

**Possible Dialogues between Public Understanding of Science and Community
Engagement in Health Research**

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Abstract

Research has shown that for a technical-scientific innovation to be successful it must involve a social dimension, be attentive and autonomous regarding the use and consequences of the new knowledge generated. There is a wide variation in the definition of what constitutes Community Engagement (CE) and what are the motivations behind the research projects which incorporate it. The emphasis on dialogue, information sharing, collaboration and shared decision-making makes Community Engagement close to the area of Public Understanding of Science (PUS), which advocate effective forms of involvement and participation of society in science. Therefore, the questions that guide this study are: Do these fields share any research orientation? Do they come from similar theoretical and institutional backgrounds (authors, institutions, subjects of interest)? As

an exploratory study, a review of the scientific literature was conducted in Biological Abstract, EMBASE and Web of Science. Following the search strategies developed, the record recovery was 1.110 for CE, 311 for PUS and 60 for ES. References were then organized and analyzed into text mining software. There was a predominance of production by the United States, England, Canada and Australia. Research was conducted by different institutions, evidencing little dialogue between them. The field of Health and Education has a stronger presence in the three traditions, with due particularities. EC has a predominance of clinical research and PUS in public health. ES focuses mainly on nanotechnology and there are indications of a convergence towards education and other similar areas. Further analysis should point to synergies which strengthen the convergence of these fields.

Introduction

Science has its authority questioned by society today. In response, a promise to “listen” to society and expand its forms of participation aims to recover the credibility of science. This raises the need to rethink the model of public communication of science. In the relationship between science and society, the area of Public Understanding of Science has explored different strategies for social participation, where society itself is both the main research subject as well as the critical point of application of its results (Wilsdon & Willis, 2004). In this sense, there has been mainly three approaches which have dedicated themselves to understanding the relationship between science and society: Public Understanding of Science (PUS), Community Engagement (CE) and Engagement in Science (ES)

The PUS approach flourished in the 1980s, gained scientific status, with a particular journal devoted to the subject (<http://pus.sagepub.com/>) and became a matter of state, especially in the UK. As a theoretical perspective, PUS seeks to explore different strategies to approach these two actors, the state and society and it involves a number of fields of knowledge, such as sociology, psychology, history, political science, communication studies and analysis of science policy in the search of finding answers for this challenge (Bauer, Allum & Miller, 2007; Rowe & Frewer, 2005; Bucchi, 2008).

The PUS strategy found its own limits in the late twentieth century, when it seemed to not go beyond the so called “deficit model”, shaping itself as mainly “downstream”. Although the model recognizes and incorporates contextual dimensions which models the “understanding” of society and uses more participatory mechanisms of interaction, it is not enough to voice society’s claims and for it to be incorporated into science. It has been recognized that none of the strategies proposed for this “dialogue” between science and society has achieved abundant success.

The concept of Community Engagement emerges currently as a constituent part of the international movement in Global Health as a strategy which advocates equity in health for the entire world population. Has its research focus and funding concentrated on the problems and diseases of the developing world, worsened by poverty, highlighting its ethical dimensions. However, even when ethics is present, especially in the case of increasing clinical trials in developing countries, it is not sufficient to ensure participation, knowledge and support groups of the research subjects. Thus, Community Engagement has been the strategy pursued mainly in health research.

On yet another research front and mobilized by other challenges, the field of Engagement in Science emerges and becomes widely advocated as a method based on dialogue and with a public participation approach. This recent movement puts science as fallible and society as having enough credentials to contribute to the production of scientific knowledge. Far from taking control of science and technology, the approach of ES presupposes dialogue, building mutual interests and bonds of trust in an essentially “upstream” movement. Thus, ES aims to go beyond the “downstream” model of PUS, through dialogue and deliberation among all parties affected; from all the initial stages of the research process up to its final developments (OECD, 2012).

Therefore, informed by these theoretical frameworks, Community Engagement (CE), Public Understanding of Science (PUS) and Engagement in Science (ES), lies the main questions that guides this study: Do these fields share any research orientation? Do they come from similar theoretical and institutional backgrounds (authors, institutions, subjects of interest)? As an exploratory bibliometric study, a review of the scientific literature was conducted and through literature search, identification and analysis of the scientific fields of CE, PUS and ES was made possible.

Methodological procedures

This work is characterized as exploratory. Two main steps were performed: 1) bibliographic search and; 2) bibliometric analysis of the results. The objective was to search the international literature in order to map bibliographic dimensions (author, institution, research topics, collaborations, among others), here understood as important in order to delimit a domain knowledge (figure 1).

Figure 1. Methodological flowchart

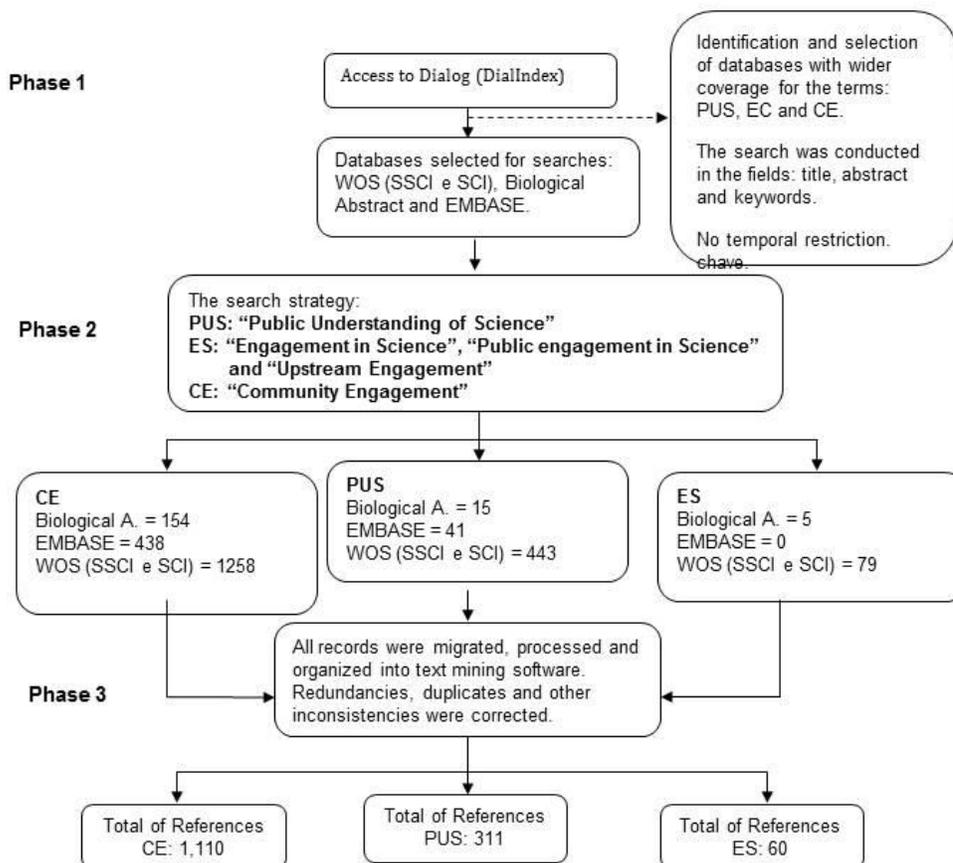


Figure 1. Methodological flowchart.

For the first step, a consultation was done in the Dialog Information Services (Dialog) in order to identify which scientific reference databases is more appropriate for the concepts of CE, PUS and ES. The literature search as done in the following

databases: Biological Abstract (EMBASE), Web of Science - Science Citation Index (SCI), Social Sciences Citation Index (SSCI). The search strategy for the following keywords was: “Community Engagement”; “Public Understanding of Science”; “Engagement in Science”, “Public Engagement in Science” e “Upstream Engagement”. The search was conducted in the fields: title, abstract and keywords. There was no temporal restriction.

The search then generated a set of references organized into three groups: Community Engagement with 1,110 records; Public Understanding of Science with 311 records and Engagement in Science with 60 records. Excel worksheets were then generated with the data concerning the three concepts totalizing 1,481 references in the three groups.

For the second step, a bibliometric analysis of the references was conducted. All records were migrated, processed and organized into a text mining software, The VantagePoint (<http://www.thevantagepoint.com>). The software enables the understanding and navigation of a great quantity of search results, giving a better perspective on the information retrieved. Redundancies, duplicates and other inconsistencies were then sorted out.

Results and discussions

This study aimed to analyze the concepts of CE, PUS and ES in the scientific literature of the major international reference databases. The convergence and/or divergence of these fields were sought through the identification of authorships, institutions, country of origin, keywords/thematic areas and possible collaborations present in the authorship in scientific production. The results are summarized below (table 1).

Table 1: Authors, institutions and keywords for PUS, ES and CE.

| | Author | Institution | Keyword |
|---------------------------------------|---------------------------------|---------------------------|-----------------------------------------------|
| Community Engagement (CE) | Jones, L. | Univ. California | Health/Public Health |
| | Wells, K. B. | Univ. Toronto | HIV/AIDS |
| | Newman, P.A. Vancly, F. | Univ. Duke | Education |
| | Lavery, J.V. | Univ. Carolina do Norte | Participatory research based on the Community |
| | Molyneux, C.S. | Washington University | Australia |
| | Meade, B. | Univ. British Columbia | Clinical Trial |
| | Aguilar Gaxiola, S.A. Bandewar, | Univ. Michigan | Inequalities in Health |
| | S.V.S. Chung, B.W. | CSIRO | Prevention |
| | Jones, F. | Univ. Melbourne | USA |
| | Schirmer, J. | Univ. Tasmania | Model |
| | Smith, T.F. | LSTMH | Politics |
| | Williams, K. | Med Univ. Queensland | Population |
| | | Univ. Johns Hopkins | Health Promotion |
| | Univ. Colorado | Medical Research | |
| | Univ. Liverpool | Society | |
| | Univ. Oxford | | |
| Public Understanding of Science (PUS) | Bauer, M.W. | Univ. College London | Knowledge |
| | Michael, M. | Cardiff University | Genetics |
| | Condit, C.M. | London University | Education |
| | Allum, N. | Open University | Risk |
| | Barton, A.C. | Univ. Nottingham | Technology |
| | Locke, S. | University of York | Communication |
| | Nerlich, B. | | Biotechnology |
| | Osborne, J. | | Attitudes |
| Raza, G. | | Information | |
| | | Media | |
| | | Research | |
| Engagement in Science (ES) | Barton, A.C. | Univ. of Columbia | Scientific Education |
| | Tan, E. | King's collage | Science and Technology |
| | Pidgeon, N. | London University | Nanotechnology |
| | Abd-El-Khalick, F. | Univ. Lancaster | Public Participation |
| | Bubela, T. | Univ. Michigan State | Government |
| | Chilvers, J. | American Univ. of Beirut | Literacy |
| | Fortus, D. | National Sun Yat-sen Univ | Motivation |
| | Hong, Z.R. | Univ. Alberta | Attitudes of teachers |
| | Lin, H. | Univ. Birmingham | Public Attitudes |
| | Vedder-Weiss, D. | Univ. California | Citizens |
| | | Univ. Illinois | Scientific Communication |
| | | Univ. of North Carolina | School Culture |
| | | Univ. Toronto | Gender |
| | Washington University | Identity | |
| | University of Western | Nanoscience | |
| | Weizmann Institute of Science | Environmental risk | |

Table 1: Authors, institutions and keywords for PUS, ES and CE.

Community Engagement (CE)

For CE a total of 1,850 records were retrieved. Then, in the text mining software inconsistencies and redundancies were excluded, generating a set of a total of 1,110 final references. The scientific production of the area begins in the 1990's with the first article containing the term "community engagement" appearing in 1994. The production increases exponentially from 2005 onwards. The area is recent, where the period of 2005 to 2013 represents 96% of the total number of records retrieved. The country that registers the largest number of scientific production in the area is the USA, representing 45.7% of the total production, followed by Australia with 17.4%; England with 13.9 percent and Canada with 10.6%. Together, these four countries account for 70.2% of all of the production for CE.

As for author collaboration, the USA has the largest collaboration, although this collaboration is mainly of endogenous character, where virtually all collaboration is between institutions within the country. As for the main themes of the area, among the first 10 keywords, there is a high recurrence of themes dealing with issues involving the Health area, where five are directly linked, namely: Health/Public health (first in the ranking), HIV/AIDS (second), clinical trial (sixth), inequality in health (seventh), Promotion in health and medical research (tenth). The data seems to indicate that the scientific production on the theme of Community Engagement has a strong linkage to the health field and its intervention models.

Public Understanding of Science (PUS) and Engagement in Science (ES)

For PUS, 311 records were recovered and for ES 60 records, totalizing 371 references. These were then merged, since the two concepts represent the relationship between science and society. After the removal of duplication in the text mining software, the total final references for PUS and ES were 368.

The growth of the scientific literature of these two concepts begins to stand out in the late 1990's and early 2000, more specifically from 2003 onwards. Until then, the production was minimal. The most productive countries in the area is England, followed by the USA and other countries such as Canada, Australia and Switzerland. These have a bibliographical production far lower if compared with the first two countries.

In relation to the ranking of authorship, the production is scattered across multiple authors, evidencing that there are many authors producing few scientific articles. As seen in table 1, the terms of the keywords are differentiated among themselves and it can be inferred that the area of PUS and ES have fairly diverse study interests. There is also an indicative of a bias for the field of social sciences and the processes of knowledge and information studies.

As for the author collaboration network of PUS and ES, the ranking of authors shows that authors from the USA have few partnerships outside their country. As for the British authors, there is greater external collaboration present, evidencing greater dialogue with institutions from other countries. More recently, an author from India comes into the network showing other possibilities for authors from developing countries

to participate. As seen in the results of PUS and ES, PUS has a much larger number of publications than ES records, partly because ES is a recent domain of knowledge.

Final remarks

The analysis of the records indicated a predominance of bibliographical production by the United States, England, Canada and Australia. Even though these four countries have a high production of research in the area of CE, PUS and ES, they are constituted as distinct movements, since the bibliographic productions of these concepts are from different institutions. At first sight, there is also indication that the domains of knowledge of CE, PUS and ES have different traditions according to the keywords which represent the scientific production of the areas. However, there are also indications that certain areas could be complementary, depending on the themes addressed, particularly in the case of health issues.

The mapping of the scientific production of the research in CE, PUS and ES aims to understand how the fields intertwine and represent the relationship between science and society. Future studies are needed in order to deepen this knowledge and may help in defining and developing strategies for further research.

References

TINDANA, P. et al (2007). "Grand Challenges in Global Health: Community Engagement in Research in Developing Countries". Plos Medicine, 4, pp.I9.

BAUER, M.W. ALLUM, N. MILLER, S (2007). "What can we learn from 25 years of PUS survey research? Liberating and expanding the agenda". Public Understanding of Science, 16(1), pp. 79-95.

POPAY, J (2006). "Community engagement for health improvement: Questions of definition, outcomes and evaluation: questions of definition, outcomes and evaluation". Available at: <http://www.nice.org.uk/niceMedia/pdf/smt/070306item13.pdf>

LAVERY, J.V., et al (2010). "Towards a framework for community engagement in global health research". Trends in Parasitology, 26(6), pp. 279-283.

WILSDON, J. & WILLIS, R. (2004) See-through science: why public engagement needs to move upstream. Project Report. Demos, London.

ROWE, G. FREWER, L. J (2005). "A Typology of Public Engagement Mechanisms". Science Technology & Human Values, 30(2), pp. 251-290.

BUCCHI, M (2008). Of deficits, deviations and dialogues: Theories of public communication of science. In: Handbook of Public Communication of Science and Technology. London: Routledge, pp. 57-76.

ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT (OECD). Planning guide for public engagement and outreach in Nanotechnology. 2012. Available at: <http://www.oecd.org/sti/biotech/49961768.pdf> [Accessed in: January, 2014].