‘There and back again’: International Collaboration for Participatory Health Researchers’ journeys to evidence based practice and practice based evidence

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Based on oral histories, this paper outlines the individual and collective stories of eight members of the International Collaboration for Participatory Health Research (ICPHR): how they came to embrace participatory action research within a health context; challenges they faced; and how they came together to strengthen and develop their understanding of their research practice. In particular, their collaboration provided for discourse around research rigour related to community relevance and impact. While they initially formed the ICPHR in response to Evidence Based Practice imperatives, they came instead to understand their work more as Practice Based Evidence.

Key words: Oral history, participatory health research, evidence-based-practice, practice-based-evidence

‘Allí y de vuelta otra vez’: Colaboración Internacional de los trayectos de los investigadores participantes en salud para la evidencia basada en la práctica y la práctica basada en la evidencia

Basado en historias orales, este artículo esboza historias individuales y colectivas de ocho miembros del International Collaboration for Participatory Health Research (ICPHR): como llegaron a abrazar la

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investigación-acción participativa dentro de un contexto de salud; desafíos que enfrentaron; y como se unieron para consolidar y desarrollar su comprensión de su práctica investigativa. En particular, su colaboración proporcionada en el discurso en torno al rigor de la investigación relacionada con el impacto y la relevancia para la comunidad. Mientras que inicialmente formaron la ICPHR, en respuesta a los imperativos de la Evidencia Basada en la Práctica, ellos vinieron en vez de comprender su trabajo como Practicas Basadas en Evidencias.

Palabras clave: Historia Oral, Investigación Participativa en Salud, Evidencia Basada en la Práctica, Práctica Basada en la Evidencia

1. Introduction

In 1937, JRR Tolkin published *The Hobbit*, also known as *There and Back Again*. This well-known story traces the adventures of Bilbo Baggins to treasures guarded by a dragon and eventually back to the comforts of his home as a matured and wiser hobbit. The stories outlined in this paper recount the journeys of a number of experienced participatory health researchers who have sought to defend their work against the dragons of traditional research, found support in their trials through each other, and eventually a place of comfort that strongly resembled "home". This paper is based on the oral histories of eight international participatory health researchers. I briefly trace the separate paths of each researcher, highlighting common markers and obstacles, before exploring the formation of the International Collaboration for Participatory Health Research (ICPHR). While the ICPHR initially had a strong agenda to "legitimise" participatory health research along similar lines used in more traditional medical research, the collaborative journey that emerged for these researchers through the ICPHR instead brought them to an understanding of scientific integrity that was much more consistent with the participatory paradigm in which they worked. Thus, this collaborative journey provides an opportunity to examine the desirability of Evidence Based Practice within participatory health research, as well as the relevance of community-based and Practice Based Evidence. As experienced travellers, these researchers are able to provide insights into how their participatory research has changed over many years, how their critical reflections have matured their practice, and what challenges continue to await others who venture down a participatory health research path.

2. Setting the scene

This paper is written in a narrative form, as is common in history research. However, before I outline the individual and collective stories of the researchers featured here, it is worthwhile briefly outlining the broader context of health research and practice. Health, as a collection of disciplines, has been strongly influenced over the past 30 years by a movement that has sought to embed research evidence into the daily work of practitioners. Developed initially within medicine, Evidence-Based-Practice (EBP) aims to focus the practice of clinicians on those interventions that have been shown to be the most effective using random controlled trials (RCTs) (White, Stallones, & Last, 2013). Based on the work of Archie Cochrane, an epidemiologist from the UK, the Cochrane Collaboration was established in 1993 for the purpose of undertaking systematic reviews of evidence and presenting these in an accessible manner for clinicians who were expected to adapt their practice accordingly. The emphasis on RCTs as part of the evidence hierarchy within the Cochrane Collaboration,[1] reflected the post-positivism inherent in medicine that gave priority to individualistic, internally valid, controlled quantitative research (Trickett, et al., 2011). Throughout the 1990s, a number of social and health disciplines adopted EBP, although many also provided a counter-narrative to the RCT mantra and pushed for the recognition of qualitative studies as relevant research (Anderson & McQueen, 2010). The need to persuade clinicians and practitioners to adopt evidence-based-practices spawned the development of "translational" research which is focused on

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[1] The hierarchy of evidence categorises evidence from interventional studies. Preference is given to systematic reviews of RCTs, then RCTs, then other controlled studies, then case studies, and finally expert opinion (Littlejohns, Chalkidou, Wyatt, & Pearson 2010).

addressing those factors that impede the adoption of EBP (Anderson & McQueen, 2010).

Coinciding with these developments in EBP, a number of social and health practitioners, particularly those working in community-based services, were adopting participatory action research (PAR), or variations of PAR, as part of their practice (Baum, MacDougall, & Smith, 2006). In the health field, many argued that a participatory paradigm brought a new understanding of knowledge democracy and knowledge creation, as a socially constructed arena to improve health status and equity (Baum, MacDougall, & Smith, 2006; Trickett et al., 2011). Indeed, this paper outlines how some practitioners started undertaking PAR in this way before developing participatory practices as the central platform of their research. I should note participatory practice and research has not been without controversy within health circles, with considerable criticism and debate around issues related to power in decision making, benefits to communities and potential negative consequences of participation (Khanlou & Peter, 2005; Banks et al., 2013; Wallerstein, Mendes, Minkler, & Akerman, 2011). While variations in terminology associated with participatory research exist in different countries, recognition of the similarities in the health contexts prompted the adoption of the term Participatory Health Research (PHR) by the ICPHR. This approach is founded on a common set of core principles: starting from community priorities and needs; building from community identity and strengths; and creating collaborative co-equal relationships where the knowledge of all members is equally valued. These principles are outlined in first Position Paper of the ICPHR (2013).

In order to write the narrative outlined in this paper, I undertook oral history interviews with eight international participatory health researchers (Michael Wright, Jane Springer, Brenda Roche, Tina Cook, Margareta Ramgard, Francisco Mercado, Nina Wallerstein, Sarah Banks) between 25 November 2014 and 5 June 2015. The interviews were digitally recorded, transcribed verbatim and returned to the researchers for checking. They were then analysed according to standard oral history method that emphasises the development of a narrative based on the patterns of contiguity and commonality (Abrams, 2010).

Oral testimonies have been used in historical research for a number of centuries, while its current form, based on a recorded interview, has evolved from the 1940s (Ritchie, 2011). Oral history gained considerable popularity in the 1970s as part of a groundswell interest in rethinking history to be more representative of everyday people (Grele, 2007). Because this project explored the history of everyday practices of the ICPHR researchers, oral history was an appropriate data collection and method. However, oral history is also a method that serves to open up new avenues of historical consciousness (Grele, 2007), so the interviews have been interpreted within the context of international health research discourse for the purpose of 'holding up a mirror' to the ICPHR so its members and other participatory researchers may further reflect on and deepen the scholarship of their work.

3. The adventurers on separate paths

The interviews revealed most of the researchers had come from a practice background that had strong connections to various communities: Michael had a background in liberation theology, social work and HIV/AIDS research in the USA and Germany; Brenda's medical anthropology background led her to work with a number of disadvantaged communities in Canada and the USA; Tina's special education background fostered an interest in working with adults with learning difficulties in the UK; Margareta had worked as a politician in Sweden before her studies in human geography led her to working with health services professionals; Francisco was a physician in Mexico who practiced community medicine; Nina's background in Freirian adult education preceded her long career in working with tribal communities in the USA; Sarah had worked in community development and social work in the UK. Only Jane followed a 'traditional' academic path of completing her doctoral studies directly after her undergraduate degree as a young adult, although her urban geography soon lead to involvement in the Healthy Cities movement in the UK and the very pragmatic world of health promotion evaluation. Indeed, each of the researchers have crossed a number of disciplinary boundaries in their careers.

As such, none of the various career paths each of the researchers followed to become an academic or researcher were straight-forward. However, their strong practice backgrounds often introduced them to community-involved work that provided a solid foundation for their later participatory health research work. For example:

> I mean most of the things we did weren't on the far end of the participatory spectrum but they were very community involved and very driven in a certain way, at least the questions were driven a lot by community… So I was included as a member of a team in participatory research projects while working as a social worker (Michael).

> I had come out of a Freirean background. I had been an adult education teacher… So I came out of that. I also came out of the anti-war movement and women's movement and volunteering with the United Farmers Union, a lot of political activism (Nina).

> I guess when I was working as a community development worker we did various sorts of research with community groups although at that point I wouldn't have called it research but we were doing things like community profiles and village appraisals where I would work with a group of local people to design a survey and go door to door and then write a report (Sarah).

As each completed postgraduate qualifications, they came to be drawn towards applying their participatory principles to academic research, with the exception of Francisco, whose postgraduate studies in social medicine and medical anthropology supported his interest in community and social participation. The range of postgraduate topics, mostly undertaken in the 1980s and 1990s, reflects the eclectic nature of this group of researchers. Some were in public health (Michael, Nina, Brenda), some in human geography (Jane, Margareta), methodological approaches (Tina) and social work (Sarah, Michael). These qualifications led either directly to an academic position or to a research role within the social and healthcare sector, which is how some of the researchers were introduced to health research (Margareta, Tina). It has been primarily in these positions that their participatory health research practice became firmly established and developed. Most have been taking this approach to research for more than 20 years.

4. 'Making the road while walking'

In their examination of the participatory action researchers' reflections, Patricia Wicks, Peter Reason and Hilary Bradbury (2008) highlight that for many, they worked out how to "do" participatory action research as they were doing it; that is, they were "making the road while walking" (p. 24). This was a similar experience for the researchers examined here. Although Nina was fortunate enough to be guided early in her studies by experienced participatory researchers, Meredith Minkler (2008) and Barbara Israel (Israel, Eng, Schulz, & Parker, 2013), who went on to lay the foundations of Community-Based Participatory Research (CBPR); most gained their learning and experience simultaneously.

> Although I had learned the theory early, it wasn't until I was actually working with tribal communities in New Mexico, where I had to learn how to really walk my talk. I didn't know the extent of work it would take to receive approval to work with a sovereign nation; nor how deeply I would need to listen to my tribal partners in order to integrate indigenous knowledge with evidence-based knowledge into our National Institutes of Health funded health intervention (Nina).
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> Quite often I was a fly on the wall or I was helping out with projects in Liverpool because the way they developed work with Healthy Cities was through participatory research methods (Jane).
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> So I started off doing action research in the early 90s with my service and I did it for my masters but we took over the way of doing action research as a whole service department plan. That's how we planned every year, by doing the Lewinian action research cycle on the basis of what have we done well, what do we go home and moan about, what do we need to know more about to improve what we moan about (Tina).

The people who influenced the thinking of these researchers varied considerably depending on the context in which they worked. Francisco was influenced by political migrants from South America who went to Mexico in the 1970s in order to escape the political turmoil of their own countries. These health professionals brought with them an ideological background:

> I wouldn't say theoretical, but I would say very political and ideological [based on] Allende, the President of Chile who was a physician, who used to work in Chile as a physician. Later came Freire, Fals Borda and others[2] (Francisco).

Margareta was influenced by the people she worked with as well as her own reflections on her practice: 'Well of course I read Freire and the traditionals, so to say, but I must also say that I try very much to find my own way in this'. Similarly, Brenda saw the value of Paulo Freire's writings:

> I initially was quite taken with that idea. I became slightly disillusioned because I saw how people could appropriate the language and say they were using those concepts and then it became very distorted (Brenda).

For Nina, Freire remained an important influence: 'From a participatory philosophical stance in how I work with communities, definitely Paulo Freire and Saul Alinsky… The Highlander Centre was very pivotal'. Meredith Minkler was an early influence for Michael while he studied in the USA. Those coming out of the UK were more likely to be influenced by participatory action research:

> I very much like the work of Peter Reason and the early work of Reason and Heron. Particularly their work around co-inquiry groups, so that's a model that we've adapted (Sarah).
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> Stephen Kemmis, Bridget Somekh, all the action researchers, Susan Noffke, but Stephen Kemmis' *Becoming Critical* [Carr & Kemmis, 1996] blew my mind. I just thought, 'This is really it', and it got me thinking about Habermas (Tina).

Brenda's experience of gradually finding writings that resonated with her work was reflected in the testimonies of the others:

> And so it sort of felt like there wasn't a lot of guidance there initially and then eventually I discovered the work of two sorts of streams. The North American sort of traditions with Nina Wallerstein and Barbara Israel but at the same time when I was doing work in the UK, it was much more development, and the Institute for Development Studies, I would say, at Sus-

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[2] A number of influential authors are mentioned within the interview quotes. I have included an example of the work of those mentioned within the reference list.

> sex, so the thinking that was coming out of there I felt very influenced by (Brenda).

While a number of the researchers talked about being influenced by feminism, particularly Jane and Nina, it is evident three threads of thinking were particularly important in the development of their participatory health research for all those interviewed: "Southern" participatory action research, particularly the writings of Paulo Freire; CBPR and the work of Meredith Minkler and Barbara Israel in the USA; and the development of participatory action research in the UK. However, as researchers in the 1980s and 1990s, these participatory researchers were also aware this was a marginal field of research, and the theoretical thinking underpinning this approach to research was also only emerging.

> I first got involved as a programme person, then it became the subject of my dissertation and my first real research academic publishing, but it wasn't that I decided I was going to be a participatory researcher. It just evolved as I did… I've been involved with Latin American colleagues for more than two and a half decades; they really ground me in to their realities…and then I've been working with Native communities since 1980s. So I was able to grow my understanding of participatory research through a Southern and Indigenous model (Nina).

For some, the path became easier over time:

> I got to the point, certainly in Liverpool, because everybody was engaged in this type of approach, I got to the point where I could actually say, when I was applying for evaluation funding, "I will do a participatory approach, it will involve this", and it was a case of take it or leave it, really. But it took ten years (Jane).

All the researchers have found ways to gain significant funding for participatory research, although for most this has only become easier in the past decade. As will become clearer in the next section, making these individual roads while walking has required finding ways around a number of obstacles along the path.

5. Navigating obstacles

The disrupted history of participatory research, with its various strands emerging in different national contexts (Glassman, Erdem, & Bartholomew, 2012; Glassman & Erdem, 2014), has meant the types of challenges these researchers have faced have varied according to their country of practice. In Mexico, for example, Francisco relayed a history of participatory research being seen as quite a conservative approach:

> Participatory action research, action research and those who were doing PAR were not only marginalised, I think they were very, very criticised not only from the right, but also from the left. One of the main criticism from the latter was that they were too naïve because they couldn't understand theoretically or socially the main forces that moved society (Francisco).

Michael noted action research had gained some popularity in Germany in the 1970s but had been discredited by the 1980s. Furthermore, action or participatory research was not considered to be "proper" research.

> It's important to know that here in the German speaking countries there isn't a long tradition of applied social research. When I came here twenty years ago, I was told that applied research isn't research in the true sense (Michael).

Conversely, in Sweden, there was some social precedence for action and participatory research:

> Yes, there is a tradition but it is not really participatory health research, more action research that contributes to a specific organisation. There is a long tradition in Sweden of getting together in local places or in working places in "circles", learning and discussing a topic. This started in the labour movement with a purpose to give education to the working class. For example, the labour associations had the kind of "research circles" for education, well not research but a circle to do things with people in their community. It's more outside the university that it has started with circles as a sort of, you know, some people in the community go to certain associations for leisure and learning, that want to do this and try to get better knowledge for people living in their communities. The action research in

> Sweden I think, very much grew from the tradition of these knowledge circles. It's very common with knowledge circles and it's been in since the 1930s/1940s in Sweden…. Action research is developing in the academic world, in disciplines that educate professionals from education, social work, public health and nurses but not a high status in medicine for participatory health research (Margareta).

In the USA, action research has been established from the 1940s, and there had been an increasing acceptance of CBPR, but as Nina noted, "The US context is very empirically scientistic driven. Positivist in many ways and so that's how we get our funding". While avenues of funding were available in the USA for research that were consistent with participatory approaches, mostly with First Nations People, this context has meant participatory researchers have needed to learn to work within a National Institute of Health (NIH) system that has quite a different philosophical basis.

> I mean actually, working with Native communities changed me and kept me very focused on my philosophical social justice base, that I learned in my own maturing during the anti-war movement and my knowledge of Paulo Freire. So it changed me as becoming quite good at using the NIH system to add to the field of community-based participatory research as a social justice movement with a bigger purpose (Nina).

In Canada, participatory research was also seen as an acceptable form of research for First Nations People, but which has limited its use elsewhere:

> Canadians have done a lot to move it forward and they've done quite a lot of PAR work in-house, but the way the funding systems work is that it's all aboriginal work, HIV… But that marginalises in the same way as aboriginal populations are marginalised in the norm… It means it marginalises PAR to those areas, so in other areas you have to call it integrated knowledge translation (Jane).

Funding has become increasingly available in the UK for participatory research, but with this has been a concern that participatory approaches to research would be co-opted:

> It definitely is improving…. In the UK there is a [National Institute for Health Research] policy commitment to what they call PPI – Public and Patient Involvement in research in health and that's also mirrored in social work, so in getting people more involved, service users more involved in

> research. So I think it's an enormously good start… except it gets used as a somewhat technical approach. And certainly in health, originally it was about if people get more involved, they're more likely to get involved in trials so we can have better recruitment (Tina).
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> Yes, it is actually, but as I say it's also getting to be a little bit scary because it takes you back a bit because you think, 'Well, this was something that was marginal', and then it seems to be, not exactly mainstream but it's recognised by the mainstream and that, of course, is the point where you get really scared because once it gets pulled into mainstream it becomes something else and it gets co-opted (Sarah).

Co-option was also raised as a concern by Brenda, who had worked in Canada, the USA and the UK:

> People are involving community members in their research but after, they're not sort of involving them in the consultative process around the work, they're hiring them to do some of the research and that feels like there's a mismatch (Brenda).

Thus, the obstacles faced by participatory researchers have related to: 1) a history of action or participatory approaches being linked with community development and devalued as research; 2) questioning the rigour of participatory approaches to research based on positivist criteria; 3) co-opting aspects of participatory research for utilitarian purposes but devaluing the underlying principles and values of this approach to research. It was the experiences the researchers had with these various obstacles that drew them together to form the International Collaboration for Participatory Health Research.

6. Developing a collaborative journey

The ICPHR was established in 2009 and emerged from ideas around a German-speaking network that had been established two years earlier. There are a number of reasons these researchers joined the ICPHR, including seeking collegial support and opening up opportunities for international collaboration. One of the early visions, which forms the basis of this paper, was that of shoring up scientific integrity for a participatory approach to health research. In particular, the researchers were inspired towards establishing a participatory research equivalent to the Cochrane Collaboration.

> I feel like in the beginning it was partly about trying to, it was slightly different, it was about trying to establish something like a Cochrane Collaboration for participatory research, and it was a little bit more about that idea of fidelity to principles or guidelines (Brenda).

In an article outlining the establishment of the ICPHR, early members Michael Wright, Brenda Roach, Hella von Unger, Martina Block and Bob Gardner (2009) identified the need to clearly define participatory health research, to uncover the contribution to science PHR makes and to set standards for PHR quality. The authors compared the need for a PHR collaboration to the work of the Cochrane Collaboration, because of the strong influence within health disciplines of the systematic reviews coming out of that institution. The felt need was not only to defend participatory health research as scientifically rigorous, but to argue this approach offered a valuable contribution to health research and practice.

The need to defend action research, particularly participatory research, as being ‘scientific’ seems to have particularly emerged in those disciplines and countries dominated by positivism and post positivism. In an effort to minimise the perceived divide, John Stephens, John Barton and Tim Haslett (2009) argued action research and scientific methodology had similar roots back to ancient Greek times and that dialectic and argument iteration characterised both. Although in exploring the ancient Greek roots of action research, Stephen Kemmis (2010) suggested action researchers needed to move beyond the impasse of justifying their work as a ‘science’ as understood in the traditional way of producing external knowledge. Instead, Kemmis argued action research needed to be understood as contributing to changing history rather than theory; that the social change resulting from action research was more important than developing theoretical arguments. Unfortunately, this did not solve the dilemma faced by the ICPHR members: that they were hampered in getting projects started due to lack of funding based on misunderstanding the nature of their work and therefore often forced to modify their practice or justify themselves to ‘science-based’ colleagues personally, through grant applications and in publications.

> It’s that frustration [having to modify practice] that lead me to ICPHR (Jane).

> Well I suppose it's the perennial challenge compared with the kind of clinical or hard scientific research that goes on because I don't think that's going to go away because I think people, governments, policy makers and even research councils clearly do value quantitative style research (Sarah).

> Regarding the politics of science, we don't see our target groups as being communities who want to do research but rather people who fund research and the academic communities where there's actually more scepticism. And we wanted to form a group which presents this as a legitimate form of research (Michael).

The establishment of the ICPHR provided a forum in which participatory health researchers did not have to argue about the fundamentals of this research approach, arguments they had had repeatedly with other colleagues, but instead were able to start critical conversations about their work.

> It's a group that's not afraid to embrace critical thinking… I do have some folks locally, but sometimes what's missing is that critical lens and I think maybe there's a defensiveness that people feel. Like they can't say that, they can't speak openly about their concerns… in a climate where there's limited funding or the validity of your work is questioned (Brenda).

> We don't have to explain ourselves and then we can be critical and unpick what we do together and learn from each other in a way that's been so enormously supportive… we can map together, be critical of what we do and understand better, and better articulate it (Tina).

These conversations, at the annual working meetings and through work on position papers, have had the effect of shifting the direction for the group away from desiring an equivalent to the Cochrane Collaboration, although not necessarily away from establishing a stronger scientific basis to participatory health research.

> I too believe in science. I believe that we should do things that are effective and I think communities don't want us to do things that are ineffective. They want us to make a difference in health… So it really matters but if we're going to improve health equity we have to look at our own integrity and how do we do it in a way that communities can own and sustain, 'cause grant money ends and that's the problem with research grants (Nina).

In his examination of academic integrity in action research, Morten Levin (2012) identified considerable energy had gone into the external critique of action research approaches by social scientists over a number of years. He suggested this is related to the pragmatic and holistic approach associated with action research that shone an uncomfortable light on research that does not result in practical solutions or actions. However, Levin also noted the lack of visibility of internal critique; of action researchers debating key issues amongst themselves. The ICPHR provided a space for such dialogue for participatory health researchers; a space for important ontological, epistemological and methodological perspectives to be explored and deepened, thus providing a space to not only defend the academic and scientific integrity of participatory health research, but to challenge the traditional criteria used to assess rigour in health research (see ICPHR position papers 1 & 2).

EBP has emerged because of the gap between research and practice and the need to bridge this gap. The gap itself emerged out of the separation between science and practice that was institutionalised in the period after World War 2 (Adelman, 1993), despite the efforts of people such as John Dewey and Kurt Lewin from the 1920s who advocated for a closer relationship between research and practice. David Buchanan (2015) explained how the preeminent values associated with empirical, experimental research designs became formally codified in EBP through devising a hierarchy of evidence based on perceived values of different research designs, claims of what matters in health, and control of outcomes. These values have been regularly challenged. Jill Robinson and Nigel Norris (2001) argued for alternative perspectives to the conventional view of generalisation used in EBP, particularly around naturalistic generalisation that foregrounded the "real world" issues and perspectives of practitioners and policy-makers. More recently, Buchanan (2015) argued on the basis of human autonomy; that the empirical, research designs favoured by EBP frequently left out everything that makes human beings human: agency, free will, autonomy, values, volition and dignity. Buchanan (2000, p. 143) has previously advocated research in fields such as health promotion needs to be relevant to researchers, practitioners and community members alike; research that is "more understanding of the complexities of modern life” rather than the narrow, singular dimensions that characterise RCTs.

As a result of being a part of ICPHR, a subtle shift in thinking occurred for the researchers, from pursuing an agenda consistent with EBP to one more consistent with Practice Based Evidence (PBE); from thinking about evidence as a *driver* of practice, consistent with EBP, to thinking about evidence as the *result* of practice, consistent with PBE. Lawrence Green (2008), whose critique of EBP highlighted not only the wastage involved in the ‘pipeline’ conceptualisation that underpins EBP (17 years to turn 14 per cent of original research to benefit patient care), introduced PBE. He suggested that for those interventions that are embedded in cultural and socioeconomic contexts, context and external validity are just as important as experimental control and internal validity. As a remedy to EBP, Green recommended bringing research closer to, or produced within, practice situations through action or participatory research.

The critical conversations that were able to take place within the ICPHR allowed the group to start to explore evidence in their own context of participatory health research. This allowed them to understand evidence in terms of being accountable to their communities: their academic and their local communities. This is a shift in thinking that Anne Kraemer Diaz, Chaya Spears Johnson and Thomas Arcury (2013) have also advocated. In their examination of the differences in interpretation of scientific rigour between professional researchers and community researchers involved in participatory research in the USA, they found that while both groups highly valued their efforts being scientifically defendable, community researchers placed much greater humanistic value on ‘scientific integrity’: ‘For community members commitment to trust, providing benefit for the community and upholding accountability are just as vital to scientific integrity in CBPR as are following procedure, measurements and protocols’ (Kraemer Diaz, Spears Johnson, & Arcury, 2013, p. 140). Such thinking reflects discussions around rigour for participatory action research outlined by Langlois, Goudreau, and Lalonde (2014) who identified three criteria upon which to judge scientific rigour, all of which relate to community impact: the extent to which historical consciousness or situatedness is acknowledged and accounted for; the resultant actions; and the level of equity among co-participants. While not dismissing validity and reliability associated with various method designs, these participatory researchers had expanded their understanding around rigour to include these more community-based criteria:

> I realised that these were people who were actually very committed to participatory research and it was much broader than I thought and they were very skilled and articulate people who are kind of leading the way in participatory research so I felt it was important, and I like the fact that the attempt is not necessarily an attempt to compete with or to professionalise this sort of work but to actually show that is it high quality research which does make a clear difference and that there are criteria for ethics, for quality. It is scientifically rigorous in a different paradigm (Sarah).

Working from this expanded concept of scientific integrity, these researchers were addressing some of the issues around co-option of participatory research for utilitarian purposes by some social science researchers. They were doing this through better articulating the results of research in terms of the impacts for all those involved and bringing relevance and community accountability into the interpretation of scientific integrity:

> Actually what it does add is this churn and this knowledge development that is actually developmental and so we need to get better at articulating our own impact because I think we haven't been good at doing that and there's a difference between research that's called participatory because people have been on a steering group and research that is participatory because people with experience want to do this research because it's fundamental to their lives and this is why they want to do it (Tina).

Tina Cook (2012) argues participatory research has the possibility of having a direct effect on: participants' thinking, knowledge and practices; researchers and the theories that underpin research practice; the design, rigour and trustworthiness of the research process; knowledge about practice; policy and practice. She highlights the weakness of the interpretation of "objectivity" so readily found in the language of systematic reviews; that without the authentic participation of those involved, the policy or practice that is based on such evidence will be lacking a vital dimension. As such, the timing of ICPHR's focus on impact contributes to the emerging focus on PBE and is part of changing the conversation around what is considered to be rigorous research in health.

7. Conclusion

The fervour surrounding EBP from the 1990s has strongly influenced a number health disciplines. It has infiltrated the language of practitioners and policy makers, and driven a research agenda that has placed higher value on empirical, experimental research designs and contributed to the spawning of translational research. Within this climate, those who took a participatory approach to their health research have often found themselves marginalised and criticised. This paper has outlined the stories of eight experienced participatory health researchers, how they came together to find support and ways of defending the participatory approach to research. What they ended up doing was much more. The ICPHR became a forum for debating and developing the members' understanding of participatory health research that allowed them to articulate the value of this approach to research beyond the criticisms that had been levelled at this work. The foundations on practice and community relevance, historical consciousness or situatedness, action and equity, so inherent in PHR allowed them to shift their thinking away from EBP and an equivalent to the Cochrane Collaboration, to focus on issues more closely aligned with PBE and impact; on evidence that demonstrated the effects of research and that made a difference to practitioners and communities. In many ways, this is the natural home for participatory researchers. It is a place that collapses the artificial divide between practice and science while valuing both and in doing so challenges other social scientists to consider relevance and impact as essential criteria for judging scientific rigour.

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About the author

Wendy Madsen has been researching the history of health for twenty years and has combined this with her practice backgrounds in nursing and health promotion. It was through the latter she was introduced to participatory action research.

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