

Trends and Challenges in Biobanking

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Introduction

At the end of last century, if you searched for the term ‘biobank’ it would be difficult to find anywhere. Twenty years later, ‘biobank’ has become the standard term in English for collections of samples and data that are systematically organised and curated so that they can be used for many different research purposes by many researchers over time.¹ Biobanks are now considered intrinsic to the research process and are regarded as essential infrastructure for hospitals and research institutions in most countries around the world. There are dozens of biobanks in Australia alone and thousands internationally, including some nation-wide repositories that have required considerable investment. The next stage of development in the field of biobanking has seen biobanks being brought together in organised networks through the establishment of national registries and standardised processes for the collection and curation of samples.² However, the development of biobanking as a field has not been without some challenges to existing norms, best practice and established legal requirements.

There are a number of key legal challenges that have emerged from biobanking activities such as the nature of the consent that should be obtained, the protection of privacy, property rights in tissue and information, and how to enable access to researchers and commercial entities. Over time, other issues have emerged in line with evolving technologies and changing social attitudes such as if, and how, incidental findings should be returned to participants as well as concerns about the long-term sustainability of biobanks. As the costs of genome sequencing have fallen, biobanks have often enriched their collections by adding genetic samples, which has intensified issues about the return of results. The purpose of this chapter is to discuss these issues that have dominated legal and ethical debates in biobanking over the past 20 years and to demonstrate how the concerns have evolved over time. We will focus on United Kingdom (and European law when it is relevant) and Australian law to bring out some of these issues and illustrate the complexity of the law in these jurisdictions, but also the similarities between them.

1 European Commission and Directorate-General for Research and Innovation, *Biobanks for Europe: A Challenge for Governance* (EUR-OP, 2012) 13.

2 An example of this is BBMRI-ERIC, which co-ordinates the activities of biobanks across Europe, though the development of national nodes to make samples more accessible to researchers wherever they are located around the world.

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