

## **In a marginal voice. From participatory to emancipatory research**

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Recent controversies about human rights and research ethics have put the issue of community and citizens' participation in research into the forefront.<sup>1-2</sup> As an illustration, amongst other qualms, researchers are concerned about the difficulty to recruit subjects for clinical trials, HIV vaccines being one of the representative areas of concern.<sup>3</sup> The recruitment process is heavily influenced by the degree of trust society has towards the scientific establishment, which has been severely challenged in current times.<sup>4</sup> Participatory research may be a way to recover social trust in the research process and the scientific enterprise by recognizing citizen's rights and worthiness, but other considerations are to be made referred to marginalized and oppressed people.

There are two main sets of reasons typically utilized to promote citizen's participation in research.<sup>5</sup> First, and most frequent, utilitarian considerations about its advantages i.e. better compliance, easier recruitment, and the like. On the other hand, citizen's involvement may be seen as a human and citizenship right, arising from a democratic perspective of human beings as social agents with full rights.<sup>6</sup> From this viewpoint, the complaint of researchers and industrial sponsors about the time-consuming process of guaranteeing people's participation "from P to P" (from planning to publishing) lacks substance, as the respect of human rights is not a task to be assumed as easy, brief or time-saving. To compare with the cost of respecting human rights, millions of dollars, researcher's worktime and subject's self-donation are annually spent in "me-too" and patent prolonging "research" having no utility for people's health but useful to researchers and sponsors' interests. Voices otherwise raised about the difficulties of participatory research keep a discreet silence about this fact.

There is a great conceptual difference between public health viewed as a human right or as a merchancy apt to be sold through marketing procedures.<sup>7</sup> The first perspective sees people as citizens who should be granted all corresponding rights irrespective of other considerations, and the second conceives persons as important only in the measure of their market participation. There is no room in this conception for excluded, marginalized and oppressed people as such, as the model is sustained by the ideology that causes such state of affairs.

Participatory research calls for the inclusion of all people in the research process, regardless of market patterns. Each citizen's judgment is worth considering at the moment of deliberating about public issues independently of her/his possibility to consume.<sup>8</sup>

But there is yet a further step to be taken and it is the progress from a participatory frame to the envisioning of the liberation of oppressed people from situations of domination and exploitation, as proposed by emancipatory research.<sup>9-</sup>  
<sup>10</sup> The main consideration in this case is that researchers cannot be indifferent to social unjust and oppressive situations, and that oppressed people should advance in their liberation processes as a result of the research enterprise. Well known current references in this field are mental health "survivors", disabled people groups, feminists and ethnic minorities, but as a matter of fact Brazilian Paulo Freire pioneered this kind of research more than 30 years ago in Latin America in the educative domain.<sup>11</sup> In Freire's words: "The methodology we are defending requires that in the research course both investigator and research subject become subjects of research itself"<sup>12</sup>, and "research... has this fundamental dimension to its meaning: the critical presence of people's representatives from its beginning to its final phase, the analysis of the results... to become a liberating cultural action."<sup>13</sup> Although originally conceived for educational action-research this frame was influential in Latin America social medicine field research.<sup>14</sup>

There are several standpoints significant to emancipatory research. One of the most important is that research intending to describe the world as a natural and given set of phenomena will perpetuate the current domination and exploitation state of affairs. Confronted with the suffering of excluded and marginalized people scientists cannot just stand by without taking options in power struggles. Justice seeking through human rights achievement turns out to be in this way an obligatory baseline for researcher's perspectives when planning research development.<sup>15</sup> But a "human-rights-laden" proposal as this encompasses the need of a shift in power from professional elites to the people, and of course this is not a popular view within the scientific establishment.<sup>16</sup> As a matter of fact, the transforming of current funding practices to emancipatory alternatives would be impossible without a complete refurbishment of grant-seeking and awarding processes. Job tenure rules and academic controls would have to be significantly redesigned to admit the introduction of participatory investigation requirements.<sup>17</sup>

Emancipatory research means also a radically critical look towards current research practices that pretend to sustain the so-called "neutral" approaches to a conflict-

ridden capitalist society. The pretension of "scientific objective neutrality" is pervaded by a systemic perspective that sustains the statu quo.<sup>18-19</sup>

Current research ethics thought rightly worries about the so-called vulnerable populations. Most discussed initiatives on how to protect vulnerable participants lay emphasis on regulatory procedures which seem to consider persons participating in research as passive entities whose capacities are severely reduced. This may well be the case but is not necessarily so. In an enlightening paper Faulkner<sup>20</sup> reports that "The chief concerns of ethics committees are that participants should not be harmed by the research (a principle often called 'non-maleficence'), that the research is for the common good ('beneficence'), and that confidentiality be maintained and fully informed consent obtained. This *can* result in overly protective or paternalistic committees unwilling to consider research that may upset people. In the consultation for developing research ethics for social care, it was argued that the current system of RECs was designed to protect vulnerable people, **rather than to hear their voices and support a greater role for service users in research**" [emphasis added]. But some collectives are developing more definite goals and expectations in the research arena so perhaps more than paternalistically formulating protective regulatory measures it is time to listen to Oliver who alerts us that "as oppressed groups such as disabled people continue the political process of collectively empowering themselves, research practice based upon the investigatory discourse and utilising 'tourist' approaches by 'tarmac' professors and researchers will find it increasingly difficult to find sites and experiences ripe for colonization."<sup>21</sup> "The real challenge therefore for research in the 21st century is how to build an enterprise that exposes the real oppression and discrimination that people experience in their everyday lives without merely contributing to the classification and control of marginalised groups who seek nothing more than their full inclusion into the societies in which they live."<sup>22</sup>

As described, emancipatory research means changing the social and material relations in the research endeavor, and this is a demanding goal to be achieved. But it should be noted also that emancipatory research is not just a simple procedure which will by itself attain the inclusion of otherwise marginalized people. It is instead a complex proposal of paradigm change, and its implementation will need debate and academic integrity to revise its validity and outcomes, as shown by Oliver.<sup>23</sup> In this sense there are some "postcolonial" processes that have constructed research frames with space for emancipatory development, as exemplified by debates in Australia, New Zealand and Canada on regulations for health research within aboriginal peoples.<sup>24</sup>

Times call us to be aware of the struggle of marginal voices to be integrated into the social power distribution as it is their right, so our intellectual duty urges us to make an attempt to frame research into an emancipatory context since otherwise we'll limit our goal to a descriptive register of an unjust and oppressive reality. But the rightful thrust for inclusion must not make us forget that to be included in a consumer's society, the capitalist way of life, might not be the most desirable aim. If it is not, perhaps the ultimate finality of emancipatory research should not be mere inclusion but rather a radical societal change to achieve the democratic goals of equality and justice.

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- <sup>16</sup> Indeed one of the establishment reactions has been the concession of cosmetic participation, criticized by involved citizens as "tokenism". For a more detailed revision see Heyes S: A critique of the ideology, power relations and language of user involvement. [www.simon.heyes.btinternet.co.uk](http://www.simon.heyes.btinternet.co.uk), access 2/12/2002.
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- <sup>21</sup> For confirmation "wonderfullynutty" says in a survivors mail-list "Yeah we are at about due a paradigm shift and boy are the conservative elements letting us know that we need to revolt because they aint gonna evolve from their profitable acquiescence". <http://groups.yahoo.com/group/uksurvivors>, access 5/14/04.
- <sup>22</sup> Oliver M. Op. cit. This perhaps is a reaction linked to some "overresearched" groups but, as research possible participants continue getting strenght by associating themselves, it may well extend.
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