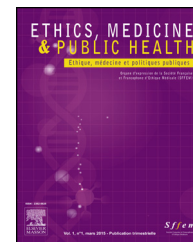




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Ethics and governance in translational research



Éthique et gouvernance dans la recherche translationnelle

M.T. López de la Vieja (PhD)

Catedrática de Filosofía Moral, Facultad de Filosofía, Edificio FES, P^o F. Tomas y Valiente s.n, Campus Unamuno, University of Salamanca, 37007 Salamanca, Spain

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KEYWORDS

Ethics;
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Summary This paper analyzes three ethical and governance implications in the translational model for scientific research: some pragmatic arguments in favor of efficient governance; norms and ethical principles, like responsibility, to shape good practices; and why ethics and criteria of governance are significant for translational research. The gap between scientific discoveries and clinical improvements has been registered for decades; however, recent discussions about inefficiency and possible waste of knowledge could justify the translational turn in quality research.

Objectives. – To clarify the role of the translation approach in biomedicine and, in general, in scientific research. To identify pragmatic and normative arguments in favor of efficiency, justice, and responsibility in the translational turn.

Method. – A review of recent contributions to research ethics, governance, and translational research.

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MOTS CLÉS

Éthique ;
Recherche
translationnelle ;

Résumé Ce document analyse trois implications d'éthique et gouvernance pour la recherche translationnelle : quelques arguments pragmatiques en faveur d'une gouvernance efficiente ; normes et principes d'éthique, comme la responsabilité, pour élaborer bonnes pratiques ; et pourquoi l'éthique et les principes de gouvernance ont relevance dans la recherche

E-mail address: tlv@usal.es

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Gouvernance ;
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translationnelle. En décades précédentes, la distance entre les innovations scientifiques et les avancées cliniques a été notée, des récents débats sur l'inefficience et la possible perte des connaissances justifient le tournant translationnelle pour la recherche scientifique de qualité.

Objectifs. – Clarifier le rôle du model translationnel ou de transfert en biomédecine et dans la recherche scientifique. Identifier les arguments pragmatiques et normatifs en faveur de l'efficience, la justice et la responsabilité dans le tournant translationnel.

Méthode. – Une revue de la récente littérature concernant l'éthique de la recherche, la gouvernance et la recherche de transfert.

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Introduction

“Researchers should focus their research for the good of mankind and for expanding the frontiers of scientific knowledge, while enjoying the freedom of thought and expression, and the freedom to identify methods by which problems are solved, according to recognised ethical principles and practices” [1].

The European Charter for Researchers of 2005 stressed that ethical principles are or should be fundamental for researchers. They have to adhere to ethical practices; it is also their responsibility that scientific research will become more relevant for society. For this reason, the scientific research performed according to ethical standards could go beyond respect for rights, autonomy of subjects, justice, and the right balance between risks and benefits. Firstly, research should always respect basic rights; these draw a distinct line between good practices and malpractice or between good science and abuses. In addition, scientific research has to be responsible and, thus, committed to agents and societies. In this sense, theories would be closer to practices, as the expression “from the bench to the bedside” – and from the bedside to innovations – suggests; currently, there is a growing interest in programs, centers, and groups intent on applying or transferring basic research into efficient therapies.

“Translational” research refers to integrated processes in biomedicine and, in general, in scientific knowledge. This should be considered a continuum, in order to connect research findings with practical developments, especially in clinical areas; offering the best prevention, diagnosis, treatments, and care for patients is the main goal. Moreover, clinical observation could open unexplored paths for patient-oriented research and, eventually, for the quality of public health. This accent on a continuum of knowledge and real applications of course will require more communication and collaboration from institutions and from several agents. These quests for practical translation could show some limits, though. For instance, Alzheimer’s disease and some forms of dementia still require more information and basic research. Research funding has to be increased, as well. Then, translation of knowledge and care would prevent, face and, eventually, reduce the serious impact of these diseases on society, as the international Dementia

Communiqué of 2013 maintained [2]. Besides, the notion of “applied knowledge” itself has many levels and nuances in different fields, from medicine, biology, social sciences to human studies.

In this context, the ethical perspective could bridge the general principles, like autonomy, justice, and also responsibility, with a more pragmatic approach to research. Between the need of autonomous thought for researchers and more efficient answers for concrete needs, ethics usually argues about norms as guidelines for action, including scientific activities. Therefore, researchers should make considerable efforts to offer positive contributions for agents and society; at the same time, they have to value the normative framework that regulates scientific discoveries and their application. This paper analyzes three ethical and governance implications in the translational model for research:

- the “translational turn”, its definitions and some pragmatic arguments in favor of efficient governance;
- the positive impact of norms and ethical principles, like responsibility, in order to shape practice, quality practices;
- why ethics and the criteria of governance are significant for translational quality research.

Two levels of argumentation support the emerging translational turn. On the one hand, recent circumstances and some evidence-based reasons speak in favor of a more efficient management of research. Nowadays, a possible waste of knowledge seems just unacceptable in contexts of limited resources. On the other, normative arguments – ethical and political reasons – emphasize justice and responsibility as complementary principles to discuss competently biomedical and bioethical issues. Autonomy is the key principle in these fields; additional criteria, like equality, justice and responsibility, are also relevant for the good governance in every level of quality research. In sum, data and normative framework present collaborative and responsible research as the right answer for distinct claims – efficiency, openness, participation, accountability, coherence – of experts and non-experts. They are citizens, above all. Since 2005, ethical standards have been defined for research in the European Union. Freedom of thought and the good of humans come together, in The Charter for Researchers. Since 2001, the criteria of governance indicate not only what good

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