”The place of “ patient engagement ” in Health Research: Bibliometrics and bibliographic contribution”

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The place of « patient engagement » in Health Research: Bibliometrics and bibliographic contribution

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(Author's translation)

The nature of the regimes under which patient participation in care, education and research systems and their governance is organized seems to be one of the key issues for health actors today. This is reflected both in the growth of publications on these topics in international documentary databases (biomedical databases such as PubMed or less specialized databases such as Google Scholar) and in the speeches of policy experts who have been repeating themselves on this subject for at least a decade (as can be seen from an analysis of the EHESP file) observing the rise of a "contemporary" patient (Fainzang, 2006) and the recognition of experimental knowledge (Jouet et al., 2014). In this context, this work proposes a progress report on this participation based on data from a bibliometric study that has just been conducted by the authors associated with Sophie Renet (pharmacist, hospitals Paris Saint Jospeh and A. Beclère AP-HP) for a dossier for a research journal in information and communication sciences (Las Vergnas, Jouet and Renet, 2017).

Analysis of the triptych : *engagement/participation/involvement*

In this study, references to the three terms currently characteristic of patient cooperation (i. e. patient engagement, patient involvement and patient participation) were first analyzed from a corpus of 5,398 articles identified via the PubMed bibliographic database as mentioning at least one of these words in its title or abstract (T/A).

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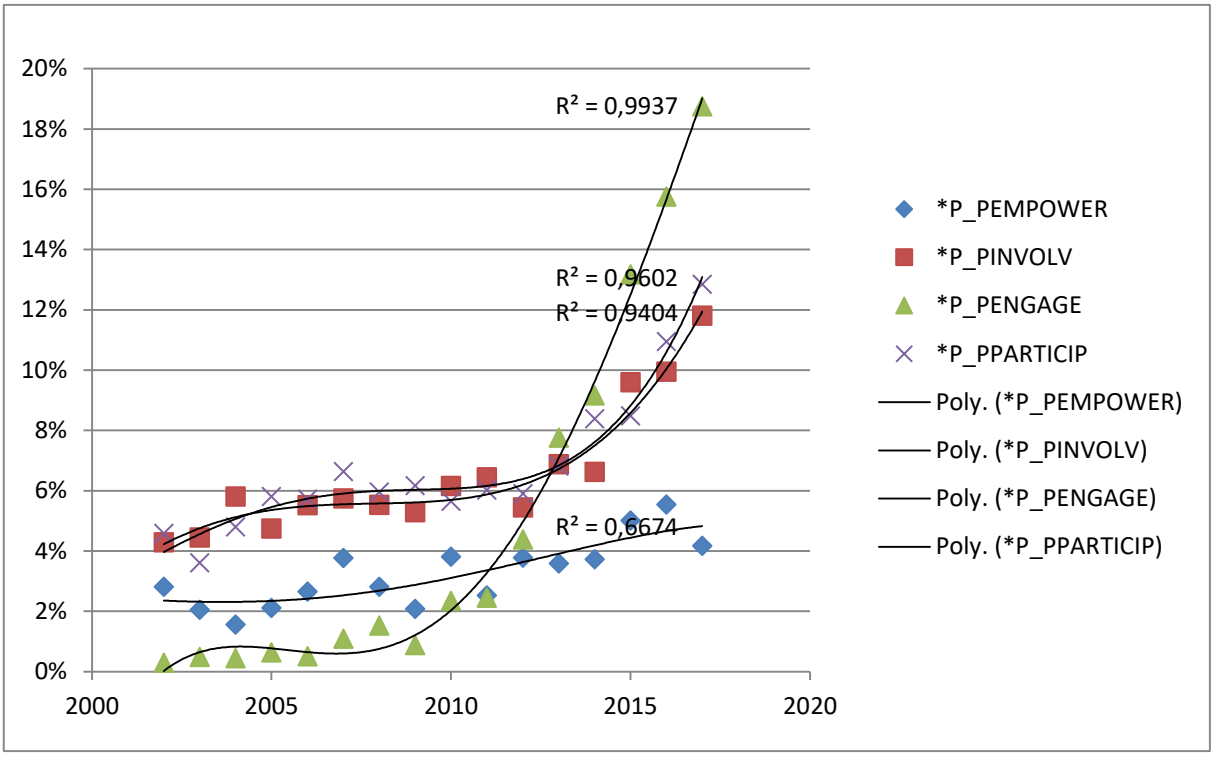

Figure 1: Ratios of publications mentioning patient engagement, patient involvement and patient participation compared to those mentioning "pneumothorax" and "psoriasis" in their titles and summaries according to PubMed. (Figure from: Las Vergnas et al., 2017)

This initial analysis concluded that these three terms are used interchangeably - in the vast majority of publications - as synonyms (only 8 of the 5,398 publications mention the 3 terms simultaneously in T/R and these words are synonymous in MeSH or MedLine): one or the other is used to designate individual patient participation or cooperation regimes (or more precisely dyadic, i.e. in his or her interaction or that of his or her relatives with "his or her" carers or doctors) allowing better compliance, or even empowerment (in the sense of "empowerment" of the person with regard to the deleterious effects of the symptoms of the disease). The link is sometimes made with an improvement in the design of care or protocols (more "patient-centred") thanks to feedback from patients or relatives.

Overall, in these publications, the phenomena most studied remain the targeted listening of patients' voices (e. g. Domecq *et al.*, 2014), the association with data collection protocols related to biomedical therapeutic education and the accelerated engagement or empowerment by connected eHealth objects in a patient-centred ergonomics perspective. Only a few dozen publications of meta-review of the literature focus on the analysis of the couplings that can exist between the wishes of empowerment or even ergonomics controlled by patients and devices thought of as "patient-centred". (Barello *et al.*, 2014 ; Fumagali *et al.*, 2014 ; Menichetti *et al.*, 2014 ;

Snape *et al.*, 2014 ; Castro *et al.*, 2016 ; Cerezo *et al.*, 2016 ; Rodgers *et al.*, 2016 ; Scand *et al.*, 2016 ; Tzeng et Pierson, 2017).

But the most striking result of the study of these 5,398 publications is the lexical analysis of the abstracts. Conducted with the Iramuteq software (Ratinaud et al., 2009), it shows that in fact, in the vast majority of cases, these terms refer to individual or dyadic (patient/professional) " engagements " or " implications " of patients or their relatives, in accordance with MedLine's recommendations to use the terminology of involvement to refer " more to the individual's commitment to health than to his participation in health research ".

This situation leads to a paradoxical situation that could be described as "the blind spot of collective reflexive cooperation" (CRC). Despite some marginal exceptions, the literature review, via PubMed, shows a spectrum of work focused on individual or dyadic cooperation and an almost invisibility of these CRCs. However, particularly in Europe and Quebec, expert or policy speeches on cooperation between patients and health professionals refer not only to such individual commitments but also to commitments with collective, or even societal, dimensions and challenges, as is the case for engagement as a representative of users (CRC1), patient-educator or peer health mediator (CRC2) or patient co-researcher in co-managed research protocols (CRC3). This means that, unlike individual or dyadic cooperation, the part of the spectrum of such cooperation normally linked to the engagement and involvement of patients and relatives is almost invisible in bibliometrics.

Search for collective reflective cooperations

The second part of the bibliometric study reported here therefore aimed to look for bibliometric ways to find traces of these CRCs in publications referenced in PubMed and particularly in these three complementary categories:

- CRC1: the joint improvement of the health system through the development of a representative health democracy. This corresponds to the participation or involvement of patients (or their relatives) in the organization or regulation of the health system (i.e. effective presence of user representatives in hospital or territorial bodies, consultation and advice on research protocols);

- CRC2: the integration of patients and relatives into the transmission circuits of knowledge about diseases and the regulation of disease experience. This corresponds to patient trainers or educators involved in patient therapeutic education (TVE), peer mediators and other peer helpers, and patients included in training systems for health professionals, such as the Bobigny and Montreal medical schools or the Lyon-based "patients involved in medical education" programme;

- CRC3: co-production of knowledge on health problems and treatments based on the experience and reflexivity of patients and relatives (users), which corresponds to co-researcher patients.

To this end, two additional explorations were carried out. The first was to maintain a search logic via the PubMed database by expanding the types of queries beyond the three terms engagement, involvement and participation, and the second was to directly search for articles identified via specialized sources.

As for the first complementary exploration, it was conducted by adding empowerment and patient-centeredness, then even more open terms such as peer education, social control, patient advocacy, participatory research, which provided nearly 5,000 new publications. The second consisted in directly searching references to CRC publications in a specific EHESP documentation file (Calvez, 2016) for CRC1 and CRC2, and in the Journal of Participatory medicine (JoPM) for CRC3. With this new corpus, CRC-type publications that were not found with the triptych of the terms engagement-involvement-participation actually appear. These remain few in number but are indeed present in lexical analyses.

Moreover, when we observe the different evolutions of these words, we notice a very strong and recent acceleration of patient engagement and patient centeredness, which can be qualified as an explosion of this category, comparable with requests on e-health and m-health (connected and mobile health), especially in comparison with the decrease in compliance or the decline in advocacy.

Conclusion

Thanks to these data, we can see that publications interested in patient engagement have increased dramatically over the past ten years, but that the vast majority of researchers who publish on this subject are more interested in individual or dyadic patient involvement than in opportunities for collective cooperation. Their priorities are to improve the quality of care, compliance or empowerment of each patient or to study ways of combining them with the ergonomics of protocols - in particular via e-health and m-health.

In fact, there are not yet any bibliometric means of monitoring the deployment of work involving patients with co-productions of biomedical knowledge. Qualitatively, it can be seen that such participatory medicine publications exist, but are not massively identifiable, due to a lack of interest on the part of database and thesaurus managers: undoubtedly one of the reasons is that their semantic constructions are still linked to a top-down vision of medicine and very strongly marked by the very formal protocols of

evidence-based medicine in which the roles of the protagonists are not easily interchangeable.

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