

# 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  
Sarah V. Harlan

*Preface by*  
Archbishop Desmond M. Tutu



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Authors: Elizabeth T. Robinson, Deborah Baron, Lori L. Heise, Jill Moffett, Sarah V. Harlan

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AVAC: Global Advocacy for HIV Prevention

423 West 127th Street, 4th Floor

New York, NY 10027 USA

Tel: +1.212.796.6243

Email: [avac@avac.org](mailto:avac@avac.org)

Web: [www.avac.org](http://www.avac.org)

FHI 360

P.O. Box 13950

Research Triangle Park, NC 27709 USA

Tel: +1.919.544.7040

E-mail: [publications@fhi.org](mailto:publications@fhi.org)

Web: [www.fhi360.org](http://www.fhi360.org)

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To request a printed or CD-ROM version of the handbook, e-mail: [commshandbook@avac.org](mailto:commshandbook@avac.org).

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# Preface

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.

A handwritten signature in black ink, appearing to read 'Desmond', followed by several horizontal strokes that suggest a flourish or the end of a signature.

Archbishop Desmond M. Tutu

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Quarraisha Abdool Karim  
CAPRISA  
South Africa

Salim Abdool Karim  
CAPRISA  
South Africa

Natasha Arulappan  
CAPRISA  
South Africa

Nomampondo Barnabas  
GCM  
South Africa

Deborah Baron  
MMCI/GCM  
South Africa

Cheryl Baxter  
CAPRISA  
South Africa

Kim Best  
FHI  
USA

Sarah Chiduo  
Kilimanjaro Christian Medical Centre  
Tanzania

Anne Coletti  
FHI  
USA

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	Nkosinathi Mhlongo Africa Centre South Africa
Michelle Folsom PATH South Africa	Margaret Mlingo UZ-UCSF Zimbabwe
Glenda Gray Perinatal HIV Research Unit (PHRU) University of the Witwatersrand South Africa	Neetha Morar MRC South Africa
Sarah V. Harlan FHI USA	Nelly Mugo University of Nairobi University of Washington (UW)/International Clinical Research Center (ICRC) Kenya
Norma Hatcher CAPRISA South Africa	Misiwe Mzimela Africa Centre South Africa
Lori L. Heise GCM/LSHTM USA/UK	Kalendri Naidoo CAPRISA South Africa
Kenneth Kintu Makerere University-John Hopkins University (MU-JHU) Research Collaboration Uganda	Tarryn Naidoo MRC South Africa
Nadine Landsmann MRC South Africa	Vivienne Naidoo GCM South Africa
Londiwe Luthuli CAPRISA South Africa	Teopista Nakyanzi MU-JHU Research Collaboration Uganda
Silvia Maarschalk CAPRISA South Africa	Sibusiso Nhleko MRC South Africa
Leila Mansoor CAPRISA South Africa	Fanele Ntombela CAPRISA South Africa
William Mapham Reproductive Health & HIV Research Unit (RHRU), University of the Witwatersrand South Africa	Victoria Oyier International Centre for Reproductive Health (ICRH)/IPM Tanzania
Nyaradzo Mgodli University of Zimbabwe/University of California San Francisco (UZ-UCSF) Zimbabwe	Gita Ramjee MRC South Africa

Malebo Ratlhangana Setshaba Research Centre/Medical University of Southern Africa (MEDUNSA) South Africa	Morenike Ukpong New HIV Vaccine and Microbicide Advocacy Society (NHVMAS) Nigeria
Cheri Reid Centre for Infectious Disease Research in Zambia (CIDRZ) Zambia	Vulindlela trial participant (name withheld) CAPRISA South Africa
Sechele Sechele Centers for Disease Control (CDC)/BOTUSA (Botswana-USA) Botswana	Mitchell Warren AVAC USA
Junaid Seedat International AIDS Vaccine Initiative (IAVI) South Africa	Constancia Watadzaushe UZ-UCSF Zimbabwe

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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

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

Stella Kirkendale  
FHI  
USA

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 Mgodzi  
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

Fanelisibonge 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  
MVI/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

Lisa Rossi MTN USA	Doug Taylor FHI USA
Seema Sahay National AIDS Research Institute (NARI) India	Brad Tytel Global Health Strategies (GHS) USA
Jorge Sanchez Asociación Civil Impacta Salud y Educacion Peru	Morenike Ukpong NHVMAS Nigeria
Sechele Sechele CDC/BOTUSA Botswana	Francois Venter RHRU, University of the Witwatersrand South Africa
Junaid Seedat IAVI South Africa	Mitchell Warren AVAC USA
Kathleen Shears FHI USA	Debra Weiner FHI USA
Nirupama Sista HIV Prevention Trials Network (HPTN) USA	Katie West Slevin GCM USA
Dirk Taljaard Progressus South Africa	Merywen Wigley FHI USA
Roger Tatoud MDP/Imperial College London UK	Christina Wong FHI USA

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