

# Selected Additional Resources

## **Disseminating Research**

### **Explaining Research: How to Reach Key Audiences to Advance Your Work**

Dennis Meredith. 2010. Oxford University Press, New York.

*Explaining Research* is a comprehensive communications guidebook for scientists, engineers, and physicians. It explains how to use Web sites, blogs, videos, webinars, lectures, news releases, and lay-level articles to reach key audiences.

### **Communicating Public Health Information Effectively: A Guide for Practitioners**

David E. Nelson, Ross C. Brownson, Patrick L. Remington, Claudia Parvanta. 2002. American Public Health Association, Washington, DC.

This U.S.-oriented 230-page guide explains what is involved in translating public health data into messages for different audiences, persuasive health communication approaches, risk communication planning, and more.

### **Developing an Effective Dissemination Plan**

National Center for the Dissemination of Disability Research. 2001. Austin, TX. Available from: <http://www.researchutilization.org/matrix/resources/dedp/index.html#ten>.

This online guide is easy to read and provides checklists for basic elements of a plan. It walks readers through steps needed to conceptualize a dissemination plan that ensures dissemination efforts will promote the use of new knowledge in programs and policies.

### **Smart Chart 3.0: An Interactive Tool to Help Nonprofits Make Smart Communications Choices** Spitfire Strategies. 2010. Washington, DC.

The Interactive Smart Chart is a planning tool that helps nonprofits develop high-impact communications strategies. It explains how to use “message boxes” to develop messages that will resonate with your audiences and overcome existing misconceptions. It is available at no cost after online registration from: <http://www.smartchart.org/about.php>.

## **Issues Management and Crisis Communication**

### **Strategic Issues Management: Organizations and Public Policy Challenges**

Robert L. Heath. 1997. Sage Publications, Inc., Thousand Oaks, CA.

This 410-page text reviews theory and evidence on issues management. It focuses on four key challenges: strategic planning, constant issue surveillance, organizational responsibility, and public discussion of ideas and issues. Chapters on crisis communication and risk communication are particularly pertinent to health research.

**Best Practices in Crisis Communication: Evolution of Practice through Research**  
Robert L. Heath. 2006. *Journal of Applied Communication Research*. 34(3):245–8.

This article provides a concise summary of best practice in crisis communication. It is available for purchase online from: <http://www.informaworld.com/smpp/title~content=g748001667~db=all>.

**A Case Study of Crisis Communication at Mercyhurst College**  
Melissa Hancock, Anthony Peyronel, Jennifer Allen. Date unavailable. Edinboro University, Department of Communication and Media Studies, Edinboro, PA.

Mercyhurst College, located in Erie, PA, was faced with a crisis after a six-page story in the Erie Times-News accused then president, Dr. William P. Garvey, of physically and sexually abusing boys from the 1960s through the 1980s. This article analyzes efforts to respond to the accusation, applying Heath's best practices in crisis communication.

**The Peter M. Sandman Risk Communication Web site**  
Peter M. Sandman, 2010. Princeton, NJ.

This Web site includes useful tips and guidance about managing health and environmental crises. It includes numerous case studies of past communications challenges and useful articles, such as "Managing Justified Outrage: Outrage Management When Your Opponents Are Substantively Right." See: <http://www.psandman.com>.

**Crisis Communication for the Social Media Age**  
Aliza Sherman. 2009. *WebWorkerDaily.com*.

Tips on how to anticipate and respond to media flares in cyberspace, the blogosphere, and other social media are provided in this short online article, available for download from: <http://gigaom.com/2009/06/01/crisis-communications-for-the-social-media-age/>.

## **Useful Case Studies of the Communications Challenges of Trials**

**South Africa's Experience of the Closure of the Cellulose Sulphate Microbicide Trial**  
Gita Ramjee, Roshini Govinden, Neetha S. Morar, Anthony Mbewu. 2007. *PLoS Policy Forum*. 4(7):e235, 1167–73.

This article is available online from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1950203>.

**Research Rashomon: Lessons from the Cameroon Pre-Exposure Prophylaxis Trial**  
Elizabeth McGrory, Andrea Irvin, Lori Heise. 2009. *Global Campaign for Microbicides*, Washington, DC.

Available for download from: <http://www.global-campaign.org/clientfiles/Cameroon.pdf>.

**Preventing Prevention Trial Failures: A Case Study and Lessons for the Future from the 2004 Cambodia Tenofovir Trial**  
Anna Forbes, Sanushka Mudalier. 2009. *Global Campaign for Microbicides*, Washington, DC.

Available for download from: <http://www.global-campaign.org/clientfiles/Cambodia.pdf>.

## **Dealing with the Media**

### **A Media Handbook for HIV Vaccine Trials for Africa**

Yinka Adeyemi. 2001. Joint United Nations Programme on HIV/AIDS (UNAIDS), Geneva.

This handbook is designed to help equip scientists, communications staff, and others who work on HIV vaccine trials to deal effectively with the media. It describes how to write a press release, plan a press conference, and handle “nightmare” scenarios. Available for free download from: [http://www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub05/jc475-mediahandb\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub05/jc475-mediahandb_en.pdf).

### **Handling the Media: A Toolkit**

Karen Hurt. 2004. CIVICUS: World Alliance for Citizen Participation, Johannesburg.

This toolkit is especially useful for those who provide interviews to news media, and offers practical guidelines and detailed checklists to help you prepare for interviews with newspaper, radio, or television journalists; issue press statements; or write press releases. It is available free online from: <http://www.civicus.org/new/media/Handling%20the%20Media.pdf>.

### **Spin Works! A Media Guidebook for Communicating Values and Shaping Opinion**

Robert Bray. 2000. The Spin Project, Independent Media Institute, San Francisco, CA.

The book uses easy-to-understand language and provides concrete examples of media plans, press releases, and other communications materials. It also offers case studies of social justice organizations and step-by-step guidelines for creating and sticking to a strategic communications plan. Information on a newer edition—Spin Works! A Media Guide for the Rest of Us—is available from: <http://www.spinacademy.org/wp-content/uploads/2012/04/SPIN-Works.pdf>.

### **100+ Resources to Boost Your Social Media Savvy in 2009: Top Tips and Advice from the Experts.**

Robin Broitman. 2009. Interactive Insights Group, Reston, VA.

This Web site compiles easy-to-read articles on social media, such as “50 Ways to Use Social Media, by Objective,” “Blogging for Beginners,” and tips for using Twitter, Podcasts, wikis, and other electronic communications. 100+ Resources is available online from: <http://www.interactiveinsightsgroup.com/blog1/100-resources-to-boost-your-social-media-savvy-top-tips-advice-from-the-experts/>.

## **Resources for Communicating Science Clearly**

### **News and Numbers: A Guide to Reporting Statistical Claims and Controversies in Health and Other Fields.**

Victor Cohn, Lewis Cope. 2001. Iowa State University Press, Ames, IA.

Written by two former science writers for the *Washington Post* and the *Minneapolis-St. Paul Star Tribune*, this book helps the reader answer three key questions about all scientific studies, polls, and other statistical claims: What can I believe? What does it mean? How can I explain it to others? It is a useful resource for helping trial staff communicate clearly about scientific concepts.

**Developing Materials on HIV/AIDS/STIs for Low-Literate Audiences: A Guide**  
Program for Appropriate Technology in Health (PATH), Family Health International (FHI). 2002.  
Washington, DC.

This manual offers guidelines for developing materials for illiterate and low-literate groups. Among other topics, it includes chapters on how to conduct "audience" research to assess and understand community members' needs and concerns and on using data from focus group discussions to develop messages and communicate them pictorially in a clear, sequential manner. The manual is available free for download from: <http://www.path.org/publications/details.php?i=688>.

**Communicating Science News: A Guide for Public Information Officers, Scientists and Physicians**  
National Association of Science Writers (NASW). 2006. Berkeley, CA.

This short online guide contains useful information, especially about interacting with international media at scientific conferences. It can be accessed on NASW's Web site at: <http://www.nasw.org/csn>.

## **Resources for Advocacy**

**Advocacy Tools and Guidelines: Promoting Policy Change**  
Sophia Sprechmann, Emily Pelton. 2001. CARE, Atlanta GA.

This document is an easy-to-use manual on how to plan and implement advocacy strategies including developing compelling messages, delivering messages strategically, building constituencies, and other useful strategies. It is available for download from: [http://www.careclimatechange.org/files/toolkit/CARE\\_Advocacy\\_Guidelines.pdf](http://www.careclimatechange.org/files/toolkit/CARE_Advocacy_Guidelines.pdf).

**Engaging Advocates from Concept to Results: Summary Report of the Advocates' Consultation on HIV Prevention Trials: Carraguard and VOICE Studies.**  
Microbicide Trials Network, Population Council. 2007. Johannesburg.

Available online from: [http://www.popcouncil.org/pdfs/MIC\\_AdvoConsultationOct2007.pdf](http://www.popcouncil.org/pdfs/MIC_AdvoConsultationOct2007.pdf).

**Community Engagement in HIV Prevention Trials: Evolution of the Field and Opportunities for Growth**  
Katie West Slevin, Mornike Ukpong, Lori Heise. 2008. *aids2031*, Science and Technology Working Group, New York.

Available online from: <http://www.path.org/publications/detail.php?i=1647>.

## **Translating Research into Practice**

### **Going Beyond Research: A Key Issues Paper Raising Discussion Points Related to Dissemination, Utilization and Impact of Reproductive and Sexual Health Research**

Ian Askew, Zoe Matthews, Rachel Partridge. 2002. University of Southampton, Southampton, UK.

Written for individuals responsible for health service programs and policy, researchers, and research and program funders, this paper provides pointers for effective communication of research findings and approaches to promoting their use in policies and programs.

### **Communication of Research: Guidance Notes for Research Programme Consortia Communications Team, Central Research Department, UK Department for International Development (DFID), The Communication and Information Management Resource Centre (CIMRC). 2005. DFID, London.**

This resource focuses on how to develop a communication and advocacy strategy to encourage the translation of research findings into policy and practice reforms. It includes links to many other useful documents. Available for free download from: <http://r4d.dfid.gov.uk/PDF/Publications/communication-research.pdf>.

### **Making a Differences to Policies and Programs: A Guide for Researchers**

Robert W. Porter, Suzanne Prysor-Jones. 1997. Support for Analysis and Research in Africa (SARA) Project. Academy for Educational Development, Washington, DC.

Developed in collaboration with the Joint Health Systems Research Programme, the Essential National Health Research (ENHR) Africa Secretariat, and the Council on Health Research for Development (COHRED), this booklet includes a summary of key steps in communicating research results using a three-way process linking researchers, decision makers, and communities. It is available free online from: <http://www.luc.edu/media/lucedu/curl/pdfs/Making%20a%20difference%20to%20policies%20and%20programs.pdf>.

### **IHE Report: Effective Dissemination of Findings from Research Institute of Health Economics (IHE). 2008. Alberta, Canada.**

This 80-page report analyzes approaches to knowledge translation, and knowledge transfer and exchange, with a focus on health research. It identifies evidence-based strategies and offers case studies. The report can be downloaded from: [http://www.ihe.ca/documents/Dissemination\\_0.pdf](http://www.ihe.ca/documents/Dissemination_0.pdf).

## **Evaluating the Impact of Communication Efforts**

### **Monitoring and Indicators for Communication for Development: Technical Note Ministry of Foreign Affairs of Denmark. 2007. Technical Advisory Service, Danish International Development Agency (DANIDA), Copenhagen.**

Full text of this publication, which contains indicators of use to groups interested in evaluating the impact of research dissemination, can be downloaded from: <http://www.commit.com/node/71216>.

## Guide to Monitoring and Evaluating Health Information Products and Services

Tara M. Sullivan, Molly Strachan, Barbara K. Timmons. 2007. Center for Communication Programs, Johns Hopkins Bloomberg School of Public Health, Washington, DC; Constella Futures, Cambridge, MA; Management Sciences for Health, Boston, MA.

This guide is available from: <http://www.k4health.org/sites/default/files/guide-to-monitoring-and-evaluating-health-information.pdf>.

## **Web sites with Easy-to-Understand Information on Prevention Research**

### **AIDSMAP/NAM**

<http://www.aidsmap.com>

### **AVAC: Global Advocacy for AIDS Prevention**

<http://www.avac.org>

### **Clearinghouse on Male Circumcision for HIV Prevention**

[www.malecircumcision.org](http://www.malecircumcision.org)

### **Family Health International (now FHI 360)**

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

### **Global Campaign for Microbicides (GCM)**

<http://www.global-campaign.org>

### **Joint United Nations Programme on HIV/AIDS (UNAIDS)**

[www.unaids.org](http://www.unaids.org)

### **SciDev Net (Science and Development Network)**

<http://www.scidev.net/en/health>

# Acronyms

ACSA: Asociación Civil Selva Amazonica  
AMAG: African Microbicide Advocacy Group  
AVAC: Global Advocacy for HIV Prevention  
ART: Antiretroviral therapy  
BMJ: The British Medical Journal  
BST: British Summer Time  
CAB/CAG: Community Advisory Board/Community Advisory Group  
CAPRISA: Centre for the AIDS Programme of Research in South Africa  
CDC: U.S. Centers for Disease Control and Prevention  
CEO: Community Educating Officer  
CIDRZ: The Centre for Infectious Disease Research in Zambia  
CIRA: Center for Interdisciplinary Research on AIDS  
CROI: Conference on Retroviral and Opportunistic Infections  
CS: Cellulose sulfate  
DAIDS: Division of AIDS  
DFID: U.K. Department for International Development  
DMC: Data Monitoring Committee  
DSMB: Data and Safety Monitoring Board  
DST: Daylight Savings Time  
FAQ: Frequently Asked Questions  
FHI: Family Health International  
GCM: Global Campaign for Microbicides  
GCP: Good Clinical Practice  
GHS: Global Health Strategies  
GLBT: Gay, Lesbian, Bisexual, and Transgender  
GOI: Government of India  
GTZ: Gesellschaft für Technische Zusammenarbeit (German cooperation agency)  
HPTN: HIV Prevention Trials Network  
HSV: Herpes simplex virus  
HVTN: HIV Vaccine Trials Network  
IAVI: International AIDS Vaccine Initiative  
ICRH: International Centre for Reproductive Health  
IDMC: Independent Data Monitoring Committee  
IPM: International Partnership for Microbicides  
IRB: Institutional Review Board  
IRIN: Integrated Regional Information Networks

LSHTM: London School of Hygiene and Tropical Medicine  
MDP: Microbicides Development Programme  
MEDUNSA: Medical University of South Africa  
MHRP: U.S. Military HIV Research Program  
MMCI: Microbicides Media and Communications Initiative  
MOH: Ministry of Health  
MOPH: [Thai] Ministry of Public Health  
MRC: Medical Research Council  
MSM: Men who have sex with men  
MTN: Microbicide Trials Network  
MU-JHU: Makerere University-Johns Hopkins University  
NARI: National AIDS Research Institute  
NEJM: New England Journal of Medicine  
NHVMAS: New HIV Vaccine and Microbicide Advocacy Society  
NGO: Nongovernmental organization  
NIAID: National Institute of Allergy and Infectious Diseases  
PATH: Program for Appropriate Technology in Health  
PC: Project Coordinator  
PHRU: Perinatal HIV Research Unit  
PI: Principal Investigator  
PIP: Partners in Prevention  
PLWHA: Person living with HIV/AIDS  
PR: Public relations  
PrEP: Pre-exposure prophylaxis  
Q&A: Question(s) and Answer(s)  
REC: Research Ethics Committee  
RHRU: Reproductive Health & HIV Research Unit  
SAAVI: South African AIDS Vaccine Initiative  
SEC: Securities and Exchange Commission  
SIV: Simian immunodeficiency virus  
SOP: Standard operating procedure  
STI: Sexually transmitted infection  
VCT: Voluntary counseling and testing  
UNAIDS: The Joint United Nations Programme on HIV/AIDS  
USAID: U.S. Agency for International Development  
UW/ICRC: University of Washington/International Clinical Research Center  
UZ-UCSF: University of Zimbabwe-University of California San Francisco  
VOICE: Vaginal and Oral Interventions to Control the Epidemic  
WHO: World Health Organization



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Lori Heise is a lecturer in gender and HIV at the London School of Hygiene and Tropical Medicine (LSHTM). She served as the founding director of the Global Campaign for Microbicides from 1998 through 2009 and was one of the original founders of the MMCI. She is an internationally recognized expert on the dimensions, causes, and prevention of intimate partner violence and is widely credited with getting violence against women onto the global health agenda and spearheading the search for new women-controlled methods of HIV prevention. In 2001, Lori received the President's award for excellence in advocacy from the American Social Health Association and was recognized by *Ms. Magazine* in 2003 as one of the "50 women who made a difference." Most recently, a jury of her peers awarded her the Omolulu Falobi Memorial Award for her contributions to ethics and community engagement in HIV prevention research.

### Jill Moffett

Jill Moffett, PhD, MPH, is a science writer at Family Health International. Jill did her graduate work at the University of Iowa. Her doctoral thesis—on a two-year ethnographic study of the breast cancer movement in the United States and Canada—explores how activists influence healthy policy. Jill taught courses on women's activism and global health at the University of Iowa and Cornell College and served on the board of a regional domestic violence prevention organization for three years. Before joining FHI, she worked at the Sheps Center at the University of North Carolina-Chapel Hill on the National Institutes of Health Patient-Reported Outcomes Measurement Information System (PROMIS) Roadmap initiative.

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# Communications Handbook for Clinical Trials

*Communications Handbook for Clinical Trials: Strategies, tips, and tools to manage controversy, convey your message, and disseminate results* provides practical guidance to clinical trial staff and research partners on how to anticipate and respond to the special communications challenges posed by the conduct of clinical research.

Designed to be accessible and relevant to a wide audience, *Communications Handbook for Clinical Trials* will make your job easier, whether you are a researcher, a study coordinator, or a communications professional. The handbook contains diagnostic tools, sample templates, and materials that research sites can adapt for use.

- **Sample communication plans for clinical trials**
- **Communications and crisis-planning templates and checklists**
- **Scenario-planning tools to facilitate planning for the release of trial results**
- **Ideas on delegating communications tasks to reduce demands on key site personnel**
- **Tips and techniques on how to communicate effectively in interviews, in meetings, and with the media**

*Communications Handbook for Clinical Trials* contains more than 40 contributed pieces by researchers and communications experts who share their ideas, lessons learned, and advice based on their experiences with trials in Africa, Asia, Europe, Latin America, and North America.

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## **Praise for *Communications Handbook for Clinical Trials***

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“Too often clinical trial researchers think a clinical trial starts with participant enrollment and closes with the final clinic visit of the last participant, but in fact the life of a trial extends well before and after these points. This manual addresses all of the things they don’t teach one at university—how to communicate effectively with a range of stakeholders, how to work with the media, and how to build relationships to navigate some of the challenges and unexpected outcomes we encounter all too often in research.”

—Prof. Linda-Gail Bekker, Desmond Tutu HIV Foundation, University of Cape Town, South Africa

“The authors have combined their wealth of communications experience into a lively how-to guide with illustrations from many different fields ... Essential reading for all involved in designing or implementing clinical trials, including those who think they know it all.”

—Dr. Timothy M. Farley, Department of Reproductive Health and Research, World Health Organization, Geneva

“In an era where research into tangible health-related interventions is a global effort, this handbook represents a thoughtful, well-organized approach to developing communication strategies that address today’s challenges.”

—Dr. Patrick Ndase, Microbicide Trials Network and International Clinical Research Center, University of Washington, Kampala, Uganda

Preface written by ARCHBISHOP EMERITUS DESMOND M. TUTU, who is a tireless champion in the fight against AIDS and tuberculosis, and serves as patron of the Desmond Tutu HIV Foundation and the Desmond Tutu HIV Centre at the University of Cape Town’s Institute of Infectious Disease and Molecular Medicine.