Semantic, Pedantic or Paradigm Shift? 
Recruitment, Retention and Property in Modern Population Biobanking

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Abstract 
Evolving uses of human biological material, including their collection and retention in biobanks and their distribution to diverse projects, are sites of great tension from the human rights perspective. In the medical-legal setting, these rights are often protected and realised through consent practices. In the biobank setting, there endures a widely shared concern over consent, and the many divergent ways it is fashioned and deployed. This article reconsiders consent in the biobank setting, first, addressing the theoretical foundation of consent and its deployment in the broader medical context, second, examining the nature of biobanks and the uncomfortable position of consent therein, and finally, offering a means of approaching recruitment and retention in the biobank setting which is sensitive to originator interests, including human dignity, doing so within the rubric of a property model. 

Keywords 
Population biobank; human tissue; consent; withdrawal; property; interests 

1. Introduction 
Evolving medical and research practices, including the collection and retention of human biological material in biobanks for distribution to researchers of diverse background and interest, are considered to be of significant scientific, healthcare and commercial value, but they are also sites of great tension from the human rights perspective, implicating rights to bodily integrity, self-governance, personal security, public interest and common good. In the medical setting, many of these rights are protected and realised at least in part through consent practices (as well as privacy and information security practices). Indeed stakeholders have worked

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terribly hard — in a setting characterised by a long history of medical paternalism and recent revelations of research abuses — to empower patients and human research subjects, and to transform their interaction with the medical-research community into a relationship of mutual trust and dialogue which operates on a morally-grounded conception of consent (ie: consent which unfolds as a process). These were achievements fought for under the banner of human dignity, and they remain incomplete and ongoing.

But biobanking is a medical endeavour of a different character and magnitude. It sits uncomfortably at the “common good” and “individual interest” intersection, as evidenced by the pools of ink spilled, and numerous concerns aired, over its practice, and the construction and deployment of consent in the biobank setting, which is diverse and inconsistent. Indeed, consent practices represented a central issue in the recent Tiss:EU conference, the inaugural output of a European FP7 project intended to assess the impact of European Union regulatory activities on member states with respect to the procurement, storage and transfer of human tissue and cells in Europe. My own concern derives from the (sometimes) unreflective use of consent in combination with its uneasy interaction with the needs and aims of the biobank setting.

Given the above, this short article reconsiders this setting, and suggests a way forward that eschews the consent paradigm, places greater emphasis on the common good elements of biobanking, and might permit us to avoid the knots in which we tie ourselves trying to make consent work in this unique and critical field of health research. First, it briefly considers the theoretical foundation of consent and its deployment in the clinical and clinical trials contexts, where its continued strength and robustness is essential (because it actually has a chance of addressing the risks to which individuals are exposed). Second, it briefly considers the sui generis nature of biobanks and why consent is such a vexing issue therein. Finally, it offers an alternate means of approaching recruitment and retention of participants in the biobank setting, suggesting a governance framework which is both more intellectually honest (than many current practices) and still protective of human dignity, which is such an important value in this field.

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4) For more on the Tiss:EU Project, see http://www.tisseu.uni-hannover.de/index.php.
5) I concede that some of the argument may be seen to rest on semantics (ie: the characterisation and naming of what is transpiring at the recruitment/retention phase), but it is ultimately important for our broad understanding of the term “consent” and its retention of power, and for the theoretical basis on which we construct our involvement in biobanks more generally.