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#### ORIGINAL ARTICLE

The role of Participatory Action Research in developing new models of healthcare: Perspectives from participants and recommendations for ethical review and governance oversight



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Reçu le 24 janvier 2022 ; accepté le 18 août 2022 Disponible sur internet le 17 September 2022

#### KEYWORDS

Healthcare research ethics; Healthcare research governance; New model of care; Participatory action research; Plan-do-study-act

#### Summary:

Background. — Participatory Action Research (PAR) is a methodology often used in social sciences, which involves groups of people in action, reflection and iterative change. In PAR, "traditional" researchers become participants, and people who comprise "traditional" participants become researchers, facilitating cohesiveness and communication within the team. However, PAR is less used in healthcare, despite the complexity of providing and receiving health and social care. Development and testing of the delivery of new models of care is an area with increasing service-user participation, but often with no structured or formalised framework to embed end-users. This may be due in part to the complex ethical and governance systems in healthcare research, and the lack of practical guidance on using PAR as a research method within this context.

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Authorship: all authors have contributed equally to the writing of this article.

<sup>2</sup> Deceased.

**Hazel Barnes** 

People's Self Development Muhammad Anisur Rahman,1993 Comprises ten papers from 1974 to 1989 on development through collective local initiatives by people themselves and how to promote such development **Handbook on**Participatory Action Research and Community Development Stoecker, Randy,Falcón, Adrienne,2022-04-08 This Handbook is a critical resource for carefully considering the possibilities and challenges of strategically integrating participatory action research PAR and community development CD Utilizing practical examples from diverse contexts across five continents it looks at how communities are empowering themselves and bringing about systemic change

Participatory Action Learning and Action Research Lesley Wood, 2019-10-01 Participatory Action Learning and Action Research offers a concise yet comprehensive explanation of the theory practice and process of this emerging paradigm methodology and theory of learning PALAR is a transformative collaborative and democratic process for resolving complex problems within the context of sustainable professional organisational and community development The book draws on real life examples from socially and economically challenged contexts and features critical reflections on the strengths and challenges of this evolving methodology in relation to the increased interest in community engagement and project based learning among institutions of higher education Analysing theory in the context of sustainable professional organisational and community development this book Provides a comprehensive research based manual on the use of PALAR within actual research projects Explains a means of engaging in research that promotes the mobilisation of human potential relevant in a rapidy changing society Addresses the challenges of doing participatory research within institutions Provides applied specific examples of how PALAR can be adapted for use in socially and economically challenged contexts typical of developing economies Offers critical reflections by researchers and community participants on the challenges and uses of PALAR Innovative and offering clarity on ethics and research questions Participatory Action Learning and Action Research will be of interest to both emerging and experienced researchers looking to bring about change at a personal professional organisational or community level Education, Participatory Action Research, and Social Change D. Kapoor, S. Jordan, 2009-09-28 Drawing primarily from critical traditions in social and educational research this book frames contemporary issues and several conceptual theoretical analytical and onto epistemic approaches towards the development and practice of PAR Participatory Action Research in multiple educational spaces and initiatives for socio cultural change

CRITICAL PERSPECTIVES ON NEOLIBERAL GLOBALIZATION, DEVELOPMENT AND EDUCATION IN AFRICA AND ASIA Dip Kapoor, 2011-10-30 This interdisciplinary collection of readings pertaining to schooling higher education adult and community development education indigenous education and social movement learning in the African and Asian regions is a contribution to anti critical colonial scholarship in comparative international education and the sociology of education The political and analytical standpoint that weaves through the text considers the imbrications of the colonial and imperial

projects currently referenced as neoliberal globalization globalization of capitalism and development compulsory Eurocentric modernization and their attendant and mutual implications for education social reproduction and hegemony Counter anti hegemonic and indigenous education projects and pre existing alternatives are registered in the critique At last a remarkable collection of essays written by a range of scholars mostly originating from Asia and Africa demonstrating with admirable clarity how policies and practices of neo liberal globalization in those regions cannot be adequately understood without appreciating how they are a product of the exploitative histories of colonialism Written with conceptual sophistication personal knowledge and deep conviction these essays represent a major scholarly intervention in contemporary debates about globalization and education Fazal Rizvi Professor Graduate School of Education University of Melbourne Australia Professor Emeritus University of Illinois at Urbana Champaign USA This intriguing and provocative volume deals with crucial intersections between global forces and national initiatives with respect to the most crucial agency of transformation education The cumulative efforts of this assembly of committed intellectuals reveal the forces that retard progress in the two largest continents and offers compelling suggestions on how to redefine the boundaries of power the contents of knowledge and the use of critical thinking to create alternative spaces of autonomy freedom liberation and empowerment Toyin Falola University Distinguished Professor Frances Higginbotham Nalle Centennial Professor University of Texas at Austin This volume well crafted by Dip Kapoor one of the finest scholars in the postcolonial education field brings together writers who examine processes of learning and education more broadly within the context of the dominant discourses of globalisation and development They unveil the underlying neocolonial neoliberal tenets of these processes strongly echoing what Hardt and Negri would call Empire In short another important reading resource provided by Dip Kapoor and colleagues Peter Mayo Professor Chair Educational Studies University of Malta Finally a much awaited intervention on neoliberal globalization from Asian and African perspectives This book makes a compelling case for a historically grounded regionally specific analysis of globalization The contributions are extraordinary for their textured and embedded analysis of neoliberal globalization One of those rare books that deserve to be read across the social sciences Sangeeta Kamat Associate Professor International Bradbury, 2013-03-26 For anyone seeking to create meaning out of life inspire others with publication of research discoveries and insights and help the world become a better place within which to live and work action research holds great promise as an approach The challenge is to do it well and with rigor The Handbook is a magnificent collection of articles that will help the reader do all of that Richard E Boyatzis Case Western Reserve University and ESADE This second volume will be a welcome extension of the landmark first volume of the SAGE Handbook of Action Research It effectively secures the field s second wave in a particularly powerful and creative articulation of well theorised practice. It could not be more timely for a fast growing field that has attracted recent appreciation from parties as disparate as Shell 3M Australian Aboriginal women

in outback Australia working to prevent harm to children and the Secretary General of the UN Yoland Wadsworth For anyone thinking about or doing action research this book is an obligatory point of reference If any one text both maps the action research paradigm and at the same time moves it on this is it Bill Cooke Manchester Business School Building on the strength of the seminal first edition the The SAGE Handbook of Action Research has been completley updated to bring chapters in line with the latest qualitative and quantitative approaches in this field of social inquiry Peter Reason and Hilary Bradbury have introduced new part commentaries that draw links between different contributions and show their interrelations Throughout the contributing authors really engage with the pragmatics of doing action research and demonstrate how this can be a rich and rewarding reflective practice. They tackle questions of how to integrate knowledge with action how to collaborate with co researchers in the field and how to present the necessarily messy components in a coherent fashion The organization of the volume reflects the many different issues and levels of analysis represented This volume is an essential resource for scholars and professionals engaged in social and political inquiry organizational research Participatory Health Research Michael T. Wright, Krystyna Kongats, 2018-10-10 This groundbreaking and education resource explores core issues in participatory health research PHR and traces its global emergence as a force for improving health and well being healthcare services and quality of life The PHR approach is defined as including community members health practitioners and decision makers as co researchers using local knowledge to reduce disparities in care advocate for responsive health policy and accelerate positive change in society as a whole The book s first half surveys themes essential to the development of the field including evaluating PHR projects training professionals in conducting PHR and the ambitious work of the International Collaboration for Participatory Health Research International perspectives showcase the varied roles of PHR in addressing urgent local health problems in their specific public health and sociocultural contexts Among the topics covered Demonstrating impact in participatory health research Reviewing the effectiveness of participatory health research challenges and possible solutions Kids in Action participatory health research with children Participatory health research an Indian perspective Participatory health research in Latin America scientific production on chronic diseases Participatory health research in North America from community engagement to evidence informed practice Participatory Health Research benefits those teaching and learning about participatory health research at institutions of higher education and in community settings addressing diverse fields including health promotion and disease prevention medicine and public health quality of life social work and community development The well-connected community Gilchrist, Alison, 2009-07-22 Since the publication of the first edition of The well connected community there has been a growing recognition in practice and policy of how networks contribute to the vitality of community life and civil society Government policy has increasingly emphasised the need to involve communities in decision making while social capital is increasingly associated with health low levels of crime educational achievement and a strong sense of community The well connected community aims to strengthen

and extend informal networks support partnership working across boundaries and promote social cohesion It explores the concept of community in relation to patterns of interaction social identity and mutual influence advocating a new model of community development that promotes networking as a skilled and strategic intervention and providing recommendations for good networking practice This fully updated second edition includes new ideas drawn from recent research on social capital and the policy context for community practice reflecting the increasing emphasis on community engagement and empowerment Recent case studies and examples have been added throughout The well connected community is aimed at practitioners trainers policy makers and managers working with communities or responsible for community participation strategies both in the UK and internationally Academics will also find it a useful source for teaching and research **Ethics** in Participatory Research for Health and Social Well-Being Sarah Banks, Mary Brydon-Miller, 2018-08-06 Participatory research is well established as an approach involving people with a direct interest in or experience of the issue being studied in carrying out research However it raises unique and challenging ethical issues Traditional concerns with respect for the rights to confidentiality consent privacy and protection of research informants do not translate easily into participatory research Boundaries between researchers and those researched are often blurred research trajectories may be emergent and unpredictable and major ethical issues revolve around partnership power equality and respect for diverse knowledges The book introduces the key ethical issues in participatory research drawing on ethical theory and relevant literature before presenting seven substantive chapters each on a different theme such as power ownership confidentiality and boundaries The chapters feature an introductory overview of the topic with reference to the literature followed by four real life case examples written by participatory researchers and short commentaries on each case Drawn from around the world from Denmark to Tanzania the cases illustrate a range of ethical issues outlining how they were handled and the reflections and feelings of the contributors Focusing on developing ethical awareness confidence and courage to act in ethically challenging situations in everyday research practice this book is an invaluable resource for all participatory researchers The SAGE **Encyclopedia of Action Research** David Coghlan, Mary Brydon-Miller, 2014-08-11 Action research is a term used to describe a family of related approaches that integrate theory and action with a goal of addressing important organizational community and social issues together with those who experience them It focuses on the creation of areas for collaborative learning and the design enactment and evaluation of liberating actions through combining action and research reflection and action in an ongoing cycle of cogenerative knowledge While the roots of these methodologies go back to the 1940s there has been a dramatic increase in research output and adoption in university curricula over the past decade This is now an area of high popularity among academics and researchers from various fields especially business and organization studies education health care nursing development studies and social and community work The SAGE Encyclopedia of Action Research brings together the many strands of action research and addresses the interplay between these disciplines by presenting a state of

the art overview and comprehensive breakdown of the key tenets and methods of action research as well as detailing the work of key theorists and contributors to action research Feminist Community Research Gillian Creese, Wendy Frisby, 2011-10-20 Feminist community research is a collaborative methodology that holds the promise of building a more just society But in the absence of critical analysis and responsible use of power the approach can lead to naive or harmful practices This interdisciplinary volume acknowledges the challenges that researchers can encounter and discusses strategies that have been employed to overcome them By sharing collective wisdom gained from research among diverse groups from immigrant and Aboriginal women in Vancouver to poverty reduction practitioners in Vietnam this book will help researchers and government agencies build better bridges between research institutions and communities The Essential Guide to Doing Research Zina O'Leary, 2004-06-09 The Essential Guide to Doing Research is a comprehensive practical and engaging guide to understanding and embarking upon social science research By adopting a clear and accessible approach Zina O Leary encourages students to think about and engage with every aspect of the research process The book stresses that all good research should be seen as a process of constantly assessing one s work and making decisions about the best possible **Researching Real-World Problems** Zina O'Leary, 2005-11-04 This is the means for obtaining credible data and results perfect book for any student new to Research Methods It is brilliantly written witty and always easy to understand Taking as her starting point the need for students to conduct research for themselves in the real world Zina O Leary guides those new to research through the whys and how tos of the entire research process Always student focused this book offers a hands on and practical guide to the research process from the initial process of coming up with a good guestion via methods of gathering information through to the writing process itself Researching Real World Problems Makes the entire research process a meaningful experience Provides a jargon busting hands on guide to the entire research process Is illustrated throughout with real life examples Speaks directly to the needs of the new researcher Locates the researcher and research process at heart of a complex web of social structures O Leary draws her examples from the full range of the Social Sciences and this is the perfect text for any student in Health Education or Applied Social Science **Transitional Justice from Below** Kieran McEvoy, Lorna McGregor, 2008-07-15 Although relatively new as a distinct field of study transitional justice has become rapidly established as a vital field of enquiry From vaguely exotic origins on the outer edges of political science the study of justice in times of transition has emerged as a central concern of scholarship and practical policy making A process of institutionalisation has confirmed this importance The ICTY the ICTR the ICC hybrid tribunals in Sierra Leone and East Timor and local processes such as the Iraqi Higher Tribunal IHT have energised international law and international criminal justice scholarship The South African TRC was for a time lauded as the model for dealing with the past and remains one of the most researched institutions in the world It is one of approximately two dozen such institutions established in different transitional contexts over the past twenty years to assist conflicted societies to come to terms with a violent past At the

national level international donors contribute huge sums of money to Rule of Law programmes designed to transform national justice systems This collection seeks to offer something quite different to the mainstream of scholarship in this area emphasising the need for bespoke solutions to different transitions rather than off the shelf models The collection is designed to offer a space for diversity prompted by a series of perspectives from below of societies beset by past violent conflict which have sought to effect their transition to justice In doing so the contributors have also sought to enrich discussion about the role of human rights in transition the continuing usefulness of perspectives from above and the still contested meanings of The Well-Connected Community Alison Gilchrist, 2019-09-18 There is growing recognition in practice and policy of how networking contributes to the vitality and cohesion of community life and civil society The Well Connected Community provides theoretical insights and practical guidance for people working with and for communities This updated edition takes account of the changing political and economic context including rising social inequalities and community tensions It considers new approaches to well being such as social prescribing and the use of social media for local and global organising This model of community development explains and promotes networking as a skilled and strategic intervention and provides recommendations for good practice From Subjects to Subjectivities Deborah L. Tolman, Mary Brydon-Miller, 2001 From Subject to Subjectivities profiles the recent debates about the role of qualitative and participatory methods in psychology a discipline which has traditionally seen itself as a form of positivistic science Contributors explain how fundamentally different views of the nature of reality and of scientific theory have shaped these debates and how psychology is being transformed through the use of these methods At the heart of the book are 10 exemplars of interpretive and participatory action research which describe the rationale for and process of using these methods in actual cases They also articulate some of the challenges psychologists may face in adopting them offering insights into how these complications can be successfully negotiated Relevant beyond psychology the models provided can be used within the context of a wide array of social science disciplines from sociology and anthropology to women s studies and public health The contributors represent a veritable who s who of qualitative scholars including Lyn Mikel Brown Larry Davidson Michelle Fine Louise Kidder M Brinton Lykes Jeanne Marecek Abigail Stewart and Niobe Way No previous book has examined qualitative and participatory methods specifically within the context of psychology From Subjects to Subjectivities provides a unique and badly needed resource for those interested in learning about the practice of these methods in the field Applied Drama and Theatre as an Interdisciplinary Field in the Context of HIV/AIDS in Africa Hazel Barnes, 2014-03-25 Drama for Life University of the Witwatersrand aims to enhance the capacity of young people theatre practitioners and their communities to take responsibility for the quality of their lives in the context of HIV and AIDS in Africa We achieve this through participatory and experiential drama and theatre that is appropriate to current social realities but draws on the rich indigenous knowledge of African communities Collected here is a representative set of research essays written to facilitate dialogue across

disciplines on the role of drama and theatre in HIV AIDS education prevention and rehabilitation Reflections are offered on present praxis and the media as well as on innovative research approaches in an interdisciplinary paradigm along with HIV AIDS education via performance poetry and other experimental methods such as participant led workshops Topics include the call for a move away from the binaries of much critical pedagogy a project undertaken in Ghana and Malawi with people living with AIDS to create and present theatre the contradictions between global and local expectations of applied drama and theatre methodology in relation to folk media participation and syncretism Three case studies report on mapping as a creative device for playmaking the methodology of Themba Interactive Theatre and applying drama with women living with HIV in the Zandspruit Informal Settlement The essays validate the importance of play in both energizing those in positions of hopelessness and enabling the distancing essential to observe one s situation and enable change The book stimulates the ongoing investigation of current practice and extends an invitation to further develop innovative approaches Hazel Barnes is a retired Head of Drama and Performance Studies at the University of KwaZulu Natal where she is a Senior Research Associate Her research interests lie in the field of applied drama including the contexts of interculturalism and post Qualitative Research Maggi Savin-Baden, Claire Howell Major, 2025-10-15 The second edition of traumatic stress Qualitative Research is a one stop resource for all those approaching qualitative research for the first time as well as those revisiting core concepts and issues It presents a comprehensive overview of this rapidly developing field of inquiry cleverly combined with practical hands on advice on how to conduct a successful qualitative study Written in an engaging and accessible style this new edition includes updates such as further readings and case studies to help researchers to recognize developments in the field Further updates include how to use social media in ethical and responsible ways working with participants at a distance and the pros and cons of analyzing data online The authors break through difficult terminology to guide readers through the choices they will face during research design implementation and publication Each chapter is brought to life by relevant real life examples from expert researchers around the globe Divided into seven sections this unique text covers Considering perspectives Acknowledging a position Framing the study Choosing a research approach Collecting data Working with data and findings Writing about the research This book is enhanced with the addition of online Instructor and Student Resources including videos diagrams an instructor manual PowerPoint slides and links to further resources These can be found at routledgelearning com qualitativeresearch This new edition is an indispensable companion and makes for ideal reading for all those involved in qualitative research worldwide Handbook of Development Policy Studies Gedeon M. Mudacumura, M. Shamsul Haque, 2004-04-23 Considering the current challenges to human progress this reference book examines recent theories policies and sectoral priorities as well as various social economic and administrative factors that impact worldwide modernization and development The book emphasizes the fact that communities must evaluate Capabilities Equality Alexander Kaufman, 2007-05-07 In this volume leading continuously and adjust their program

scholars present new and original essays to address controversies raised regarding the focus structure and justification of the capabilities approach to equality

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