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**Title: Action researchers encountering ethical review: a literature synthesis on challenges and strategies**

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**Abstract**

Action research (AR) comprises a diverse family of methodologies. Common amongst most types of AR are both an emergent design – leading to action or change - and participation or community involvement. While this type of research has expanded considerably since the early 2000's, the criteria used for ethical review have apparently been slow to adapt to the emergent and participatory nature of this research. This has resulted in researchers reporting negative attitudes towards, and experiences with, review boards and ethics review processes; painting ethical review committees at times, as insufficient or unnecessary.

A review of the literature was undertaken to assess the state of play in this regard. Few articles disclose the side of the ethical review boards or committee members and the issues they face in undertaking ethical review of studies with an emergent, action, or participatory focus. A larger number of peer-reviewed journal articles report on the views of the researchers, but mainly through specific case examples where ethical review processes presented challenges to researchers and communities employing a participatory approach to research. The focus of this article will be on both the generic challenges researchers report in managing ethical review and of strategies utilized or recommended to conduct participatory research in an ethical manner. The contrasting experiences of researchers and ethical review committee (ERC) members will be considered where available.

**Key Search Terms:** *Participatory approaches, Action Research, Institutional Review Boards, Ethical Review*

## Introduction

It is widely accepted that ethical review is a necessary process to safeguard researchers and participants whilst ensuring accountability by both researchers and organizations (Stoecker, 2008). Institutional review boards (IRBs), human research ethics committees (HRECs), research ethics boards (REBs), research review committees (RRCs), and ethical review boards (ERBs) (all of these referred to as ethical review committees (ERCs) for the purpose of this article), are appointed to apply and approve the ethical standards through which research is implemented. These standards are for the most part firmly guided by a biomedical framework, suggesting that ethics are managed primarily on how the *individual* researcher(s) will satisfy the principles of autonomy, non-maleficence, beneficence, and justice rather than consideration of potential *community* harm (Glass & Kaufert, 2007). Traditional guidelines for ethical review processes often leave little space for participatory approaches where communities are actively involved in the research.

Ethical considerations to be contemplated in implementing various forms of participatory research studies are comprehensively discussed and synthesized in the literature (Mikesell, Bromley, & Khodyakov, 2013). Of the articles that highlight challenges in addressing these ethical considerations, some discuss the role of ERCs. Research on ethical review processes reveal that there is over 50% variability in formal policy guidelines for ethical review processes in the United States (Silverstein, Banks, Fish, & Bauchner, 2008) and this diversification is echoed by studies conducted in other countries (Flicker, Travers, Guta, McDonald, & Meagher, 2007; Shore et al., 2011). A divide exists between ERCs and researchers employing participatory approaches (Reid & Brief, 2009). Despite efforts made in some institutions to adopt a more inclusive ethical review process that considers the safety of the communities and is open to collaborative relationships within the research process, scholars argue that ERCs mostly remain uninformed, underprepared and often unwilling to deal with projects of such nature (Flicker et al., 2007; Ross et al., 2010; Shore, 2007; Sigler, 2009). This can either result in sub-standard reviews, which may approve projects that have not adequately dealt with tensions that might have devastating effects for both the researcher and the community or the project. Or, for review committees who find the participatory paradigm uncharted territory, it may lead to the rejection of a perfectly viable project. Conversely, scholars encourage dialogue in early project stages. This enables stronger relationships between ERC's

and researchers, as to address the potentiality of harm resulting from poorly communicated objectives on the part of ERCs, and the disregard of researchers to take responsibility (Wolf, 2010). This article aims to identify the ethical challenges different researchers have reported when going through the ethical review process and to identify the strategies documented in the literature to facilitate more effective ethical review in participatory studies.

### **Focus of the literature review**

The family of action research (AR) methodology is manifest in traditional, radical, educational, and contextual forms (Reid & Brief, 2009). Each type fathers research approaches that have developed out of a specific style of AR. These approaches include but are not limited to participatory action research (PAR), community-based participatory action research (CBPR), feminist AR, educational AR, community-based research (CBR), appreciative inquiry, collaborative AR, co-operative research, as well as organization or institutional AR (Burns, 1999; Heron & Reason, 2001; Reid & Brief, 2009).

When discussing AR and any of its relatives, it is important to note their common denominator - the emergent design. Top-down or linear approaches to research that typically characterize proposals submitted for ethical review, are aimed at the development of new knowledge; leaving little space for reflection, flexibility or incorporation of the diverse voices of individuals (Reid & Brief, 2009). AR methodologies transcend this traditional research approach. They enable community capacity building, empowerment of groups and action plans as a result of (and often as part of) the project. As knowledge generation is not the sole goal, ERCs are often perplexed by these approaches (Pritchard, 2002).

Since its earliest roots, AR has always been linked to community participation (Kemmis & McTaggart, 2005). However, not all community-based research produces action and not all action research can be said to involve communities. For a literature review on research ethics processes related to non-traditional research to be comprehensive, a decision was made to include any approach in the AR family, as long as it was primarily defined by its 'community-participatory' nature. 'Community' is defined based on the study context, and 'participation', involved any studies working directly with, and not on, community members. This decision was made to address Cahill's (2007) concern that "broad applications of the term

‘participation’ may mask tokenism and provide an illusion of consultation” (p.362). This review therefore focused on published material reporting on participatory research studies, which actively engaged communities and underwent ethical review processes.

## **Method**

The literature search comprised conference papers, peer-reviewed articles, newspapers and abstracts relating to this topic. Titles, abstracts, and keywords of international databases were searched, such as Google Scholar, Social Care Online, Social Work Abstracts Plus, ProQuest Social Science Journals, SAGE publications, Taylor & Francis Online, and Web of Science Core Collection to explore and source relevant literature. A broad list of search terms were used to find studies describing AR (e.g., “action research,” “PAR,” “CBPR,” “co-inquiry,” “collaborative research,” “community-engaged,” “community engaged,” “community engagement,” “partnership research”, “participatory approaches”). The aforementioned terms were combined with those concerning ethics (e.g., “ethics,” “harms,” “power,” “ethics and community research,” “ethical challenges,” “ethical review processes,” “IRBs,” “RECs,” “institutional review boards,” “ethical dilemmas,” “ethical guidelines,” “harm,” “research ethics committees,” and “research oversight”). The wide-range of search terms generated an extensive amount of articles of differing value. On identification of relevant material, several criteria were used for the inclusion of articles for review:

- 1) the research methodology was grounded in the AR family;
- 2) either a formal or informal ethical review process was reported;
- 3) the researcher engaged with a community (loosely defined);
- 4) issues related to ethical review were the primary focus of the article - not on how participatory studies could be conducted in a more ethical manner;
- 5) published between 2000 and 2014; and
- 6) written in or translated to English.

Several of the articles that were discarded, did not focus exclusively on community-participatory approaches, but undoubtedly make valuable contributions about how ERCs can improve their review processes for various types of research. This review focuses specifically on those studies that documented actual challenges

which were experienced by ERC members or occurred during the relationship between the review process and when participatory approaches were applied by researchers. The initial search returned 240 sources. After locating the articles and scanning their abstracts, 102 were deemed potentially eligible to meet the inclusion criteria. A primary reading of sections of these articles indicated that the full text of 84 articles needed to be read as they mentioned ethical challenges related to AR studies. While many of these articles had sound conclusions about ERC's evaluation of AR studies and how participatory studies could be made more ethical, a final sample of 39 articles were selected for review. These 39 articles were most closely connected to the primary focus of this article, namely identifying challenges and strategies for ethical review to enhance review processes for AR based studies.

In-depth reading of each of these articles highlighted that they shared reference to one or more of three themes: 1) discussions about the ethical challenges of conducting CBPR and recommended strategies to improve ethicality; 2) suggestions on what should and should not comprise ethical review of studies employing AR methodology; and 3) the role of ERCs in the process of initiating an AR project. Further analysis of these themes highlighted two key focus areas for the discussion: challenges with the ethical review of community-participatory research; and strategies utilized by both community-based researchers and ERCs to improve ethical review processes.

The pool of literature documenting ERC member experiences of reviews is extremely small – especially in the case of community-participatory studies. Databases were comprehensively searched for literature relating to ERC members' experiences of reviewing AR studies. The focus was on specifically identifying recommendations from, and not for, ERC members reviewing action research studies. Synonymous terms were inputted into search criteria as well, and zero results were returned. However, through systematically reading full-text articles that were identified as relevant to this review, one study (Wolf, 2010) offered the position of an ethical review committee member and is considered in this article.

The final selection of articles still proved to be highly diverse in type, scope, purpose, and field of research. Nevertheless, variability allowed us to identify unique aspects of ERC review in community-participatory approaches that had been rarely discussed and definitely not condensed in previous literature. While a systematic approach to reviewing literature was at times overwhelming due to the quantity of

research available (not specifically related to our review) it allowed us to have a greater understanding of challenges and successes of all those involved in the ERC reviews of community-participatory studies. The specific AR methodological focus of articles chosen for review was also wide-ranging. This was due to the dilemma of multiple definitions that describe similar and different approaches to participatory AR approaches, often under the same label.

### **Challenges with ethical review committees in community-participatory research**

Individualistic, agenda-driven, and outcome-guided research characteristically defines the academic world. These characteristics can create a tension with values of collaboration, flexibility and adaptability, which underscore community-participatory research approaches (Glass & Kaufert, 2007; Klocker, 2012). The review of selected articles revealed that ethical dilemmas experienced by researchers differed depending on the contexts in which the studies were conducted. Seven articles reporting on six cases predominantly from North American countries (4 USA; 2 Canada), and one from Australia (Iacono, 2006) recorded alleged harm imposed on the community and researchers because of ERCs oversight of various aspects of the studies under review. The remainder of the articles were grouped around the challenges identified from these cases. As will be clear from the discussion below, these themes are certainly not mutually exclusive.

#### ***Defining community and/or research participants***

Researching *with* a community and using participatory processes, necessitates a decision on boundaries; those who are included or excluded, participating or not. Subsequently, ethical reviews require iterative approval and engagement processes due to continual re-negotiation of consent, project design, ownership, and dissemination between those regarded as community and the researchers (Glass & Kaufert, 2007; Mackenzie, McDowell, & Pittaway, 2007). Sharp and Foster (2002), in describing challenges of implementing participatory models in genetic research with American Indian and Alaskan Native populations, reported an expectation by the ERC to define ‘affected community’. This was considered a ‘moral imperative’ by the ERC (Sharp & Foster, 2002, p.146). The authors found this expectation reportedly challenging, especially when considering the non-participatory community members who were external to, but with potential to be affected by the research.

Reid and Brief (2009) described how, in their study (“The Women’s Employability Project,” which ran from 2004 to 2007), they hired community researchers to help examine the relationship between employability and health of First Nations women in British Columbia, Canada. An ERC decision to instate a confidentiality clause, requiring removal of any reference to the community in an attempt to protect the community, was viewed as counter-productive. Creating distance between the community members (especially those involved in implementation) and the research processes were seen as dismantling the principles of the methodology by withdrawing capacity building opportunities. In their view, this lack of understanding of community undermined the values that characterize AR studies – working *with* a community and not *on* them. Sharp and Foster (2002) discussed related challenges in explaining abstract concepts such as ‘respect for community’ within the framework of a formal ethics applications. They reported difficulties in anticipating ‘collective risks’ where ERCs have limited interaction with, or knowledge of, the research population and when there are differing interpretations of what these relations and the subsequent risk constitute. According to Glass and Kaufert (2007), ERC members view researchers as experts and community members as subjects under investigation. As such, community members are assessed based on their suitability to engage in the research as participants and not on their qualifications as researchers. This notion closely relates to the next theme of framing the partners to a participatory study as vulnerable.

### ***Vulnerability of participants***

In her article, Iacona (2007) discussed ERC decisions related to the vulnerability of persons with intellectual disabilities. She suggested that these decisions have become progressively conventional, discounting individuals who could possibly benefit from participation in such research. ERC decisions that restricted the capacity of persons with disabilities to engage in research, denied those persons any potential benefit. It is regarded by Iacona (2007) as exceedingly unjust to judge a person incapable of giving their own consent, or not having a direct benefit by participating, based on the premise that they have an intellectual disability. This marginalizes and excludes entire groups of people who could benefit from partaking in, and helping find answers to, research questions proposed through various community-participatory projects.

Procedures for obtaining consent were also identified by Cahill (2007) as imposing unintentional harm for both participants (with or without disability) and researchers. It may well jeopardize months of dedication by the researchers to develop a balance in power, when community members are required to sign a form. This can be seen as representing a legal contract and reaffirms power differentials. In their article, Gustafson and Brunger (2014) discussed the frictions that erupted during a feminist participatory action study that sought to develop more fulfilling and sustained employment for women with disabilities by using adaptive technologies. The ERC reasoned that sensitivities around how persons with disabilities can become involved in research had to be contemplated. The researchers questioned why the ERC was framing this population as vulnerable, as well as how and why they had the power to do so.

In the same study by Gustafson and Brunger (2014) a student researcher was on the board of directors of the Center that were a partner to the research. The ERC viewed this as a conflict of interest whereby as an insider, she could be seen to exploit a population without capacity to arrive at informed decisions on their own accord. This framed the disability community as vulnerable, placing them in a victimized position they did not feel they occupied. A similar challenge in the ethical review process from Reid and Brief's 2009 study was the unintentional silencing of voices. When the ERC required consent from First Nation Band governors (who were all male), the very women whose opinions the researchers were working to help uncover and share, were considered to be ignored.

### ***Participants as researchers***

The 'Protecting the Hood Against Tobacco (PHAT) project' began in 2002 in San Francisco, California, United States, as an initiative to systematically assess the practices of convenience stores selling single cigarettes in the community (Malone, Yerger, Mcgruder, & Froelicher, 2006). The project was designed in partnership with the community and researchers hoped to record each time a community member reported the successful purchase of a single cigarette. The ERC expressed concern about the absence of trained researchers, whilst the researchers regarded such an expectation as retracting opportunities for community capacity building and the transfer of research skills, which was a primary goal of the community-participatory approach to the study (Mikesell, Bromley, & Khodyakov, 2013).

In the study by Brown and colleagues (2010) about monitoring levels of dust in households, there was confusion between what constituted researcher and participant, and what constituted grounds for ERC control versus community organization control. ERCs reportedly had unease related to higher level of participation by people from outside the research institution (Brown et al., 2010). Requests were made by the ERC for extended and additional training for project partners. While this does not cause harm, and in most cases is beneficial to the research project and the community itself, it causes significant delays and frustrations with ethical reviews (Brown et al., 2010; Glass & Kaufert, 2007; Guta, Nixon, & Wilson, 2013). This could also unintentionally involve the loss of partnership with already over-qualified community-based organizations.

### *Exerting control*

Management of the “surveilling gaze” was a phrase used by Patricia Krueger and the community co-researchers she worked with throughout her doctoral research in the education field (2011, p. 413). Researchers in this study felt the ERC inflicted stigma for approaches falling outside traditional research. The original goal of the study was to contest hegemonic ideologies for school safety procedures that might foster inequality within schools in New York. The omissions and deletions required by an ERC directly prohibited the researchers from investigating this aspect. Krueger (2011) stated that ERC protocols favored research that subscribes to dominant ideologies, leaving little space for community-participatory approaches. The result was prolonged waiting periods and bureaucratic tasks that suspended the aims of the research. Physical and emotional stress ensued after multiple rejections, constraints placed on time, and re-negotiation of study aims. This challenged the researcher and co-researchers to remain engaged in the research, and to maintain a high level of passion for the project. This study has particular implications for those individuals in the beginning of their research careers, especially at the graduate level. The researchers felt as though the ERC was exerting control, micro managing the proposal, and ultimately boxing in the potential reach of the study.

These concerns of exerting control in community-participatory approaches to research were reiterated in articles by Cahill (2007), Brydon-Miller and Greenwood (2006) in reference to ERC procedures and policies guiding reviews. Omitting and deleting aspects of the study, also forced Krueger (2011) to violate some of the

original codes of ethics she had established with her co-inquirers. This creates doubt in the strength of the partnership and the viability of the study to proceed, while regulating both the research objectives and the participants (Butz, 2008; Krueger, 2011). Many scholars (De Vries et al., 2004; Flicker et al., 2007; Griebeling et al., 2009; Ross et al. 2010; Shore, 2007) would have us believe that ethical committees are serving their own interests by imposing confidentiality clauses that deny or stunt community research.

### **Strategies to improve ethical review**

The challenges highlighted above led some researchers and communities to develop their own approaches to ethical review. These are reported in a number of the articles identified for review (Buchanan et al., 2008; Edwards, Lund, Gibson, 2008; Gilbert, 2006; Iacono, 2006; Wiwchar, 2004; Minkler, 2004; Mohammed et al., 2012). Many of the studies recommend changes ERCs can make to their review processes and a few highlight the potential when ERCs, communities and researchers work together. These experiences were captured in three themes, as discussed below.

#### *Sensitivity to power relationships*

In a condensed discussion of four Canadian studies that offered recommendations for ERCs engaging in community-based research in the mental health context, Johnston and Woody (2008) highlighted power differentials as a common theme amongst these studies. These authors recommended that researchers and ERC members connect in the initial stages of the research to establish a working relationship that will allow conversations to address power imbalances (Mikesell et al., 2013). Mackenzie, McDowell and Pittaway (2007) recommend that researchers and ERC members engaged in participatory–community approaches at least collaborate on ad-hoc ethics approval processes to manage the power relationships and shifting needs of such projects.

In response to Malone et al. (2006), Wolf (2010) (an ethics review committee member who sat on the ERC to review the ‘PHAT’ project), detailed the ERC’s decisions. According to Wolf (2010), ERCs often have to draw their own conclusions about the researcher and the subjects when researchers themselves ignore or underplay the power differential. It is recommended that support for participatory and collaborative research approaches is fostered at all levels – not just with communities,

so that ERCs can share in the move from the power-in-dominance model towards a power-sharing model for complex social contexts (Boser, 2007; Wolf, 2010).

### ***Balanced consideration of participants' safety***

ERCs will have their own protocols to manage decisions and it can be expected that results of project reviews will vary between ERCs. However, the safety of participants is always a non-negotiable for ERCs. Even if multiple steps are put into place to safeguard confidentiality, ERCs must make executive decisions that minimize harm for the maximum number of people. According to Wolf (2010), ERC guidelines are however, flexible in this respect and members do not always exercise this appropriately. Due cause she admits, for frustration on the part of researchers and the communities they work with. This was identified as a concern in the PHAT Project, where protection promises for participants were obtained from a district attorney, which the researchers felt ultimately, protected storeowners and their employers against prosecution. However, Wolf (2010) justified the ERC decision that this was insufficient, arguing another attorney may not honor that same agreement. As an ERC member, Wolf (2010) felt their decision to discontinue the study in interest of protecting storeowners and workers identities was justified. Understanding that this decision may dredge up feeling of betrayal between researchers and community members, the potential harms that could arise in terms of confidentiality posed a greater risk to developing notions of mistrust for research, AR, and the researchers themselves. Wolf (2010) reiterated Sharp and Foster's (2002) point that consideration of safety for non-participants is just as important as protecting those directly involved in the research and this will always be a core consideration for ERCs.

### ***Increased engagement***

According to Guta, Nixon, and Wilson (2013), ethical review processes have become increasingly complicated, especially for those ERC members reviewing participatory and community-based studies. In the selected articles, authors offered recommendations for how ERC review processes could be changed. In considering these changes, it seemed to center around increased dialogue and engagement between ERCs and researchers (Glass & Kaufert, 2007; Guta et al., 2013; Wolf, 2010). Guta and colleagues proposed electronic submission formats to allow

researchers to submit applications that are more detailed and to allow ERCs to perform more mindful reviews (Guta et al., 2013). Boser (2007) suggested that researchers in this field of inquiry approach ethical review processes the same as they would their practice in the field – by active engagement. She proposes that researchers make the effort to actively engage members of their ERCs, including recognizing each board member’s epistemological lens. In turn, that would require that the researcher share their own as to ensure two-way sharing processes and identification of confusion as they arise. Other scholars echoed these suggestions in their studies (see Buchanan, Miller & Wallerstein, 2007).

Wolf (2010) contended that it is not the case that all ERCs are unprepared to deal with community-participatory approaches, and that one hostile interaction with an ERC is not representative of all ERC decisions concerning these methodologies. It is suggested that it is not solely the task of ERC’s to accommodate AR researchers, but also that researchers take time more time to dialogue, educate, and clarify the tenants of their proposed studies with these review bodies. Wolf (2010) suggested that an ethics review needs to shift to a two-way educative-learning journey. It is claimed that researchers race through ethics applications as quickly as possible, but lose sight of the importance of the review (Guta et al., 2013; Wolf, 2010). Institutional cultures impose constraints on time, while emphasizing increased output of research (Lightfoot, Strasser, Maar, & Jacklin, 2008; Guta et al., 2013). Researchers view ERC processes as a pain or hindrance to study progress and not a necessary part of the process. On the other hand, it is claimed that ERCs slow research production or inhibit institutions from receiving funding as they only focus on the safety of those involved.

Despite widespread agreement on the need for increased engagement, various authors identified a number of constraints in developing a relationship between ERCs and researchers, and subsequently communities. As alluded to earlier, ERC members traditionally operate within a biomedical framework; a framework which is too narrowly focused on individual participants to easily allow for studies with a community-participatory approach (see Glass & Kaufert, 2007; Khanlou & Peter, 2005). Resourcing of ERCs limits the ability to develop a knowledge base of different research methodologies (Guta et al., 2013). This challenge is compounded by the life experience, culture or customs of ERC members that often do not adequately reflect diverse values, skills, and practices of different cultural contexts or

population groups, such as Aboriginal, tribal or collectivist cultures highlighted by Glass and Kaufert (2007). Increased engagement will also be limited in a context of ‘ethics creep’, where ERCs increasingly focus on risk management rather than on the ethical issues of the project (Guta et al., 2013).

While the ERC members’ perspectives present salient concepts about ethical review processes, it is evident that various constraints make community-participatory research approaches difficult for ERC members, researchers and members of its partner communities.

## **Discussion**

The review of selected articles highlighted the challenges researchers face and strategies utilized in managing ethical review processes to conduct participatory research. This review serves as a reminder for ERC members, AR researchers and the communities they work with to be reflexive in their relationships. It encourages openness about the concepts ‘community’ and ‘participant’, about how we assess the vulnerability of participants and their role as researchers, and how we exert control in this context. Sensitivity to power imbalances and how we perceive participants’ safety are encouraged. Engagement throughout this iterative research process is seen as crucial, even though the nature and process of this engagement between communities, researchers and ethical review committees is unclear. This is probably the strongest message from this review: that action researchers should explore ways to develop and implement such processes; and that ERC members should increasingly record experiences of reviewing applications based on community-participatory methodologies and of feasible strategies to manage tensions.

Action research (AR) has become an increasingly popular research methodology, but also displays progressively complex procedures and processes. There are many worthy suggestions in the literature for how researchers and community research teams can take appropriate precautions to uphold the principles of AR and ultimately, protect the community. ERC members must be prepared to adapt their procedural review guidelines, and provide sufficient evidence to support their decisions. By allowing researchers to indicate early in an ethics review process that a project will use an emergent design, researchers can be allowed to use a different form to that of the usual ‘checkbox’ nature. This may conceivably trigger an opportunity for early engagement – either electronically or eventually in person. In

turn, researchers must provide sufficient information to ERCs that will enhance their knowledge of the community with which the researcher wishes to conduct research. Researchers can be expected to clarify concepts of ‘community’ and ‘participant’, and how they view vulnerability and their role as researchers. Ethical principles such as potential harm, conflict of interest and confidentiality used by ERCs and researchers should further be interpreted through the lens of the community partners. These are real-world dilemmas that many professionals, community members and business owners deal with on a daily basis and navigate according to professional codes, business ethics and commonsense mediation and negotiation. To view any ‘business as usual’ by these community partners through a research ethics lens is bound to create tension. ERCs must take into consideration the status and integrity of researchers and communities when reviewing these types of studies. It is not suggested that all ‘business as usual’ is blindly accepted as ethical, acceptable or even moral by ERCs, but allowing professionals, operating under a professional ethical code overseen by a professional body, to make a call on appropriate conduct in communities, seems a good place to start. Researchers in turn, must do their part to foster a dialogue that promotes education between the ERC, researchers, and the community. It is the responsibility of the researcher to inform ERC members about their ‘regular’ activities and professional codes of conduct that informs these activities, as to allow ERCs to put the research activities in context. The successes and challenges resulting from increased engagement and bi-directional learning should be documented to help grow evidence of effective ethical review of participatory approaches to research.

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