

If public engagement is the solution, then what is the problem with biobanking?

Over the past two decades public engagement in biobanking has become a central element in discussions of how to make biobanking sustainable. However, while we can find narratives of successful integration of patients in disease-specific biobanks, we find fewer clear visions on public engagements in other kinds of biobanks. In this paper, we explore different understandings of the problems that public engagement can solve and what kind of publics are constructed in engagements.

Methodologically, we will review the existing literature of patient/citizen engagement in particular with regard to case studies presented.

The paper proceeds in two steps. First, it explores the diversity of reasons why publics should be involved in biobanking and how such reasons are linked to specific kinds of biobanks, identifying what is seen as the problem to which engagement is the solution. In a second step, we look at who is to be engaged and how, reflecting on the construction of the publics to be engaged, ranging from citizens more broadly speaking to publics affected by a specific medical condition.

The paper aims at outlining a classification of different understandings of the challenges of biobanking and how they related to diverse ways of seeing public/patient engagement as a solution. It will also argue, that in order to allow for a more comprehensive understanding of public engagement in biobanking, we also need a better understanding of the complex infrastructures biobanks have become.