# Extended communities for action-research as a tool for the emancipatory promotion of health: conceptual and methodological bases

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> **Abstract** This article is a contribution to methodological discussions on the "participation" pillar that guides strategies for Health Promotion. It reflects the conceptual and methodological bases of the Extended Communities for Action-Research (ECAR) as a tool for the Emancipatory Promotion of Health (EPH), taking as reference the experiences from the Territorial Laboratory in Manguinhos. The ECAR brings together researchers and mainly residents who live in the territory with their knowledge and distinct viewpoints who reflect on socioenvironmental problems, public policies and alternatives in a given context. Three key aspects for EPHare discussed: social participation, social determination and shared production of knowledge. Based on the experiences of the action-research model in areas with slums, we found a massive gap between what is written in the Policy and institutional practices where there were spaces marked by borders. We also noted a lack of rights and major tensions between the parties. As a result of the ECAR findings, various tools were produced in accessible languages facilitating knowledge appropriation and the enhancement of actions in social movements. This article concludes with some thoughts and challenges for the Emancipatory Promotion of Health.

> **Key words** Emancipatory promotion of health, Participation, Social determination, Shared production of knowledge

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## Dialogue on Health Promotion Policy covering: social determination, participation, knowledge and the large gap that exists with practices

Participation and knowledge are keys in health promotion (hereafter HP) such as recognizing the different types of methods that exists in the National Policy for the Promotion of Health (PNaPS)<sup>1</sup>. HP ought to emphasize the development of public policies and the production and dissemination of health practices and knowhow in a participatory way. Participation in its broadest meaning is a transversal theme (III) that involves pushing for health and care and noting the relationship between health, participation and the production of knowledge:

It incorporates the theme on the logic of networks which favors humanized care practices aim at local necessities. This reinforces community action, participation and social control and it promotes recognition and dialogue between the different types of knowledge (popular, scientific and traditional) which builds up practices for complete health care<sup>1</sup>.

As mentioned in directive V, this is not just any knowledge, but it is aimed at the production and diffusion of experiences, knowledge and evidence which can support: the decision making process, autonomy, the empowerment of the collective and the construction of shared actions in the promotion of health.

Participation and knowledge overlap each other and are a part of the PNaPS as a strategy for the transformation of reality which is clear in the concept of social determinants. This is because the HP should look beyond the health sector walls and should also take into account the living conditions of the population. For many there is a necessity to face systematic inequalities and injustice. These problems continue to plague Brazilian society, exposing it to innumerable differences in society that currently exists.

Advances have been made in the PNaPS which various authors<sup>2-5</sup> have noted however, they have identified a gap between what the Policy states and what is reality in relation to the hierarchical and centralized institutions in the context of an unequal society. The way how people are treated on the SUS (the Brazilian Unified National Health System) assumes that all people are passive and homogenous conditioning them to managerial rationality and the imperatives of managers, technicians and specialists. As mentioned by Traverso-Yépez<sup>2</sup>, this

gap is particularly evident when one deals with the proposing and implementation of generated actions that have come about during the process of obtaining feedback from people concerning their needs and interests. This increases the participation of the population in relation to decisions that affect their living conditions and health. We noted however the persistence in the use of the biomedical/productivist model in the organization of the health system which favors a top-down approach where there is no dialogue with the population. This makes it impossible to have advances in social participation. It also means that people cannot exercise their rights as citizens and there are no advances in networks in society. The differences in the text between the policy and the everyday practices of the institutions come to the fore, according to Silva & Baptista<sup>5</sup>, with the problems in the PNaPS. There is a polarization between the regulatory perspective and emancipatory perspective for the promotion of health. The dispute is with the emancipatory project and the behavioral project or control over the citizens.

This imposes a big gap between system management and the population which goes contrary to overcoming inequalities and differences in territories and their populations. Boaventura de Sousa Santos<sup>6</sup> noted that this gap can be understood as the abyssal thinking that separates the world between those with rights and knowledge and the rest of the "non-subjects". This is formed by social classes, territories and different subaltern populations from the "Global South" whose knowledge and rights are systematically made invisible by colonial logic, economics and racial domination in processes involving symbolic and epistemological spheres. Knowledge and culture mix types of power which imposes limits such as on the potential for transformation.

The possible route for obtaining advances in the construction of knowledge and changes in health practices lies in getting back the potential involved in participation as a way to respond to real blockages encountered in SUS in relation to the capacity to produce and circulate knowledge and information that values the autonomy of subjects and transforms reality into the emancipatory perspective. This means overcoming the origin dispute between the behavioral model and the emancipatory perspective from the HP. It also means moving the gap between theory and practice in the direction of the Emancipatory Promotion of Health (PES)<sup>7</sup>. In this vein, we think that this paper will contribute to the debate on

the conceptual and methodological foundations concerning the ways for producing knowledge and practices in HP.

# Conceptual and Methodological bases for the Emancipatory Promotion of Health

The methodological and theoretical reflections concerning the Emancipatory Promotion of Health comes from the experiences of the Territorial Laboratory in Manguinhos (LTM) which since 2002 have brought together researchers and residents from the Rio de Janeiro slums and shanty towns for the production of shared knowledge in extended action-research communities on the realities of the territories where we operate<sup>7</sup>. The focus of the analysis is on the problems of urban and environmental health and the relevant public policies. Our reference was the social determination of health that connected health problems, living conditions, work, the environment, citizenship and human rights. As a result, the following were taken into consideration: sanitation, the environment, politics and culture related to social inequalities, problems with democracy and the asymmetric power system that is the hallmark of such territories. In other words, we looked at the collective construction of priorities in ethics and practical action through the participative processes in production, circulation and appropriation of information and knowledge in a given place.

The incorporation of theoretical references that mark the trajectory of the LTM, which also covers the search for the PES, is a part of a permanent process of construction and renovation from that which we can denominate in a critical way socioenvironmental approaches8. When looking at knowledge areas, authors and concepts the proposed approach has centered on political geography<sup>9,10</sup> and its connections with health geography<sup>11</sup> through the concept of territorialities and deterritorialization, as well as the construction of participative and critical maps. Authors in the area of social medicine who are Latin American such as Breilh12 in his critical epidemiology talked about health problems having an historical basis. He noted the reoccurrences of social inequalities and the reproduction of capital and its different forms of dominance. Our approach also covers: political ecology<sup>13,14</sup>, environmental sociology and the movement for environmental justice<sup>15,16</sup> which he viewed through the concept of environmental conflicts and sacrifice zones. This was of particular importance for connecting the environmental question with inequalities and with the fight for human rights and against racism.

Understanding socioenvironmental problems is difficult because they are complex, urgent and full of contradictions and determination processes. It brings to the debate the quality of knowledge and the framework of critical epistemology with, and for, people. We highlighted the popular education approach based on Paulo Freire<sup>17,18</sup>, with his theory on dialogic action and concepts such as the unprecedented which is viable ('inédito viável' in Portuguese). This is similar to popular education in health talked about by Victor Valla19,20 and Funtowicz and Ravetz21 and the critique of the limits of specialized normal science in understanding complex issues with high levels of uncertainties and values. This takes one to have new approaches (post-normal science) for the construction of collective knowledge as well as decisions and practices through extended peer communities. The so-called post-colonial studies, particularly the work of Boaventura de Sousa Santos<sup>22,23</sup>, are aimed at the deconstruction of hegemonic epistemology in classic science through the construction of a sociology of absences and a sociology of emergence, just like the proposition on the ecology of knowledges.

Advances in the EPH means a widening in cognitive and affective scope from languages that are normally used by the academic and technical world. In our experience communication strategies and the shared production of knowledge is expressed in different languages and ways: by means of audiovisual tools (videos and photographs) and through communication technology and IT such as through internet portals, Facebook, YouTube or the production of interactive games. In this vein we were inspired by the semiological approach developed by Inesita Soares Araújo<sup>24,25</sup> on the communication cycle which covers production, circulation and appropriation of knowledge and information.

Finally we highlight the contribution of historian Edward Thompson<sup>26,27</sup> and sociologist Pierre Bourdieu<sup>28,29</sup>. Notions such as experience, social space and symbolic power widen our understanding of the way in which residents live their realities. These concepts allow us to draw links between the everyday, individual and community levels and the generating processes of vulnerabilities and capabilities. The above helps us to understand the constitution processes for space just as the formulation of public policies. This is particularly the case for those that tackle socioenvironmental and health problems through

a comprehensive and dialogic view in which we can have access to different points of views from residents not in an isolationist way but in relation to differences and conflicts. The notion of point of view comes from the work of Boudieu<sup>28</sup>.

Such pedagogical-political and epistemological guidance is present in the construction of the Emancipatory Promotion of Health. We searched for routes through territories always trying to avoid traps placed by institutionalized knowledge and powers looking for that which is unprecedented and viable which is mentioned by Paulo Freire. This was through experiences that overcome dichotomy between subject and object, the individual and the collective.

This frees us from the temptations of the paths and means invested in solitary paths for the production of knowledge and action for the expansion of participation with people that live in given territories where we acted. The most challenging element for the proposal is in the construction of languages and practices that allow for dialogue between the technical-scientific world and the popular space and everyday lives of people and communities. We were dealing with a challenge that was not just of an ethical nature but was essentially epistemological and involved communication.

## The Slums as areas with borders, tensions and mediations in search of that which is unprecedented and viable

The slums with all of its dynamism and its correlations with social and political forces have been a space that has feed us in the development of methodologies which makes it possible to better understand the health-disease process and the production of emancipatory knowledge. Participation is affirmed through the residents in territories as subjects of knowledge<sup>7,30-32</sup>. The research and the social work in this space ought to be understood from the different interfaces:

For some people that live in the slums, it can be a place from which to flee. For others that meet up in supra-local structures, it's an entrance. For others situated in different positions on the ground, it is a place of achievements. For many more people that move there it is a place of interlocution, pressure and tension. For all it is mediation. In a place of mediation, tensions and movement one can find resident community leaders in the slums as well professionals from public institutions, NGOs, religious leaders, politicians, researchers, drug dealers and local militia [...]<sup>33</sup>.

Statements from residents (and even their silences) gave us clues that put into question some models of analysis that did not consider experiences and knowledge produced by the subjects that live in the territories and came close to a technical-scientific production that is more critical on specific problems on health.

This idea expresses itself in some guiding questions on the social determination of health in the space of these slums and shantytowns. How does this place apply itself in the bodies of people and organize their ways of living, falling ill and dying? How does this express itself in the day to day lives of those in the slums and how do such experiences and knowledge open spaces for reflection and political fight for the residents and their community organizations as well as professionals, public institutions and engaged researchers?

Certainly such questions require a lot in order to be responded to. It involves an understanding of the production of place, meaning the history of the place that connects with the people. They are dimensions that take us from the individual and their health-disease processes to society and vice-versa. In other words an understanding of falling ill is not just viewed as an individual phenomenon or one that is both biological and genetic, but it is viewed as being marked by its history and social context.

From this we have the notion of experience noted by Thompson<sup>26,27</sup> which is a key for accessing the articulation between these different dimensions of the processes of health-disease. It is possible to state that the experience of the residents, even though they are written in macro-structural processes from the social world, have been lived by people. These experiences are dealt with in a special way in accordance with their culture, vision of the world and history. In this way, in spite of having being inserted into specific living conditions that means increased socio-environmental vulnerability and conformity in actions, the residents did not respond reactively to the above. Through their experiences there is an appropriation of reality and the possibilities of actions<sup>33</sup>.

The notion of experience constitutes itself as a fundamental form of mediation in the process of understanding the constitution of space and the process of social production in health just like the formulation of public policies and particularly those that deal with the health situation in vulnerable areas where consideration is given to the participation of the residents beyond institution-

al channels. This is because it is fundamental that there is a mediator element in the production of knowledge that articulates research and actions in health with the perspective of dialogue and a promotor of autonomy for the subjects involved in both processes that include investigation and intervention.

This movement is alternating and dialectic with on one side the singularity of the individual, the community and its place and on the other side the determinants and conditioners that mark territories and their populations including social class and other elements that help us to understand the different forms of oppression and emancipatory fights. It allows us to have a wider and more sensitive perception of problems. It also creates conditions for more effective dialogue so that the researchers, professionals, people and organizations that are currently active in communities can articulate tangible dimensions and relative intangible ones in the processes of life, getting ill and dying.

The tangible social determinants refer to economic, social, environmental and epidemiological indicators. However the picture is not sufficient if one does not consider the intangible determinants expressed in the statements and experiences from the residents upon evaluating their living conditions and the impact of the public policies in their daily lives.

The statements and narratives is information for sensitive themes covering suffering, sadness, anguish, self-esteem, impotency, disenchantment, hope/lack of hope, alternatives to surviving and fights, amongst others. Their impacts on health are being discussed through the means of concepts of diffuse suffering<sup>34</sup>. Intangible determinants are strongly associated with the effects of the place on ways of living and becoming ill. The slums are thus understood as socially reified spaces, a concept that comes from Bourdieu<sup>28</sup>.

The space in the slums which is simultaneously social and geographical tends to be looked on, historically in a negative way where lots of abodes are in one place. These places are often illegal where the neediest people live in precarious situations. These are also living spaces where people fight to eke out a living and for human rights. Thereare also cultural expressions and a production of meaning and knowledge. The statements reveal, amongst others, stories and memories of having to live through suffering and violence in life without sanitation marked by negligence

from institutions and the temporary nature of public policies as well as the absence of rights. They also show processes and moments that involved struggles and wins which is akin to the reoccurring cycles of promise-lack of trust-hope that arise from each public policy announcement and intervention in the places where they live which are characterized by despair, disenchantment and a feeling of impotence in the face of a lack of power to transform their health conditions. For us the intangible determinants are the keys for analyzing the health situation in a way that is more human and closer to real life.

The work of the LTM finds itself between institutional, academic and social borders and between the tangible and intangible.

That which is fundamental in guiding us in the production of information and knowledge which states that the participation of the residents is necessary, is the experience of people based on the accounts of their problems, their territory and their memories. This narrative based on experiences mentions by Thompson<sup>26</sup>, allowed us to widen our vision in relation to the living conditions and health situation in the territory. Continuing on this vein, the narratives contribute in interrogating the data produced by the information systems and the models of analysis that do not connect dynamism with the experiences in the territory and which generates emptiness in understanding. According to Thompson<sup>26</sup>, real analysis through a dialogue of knowledge that reorders the groups of concepts so that they are not transformed is necessary to combat discriminatory concepts.

The emancipatory force should be forged in humane spaces that emerge from facing challenges in life from populations struggling for dignity and their rights which makes it necessary to understand the possibilities and motivations for local engagement in light of the current situation. In this process the researchers should assume the political and pedagogical role providing, as mentioned by Sergio Arouca<sup>35</sup>, content on the social movement struggle. Such meetings, when they are fruitful, can construct what Paulo Freire states as that which is unprecedented and viable<sup>17</sup>, sharing the search for alternatives and the reconstitution of the space of political struggles having a realistic perspective of an historical moment and the correlation of forces taking into account the viable history<sup>36</sup>. According to Freire this means waging the fight without inconsequential adventurism.

### The Extended Communities of Action-Research in the Experiences of the Territorial Laboratory of Manguinhos

The methodological path for shared construction developed by LTM means a constant dialogue with residents and community organizations from the territories in which we act with colleagues from Fiocruz and other institutions that do research or act in health services through to partnership in projects and collaborations. We established a communication that was closer to the professionals in primary health care. All of the exchanges and their focus are on health problems, living conditions and public policies. This has meant redefining paths, abandoning some routes and finding some successful ways.

The methodological pillar that was constructed in this way is what can be called the Extended Communities of Action-research (ECAR). The idea of the ECAR is to be a space for mediation, borders and a meeting of formal scientific knowledge for research with common know-how based on experiences from those that live and work in the territories. In this vein, ECAR brings the perspective of experience and confrontation with others as keys for the production of knowledge, opening hidden agendas that are able to broaden our understanding of processes that generate socioenvironmental vulnerabilities and health situations in certain territories. They are also spaces for alternative propositions that aim to minimize or interrupt the effects of the processes that lead to vulnerability expressed through categories such as temporariness, uprooting and invisibility that mark such territories<sup>33</sup>.

The idea of action-research, widely exploited in Latin America<sup>37,38</sup>, is believed to be, according to LTM, a device for the production of knowledge that is simultaneously shared, contextualized, reflexive, sensitive and has the ability to transform. ECAR is formed through the coming together of researchers, workers, professionals, militants and residents in a given territory and it is materialized through forums, meetings, workshops and field work that allows for the confronting and integration of perspectives in the analysis and proposition of solutions for socioenvironmental problems and health promotion in the territories.

Since the beginning there have been experiments in different forms of constitutions for ECAR. This is a reflexive path and there is permanent negotiation with the different contexts in territories marked by violence that challenges daily life.

In the first moment in which we acted just in the territory of Manguinhos through the ECAR, information was produced, ideas were shared and content was subsequently organized in the production of political-pedagogical material<sup>30,31</sup>. The following themes were seminal: History of People and Places which brings back the history of various communities in Manguinhos based on research into oral history and memories developed in partnership with researchers from the House of Oswaldo Cruz<sup>39</sup>; Communication – that developed research on the production and circulation of information on the environment with guidance from researchers from the Institute of Communication, Information Technology, Science and Information<sup>24</sup>. Environmental Health involved mapping the various risks and environmental problems that currently exist in Manguinhos based on the discussions with residents and health care professionals, for example floods and tuberculosis. For the last point, in collaboration with the Germano Sinval Farias Health Center School, the result was the production of an interactive game (the RPG type) that was produced with and for young people in the territory<sup>30,31</sup>. The whole process was registered in videos and is available online at: www.conhecendomanguinhos.fiocruz.br.

Each ECAR is made up of the following people: a researcher (male or female) that is knowledgeable in the area, PIBIC receivers of grants, residents that receive extension grants and young people that are in the vocational scientific programs that are coordinated by the Joaquim Venâncio Politechnique Health School.

In 2012 based on the participative evaluation project from the PAC that was financed by CNPq (the Brazilian National Research Council) the Brazilian Ministry of Cities, we extended our activities in three territories that included different slums and shanty towns. They were located geographically far away from each other in the city. The territories were: Manguinhos, Alemão and Rocinha and they presented other challenges.

The first challenge was to respond to the need to form the extended communities for research in each area. Three were formed which we deemed as small ECARs. Each was under the responsibility of the "institutional" researchers. There was also a local resident, a receiver of a grant for the project and a field assistant. The large ECAR brought together "institutional" researchers and researchers-residents that received grants from the project which involved local coordination in three territories.

A major challenge was to establish forms of communication that allowed for dialogue and daily interaction not just within the ECARs but between ECARs from the three territories. We therefore put together a network of exchanges that involved workshops and meetings as ways of communicating between territories. Some of the highlights were: (i) the drafting of a Workshop Book covering topics to be discussed between the three territories, (ii) the use of audiovisual materials such as the production of short films that did not limit itself to register or proof from research data. But more than the aforementioned, the images and videos, just like the statements from the residents, worked as mediators in the process of resolving problems, discussions, organization and circulation of information and knowledge. Special emphasis was placed on creating videos with material covering mediation from activities permitting different subjects to recognize themselves as protagonists in producing knowledge and transformers of reality accessing and living to resolve complex questions in direct and creative ways. The video brought together multiple narratives and contributed to subjectivity and experiences. (iii) The use of the internet and social networks, exchange of emails in groups, a page on Facebook called Territories in Movement, a YouTube Channel LTM Territorios em movimento, a WhatsApp group. All of the above allowed for fundamental questions to debated and resolved not just in the territory but in the three territories in question. It was also possible to identify events very quickly and to analyze their impacts which favored intervention by residents and their collective with the PAC managers.

The network was built when there was the initial implementation of the research when partnerships were carried out with community organizations such as: the 'Raízes em Movimento' Institute in Alemão and TV Tagarela in Rocinha. Through the whole process the network kept spreading with new individual and collective participants. This network has supported the creation of ECARs. It was built in every territory and it allowed for fast development and circulation of knowledge and information, which in turn allowed for more projects to be done. It also allowed for research to be done in areas that have a lot of problems and tensions. This created and brought to maturity new and collective actions for the locals.

With ECAR training comes a process of dialogue involving researchers, residents, community organizations and technicians at institutions.

All of the aforementioned are a part of the collective learning process and the construction of knowledge. ECAR has the typical spaces that you would find on academic training courses: study groups, a selection of reading material, and discussions on concepts and how to solve problems. The debates cover academic knowledge, the experiences of residents and community organizations based around the spirit of ecology of knowledges<sup>13</sup>. ECAR participants and the content produced helped in other traditional courses at the National School of Public Health - ENSP/ FIOCRUZ (master's and doctorates, specializations and distant learning courses). The courses also stimulate debates and local actions. ECAR allowed for more meaningful participation by researchers and residents widening understanding, reflection, evaluation of public policies and strengthening their capacity to intervene.

Central to the idea of emancipatory promotion of health is that we seek to maximize communication in its phases of production-circulation-appropriation with strategies that reduce inequalities and provide better access to knowledge and information. Communicative processes have three interrelated dimensions: 1) Shared production of knowledge and political/pedagogical material through ECAR as mentioned earlier, 2) The process of translation between knowledge and experiences that defines content and language which is then organized, integrated and used to understand complex problems. 3) The process of circulation for subjects in meeting in person or virtual ones. Production, circulation and appropriation of knowledge happens in the following areas: workshops, round table discussions, social networks, forums, councils, when one participates in continuous education, study centers, field trips for work, meetings etc. They involve different people like residents (children, teenagers, young people, adults and elderly people), health care professionals, other professionals in education, sanitation and urbanization, researchers, local collectives and managers of public services.

The results, based on this perspective of emancipatory promotion of health, depend on creating confidence and shared alternatives to face the problems in the slum areas. In these harsh and conflict ridden areas, trust and confidence can only be built up where people can together learn how to learn, to dialogue and to tackle the complex problems and vulnerability processes, proposing viable alternatives. These learning opportunities and dialogues include

different perspectives and point of views. We learnt that every movement is a potential source to learn something new. Such movements involve exchanges in knowledge, experiences, culture, affections etc between those in the ECAR. There can also be tensions and differences based on different visions concerning priorities and decisions to be made.

We learned that residents' routines were not regular for different reasons. For instance the areas where they lived frequently had gun fights, which prevented them from leaving home, or spending the whole day in search of medical care or resources for their survival. This was in addition to other forms of violence that are present in their homes and in their territory. People did not want to talk about difficult issues such as violence, drug trafficking and the other threats in the area. Also the researchers and professionals were often bogged down in academic bureaucracy and searching new funds which hampered their work in ECAR. This saw some of their priorities changing.

All of the above have done the following: widened definitions for certain themes, extended work possibilities, shown people's real priorities and created didactic material that have been created by the ECAR in LTM9,30-32.

#### **Emancipation and Autonomy:** starting point and the end

Meeting world standards in relation to wholesale participation from communities and inter sectoral working can only occur where all those involved have autonomy and they see themselves and others with knowledge and rights.

Paulo Freire stated that individual autonomy is not the only thing necessary for political transformations in Brazilian society. Marilena Chauí<sup>40</sup>, a Brazilian philosopher, also states that autonomy in our days is political struggle. Social (or collective) subjects should freely address the social and political obstacles that oppress them with a view to obtaining social emancipation. For the author, the central role of knowledge production must be to redeem the stolen dignity of people, thereby transforming the quality of established and institutionalized knowledge. Also the dominance of knowledge and information should be our permanent quest in democracies. Citizens can only participate in social life based on the quantity and quality of knowledge and information that they have, as well as the possibility to access its sources and how to use it. That is, their ability to act as a producer of knowledge and participating in decision making.

The Extended Communities for Action-Research are special places for promoting health and serve as praxes for sharing and enriching the production of local knowledge with residents and their life experiences. They can be considered as places for the emergence of invisibilities where there is a search for alternatives to deal with health problems and to analyze public policies in a participative way. It allows for the unveiling of invisible information, knowledge and experiences produced by residents in their real lives and contexts. And these open up new possibilities in assessing public information systems about the city, health and the environment, as well as giving rise to academic outcomes, information from the media and government management data.

Knowledge and local experiences help to understand complex relations at community and more global structural levels and dynamics related to the social production of health and disease. Non-narrative approaches that just involve observing people may be supported by theories and models that are complex, but they cannot fully capture such dynamics or deepen the dialogue between people, the community and social movements. ECAR can be viewed as a move from a behavioral model to one which emphasizes an emancipatory approach in the promotion of health. This means having a renewed paradigm for public health where emphasis is placed on the collective and processes that function in a democratic way which will provide material, cultural and human achievements towards equity.

#### Collaborations

MFS Porto, F Pivetta e MB Cunha contributed in the design, methodology and writing, L Zancan e JD Freitas contributed in research and final review.

#### Acknowledgments

To Gleide Guimarães, Fabiana Melo Sousa, Monica Santos Francisco and Alan Brum for participation in research and production of circulators and appropriation of knowledge developed within the Manguinhos Territorial Laboratory.

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Article submitted 04/01/2016 Approved 31/03/2016 Final version submitted 02/04/2016