited to participate and comment on research, and research where participatory practices were core to all aspects of the research. This

was expected, a key purpose of our work being to find out how to support the authors in being critically analytical about the depth of participation, not to produce an exact definition of participation. Naming is a convention, not a definition and it is easy, as Eisner (1998) suggests to 'substitute concept for precept, the name of the thing for the thing itself' (p. 17). We found that having a set of broad definitions to consider their work against was helping authors consider the nature of participation in a more explicit fashion.

What proved far more difficult, however, was the authors' ability to describe the impact of the project beyond the impact on co-researchers<sup>5</sup> whose lived experience (service users/ patients) had guided/informed the study. Most authors described improved confidence and self-esteem of co-researchers as a key impact. During the conversations, however, it became clear that the participatory approach had almost always had other impacts. These included, for example, impact on the quality of the research design. A number of authors discussed how researchers with lived experience had asked more searching and more relevant questions than more distanced, academic researchers. This direct impact of the participatory approach on the quality of the research had not, however, been recorded in their published papers. In some cases, until the conversations with the APRIL team, it had not been explicitly recognised as impact by the authors. A second impact not recorded in published papers was the building of ongoing networks during the research which enhanced capacity for change in the future. A third was the transformational power of the learning from the research, not just for co-researchers but for service providers. When co-researchers were able to discuss, with confidence, the findings of their research with agencies such as Local Authority providers, their voices acted as a catalyst for change. Reasons given by authors for not having written these impacts into papers included that they tended to happen after the research funding was over and the writing up completed, reticence in making claims for research when part of a broader team working in multifaceted situations where a number of activities or interventions were focussing on similar issues and the difficulties of articulating shared learning in an explicit manner. The conversations with the first five authors revealed very clearly that the term participatory was being used in a range of ways and that impact was being under-reported.

Phase three: whilst Cornwall (2008) warns that typologies can narrow a complex activity such as participation into a set of externally imposed ways of seeing, our experience was suggesting that the term participatory was being widely used with illusory consensus, i.e. people were using the same words to mean different things but when talking to each other did not necessarily recognise the conceptual discrepancies inherent in each other's practices. Help was needed to develop a more critical and transparent articulation. Recognising what is meant by 'participation' and 'involvement' is vital to delineating the participatory research paradigm and having some legitimate expectations of type of impacts may arise from that approach (Cook 2012). Cornwall does suggest that being more specific about what is happening, 'clarity through specificity' (Cornwall 2008, 281), is a way forward. To support our next six authors, not to fix their work with a label but to articulate the participatory nature and impact of their work with a critical eye, we developed the set of descriptors used in Phase Two into a matrix. This was discussed with authors and served as a broad lens for reflection and as a means of capturing more of the complexity of engagement within projects and across time. Table 2 demonstrates how the matrix for participation was completed using one of the papers in our first cohort. It shows both the depth of participation and how this varied over the lifespan of a project.

An outline framework for discussing impact with authors was then developed by two members of the APRIL team with particular expertise in impact analysis. The team drew on the INVOLVE Impact

database (<https://www.invo.org.uk/resource-centre/evidence-library/>) and REF 2014 impact for Public health, health services and primary care (<https://www.ref.ac.uk>).

The learning from the first five authors (particularly about how the breadth of impact was not well documented in these journal articles beyond its impact co-researchers), and the below dimensions, was used to focus conversations with next six authors. For instance, additional emphasis was put on discussing/finding out the following:

**Table 2.** dimensions for participation

Cook, T., and P. Inglis. 2012. "Participatory Research With Men with Learning Disability: Informed Consent." *Tizard Learning Disability Review* 17 (2): 92–101.

Type	Deciding on research focus	Designing research methodology	Data generation	Data analysis	Report writing	Dissemination	Other
Co-option							n/a
Compliance	✓						
Consultation		✓		✓	✓		
Co-operation		✓	✓	✓	✓	✓	
Co-learning		✓	✓	✓		✓	
Collective action							

- What was the impact across various stakeholders and where did it occur?
- Were there any perceived links between participation and the quality of the research design?
- Who benefited most from the participation in the study, what did that benefit look like, and when did it occur?

Asking authors to characterise the participatory nature of their work using this matrix led to authors being much more precise about the nature of the participatory approach over the life span of their projects. It revealed not only the complexity of the notion of participation, but that using 'participation' as an overarching term in the published papers did not reveal the depth and breadth of the participation that came to light during our discussions. In effect authors had underplayed the depth and breadth of their design and engagements when writing about the research process. Like the first five authors, these authors discussed, and reported in their papers, the impacts of participation on the community of practice, impacts such as increased self-esteem, confidence and interest but broader impacts, such as shared learning and the development or consolidation of vital functional networks only became evident during conversations with the APRIL team. Being so taken for granted they were not recognised as impact and tended to be missing from their academic papers. Some authors also recounted how working with co-researchers when disseminating the findings of the research resulting in the findings being taken on board by organisations and changes begin made, changes they believed would not have happened if external researchers had reported back to those organisations. The power of the insider voice, the human power of the story, was considered to be the key element that made the difference between a report that was noted and a report that was acted on. A frustration for researchers was that they had not reported this breadth of impacts in their papers.

It would seem that the limited breadth of impact reported in papers could be a result of difficulties in conceptualising and articulating the types of impact that ensue from participatory research approaches. In some cases, speaking with a member of the APRIL team was a route to recognising certain impacts, especially when impacts had emerged during the research activity rather than

predefined prior to the research. It was not just, therefore, a matter of asking authors about impact they had not mentioned, but the conversations became a process of opening a lens for authors to consider and reflect enabling them to identify different types of impact that PR facilitates. When asked why impacts that we were now discussing had not made public the following suggestions were offered:

- (1) The prevailing paradigm for reporting impact (the predominance of what is thought to be 'acceptable' as impact, the observable and measurable) created a wariness of documenting less tangible impacts.
- (2) Short time scales for research funding meant that changes in practice as a result of changes in thinking, which tend to be longitudinal, often happen beyond the dedicated lifetime of projects and were only captured serendipitously.
- (3) Changes in thinking are not observable and explicitly articulated. They tend to emerge cumulatively as part of the process of learning during the project. People may not, therefore, recognise their own learning (change) as it unfolds develop- mentally rather than as an unambiguous outcome.
- (4) The definition of impact by those with embodied knowledge is not given credence in frameworks for reporting.
- (5) Complexity of context means that researchers are reluctant to take credit for impact, even if it is an expected outcome of such research. When working together with community partners/co-researchers, there was some questioning of who can make claims for impact. It is the tendency for those working in this way to want to attribute change as a process of shared endeavours and therefore academic researchers, the people who generally write the academic papers, tend to gloss over this aspect.
- (6) For community partners, publication is seen as less important than 'acting and doing'. Publications that do occur are not necessarily in academic journals or even in traditional written form. This means opportunities for collating, learning and building on the impacts of participatory approaches to research through a meta-analysis of academic literature is not necessarily an effective way of locating impact.

**Table 3.** outline impact analysis framework for interviews with authors.

Type of impact	Please give examples	How did the participatory nature of your project enable this impact to happen	How do you know that?	When did the impact occur? Short/ medium/ long term	Was the impact intentional? How did it arise?	What were the enablers for this impact – and barriers?
Research Process: effect on question/ design/ understanding of findings etc						
Changed direction of travel once project started						
Effect on research quality service delivery						
Technology implementation						
Has caused a change in policy: local and national						
Has created personal changes for co-researchers (including greater confidence, initiating of own initiatives, developing usable skills)						
Provided the catalyst for change: lead on change						
Affected the building of community networks (e.g. established sustainable groups beyond the timeline of the research)						
Created change in organisations not directly involved in the research						
Changed the focus and/or orientation for future research						
Other						

Phase four: designing the prototype IK drew on key elements from our own discussions as disparate researchers in the APRL team and the discussions authors of the 11 papers. Whilst the starting point for lodging research would be academic papers there would be space in the IK to link papers to disseminations that take different forms. Some would be in written form, to be found in localised publications, and reports, but there would also be space for video clips and voice recordings. In addition, authors/researchers would be able to return to the IK at a later date to describe impacts that had happened after the research has been completed. This would support a more longitudinal approach to impact and the collection of impact in a more informal manner would enable researchers to be more comfortable and confident about articulating things they might be less able to articulate if they thought it was going in a formalised peer-reviewed academic paper. As noted previously, one of the key impacts of PR, the changing perceptions of practice (i.e. the learning process) is held within communities of practice rather than located with external researchers, changes continue to surface long after an initial research project has been completed. Impact such as changes in attitudes and outlook are not measurable in the traditional sense but they are vital for transforming practice (Jagosh et al. 2012; Staley et al. 2014; Brett et al. 2012; Drahota et al. 2016). Such legacies of a study tend to remain lost within the current requirements to report more short-term impacts that have occurred by the formal end of a research project. A significant number of authors gave examples of how impact had happened after the time scale of the project and also after the publication of associated papers. Time scales for impact and legacy affect the ability of academic researchers to adequately articulate effects. A place to house ongoing impact not readily articulated in academic papers is therefore needed to provide the public face it is currently lacking.

These findings enabled the APRIL team to develop an outline for an IK using the frameworks for lodging papers presented above (Tables 1–3). The IK needed to be developmental, moving beyond the collection of purely academic publications, collected in a given time frame, to give space for different ways of locating and recording impact. We needed to find a way of linking both reports of participatory research and its impact, such as those written for funders, and stories about participatory research written for professional journals or local community publications, with the academic literature, as it had been suggested by the authors that these types of recording often added greater depth to an academic journal article. The IK was envisaged, therefore, as a space that would challenge contributors to think about their research projects as they lodged their work, to engage with the debate in relation to what might be impact. Whilst there is a conceptual difference between the ‘participation’, ‘action’, ‘impact’ and ‘research’ elements of PR, ‘in its most developed state ... there is not participation followed by research and then hopefully action ... Change does not happen at ‘the end’ – it happens throughout’ (Wadsworth 1998, 7). These conversations with authors highlighted how the more traditional forms of articulating impact elevate the importance of measuring outcomes against predetermined goals yet such instrumental and technical approaches are not sufficiently fine-tuned to enable the impact of PR to be recognised and demonstrated in a robust manner. Impact is not merely found at the end of a PR project but is woven through the process of engagement. Impact can be unexpected, indirect as well as direct, unintended as well as intended and have intangible as well as tangible effects. Tangible effects are observable, measurable, material and corporeal. Intangible effects (such as the sowing of seeds for new thinking about practice, where thoughts have become reframed but yet to be acted upon) can be the basis for future changes in practice. These all need to be recognised, articulated and valued as part of the complex process of researching and learning together for improving practice.

Whilst the initial intention of the APRIL project has been to build a free, online, open access database, the type of system envisaged by the project team could not be built within the technical development resource associated with this project. This was acutely disappointing for the team, but

the work has provided a basis for this to be taken to scale when funding can be sourced (See Figure 2).

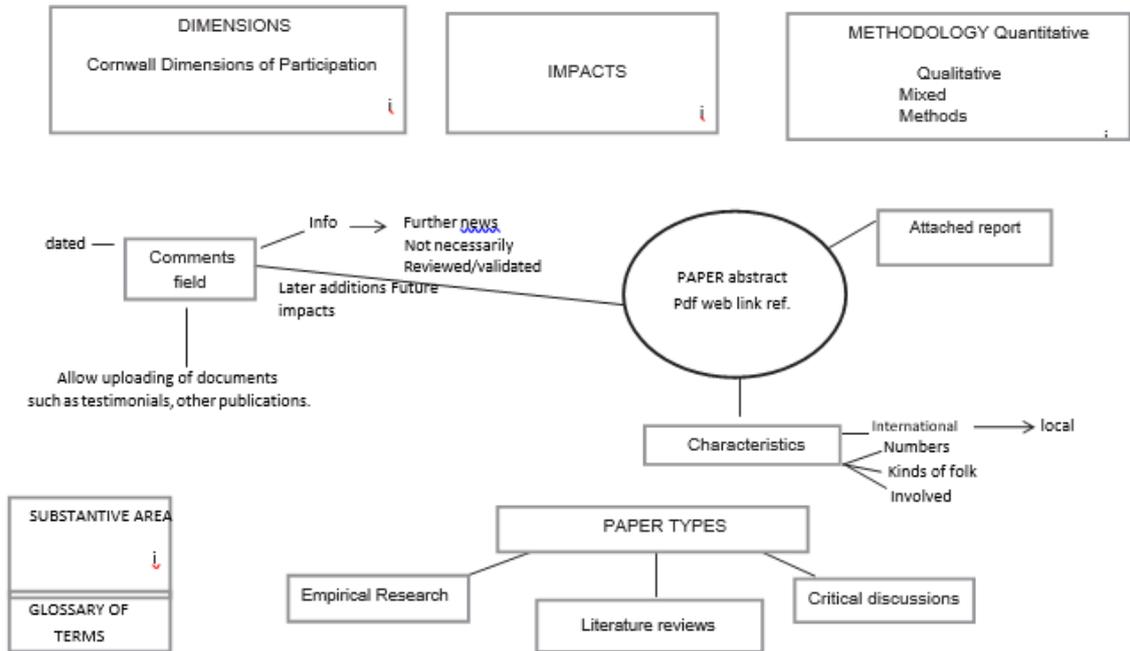


Figure 2. Authors and their papers

Table 4. Authors and their papers

1	Bostock J., and J. Freeman. 2003. "No Limits': Doing Participatory Action Research with Young People in Northumberland." <i>Journal of Community &amp; Applied Social Psychology</i> 13: 464–474
2	Broerse J.E.W., M.B.M. Zweekhorst, A.J.M.I. van Rensen, and M.J.M. de Haan. 2010. "Involving Burn survivors in agenda setting on Burn Research: An Added Value?" <i>Burns</i> 36: 217–231
3	Charnley, H., and S.-K. Hwang with members and supporters of Full circle from ARC, Stockton. 2010. "I Feel like a Giant, like a star, a Proper actor'. Reflections on a service user-led Evaluation of a drama Project using Participatory Visual Research Methods." <i>The Mental Health and Learning Disabilities Research and Practice Journal</i> 7 (2): 149–158
4	Author's own. Removed for review purposes
5	Fleming, J., H. Goodman Chong, and A. Skinner. 2009. "Experiences of Peer Evaluation of the Leicester teenage Pregnancy Prevention Strategy." <i>Children and Society</i> 23: 279–290
6	Gregory, S., F. Poland, N. Spalding, K. Sargen, J. McCulloch, and P. Vicary. 2012. "Multidimensional collaboration: Reflections on action Research in a clinical context." <i>Educational Action Research</i> 19 (3): 363–378
7	Lindenmeyer, A., H. Hearnshaw, J. Sturt, R. Ormerod, and G. Aitchison. 2007. "Assessment of the Benefits of user involvement in health Research from the Warwick diabetes care Research User Group: a Qualitative case study." <i>Health Expectations</i> 10: 268–277
8	McKevitt, C., N. Fudge, and C. Wolfe. 2009. "What is involvement in Research and What does it achieve? Reflections on a Pilot study of the Personal costs of stroke." <i>Health Expectations</i> 13: 86–94
9	Staniszewska, S., J. Brett, C. Mockford, and R. Barber. 2011. "The GRIPP checklist: strengthening the Quality of Patient and Public involvement Reporting in Research." <i>International Journal of Technology Assessment in Health Care</i> 27 (4): 391–399
10	Tsianakas, V., G. Robert, J. Maben, A. Richardson, C. Dale, and T. Wiseman. 2012. "Implementing Patient-centred cancer care: using Experience-based co-design to improve Patient Experience in Breast and lung cancer services." <i>Support Care Cancer</i> . doi:10.1007/s00520-012-1470-3
11	Williamson, T., J. Brogden, E. Jones, and J. Ryan. 2010. "Impact of Public involvement in Research on Quality of life and society: a case study of Research career trajectory." <i>International Journal of Consumer Studies</i> . 34: 551–557

## **Conclusion**

The APRIL study was initiated with the aim of designing a starting point for developing an IK with a multitude of purposes. All 11 authors approached readily agreed to participating in this initial work to develop a prototype for such an IK saying that they would welcome a space where they could find accounts of participatory approaches to research, lodge non academic literature, have a clearer way of recognising the nature of participation in research that makes claims to be participatory and that offers a means of developing the link between participatory practices and rationally expected impacts. The logic that there would be a difference in the types of impact that could be expected from different types of participation was accepted by these authors, and that a first stage to achieving this would be the improved understanding and articulation of what is meant by both 'participation' and 'impact'. The need for an IK was then clearly established and through our conversations we had begun to shape the space needed for this to happen.

A dynamic partnership approach to building an on-going, IK would contribute to lever-aging the relevance of participatory research approaches for transformational practice within the wider research community. Such a participatory approach for articulating impact, encompassing the views of the PR community, would support the establishment of firmer foundations for the participatory approach in the cannon of research paradigms. Being able to articulate alternative forms of impact is key to making the argument for this type of applied research whose focus is on the actions and impacts that result from working together, as well as the moral and ethical rationale for such work (Table 4).

## **Notes**

1. We are looking here at research approaches that are most commonly found in health research, but other terms are found in other disciplines (e.g. Inclusive Research, Design Research) that also denote more radical forms of participation.
2. For the purposes of this paper we refer to the more radical forms of research collectively as participatory research (PR).
3. Focussing on PHR aligned us with the work of the International Collaboration on Participatory Health Research (ICPHR), a network of active participatory researchers seeking to bring together systematically the knowledge and experience of participatory health research and to strengthen PHR regarding issues of quality, credibility and impact on policy and practice.
4. Our initial plan had included follow up conversations with researchers from the identified projects beyond the main authors, particularly community-based researchers, but this proved not to be feasible in practice due to time constraints of a six month project and the limited budget for the work.
5. We have used the term 'co-researcher' to support a clearer narrative, but recognise the conceptual inconsistency of using this term. In practice, the term 'researcher' should be applied to all.

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## References

- Bero, L.A., R. Grilli, J.M. Grimshaw, E. Harvey, A.D. Oxman, and M.A. Thomson. 1998. "Closing the Gap Between Research and Practice: An Overview of Systematic Reviews of Interventions to Promote the Implementation of Research Findings. The Cochrane Effective Practice and Organization of Care Review Group." *British Medical Journal* 317 (7156): 465–468.
- Blumer, H. 1969. *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice Hall.
- Boote, J. 2011. "Patient and Public Involvement in Health and Social Care Research: A Bibliography." <https://www.clahrc-ndl.nihr.ac.uk/documents/ppi/08-boote-2011-ppi-bibliography.pdf>.
- Brett, J., S. Staniszewska, C. Mockford, S. Herron-Marx, J. Hughes, C. Tysall, and R. Suleman. 2012. "Mapping the Impact of Patient and Public Involvement on Health and Social Care Research: A Systematic Review." *Health Expectations* 17 (5): 637–650. doi: 10.1111/j.1369-7625.2012.00795.x.
- Cacari-Stone, L., N. Wallerstein, A.P. Garcia, and M. Minkler. 2014. "The Promise of Community-based Participatory Research for Health Equity: A Conceptual Model for Bridging Evidence With Policy." *American Journal of Public Health* 104 (9): 1615–1623.
- Canadian Institutes of Health Research (CIHR). "Citizen Engagement Framework." Accessed April 4, 2016. <https://www.cihr-irsc.gc.ca/e/41753.html>
- Cook, T. 2012. "Where Participatory Approaches Meet Pragmatism in Funded (Health) Research: The Challenge of Finding Meaningful Spaces." *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* 13 (1): Art. 18.
- Cornwall, A. 2008. "Unpacking 'Participation': Models, Meanings and Practices." *Community Development Journal* 43 (3): 269–283.
- Cornwall, A., and R. Jewkes. 1995. "What is Participatory Research?" *Social Science & Medicine* 41 (12): 1667–1676.
- Drahota, A., R.D. Meza, B. Brikho, M. Naaf, J.A. Estabillo, E.D. Gomez, S.F. Vejnaska, S. Dufek, A C Stahmer, and G.A. Aarons. 2016. "Community-academic Partnerships: A Systematic Review of the State of the Literature and Recommendations for Future Research." Article first published online: March 14 2016. Accessed April 4, 2016. <https://onlinelibrary.wiley.com/doi/10.1111/1468-0009.12184/abstract>. doi:10.1111/1468-0009.12184.
- Eisner, E.W. 1998. "The Primacy of Experience and the Politics of Method." *Educational Researcher* 17 (5): 15–20.
- Greenhalgh, T., and N. Fahy. 2015. "Research Impact in the Community-based Health Sciences: An Analysis of 162 Case Studies from the 2014 UK Research Excellence." *Framework* 13 (232): 1–12.
- Greenhalgh, T., C. Jackson, S. Shaw, and T. Janamian. 2016. "Achieving Research Impact Through Co-creation in Community-Based Health Services: Literature Review and Case Study." *The Milbank Quarterly* 94 (2): 392–429.
- Haines, A., and A. Donald. 1998. "Looking Forward: Getting Research Findings Into Practice: Making Better Use of Research Findings." *BMJ*. 317: 72.
- HEFCE, SFC, HEFCW, DELNI. 2012. Assessment Framework and Guidance on Submissions (02.2011 updated version). Accessed April 4, 2016. [www.ref.ac.uk/media/ref/content/pub/assessmentframeworkandguidanceonsubmissions/GOS%20including%20addendum.pdf](http://www.ref.ac.uk/media/ref/content/pub/assessmentframeworkandguidanceonsubmissions/GOS%20including%20addendum.pdf)
- INVOLVE. 2010. *The Invonet Bibliographies of Public Involvement in NHS, Public Health and Social Care Research*. NHS National Institute for Health Research.

INVOLVE What is Public Involvement in Research? Accessed April 4, 2016.

<https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2>

Jagosh, J., A.C. Macaulay, P. Pluye, J. Salsberg, P.L. Bush, J. Henderson, E. Sirett, et al.

2012. "Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice." *Milbank Quarterly* 90 (2): 311–346.

Liamputtong, P. 2014. "Experiential Learning." In *Sage Encyclopedia of Action Research*, edited by David Coughlan and Mary Brydon-Miller, 324. Sage.

Martin, G.P. 2008. "'Ordinary People Only': Knowledge, Representativeness and the Publics of Public Participation in Healthcare." *Sociology of Health and Illness* 30 (1): 35–54.

McTaggart, R. 1997. "Guiding Principles for Participatory Action Research." In *Participatory Action Research: International Contexts and Consequences*, edited by Robin McTaggart, 25–43. New York: Albany.

Minkler, M., and N. Wallerstein. 2003. *Community Based Participatory Research for Health*. San Francisco, CA: Jossey-Bass.

National Health & Medical Research Council and Consumers Health Forum of Australia (NH&MRC). Statement on Consumer and Community Participation in Health and Medical Research. Published 2001. Accessed April 4, 2016.

[https://www.nhmrc.gov.au/files\\_nhmrc/publications/attachments/r22.pdf](https://www.nhmrc.gov.au/files_nhmrc/publications/attachments/r22.pdf)

National Institute for Health Research. (NIHR) Patient and Public Awareness. Accessed April 4, 2016.

<https://www.nihr.ac.uk/awareness/Pages/default.aspx>

National Institutes of Health. (NIH) Director's Council of Public representatives.

<https://www.nih.gov/about/copr/index.htm> Accessed April 4, 2016.

Pain, R., K. Askins, S. Banks, T. Cook, G. Crawford, L. Crookes, S. Darby, et al. 2016. *Mapping Alternative Impact: Alternative Approaches to Impact from Co-produced Research*. Durham: Centre for Social Justice and Community Action, Durham University.

Patient Protection and Affordable Care Act: Detailed Summary. Accessed April 4, 2016.

<https://www.dpc.senate.gov/healthreformbill/healthbill04.pdf>

Patient-Centered Outcomes Research Institute (PCORI). Accessed April 4, 2016.

<https://www.pcori.org/about-us/what-we-do/what-drives-our-work>

Ramaswamy, V., and K. Ozcan. 2014. *The Co-creation Paradigm*. Redwood City, CA: Stanford University Press.

Reason, P., and H. Bradbury, eds. 2008. *The Sage Handbook of Action Research: Participative Inquiry and Practice*. 2nd ed.. Sage, CA.

Reed, M. 2016. *The Research Impact Handbook*. Fast Track Impact. Aberdeenshire.

Research Council UK Pathways to Impact. Accessed April 4, 2016.

<https://www.rcuk.ac.uk/innovation/impacts>

Staley, K, S.A. Buckland, H. Hayes, and M. Tarpey. 2014. "'The Missing Links': Understanding How Context and Mechanism Influence the Impact of Public Involvement in Research." *Health Expectations* 17 (6): 755–764. doi:10.1111/hex.12017.

Swantz, M.L. 2008. "Participatory Action Research as Practice." In *The Sage Handbook of Action Research: Participative Inquiry and Practice*. 2nd ed., edited by Peter Reason and Hilary Bradbury, 31–48. London: Sage.

Thomson, P. 2015. *Action Research with/Against Impact Educational Action Research* 23 (3): 309–311.

Trickett, E. 2011. "Community-based Participatory Research as Worldview or Instrumental Strategy: Is It Lost in Translation(al) Research?" *American Journal of Public Health*. 101 (8): 1353–1355.

Tritter, J. 2009. "Revolution or Evolution: The Challenges of Conceptualizing Patient and Public Involvement in a Consumerist World." *Health Expectations* 12 (3): 275–287.

Wadsworth, Y. 1998. *What is Participatory Research?* Action Research International. Accessed November. [www.scu.edu.au/schools/gam/ar/p\\_ywadsworth](http://www.scu.edu.au/schools/gam/ar/p_ywadsworth)

Wallerstein, N., J. Oetzel, B. Duran, G. Tafoya, L. Belone, and R. Ray. 2008. "What Predicts Outcomes in CBPR?" In *Community Based Participatory/Research for health: Process to Outcomes*. 2nd ed., edited by M. Minkler and N. Wallerstein, 371–392. San Francisco, CA: Jossey Bass.

Wiek, A., S. Talwar, M. OShea, and J. Robinson. 2014. "Toward a Methodological Scheme for Capturing Societal Effects of Participatory Sustainability Research." *Research Evaluation* 23 (2): 117–132.