Communications Handbook for Clinical Trials

Strategies, tips, and tools to manage controversy, convey your message, and disseminate results

By
Elizabeth T. Robinson
Deborah Baron
Lori L. Heise
Jill Moffett
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Preface by
Archbishop Desmond M. Tutu
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One of the greatest joys and responsibilities of democracy is the freedom of speech. We have the luxury and the burden to communicate our struggles, our hopes, our work, and our passion. In the fight against HIV and the long journey to finding new ways for those most vulnerable to protect themselves, a key challenge is to communicate the logic and the promise of this important work.

Research to find new methods of HIV prevention is a complex and arduous endeavor. It involves building trust across divides of race, gender, culture, and privilege. It demands dedication on the part of scores of counselors, study nurses, lab technicians, outreach workers, and scientists. It requires commitment, honesty, and sacrifice from hundreds and even thousands of participants. And it requires communities to embrace an often foreign enterprise—that of scientific research.

Clinical research is hard to explain to people with little or no scientific background. It is like a foreign language, a different culture—but one that holds great promise for the poor and the rich alike. It is up to us to ensure that the potential benefits of science reach all people and that participants and communities understand and can engage productively as full partners in the research endeavor.

Global guidelines, such as the Good Participatory Practice Guidelines for Biomedical HIV Prevention Trials recently published by UNAIDS, in collaboration with AVAC: Global Advocacy for HIV Prevention, are defining new standards for equitable practice between researcher and participant, between donors and community, and between those designing and implementing research and those poised to reap its benefits. This document sets out principles and minimum standards for engaging communities in the conduct of research, including building research literacy, community engagement, and communicating with research stakeholders.

But even the greatest guidelines or constitutions in the world cannot succeed unless we have the practical tools to make them work for everyday people in their everyday lives. For the investigators, study coordinators, and community liaison officers working on the frontlines of these trials, this handbook will serve as one such tool, providing guidance for translating expectations regarding stakeholder communication into concrete practice. The Good Participatory Practice (GPP) guidelines call for a “written communication plan” as an essential element for all future trials. This handbook describes how to develop an overall communications plan, with special plans for research dissemination and crisis communication.
The HIV field is not alone in confronting changing expectations and new challenges when it comes to communicating about research. Across the board, an increasing number of actors now see themselves as stakeholders in the research process. I see this development as a positive one and an evolution we must embrace. As our world gets increasingly complex, the need for science and research literacy becomes ever more acute. This book, and others like it, is an important contribution toward bridging the worlds of science and community—of bringing more and more people into the conversation about research. Increasingly, science is touching all of our lives and we must ensure that even the most marginalized people are part of the dialogue.

God bless you.

Archbishop Desmond M. Tutu
The *Communications Handbook for Clinical Trials* grew out of the collective experience of scores of individuals* who have dedicated themselves to demystifying science and ensuring that both the process and the outcomes of clinical research are communicated clearly. From the beginning, the process of creating the handbook has been a collaborative effort, and the final product reflects the wealth of this input.

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Quarraisha Abdool Karim  
CAPRISA  
South Africa

Cheryl Baxter  
CAPRISA  
South Africa

Salim Abdool Karim  
CAPRISA  
South Africa

Kim Best  
FHI  
USA

Natasha Arulappan  
CAPRISA  
South Africa

Sarah Chiduo  
Kilimanjaro Christian Medical Centre  
Tanzania

Nomampondo Barnabas  
GCM  
South Africa

Anne Coletti  
FHI  
USA

Deborah Baron  
MMCI/GCM  
South Africa

Jo-Anne Collinge  
Meropa/IPM  
South Africa

*The contributors and others acknowledged or cited in the handbook are identified by the titles they held at the time of publication in May 2010.
Nozizwe Dladla-Qwabe
MRC
South Africa

Michelle Folsom
PATH
South Africa

Glenda Gray
Perinatal HIV Research Unit (PHRU)
University of the Witwatersrand
South Africa

Sarah V. Harlan
FHI
USA

Norma Hatcher
CAPRISA
South Africa

Lori L. Heise
GCM/LSHTM
USA/UK

Kenneth Kintu
Makerere University-John Hopkins University (MU-JHU) Research Collaboration
Uganda

Nadine Landsmann
MRC
South Africa

Londiwe Luthuli
CAPRISA
South Africa

Silvia Maarschalk
CAPRISA
South Africa

Leila Mansoor
CAPRISA
South Africa

William Mapham
Reproductive Health & HIV Research Unit (RHRU), University of the Witwatersrand
South Africa

Nyaradzo Mgodi
University of Zimbabwe/University of California San Francisco (UZ-UCSF)
Zimbabwe

Nkosinathi Mhlongo
Africa Centre
South Africa

Margaret Mlingo
UZ-UCSF
Zimbabwe

Neetha Morar
MRC
South Africa

Nelly Mugo
University of Nairobi
University of Washington (UW)/International Clinical Research Center (ICRC)
Kenya

Misiwe Mzimela
Africa Centre
South Africa

Kalendri Naidoo
CAPRISA
South Africa

Tarryn Naidoo
MRC
South Africa

Vivienne Naidoo
GCM
South Africa

Teopista Nakyanzi
MU-JHU Research Collaboration
Uganda

Sibusiso Nhleko
MRC
South Africa

Fanele Ntombela
CAPRISA
South Africa

Victoria Oyier
International Centre for Reproductive Health (ICRH)/IPM
Tanzania

Gita Ramjee
MRC
South Africa
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Quarraisha Abdool Karim
CAPRISA
South Africa

Jonathan Baum
Consultant
USA

Salim Abdool Karim
CAPRISA
South Africa

Ward Cates
FHI
USA

Silas Achar
FHI
Kenya

Connie Celum
UW/ICRC
USA

Kawango Agot
Impact Research and Development Organization
Kenya

Manju Chatani-Gada
AVAC
USA

Lisa Marie Albert
FHI
USA

Lee Claypool
USAID
USA

Nomampondo Barnabas
GCM
South Africa

Paul Cleary
Center for Interdisciplinary Research on AIDS (CIRA)
USA

Morenike Ukpong
New HIV Vaccine and Microbicide Advocacy Society (NHVMAS)
Nigeria

Vulindlela trial participant (name withheld)
CAPRISA
South Africa

Mitchell Warren
AVAC
USA

Constancia Watadzaushe
UZ-UCSF
Zimbabwe
Allison Clifford  
PATH  
USA  

Anne Coletti  
FHI  
USA  

Jo-Anne Collinge  
Meropa/IPM  
South Africa  

Somer Cooper  
FHI  
USA  

Amy Corneli  
FHI  
USA  

Sinead Delany-Moretlwe  
RHRU  
South Africa  

Gai Doran  
CIRA  
USA  

Samukeliso Dube  
GCM  
South Africa  

Paul Feldblum  
FHI  
USA  

Michelle Folsom  
PATH  
South Africa/USA  

Anna Forbes  
GCM  
USA  

Mitzy Gafos  
MDP/Africa Centre  
South Africa  

Theresa Gamble  
FHI  
USA  

Pedro Goicochea  
Investigaciones Medicas en Salud  
Peru  

Glenda Gray  
PHRU, University of the Witwatersrand  
South Africa  

David Grimes  
FHI  
USA  

James Hakim  
UZ-UCSF  
Zimbabwe  

Daniel Halperin  
Harvard University School of Public Health  
USA  

Sharon Hillier  
MTN  
USA  

Jessica Justman  
Mailman School of Public Health  
Columbia University  
USA  

Kenneth Kintu  
MU-JHU Research Collaboration  
Uganda  

Newton Kumwenda  
Queen Elizabeth Central Hospital  
Malawi  

Annette Larkin  
CONRAD  
USA  

Mary Latka  
AURUM Institute  
South Africa  

Londine Rosebud Lethuli  
CAPRISA  
South Africa  

Natasha Mack  
FHI  
USA  

Kathleen MacQueen  
FHI  
USA  

Bernadette Madlala  
CAPRISA  
South Africa  

William Mapham  
RHRU, University of the Witwatersrand  
South Africa
Derrick Mapp
Shanti/L.I.F.E. Institute
USA

Melissa May
Population Council
USA

Jowet Mayisela
Traditional Leader
South Africa

Vivian McLaurin
FHI
USA

Nyaradzo Mgodi
UZ-UCSF
Zimbabwe

Margaret Mlingo
UZ-UCSF
Zimbabwe

Mukelisiwe Mlotshwa
CAPRISA
South Africa

Allison Mobley
UW/ICRC
USA

Neetha Morar
MRC
South Africa

Monique Mueller
FHI
USA

Nelly Mugo
University of Nairobi and UW/ICRC
Kenya

Kennedy Mundia
MDP
Zambia

Kanya Ndaki
IRIN/Plus News Southern Africa
South Africa

Duduzile Ndouli
CAPRISA
South Africa

Kenneth Ngure
Partners in Prevention
Kenya

Pam Norick
IPM
USA

Fanelsibonge Ntombela
CAPRISA
South Africa

Gabisile Nxele
CAPRISA
South Africa

Ikoma Obunge
University of Port Harcourt Teaching Hospital
Nigeria

Lynn Paxton
CDC
USA

Leigh Peterson
FHI
USA

Deborah Phillips
PATH
USA

David Poland
MVl/PATH
USA

Eileen Quinn
PATH
USA

Bobby Ramakant
India

Gita Ramjee
MRC
South Africa

Malebo Ratlhagana
Setshaba Research Centre/MEDUNSA
South Africa

Cheri Reid
CIDRZ
Zambia

Lisa Reilly
U.S. Military HIV Research Program
USA

Janet Robinson
FHI
Thailand
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