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COMMENTARY

Advocating for a better engagement of patients, users, caregivers, and citizens in healthcare and social services technology assessment (HSTA)

Commentary on “Assess, triangulate, converge, and recommend (ATCR): A process for developing recommendations for practice in the social sector using scientific, contextual and experiential data”

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Introduction

Assessment for political decision making in the field of social services is an activity of great complexity. One contribution of this emerging field of evaluation has been to highlight the ubiquitous character of complexity in all aspects related to social interventions, technologies or services delivery. Complexity is at the junction of people individual life history and embedded within a specific time and place [1-2]. However, we would like to stress in this commentary that complexity is also present for any evaluation process undertaken in the health or social services domains (e.g. drugs, oncology, technology assessment, organization of services, genetics, infectiology) [3]. This complexity in the field of evaluation lies on the diverse sources and nature of collected data and on the implicit value judgements that it entails. The diversity of data sources advocates for the need to better engage all categories of stakeholders (i.e. patient, user, caregiver, citizen) in every stages of assessment and appraisal processes in order to better equip decision-makers in their decision.

In the last edition of the International Journal of Hospital-Based Health Technology Assessment (IJHBHTA), Beauchamp et al. [4] presented a new and interesting method to develop (and grade) recommendations for fair and informed decisions in the field of social services assessment (i.e. the ACTR method for assess, triangulate, converge, and recommend). In this article, the authors argue in favor of a 0 to 10 continuous score for each elaborated recommendation. This score is based on 1) the convergence of scientific data with respect to efficiency, safety, and acceptability, as well as on 2) the convergence of contextual and experiential data alongside scientific evidence. A panel of experts (including users, their families, and others representatives) are involved in developing the recommendations. Each recommendation is then assigned with a strength (i.e. low, medium, high, very high) based on the 0 to 10 continuous score. In our opinion, this article proposes a process to develop and grade recommendations which will be surely useful to prioritize recommendations and support

decision-making in social services assessment, taking into account its inherent complexity. We agree with these authors when they acknowledge that a comprehensive evaluation process should be able to identify all available scientific data (and evaluate the quality of such data), no matter their sources (e.g. quantitative, qualitative, mixed-methods studies, gray literature, systematic or narrative reviews) or their design (e.g. experimental, quasi-experimental, comparative). We also agree with the necessity to integrate experiential and contextual data in the appraisal activity. This is fundamental to produce high quality evaluations that are credible and meet the best practice standards in healthcare and social services technology assessment (HSTA). Nevertheless, we also highlight that engagement of patients, users, caregivers, and citizens (PUC) in appraisal activities in social services assessment must go beyond their sole involvement in the elaboration of recommendations.

Advocating for a better engagement of patients, users, caregivers, and citizens in HSTA

We want to highlight the necessity to better include the perspectives of the PUC in all appraisal process in order to produce high-quality recommendations (necessity which Beauchamp et al. [4] did not sufficiently stressed in their article). For the legitimacy of the evaluation process itself and for credible, feasible and contextualised recommendations (especially in the sector of social services assessment but in any other sector of evaluation as well), evaluators should give more space to the perspectives of the PUC. Towards, evaluations could integrate scientific data on these perspectives, for example the quantitative or qualitative literature on patients' experience, preferences or on social values, besides scientific data of efficiency. When this literature does not exist, the evaluation process should produce such type of data by implementing rigorous consultative methods or

procedures with the participation of the PUC. These methods could also be used to generate experiential data allowing the validation of the contextualisation of other sources of data. Moreover, in order to attain (and maintain) a good partnership, the PUC must participate in the full spectrum of evaluation processes and activities. The PUC contribute with practical experiences of care and services [5-7] which in turn increase the usefulness of an evaluation by taking into account their values and concerns [8]. The PUC must be involved from the beginning to the end of the appraisal process (with a participation component in the governance of the HSTA activities) [9]. However, despite these certainties, the best methods for PUC participation, the best moments of involvement for them and the type of PUC to be privileged remain to be specified [10-12].

The example of the HSTA unit of the CIUSSS de l'Estrie – CHUS

To move forward with the field of HSTA and to systematically engage more PUC perspectives in the appraisal process, the authors of this paper all contributed to the co-construction of an engagement policy for the PUC on behalf of the HSTA unit of the CIUSSS de l'Estrie – CHUS. First, an advisory committee has been formed to discuss about participation and engagement. This committee contained various categories of stakeholders (i.e. user, caregiver, citizen, representative of the user experience service of the CIUSSS de l'Estrie - CHUS, administrator, ethician from the Institut National d'Excellence en Santé et Services Sociaux (INESSS), HSTA representatives). A preliminary vision statement including the objectives and guiding principles of our engagement policy emerged of this committee. This preliminary statement was then deliberated in a Delphi process with three rounds of deliberation prior to reach a strong consensus.

This PUC engagement policy is now the business card of the HSTA unit of the CIUSSS

de l'Estrie-CHUS. It contains four objectives and four guiding principles that should underlie all activities in our unit. The objectives of this policy are: 1) to propose principles for the participation of the PUC in the development of our evaluation products, 2) to propose principles for the participation of the PUC in the structuring decisions of our unit, 3) to involve the PUC in the planning and realization of our evaluations, and 4) to provide guidance for collecting comments and suggestions from the PUC throughout the evaluation process and report them transparently and synthetically in our products.

We realize the importance of taking into account opinions, values, and experiences of the PUC representatives. As a result, we propose the following principles to structure the activities, products and operations of our unit.

Principle 1 (Utilitarian principle)

The HSTA unit of the CIUSSS de l'Estrie - CHUS values the participation of the PUC in its evaluation activities. Their contribution is complementary to the data gathered in the scientific literature and the contribution of other stakeholders (e.g. managers and clinical teams). This partnership helps to contextualize the evaluation object and to refocus the decision of our unit around the real needs of the PUC in order to increase the quality of services and better fulfill our mandate to support population responsibility.

Principle 2 (Ethical principle)

The HSTA unit of the CIUSSS de l'Estrie - CHUS must protect the PUC so that they contribute to enrich evaluation products freely without any risk of personal injury. Thus, it is committed to a) foster privacy and protection of personal information, b) minimize the risks associated with participation (e.g. physical, psychological, social), c) promote voluntary participation, informed and free at all times, d) recognize the contribution of the PUC through reimbursement of parking or public transit,

and e) provide effective feedback through ongoing communication.

Principle 3 (Methodological principle)

The HSTA unit of the CIUSSS de l'Estrie - CHUS promotes the adequate preparation and participation of the PUC. It is understood that a) scientific and gray literature alone cannot replace the knowledge of the PUC (experiential knowledge, regardless of source, is complementary evidence that must be taken into account), b) user participation is not equivalent to citizen participation (these are two types of contributions that provide information on different but complementary aspects; e.g. experience relating to the state of health and use of services vs. social values), and c) it must foster different kinds of implications (i.e. direct or indirect) and levels of participation (i.e. information, consultation, collaboration, partnership) in several stages of an evaluation.

Principle 4 (Feasibility principle)

The HSTA unit of the CIUSSS de l'Estrie - CHUS promotes the expression of the best production conditions to optimize the participation of the PUC and to better meet the needs of decision-makers. It is understood that a) the participation of the PUC is variable in geometry (it is sometimes light and sometimes more important. It can also involve the participation of more than one stakeholder from the population), b) it is necessary to adopt a flexible (to allow the participation of the PUC) and rigorous (to meet the methodological requirements of HSTA) evaluative approach, and c) the PUC are always partners in our assessments (at least one representative from one of these categories of stakeholders is involved in the planning of each evaluation, unless there are exceptional circumstances. This representative, together with the project team, contributes to decision-making about the intensity and level of involvement of PUC in this project).

Future direction

Regardless of the process, object and area of evaluation, more space needs to be given to the PUGC's perspectives in HSTA, including the mobilisation and generation of specific scientific data, and the inclusion of the PUGC experiential and contextual knowledge in a partnership containing various level of engagement. The legitimacy of the recommendations, including the procedural (i.e. fair process, appropriate selection and diversification of participants and management of conflict of interests) and substantive (i.e. relevant criteria and evidence, different worldviews represented) legitimacy depends on it. As a result, institutions producing evaluations will be able to support their mandate of population responsibility and increase the health and well-being of individual and communities.

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Conflicts of interest

None.

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