

# Participatory action research: considerations for ethical review

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Available online 19 December 2004

## Abstract

This paper addresses the distinctive nature of participatory action research (PAR) in relation to ethical review requirements. As a framework for conducting research and reducing health disparities, PAR is gaining increased attention in community and public health research. As a result, PAR researchers and members of Research Ethics Boards could benefit from an increased understanding of the array of ethical concerns that can arise. We discuss these concerns in light of commonly held ethical requirements for clinical research (social or scientific value, scientific validity, fair subject/participant selection, favourable risk–benefit ratio, independent review, informed consent, and respect for potential and enrolled participants) and refer to guidelines specifically developed for participatory research in health promotion. We draw from our community-based experiences in mental health promotion research with immigrant and culturally diverse youth to illustrate the ethical advantages and challenges of applying a PAR approach. We conclude with process suggestions for Research Ethics Boards.

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*Keywords:* Health research; Participatory action research; Research ethics; Research ethics boards

## Introduction

Participatory action research (PAR), as an approach for conducting research across diverse areas of inquiry and social change, has an emergent history in the social sciences. More recently it is gaining increased attention in health research, particularly in the public health context (Minkler & Wallerstein, 2003). Despite its relevance for reducing health disparities, PAR approaches to scholarship continue to be viewed dubiously by academia (Minkler & Wallerstein, 2003).

For academic practitioners of PAR, practical and structural obstacles can pose challenges to conducting research. One challenge is related to the existing

institutional processes for gaining ethical approval to conduct PAR studies. The unique nature of PAR may be misunderstood making PAR protocols difficult to evaluate well. Current ethics regulations have also been criticized as being too narrowly developed for biomedical research, which results in further challenges for reviewers and researchers (Oakes, 2002).

In this paper, we address the distinctive nature of PAR in relation to ethical review. We argue that research using a PAR framework can result in complex ethical challenges. First, an overview of PAR, action research, and participatory research are provided. Next, issues related to the ethical review process of PAR protocols are considered in light of Emanuel, Wendler, and Grady's (2000) seven ethical requirements of clinical research along with additional insights from guidelines for participatory research in health promotion developed by Green et al. (1995). Drawing from the authors' experiences in mental health promotion research with

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immigrant and culturally diverse youth, ethical advantages and challenges of applying a PAR approach are discussed. We conclude with five process suggestions for Research Ethics Boards evaluating PAR studies.

### Participatory action research

PAR originates from the fields of adult education, international development, and the social sciences (Denton, Hajdukowski-Ahmed, O'Connor, Williams, & Zeytinoglu, 1994; Maguire, 1987; Smith, Pynch, & Lizardi, 1993). It is recognized as a more inclusive form of inquiry (Stringer & Genat, 2004) and is often practised in cross-cultural contexts (McTaggart, 1991). PAR can be viewed as a way of “bringing participation into action research” (Elden & Levin, 1991). PAR is not a method of conducting research but rather an orientation to research (Minkler & Wallerstein, 2003). It can involve quantitative, qualitative, or combined data gathering methods, depending on the issue under investigation. There are variations in the degree to which studies are influenced by a PAR approach (Khanlou et al., 2002), as there is no one way of doing community-based participatory research (Israel et al., 2003). This can result in challenges in applying ethical guidelines when evaluating PAR studies.

PAR arises from two research approaches: action research (AR) and participatory research (PR). AR's roots draw from social psychological tenets associated with the “Northern tradition” of research while PR's roots are embedded in the emancipatory movements associated with the “Southern tradition” of research (Wallerstein & Duran, 2003). Within transnationalizing societies, the distinct geohistorical roots of AR and PR result in a complementary tension, allowing for creative health promotion initiatives in culturally diverse settings. Each approach is considered in more depth in the following sections.

#### *Action research*

In 1946, the term action research was introduced by Kurt Lewin to signal a “pioneering approach toward social research which combined generation of theory with changing the social research system through the researcher acting on or in the social system” (Susman & Evered, 1978, p. 586). The approach was distinct from the traditional positivist science and arose from Lewin's concern to find methods that dealt with critical social problems such as poverty, fascism, anti-Semitism, and minority issues. He believed individuals' social behaviour was a function of their social perceptions and consequently, the researcher's task was to discover “the meanings actors gave to events while they were acting” (Peters & Robinson, 1984, p. 116). Because the relation-

ship between the meanings and the objective events differed across individuals and social contexts, the importance of maintaining the gestalt of the social phenomena, that is “the background and context that the actors themselves used to derive meaning from their social environment”, was emphasized in Lewin's work (Peters & Robinson, 1984, p. 116).<sup>1</sup>

Action research involves a cyclical process resembling a spiral of steps (Brown & Tandon, 1983; Cunningham, 1976; Susman & Evered, 1978). Each circle consists of formulating a plan of action (planning), implementing the plan (action), and fact-finding about the results of the plan (evaluation) in order to concurrently solve problems and create new knowledge. Based on the evaluation, the plan is revised and a new plan is implemented, and hence another cycle begins.

#### *Participatory research*

The term participatory research came from Tanzania in the early 1970s (Park, Brydon-Miller, Hall, & Jackson, 1993). With its origins rooted in work with oppressed peoples in developing areas, variations of participatory research have developed, usually independently, in different settings (Brown & Tandon, 1983). Individuals contributing to the field come from different regions of the globe (Hall, 1981) including Africa, Asia, Europe, Latin America, and North America. Participatory research is a process that combines research, education, and action.

In a seminal paper, on participatory research, Hall (1981) identified its goal and characteristics. The goal of participatory research is structural transformation and its target of focus is “exploited or oppressed groups; immigrants, labour, indigenous peoples, women” (p. 7). People in the community or workplace control the entire research process, including identifying the problem to be studied. In participatory research, researchers can be community or workplace members. Hall observed that, “Although those with specialized knowledge/training often come from outside the situation, they are committed participants and learners in a process that leads to militancy rather than detachment.” (p. 8). Participatory research entails the mobilization of people and enhanced awareness of their abilities and resources. Hall (1981) noted that a combination of the elements of

<sup>1</sup>During the same time, there was a parallel and independent development to action research in Britain (Holter & Schwartz-Barcott, 1993; Susman & Evered, 1978). An interdisciplinary group formed the Tavistock Institute of Human Relations. Unlike Lewin who drew from social and experimental psychology, the Tavistock group was more embedded in psychoanalysis and social psychiatry. However, both were committed to utilizing the social sciences to provide solutions to social problems and to develop knowledge.

social investigation, educational work, and action in an interrelated manner is both stimulating and provides difficulty for those engaged in participatory research or those attempting to understand it.

#### *Comparison of ideologies of action research with participatory research*

While action researchers and participatory researchers share similar overall values, they differ in their ideological beliefs as to how these values can be achieved (Brown & Tandon, 1983). Both value useful knowledge and place a high value on developmental change. Useful knowledge is one that has practical use. Developmental change in action research is the attempt “to make social systems more efficient and effective, to promote the fulfilment of human potential, to solve the problems of individuals or institutions”, and in participatory research it is the emphasis on “research implications that enable oppressed groups to improve their lives” (p. 281).

Differences in the ideological beliefs of action researchers and participatory researchers arise from their background training and the context in which the research has developed (Brown & Tandon, 1983). Action researchers are usually trained in clinical and social psychology and management theory. Their ideological views, therefore, emphasize individual, interpersonal, and group levels of analysis. Participatory researchers are usually adult educators and community organizers. Drawing from sociology, economics, political science, and individual and group theory, they often emphasize community and social structures.

Developed within the context of industrialized countries, the ideological postulates of action research are influenced by the cultures of affluent nations with emphasis on such concepts as efficient and effective task accomplishment, the centrality of individuals, and consensus social theories (Brown & Tandon, 1983). Influenced by the cultural contexts of work with the poor in developing areas, participatory researchers view issues in relation to dependence, oppression, and resource inequities.

The combination of the above differences increases the relevance of participatory action research in studying health promotion in culturally diverse settings. The action research component provides an ongoing, spiral framework where the participants themselves evaluate the validity and the relevance of the research process. The participatory research component incorporates equity and resistance to societal oppression.

#### *Implications for ethics approval of PAR studies*

Numerous guidelines on the ethics of research using human participants exist internationally including *The Nuremberg Code* (1996), the Declaration of Helsinki

(World Medical Association, 1997, 2000), the Belmont Report (US National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979), International Ethical Guidelines for Biomedical Research Involving Human Subjects (CIOMS, 1993), and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (MRC, NSERC, & SSHRC, 1998).

Emanuel, Wendler, and Grady (2000) have drawn on the basic philosophies of a number of these guidelines to develop a coherent framework for evaluating the ethics of research studies involving human participants. They propose the following seven requirements: social or scientific value, scientific validity, fair subject/participant selection, favourable risk–benefit ratio, independent review, informed consent, and respect for potential and enrolled participants. We have chosen their framework because it draws on features common to many ethical review standards internationally. By focusing on these requirements, we discuss the challenges of meeting and evaluating the ethics of PAR studies.

In considering new directions, we refer to parallel concepts within the context of the six guidelines developed by Green et al. (1995) for participatory research in health promotion. The Green et al. guidelines assess: participants and the nature of their involvement, origin of the research question, purpose of the research, process and context-methodological implications, opportunities to address the issue of interest, and nature of the research outcomes. While we do not attempt to address specifics of the overlaps between Emanuel et al.’s framework and Green et al.’s guidelines, our intention is to indicate existing grounds of consensus, or disagreement, for ethical evaluation of PAR studies. We consider two of the criteria (Favourable Risk–Benefit Ratio and Informed Consent) in further detail through examples from our research under a subsequent section entitled “Applying PAR in mental health promotion research with youth.”

#### *Social or scientific value*

The wise use of scarce resources and the ethical responsibility to avoid exploiting research participants requires that health research will improve the well-being of people or will increase knowledge (Emanuel et al., 2000). PAR, like other health research, is fundamentally directed toward improving well-being. PAR, however, tends also to have political overtones. Kemmis and McTaggart (2000) state, “Participatory action research is emancipatory. Participatory action research aims to help people recover, and release themselves, from the constraints of irrational, unproductive, unjust, and unsatisfying social structures that limit their self-development and self-determination.” (p. 597). As such, the knowledge gained from PAR is focused upon action, not understanding alone (Cornwall & Jewkes, 1995).

Researchers and ethical reviewers must consider whether a protocol truly has such emancipatory potential. It is important to consider whether the purpose of the research is directed toward empowering the community to address the determinants of health and whether there is evidence of the community's and the researchers' commitment to and interest in the issue. The impetus for the research should also be considered. Did the community participate in the identification of the issue? Are community members adequately enabled to contribute their resources to the research? Does the potential exist for community participants to learn about, develop, and access resources for self-determination? These evaluation markers are concomitant to Green et al.'s (1995) origin of the research question, and purpose of the research guidelines.

#### *Scientific validity*

A research project must use rigorous scientific principles and methods to be ethical. Like the first requirement of social and scientific validity, without scientific validity a research project, because of its incapacity to produce meaningful results, could waste scarce resources and could exploit research participants by needlessly exposing them to risk and inconvenience (Emanuel et al., 2000). Because PAR is an orientation to research, as opposed to a research method per se, a variety of both quantitative and qualitative research methods can be employed. As Israel et al. (2003) argue, decisions around research design and methodology are not dictated by PAR<sup>2</sup> principles. Rather such decisions arise from the particular community context and research foci of the research partnerships.

Therefore, a number of approaches to assessing validity and rigour are applicable and appropriate for reviewing purposes. In addition, Green et al.'s guidelines regarding the purpose of the research and the process and context can be applied to determine whether the research has social validity from a community perspective.

#### *Fair subject selection*

Fair subject selection requires that the goals of the research, not the vulnerability or privilege of individuals, should be the primary basis for determining which individuals and groups are recruited. Also, as much as possible, those who bear the risk and the burdens of research should have the possibility of being able to benefit from the research (Emanuel et al., 2000). PAR generally involves groups and communities who are vulnerable and oppressed necessitating that great care is

taken that these participants will benefit from the research. One of the ideals of PAR is that the beneficiaries of PAR should be those who are directly involved in the research (Hall, 1981). A protocol using a PAR framework, therefore, should clearly state how participants have been involved and how they will benefit from participating given the articulated purposes of PAR.

Within particular communities issues can also arise with respect to the fair selection of participants. Interested members of a community should be given meaningful opportunities to participate, especially if they have been under-represented in the past (Green et al., 1995). Two of Green et al. guidelines, namely participants and the nature of their involvement, and opportunities to address the issue of interest, deal with the participation of community members in the research process and can apply here. Barriers to participation can be lessened if attention is given to such things as flexibility in scheduling, and participants' needs for childcare, transportation, and computer access.

It is also necessary to determine who belongs and does not belong to a given community, a process that can be fraught with social and political ramifications. For example, Minkler et al. (2002), whose research used PAR to explore the dilemma of death with dignity or physician-assisted suicide with a community of people with disabilities, describe the difficulty of determining inclusion and exclusion criteria. This study restricted participants to individuals with physical disabilities, which led to the dismay of individuals with other disabilities or impairments such as blindness, hearing loss or HIV/AIDS who also wanted to be involved.

#### *Favourable risk–benefit ratio*

In all research projects risks must be minimized and potential benefits enhanced to the greatest extent possible, such that the risks to participants are proportionate to the possible benefits to individual participants or to society more generally (Emanuel et al., 2000). The potential benefits of PAR studies need to be considered when weighing the potential risks. PAR is explicitly value driven in that it clearly focuses on the emancipation of a wide range of exploited or oppressed groups. It strives to help people recover and release themselves from harmful and unjust social structures (Kemmis & McTaggart, 2000). Often the impetus for the research comes from the community itself and the outcomes of the research can directly improve the well-being of those involved. Participants are enabled to contribute their physical and/or intellectual resources to the research. This process itself can facilitate learning among community members regarding resources for self-determination and research methods (Green et al., 1995). Whether community participants benefit from PAR is addressed

<sup>2</sup>We have substituted the term used by Israel et al. (2003), Community-Based Participatory Research (CBPR), with PAR. CBPR is the name used by researchers in the United States to refer to PAR.

by Green et al.'s guidelines on the nature of the research outcomes.

Nevertheless, PAR is not conducted without risks. A serious risk could develop if the results of PAR in a given community unleash serious political consequences. Because PAR is centred upon challenging the status quo, community participants can be left more vulnerable, marginalized, and exposed in some hostile environments (Cornwall & Jewkes, 1995; Farquhar & Wing, 2003; Ugalde, 1985; Williamson & Prosser, 2002). Ugalde (1985) describes how community participation in Latin America in the 1970s led to further exploitation of the power, cultural deprivation, and political violence. Moreover, Cornwall and Jewkes (1995) describe how the ideals of democracy that are used to advocate for participation can amount to nothing more than Western cultural imperialism. Therefore, it is imperative that an acute sensitivity to the politics and culture of communities is demonstrated before a PAR project is initiated.

#### *Independent review*

Independent review ensures that individuals who are unaffiliated with a research project evaluate the proposal to ensure that ethical and scientific standards are met. Independence ensures public accountability and minimization of potential conflicts of interests (Emanuel et al., 2000). The cyclical process of PAR can present difficulties for both those proposing PAR studies and those evaluating them. Although most of the scientific methods used by PAR researchers are not dissimilar from those used by researchers using other approaches, these methods are often not known before the research begins. It would be antithetical to PAR principles for PAR researchers to propose methods before having involvement with the community of interest. Yet, ethics approval must be sought before the research begins and generally, barring any major change in procedure, it is often sought only once, at the beginning of the research. PAR researchers, like other researchers using emergent designs, often cannot anticipate the specific questions and methods that will arise in the future nor can research ethics committees evaluate the scientific validity and ethical merit of a protocol that has not yet described its methods. The cyclical nature of PAR may require that researchers seek ethics approval upon each cycle of the research process. The potential burden and cost of multiple reviews could be minimized through the development of guidelines and procedures for PAR that facilitate an expedited review process for each cycle of the research.

All six of Green et al.'s guidelines can inform the review process.

#### *Informed consent*

Emanuel et al. (2000) define informed consent as the "provision of information to participants, about pur-

pose of the research, its procedures, potential risks, benefits, and alternatives, so that the individual understands this information and can make a voluntary decision whether to enrol and continue to participate" (p. 2703). Because the term "researcher can refer to both the community participants involved and external persons with specialized training" (Green et al., 1995, p. 45), researcher and participant roles are indistinct in PAR, making it unclear how obtaining informed consent should be carried out. Who should be giving or obtaining informed consent? What should the process be like?

The responsibility for obtaining informed consent should likely fall on those who initiate a project. The information provided by community members who are approached, however, might differ somewhat from many other types of research. Generally, in research not using a PAR framework, participants are given information about the purpose and methods of the research, its benefits for the participant and for society in general, its potential risks, and details regarding the protection of confidentiality. With a PAR design, it should be incumbent upon the initiator of the research to begin a process of information exchange that, in the broadest sense, would constitute informed consent. It may be more fitting to envision informed consent as a mutual negotiation process, where co-researchers determine the terms and conditions of their joint efforts.

#### *Respect for potential and enrolled participants*

Respect for participant autonomy and welfare are demonstrated through the protection of confidentiality and privacy, the disclosure of newly discovered risks and benefits, the permission to participants to withdraw from the research, the maintenance of participant welfare, and the provision of the results of the research to participants (Emanuel et al., 2000). With PAR the roles of researcher and researched are blurred, which can result in unique ethical concerns in such a way that conventional ideas regarding respect are expanded. As Cornwall and Jewkes (1995) state: "Ultimately, participatory research is about respecting and understanding the people with and for whom researchers work. It is about developing a realization that local people are knowledgeable and that they, together with researchers, can work toward analyses and solutions. It involves recognizing the rights of those whom research concerns, enabling people to set their own agenda for research and development and so giving them ownership over the process" (p. 1674).

As such, guidelines protecting research integrity could be very helpful to protect both researchers and participants, who may be more accurately considered co-researchers. Specifically, the co-researchers could form explicit agreements concerning matters related to not only research design, but also to their individual

roles and responsibilities in the project. Agreements would also need to be made regarding the interpretation and ownership of data, authorship and the dissemination of findings, and financial accountability. With the blurring of the researcher and participant roles, special concerns regarding the need to protect confidentiality would also require attention. Anonymity and confidentiality could prove difficult to maintain because a great many individuals could be involved in the research. Raising these concerns at the beginning of a project could help prevent future problems.

#### *Applying PAR in mental health promotion research with youth*

Drawing from our previous studies guided by a PAR approach, in this section we examine two of the above criteria, namely Favourable Risk–Benefit Ratio and Informed Consent, in more detail. As brief background information, in one study we researched with East Indian-Canadian female youth regarding mental health promotion in a cross-cultural context (Khanlou & Hajdukowski-Ahmed, 1997, 1999). The qualitative longitudinal study consisted of a series of focus group meetings with the same group of youth. In another study with newcomer female youth in English as Second Language classes, we considered both individual and systemic aspects to mental health promotion in the resettlement society for new immigrant youth (Khanlou et al., 2002). The qualitative study entailed focus groups and/or interviews with youth, educators, parents, and settlement workers.

#### *PAR and favourable risk–benefit ratio*

A rewarding aspect of applying PAR in our area of health research has been the inherent parallels between the tenets of PAR and developing conceptions of mental health promotion (Khanlou, 2003, Khanlou et al., 2002). These include recognizing people's capacities, improvement in the lives of those involved, and their potential for action. Participatory action research has provided us with a model in which the participants' voices have a primary place in the research process, placing their experiences within the sociocultural context out of which they arise. We have found other advantages of PAR guided studies to include (Khanlou et al., 2002; Khanlou & Hajdukowski-Ahmed, 1999, 1997):

- (1) A mutual sharing of knowledge, skills and experiences among the participants and researchers.
- (2) Support of action and development of specific skills, such as leadership, by the participants.
- (3) Positive evaluation and support of the process by the youth participants. Specifically these included new learning regarding the self within a social context,

the acquisition of new skills, and an increased sense of empowerment.

Two overall caveats that require mentioning in using PAR in community studies result from the time dimension and in-group process:

- (1) In longitudinal studies, due to attrition over time, some participants, who were active in the initial phases of the research collaboration, may not receive the direct benefits at the end of the project. Examples of direct benefits include knowledge, resources, and networks.
- (2) Because PAR often involves groups of people or entire communities, individuals who may not wish to participate in the process can feel group pressure to do so. This second issue also has implications for voluntary consent. Thus, group consent may, in effect, supersede individual consent, as the well-being of the group becomes more important.

In our case, the longitudinal aspect of the first study (Khanlou & Hajdukowski-Ahmed, 1997), i.e., meeting the same group of students over a period of several months, contributed to many of the advantages listed. However, in the case of both studies (Khanlou et al., 2002; Khanlou & Hajdukowski-Ahmed, 1997), because the groups were transient and had time limitations, the students did not take part in an important part of the process, i.e. being involved in, or at least validating, our analyses. Therefore, PAR may be more effective in long-term designs with less transient group membership. The criterion of validating findings with participants implies that PAR studies should be expected to have longer time spans.

#### *PAR and informed consent*

In our studies guided by a PAR framework we conducted pre-focus group meetings with potential participants to exchange as much information as possible prior to data gathering and attaining consent. For example, in the study with East Indian-Canadian female youth, we held two pre-focus group meetings with youth leaders and potential participants (Khanlou & Hajdukowski-Ahmed, 1997, 1999). Overlapping areas of interest by the youth and researchers, directions for future focus groups, role expectations, confidentiality and group ownership of the process were discussed prior to the gathering of data. In the study of newcomer female youth in English as Second Language classes, we met with secondary school educators and settlement workers prior to focus groups with newcomer female youth (Khanlou et al., 2002). In line with the participatory features of the study, feedback was attained on issues to be addressed with the youth. For example, copies of general questions for the focus groups and

research questionnaire were distributed and discussed for relevancy and validity.

We submit that pre-data gathering meetings can also be relevant to studies that are not PAR-driven. For example, in our current ethnographic study of immigrant youth and cultural identity (Khanlou, Siemiatycki, & Anisef, 2003), we hold pre-focus group information sessions with youth. The purpose of these meetings is to provide potential participants information about the study in terms of its focus, procedures (specifically what participation would entail for the youth), and answer any questions.

## Conclusion

As recognition of PAR-driven research in reducing health disparities and promoting the health of communities gains momentum, academic-based researchers must work toward institutional changes that facilitate PAR research. In the health field, one area of change is related to existing Research Ethics Boards (REB) processes. In this paper, we considered the overlap and tensions between ethical review guidelines based on clinical research and those formulated for participatory research in health promotion. Based on our analysis, we conclude with the following process suggestions for REBs reviewing PAR proposals:

1. PAR is an overall approach toward health research, instead of a single-method. It may entail quantitative, qualitative, or integrated designs. Therefore, REBs require members with knowledge of positivistic, naturalistic, or combined approaches to research in reviewing PAR proposals.
2. PAR draws from action research (AR) and participatory research (PR). REB members would benefit from familiarizing themselves with the differing ideologies, yet parallel values, of each. In doing so, they would recognize why the type of discourse used can vary from one proposal to another. They would also recognize whether researchers are mis-identifying the nature of their inquiry. For example, a proposed study may identify itself as PR, while in reality its goals are closer to AR.
3. Given the large variations in context, goals, and processes embedded in PAR-driven research, an itemized and list-oriented approach to evaluating the ethical merits of a PAR proposal can be ineffective. Instead REBs may want to discuss overall ethical guidelines in evaluating PAR studies, relate these to specific criteria they use to evaluate other health studies and hold them accountable to, and return back to the overall ethical concerns of the proposal. Thus, the ethical review of a PAR proposal would resemble the dynamic approach inherent to

PAR, alternating between focussing on the large picture and on specific aspects.

4. The cyclical and non-linear approach embedded in PAR, coupled with the blurring of the researcher and researched roles, and the production of knowledge both as a means and an end, also require context-bound evaluations of the ethical merits of PAR studies. Including the communities who are involved in potential PAR studies on REBs can be a step toward this direction. For example, knowledgeable community members can alert REBs to possible risks involved to participants both at the individual and group level.
5. Finally, as with other approaches to health research, PAR oriented research may not be suitable to all topics of health promotion inquiry. REBs need to consider and suggest more suitable approaches to studying particular health phenomenon and processes as necessary.

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