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0521539870 - The Human Genome Diversity Project: An Ethnography of Scientific Practice

Amade M'Charek

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The Human Genome Diversity Project

The Human Genome Diversity Project was launched in 1991 by a group of population geneticists whose aim was to map genetic diversity in hundreds of human populations by tracing the similarities and differences between them. It quickly became controversial and was accused of racism and “bad science” because of the special interest paid to sampling cell material from isolated and indigenous populations. The author spent a year carrying out participant observation in two of the laboratories involved in analysis of genetic diversity and provides fascinating insights into the daily routines and technologies used in those laboratories and also into issues of normativity, standardization and naturalization. Drawing on debates and theoretical perspectives from across the social sciences, M'charek explores the relationship between the tools used to produce knowledge and the knowledge thus produced in a way that illuminates the Diversity Project but also contributes to our broader understanding of the contemporary life sciences and their social implications.

AMADE M'CHAREK is Associate Professor at the Department of Biology and the Department of Political Science, University of Amsterdam and is Lecturer in Science, Technology and Public Management.

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Preface

Just like any other text, this book embodies many hidden stories. It combines different worlds and is based on the help and effort of many colleagues and friends. Although writing involves solitary journeys, I could not have realised that the secret to writing a book lies in collective work. In a sense, this book produced its networks of intellectual exchange; writing it taught me many things about work and life in academia and in the process it gifted me many friends and colleagues. The book was written, but it also wrote my life.

My interest in genetics existed before I started this project. However, my anxieties and excitement about its potentials came with my work on the Human Genome Diversity Project. Genetics became something that I found myself criticizing or defending, depending on the context that I was in. It thus became my intimate other. I attribute this involvement to the generosity of the scientists who allowed me to take a look in their kitchen and to try out some of the recipes myself. Gert-Jan van Ommen played a crucial role in this. He became involved with my research from the beginning and was a very careful reader of my work, providing me with valuable comments and suggestions. I thank him for long and insightful discussions, and for opening the doors to the community of population geneticists, which enabled me to enter the laboratories. One of the contacts that Gert-Jan helped to establish was with Peter de Knijff, the head of the Forensic Laboratory for DNA Research. Because of the people who work there, the laboratory is a great place to be. I want to thank them all for a very good time, especially Claus van Leeuwen, who took the effort to teach me how to do techniques such as the polymerase chain reaction and DNA sequencing. Peter I thank for taking a social scientist on board, investing all that time and space in my research and for his engagement and lengthy discussions. Since we have continued working together after that period, I am confident that our conversation and collaboration will continue.

Svante Pääbo facilitated my second field study. His Laboratory for Human Genetics and Evolution houses so many talents, and I feel privileged to have been there. I want to thank Svante for providing that space and for the many discussions that we had on topics such as population studies, issues of race and origin. I am indebted to all laboratory members, for it seemed that there was always somebody around whenever I needed help or advice, and especially for being such good company. I feel privileged to have got to know Valentin Börner and Maris Laan and I thank them for their friendship.

Numerous colleagues have contributed by commenting on chapters or versions of the manuscript. I am indebted to them all, even though I will mention just a few. First of all, there is Annemarie Mol. Her insight and ways of looking at the world have become so entangled with mine that I can no longer separate these out in this book. Many of the ideas laid down in the chapters that follow were generated during the long walks that we took. I thank her, not only for her enthusiasm about this project, for encouraging me to complete it, for being such a critical reader commenting thoroughly on the whole manuscript, but especially for her friendship. The many discussions that we had about pressing social and political issues in the world around us in fact made academia a sustainable place to work in and made academic work less of a narrow endeavor. Hans-Jörg Rheinberger's profound knowledge of both genetics and the social studies of science has contributed valuably to this book. I am grateful that he took the time to read a previous version of the manuscript and that he had supplied me with insightful comments and suggestions. I also thank Michael Lynch for careful reading of several chapters and for pertinent suggestions to improve these. Mieke Aerts and I only got to know each other in the recent years. Our mutual interest in each other's work has started an ongoing conversation. It is in discussions with Mieke that I found a way of talking about method. I am grateful for that. My work has also benefited from the insights of John Law, both in his own work and in his comments on my papers. I also thank him for inviting me to various workshops that he had organized – in Lancaster and elsewhere – and all the participants in these workshops for their feedback on the papers I presented. The University of Lancaster (Department of Sociology and the Department of Women Studies) houses many inspiring scholars and is an exceptional intellectual community. I especially want to mention Claudia Castañeda, Maureen McNeil and Lucy Suchman.

Olaf Posselt was involved in my research in various ways. Over the years, he has read my texts at various stages and grew to be one of my best critics. I cannot thank him enough for all the support that he has given me, nor for the help in solving numerous problems.

Turning my research on the Human Genome Diversity Project into a book was part of a journey through different academic institutes. I started out at the

Belle van Zuylen Institute for Gender and Cultural Studies. I am indebted to all my colleagues there, but especially to Marion de Zanger, Sybille Lammes and Catherine Lord, who helped me to see academic work in context and to place it within a much broader frame. The Amsterdam School for Cultural Analyses provided an interdisciplinary environment where I learned more about semiotics and philosophy. My friendship with Frans Willem Korsten is a precious “spin off” of my participation in the seminars of this school. My work has also benefited from the Summer and Winter Schools of the Netherlands Graduate School of Science, Technology and Modern Culture (WTMC), in which I participated first as a Ph.D. student and later as a guest lecturer. I especially thank Paul Wouters, Ruth Benschop and Ruud Hendriks for feedback and suggestions on several chapters. The department of Science Dynamics and the Department of Biology (University of Amsterdam) employed me as a lecturer, involved in developing an MA program for students in the sciences. I especially want to mention Stuart Blume and Leen Dresen and thank them for numerous conversations and collaborations, and for their friendship. Antje van de Does-Bianchi is a great “boss,” and her encouragement and comradeship is invaluable. Mirjam Kohinor and Helen Bergman I thank for being such good colleagues and for being a true team in organizing and teaching the MA course. I also thank Mirjam for her help with the Glossary.

Moving partially to the department of Political Science has created new intellectual challenges. How to do politics with DNA, so to speak, and how to go about diversity have become shared topics. I thank John Grin and Maarten Hajer for making this possible. My collaborations with John started before I joined the department and he has commented on several parts of the manuscript. I thank him not just for that but also for being such a good friend. As a member of the Amsterdam School for Social Science Research (ASSR), I find myself among so many talented colleagues. I want to especially thank Anita Hardon for her enthusiasm and encouragement, also seen in our shared project on diversity in medical practice. I am indebted to the ASSR and especially José Komen for financial support and for the infrastructure for finishing this book.

While finishing this manuscript, Dick Willems, Marjolein Kuijper, Victor Toom, Nicolien Wieringa and I were conducting a joint project on the politics of everyday medical technologies. The different issue that we were discussing in the context of this project have helped me to solve some of the problems that I was dealing with in the manuscript.

Nicholas Rose and Paul Rabinow, the editors of the *Cambridge Studies in Society and the Life Sciences*, invited me to submit my research for publication in this series. I am deeply indebted to them. I thank Nicholas also for detailed comment on each and every chapter. The manuscript has also benefited from comments of three anonymous reviewers. I want to thank them also

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for their encouraging words. Sarah Caro, the editor at Cambridge University Press, proved to be the ideal advisor throughout the process. I thank her for professional and moral support, and for her patience. Jane Ward, the copy editor, has done a tremendous job. I appreciate her professionalism and her profound interest in the arguments that I have set up.

This book is dedicated to my family and friends. They have born my absent presence for so many years now, and my guess is that they are even more relieved than I am that it is done.

I am indebted to the Netherlands Organization for Scientific Research (NWO) and the Deutscher Akademischer Austauschdienst (DAAD) for kindly supporting my research in Munich and Barcelona.