How Representative Are Research Tissue Biobanks of the Local Populations? Experience of the Infectious Diseases Biobank at King's College, London, UK

Zisis Kozlakidis, Christine Mant, Barry Peters, Frank Post, Julie Fox, John Philpott-Howard, William C.-Y. Tong, Jonathan Edgeworth, Mark Peakman, Michael Malim, and John Cason

Biobanks have a primary responsibility to collect tissues that are a true reflection of their local population and thereby promote translational research, which is applicable to the community. The Infectious Diseases BioBank (IDB) at King's College London is located in the southeast of the city, an area that is ethnically diverse. Transplantation programs have frequently reported a low rate of donation among some ethnic minorities. To determine whether patients who volunteered peripheral venous blood samples to the IDB were representative of the local community, we compared local government demographic data to characteristics of patients who have donated to the IDB. There was a good match between these statistics, indicating that the IDB's volunteer population of human immunodeficiency virus patients was similar to local demographics.

Introduction

THERE IS A RADICAL CHANGE underway in how translational research is being, and increasingly will be, performed. Traditionally, researchers devised a hypothesis and obtained funds and ethical permissions for an evaluation of the premise. This cycle was repeated with an inevitable waste of valuable clinical material at each stage. It is recognized that biobanks maximize usage of samples, supply well-characterized cohorts of biological samples and clinical data, and can provide ethical and regulatory permissions. This allows research to proceed more rapidly and efficiently, enabling a wide range of studies to be performed on the same population. Indeed, biobanking was hailed by *Time* magazine in 2009 as "one of the ten ideas which are transforming the world right now."¹ The Infectious Diseases BioBank (IDB) was established in 2006 and archived blood fractions (plasma, sera, DNA, and live lymphocytes) from patients infected with human immunodeficiency virus (HIV), hepatitis B or C viruses, or invasive bacteria, from patients with some autoimmune conditions, as well as from controls.² By far the largest archive is currently that of HIV-infected patients, wherein the IDB has selected to recruit longitudinal blood donations from patients with interesting patterns of disease (rapid progressors, long-term nonprogressors, recent seroconverters, as well as those starting therapy).

The IDB recruits volunteers from patients among the diverse population of Southeast London, UK. Organ donations can be low among ethnic minorities, and in the United States,

this has stimulated education programs, which have partially redressed the situation.³ Consequently, we had concerns that the IDB may not be representative of the local community. This is critical, because translational research will increasingly become dependent upon biobanks and a bias in the populations from the outset could lead to unrepresentative research findings. Over time this may preclude the development of appropriate diagnostics or therapies for all. There is also a strong argument against locating such clinical archives in ethnically homogeneous cities. Our local population is multiethnic, with the most commonly spoken languages after English being Yoruba (West African) and then Portuguese.^{4,5} The IDB was established in 2007 and is thus in its infancy compared with many long-established biobanks. In this analysis, we determine whether the patients who have volunteered to date are representative of the local community and, if not, devise new recruitment strategies to correct any disparities at an early stage.

Materials and Methods

The IDB has recruited 200 clinically interesting patients infected with HIV-1 clade B infections who were not initially receiving highly active antiretroviral drug therapy (HAART) in 3 main categories: (1) those who progress to disease very quickly (rapid progressors), (2) those who have a more delayed progression to disease (long-term nonprogressors), as well as (3) patients before and after initiation of HAART.

FIG. 1. Ethnicity of Infectious Diseases BioBank (IDB) volunteers. **(A)** Major ethnic populations in Southeast London boroughs of Southwark/Lambeth. **(B)** Ethnicity of human immunodeficiency virus (HIV)-positive patients in the same area in 2000. **(C)** Ethnicity of HIV-1 clade B-positive volunteers to the IDB collected between 2007 and 2010. W, White; B-A, Black-African; B-C, Black-Caribbean.

These patients were recruited at a tissue collection center at the Harrison Wing Clinics at St Thomas' Hospital London, and in September 2010, the IDB had collected samples from over 1000 patient visits of this cohort of patients. Demographic data were obtained from local government figures^{4,5} and a study of 679 HIV (all types and clades)-positive patients in the same area.⁶ For the local government data and IDB statistics, individuals self-identified as "White," "Black African," or "Black-Caribbean." In the case of the HIV study,⁶ ethnicities were recorded as "White" or "Black-African." Data were compared by 2-tailed Fisher's exact test.

Results

There was remarkable concordance between all 3 sets of demographic data, with the "White" predominating, followed by Black-African and then Black-Caribbean (Fig. 1). No significant differences were found between the 3 sets of data (all $P > 0.05$).

Discussion

The IDB is a relatively new biobank and we wanted to establish at a relatively early stage whether the samples being collected were representative of the multicultural nature of the local community. The major component of the IDB is a

cohort of HIV patients that was initially restricted to those infected with HIV-1 clade B viruses. This clade of virus accounted for around 58% of HIV infections in our locality among samples collected in 2000.⁶ The analysis of the ethnicity of the HIV-positive IDB volunteers indicated that there was a remarkable similarity to local government demographic figures for the boroughs of Southwark and Lambeth, which is the main catchment area for the Harrison Wing Clinics. Data on demographics collected by both local governments by a previous study and by the IDB depend upon self-association by the individuals and patients, and slightly different categories are present in the 2 datasets. Nevertheless, for both the government figures and IDB data, "Whites" were most common, followed by "Black-African" and then "Black-Caribbean." Thus, unlike the experience of those recruiting organ donations, volunteers for the IDB match the local demographics acceptably. There is a multitude of cultural, religious, and scientific explanations for these differences between organ donors and biobank recruits. Additionally, for the latter, there may also be a strong linkage between willingness to donate and potential self-interest, as opposed to altruism.

Acknowledgments

The IDB acknowledges funding from the Guy's and St Thomas' Charity and the National Institute of Health Research Comprehensive BioMedical Research Centre at Guy's and St Thomas' NHS Trust.

Author Disclosure Statement

No competing financial interests exist.

References

1. www.time.com/time/specials/packages/article/0,28804,188477918847821884766,00.html
2. Williams R, Mant C, Cason J. The Infectious Diseases BioBank at King's College London: archiving samples from patients infected with HIV to facilitate translational research. *Retrovirology* 2009; 6:98.
3. Callender CO, Miles PV. Minority organ donation: the power of an educated community. *J Am Coll Surg* 2010;210:708-715.
4. www.lambeth.gov.uk/services/councildemocracy/statistics/censusinformation
5. www.southwark.gov.uk/services/councildemocracy/statistics/censusinformation
6. Easterbrook PJ, Smith M, Mullen J, et al. Impact of HIV-1 viral subtype on disease progression and response to antiretroviral therapy. *J Int AIDS Soc* 2010;13:4.

Address correspondence to:

Dr. John Cason
Department of Infectious Diseases
The Infectious Diseases BioBank at King's College London
2nd Floor Borough Wing
Guy's Hospital
London SE1 9RT
United Kingdom

E-mail: john.cason@kcl.ac.uk

Received 16 March, 2011/Accepted 7 April, 2011