

Title

The role of end-users in life sciences research and innovation

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The benefits of life sciences research for healthcare innovations are highly expected, but they are taking place in a long term, complex process involving multiple actors. Policy has been focusing primarily on stimulating public–private interactions to increase transfer of knowledge and commercialization, which in turn would lead to healthcare innovations and entrepreneurship. But the role of the professional public sector (medical professionals, patients, other users) in the innovation process has a largely passive connotation, probably due to the fear of increasing healthcare costs upon dissemination and implementation of innovations in health care practice. Hence, the social relevance of the research is often ignored.

Societal relevance of research can be defined as the value that is created by connecting research to societal practice and it is based on the notion that knowledge exchange between research and its related professional, public and economic domain strengthens innovation. It requires researchers to interact with stakeholders in these different societal domains (Mostert et al. 2010; Spaapen en van Drooge 2011; Meijer 2012)

The aim of this project is to investigate the role of end users in the ex ante evaluation of cardiovascular research proposals and subsequent monitoring of projects. For many years, the Dutch Heart Foundation (a charity fund) is funding excellent research in the Netherlands (Van der Velde et al. 2010), and now they also would like to encourage quicker transfer of results to healthcare for the benefit of patients. They acknowledge that the Foundation owes it to their donators to show what has come from their donations, therefore accountability and the need to – eventually – improve health care solutions are the main incentive to engage in a process to include end users (different stakeholders) already in a early phase of research project, and define indicators in consultation with both researchers and stakeholders to monitor research. In other words, the Dutch Heart Foundation want to strengthen the societal relevance of the research funded. The objective of this study is two-fold:

- 1) To define criteria that are suitable to review the societal relevance of research proposals.
- 2) To train an end-users panel in using and refining the societal criteria in the review of research proposals that is complementary to the scientific quality.

Ad 1) The criteria for reviewing societal relevance were collected and defined in an internal (Dutch Heart Foundation) project team. The main issues concerned the definition of societal relevance: Is research societal relevant when the research topic addresses a relevant and urgent medical problem? Or is it relevant when the research proposed is taking an approach that – when successful – is offering an innovative medical treatment that is superior to existing ones (e.g. in terms of quality of life, therapy conditions, costs?). When judging societal relevance in this way, the quality of the research proposed seems to dominate the discussion, and more effort is need to be able to review the added value. Generally, this is a discussion about internal values and external esteem. In addition, criteria were defined that help reviewing the active engagement of specific stakeholders, and activities to connect the research results to partners that can take ‘the next step’ in the innovation process. Research can be more societal relevant when it is based on clearly defined societal objectives, and when monitored and evaluated in the light of the objectives. However, when the applicants weren’t asked to provide such information, little of such activities can be expected. Also, criteria for participation and potential ethical and legal hindrances were included.

Ad 2) The end-users panel was created based on the idea that research can be more societal relevant when it is planned, executed and evaluated with the involvement of users and other stakeholders. The end-users panel is one strategy to involve users and other stakeholders from the start. The end-user panel was carefully put together and includes medical specialists (in cardiovascular medicine, but NOT in research), general practitioners, nurses, nurse practitioners, patients having a cardiovascular condition and lay people, so as to take into account as many different social and medical perspectives. In order to keep the balance in the panel the patients involved were relatively highly educated. The end-users panel was trained first and educated in the criteria using an old research proposal and, and then acted in a formal research proposal review procedure without any influence on the outcome of the review process. Since this study is a pilot for the Heart Foundation, the subsequent steps were independently observed to investigate internal values of end users with regard to societal relevance, interactions between end-users to come to consent, and usefulness of the criteria. The formal procedure also includes and interaction with the principal investigators. The end-users panel will act a second time in the pilot study and subsequently criteria and organisation of the process will be evaluated.

Based on the result of the pilot study, the Dutch heart Foundation will decide whether to maintain or extend the focus on societal relevance, and include the criteria in future calls for proposals. This could be a suitable way to overcome the criticism that societal relevance (and impact) is more often postulated than demonstrated (Bornmann 2012). Early involvement of stakeholders and clear societal objectives and activities also may reduce difficulties in attribution, causality and timescale issues. And the societal criteria could serve as a starting point for future societal impact assessments as well.

However, the operationalization of societal relevance raises additional questions and issues that need to be addressed in more detail as well, such as:

- Do the researchers value the concept of societal relevance in a similar or different way than the end users?
- How can be avoided that the criteria create a bias towards applied research; for the Heart Foundation this is critical. Is it possible to catch the long-term nature of a very basic research proposal?
- Can the end users reach consensus when they have pleiotropic values on societal relevance? And how do they judge potential societal impacts (Holbrook & Frodeman, 2011)?
- How about esteem systems for societal relevant research? And is the esteem from stakeholders, in this case end-users, sufficient to convince researchers to act more societal relevant?
- Should the end-users be embedded in the scientific review, or is it better to keep it separate. If so, how to weigh the two reviews, and where to have decision power?
- Are the criteria also suitable for monitoring and evaluation?

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