



## Summit Agenda

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**9:30am**     **Registration/Refreshments**

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**10:00am**     **Welcome/Introduction**

**Andrew Dreyfus**, President and CEO,  
Blue Cross Blue Shield of Massachusetts

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### **Update on Coalition Activities**

**Maureen Bisognano**, President Emerita and Senior Fellow, Institute for  
Healthcare Improvement

**Susan Lysaght Hurley**, PhD, RN, Director of Research, Care Dimensions, Inc.

**Rev. Gloria White-Hammond**, Co-Pastor, Bethel A.M.E. Church,  
and Swartz Resident Practitioner in Ministry Studies, Harvard Divinity School

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### **Presentation of Consumer Research on Messaging**

**Atul Gawande, MD**, CEO, Haven, the Amazon, Berkshire Hathaway,  
and JPMorgan health care venture; Chair, Ariadne Labs;  
Surgeon, Brigham and Women's Hospital; Professor, Harvard T.H. Chan  
School of Public Health and Harvard Medical School

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### **Recommendations on Messaging / Communications** *Followed by Video*

**Zamawa Arenas**, Founder & CEO, Flowetik

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## Summit Agenda *continued*

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### Panel: “The National Landscape for Messaging to Support Advance Care Planning”

**Ellen Goodman** (Moderator), Co-Founder and Director, The Conversation Project

**Marian Grant**, Principal, Marian Grant Consulting; Senior Regulatory Advisor, Coalition to Transform Advanced Care (C-TAC)

**Peggy Maguire**, President, Cambia Health Foundation; Corporate Social Responsibility and Palliative Care Solutions

**Shoshana Ungerleider**, MD, Hospitalist, California Pacific Medical Center; Founder, End Well Symposium; and an executive producer of “End Game”

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**12:00pm** **Lunch**

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### Messaging Research Workshop

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**2:00pm** **Closing**

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## Coalition Goals

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The Coalition has six core priorities that all fall under the umbrella of “ensuring that health care for everyone in Massachusetts is in accordance with their goals, values and preferences at all stages of life and in all steps of their care.”

Specifically:

- Everyone in Massachusetts, 18 or older, has designated a health care decision-maker (health care proxy);
- Everyone in Massachusetts, 18 or older, has had a conversation (and continues to have conversations) with their proxy to communicate their goals, values and preferences for care at the end of life;
- All Massachusetts clinicians have appropriate training to facilitate high-quality communication with patients on advance care planning and serious illness;
- Everyone in Massachusetts facing a serious illness has had a high-quality, informed goals and values conversation with their care team;
- All Massachusetts health care providers have systems in place to elicit and document goals, values and preferences for patients with serious illness;
- All Massachusetts health care providers have systems in place to share patient goals, values and preferences across care settings, to ensure they are accessible regardless of place of care.



## Notes on Current Coalition Activities

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- **Medical Schools** – In early 2017, we approached deans at the four Massachusetts medical schools about a cooperative effort to require training for medical students in serious illness communication as a graduation requirement. As a result, a group of expert faculty and administrators was convened to develop plans for ongoing collaboration. The group is led by Dr. Jennifer Reidy from UMass Medical School. She presented an update on our progress at the Coalition's 2018 summit, including the group's development of core competencies in serious illness communication for medical students. Current efforts are aimed at mapping existing curricula at the four schools and convening focus groups of medical students to explore their attitudes and perspectives regarding the care of people with serious illness. We are also planning for shared faculty development as a way to build capacity for instruction in serious illness care at each school. The initiative has generated significant media interest, including coverage in the Boston Globe, the Boston Herald, and WBUR (an NPR station in Boston).
- **Nursing Schools** – Collaboration on a curriculum for nurses caring for those with serious illness continued throughout the past year. The group of over twenty nursing faculty members, led by Diane Welsh (Regis College) and Joan Vitello (Graduate School of Nursing, UMass Medical School), share a common interest in reviewing existing programs and sharing best practices to accelerate progress across the state. A sub-committee co-chaired by Susan Lysaght Hurley (Care Dimensions, Inc.) and Anne-Marie Barron (Simmons College) met regularly during 2018 to discuss current guidelines and competencies for nursing education related to serious illness care and conversations. We met with Dr. Jennifer Reidy (UMass Medical School), who is leading the Coalition's medical school initiative, to align our work with theirs. The group will soon present their recommendations for adopting core competencies to the Massachusetts Association of Colleges of Nursing. The sub-committee also developed a survey for schools of nursing to identify current practices within baccalaureate education for teaching and evaluating content related to serious illness care. The survey is currently being piloted at UMass Boston School of Nursing (Priscilla Gazarian, PI) and Simmons College, and will be made available



## Notes on Current Coalition Activities

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to additional schools in early summer 2019. The sub-committee hopes to release findings from the survey to the MACN Deans and Mass Coalition members next year. Additionally, several members of our sub-committee led by Anne-Marie Barron, Connie Dahlin, (Hospice & Palliative Nurses Association), and Susan DeSanto-Madeya (Boston College) held an ELNEC Train-the-Trainer course in April 2019 for nurses across the state.

- **e-Sharing of Advance Directives** – This joint effort with the Massachusetts eHealth Institute, in formal partnership with the Department of Public Health (DPH), is focused on how we might use technology to share ACP documents electronically, across various systems and platforms. In 2017, the group issued an RFI to learn more about best practices around the country, and we hosted a public meeting to explore the issues and challenges involved in implementing e-sharing in Massachusetts. We've also been engaged in ongoing conversations with colleagues from other states who have experience with digitizing ACP documents, or who are contemplating such an effort. They shared valuable insights about the process and the resources required to make this a success. Meanwhile, DPH through its Palliative Care Advisory Committee, is working to revise the state's MOLST form to comply with National POLST Paradigm standards. Excitingly, via a contribution from BCBSMA, the coalition will be able to help cover the state's one-time technology costs associated with creating an eMOLST pilot. We're working on trying to secure the necessary additional funding in the 2020 state budget. If this funding is secured, and upon reaching consensus on the updated MOLST form, the overall effort will significantly accelerate. If you would like to learn more or get engaged in this initiative, please contact Judy Iwanski at [iwanski@masstech.org](mailto:iwanski@masstech.org).
- **Divinity Schools** – Another important curriculum-related effort involves outreach to educators at area seminaries and divinity schools. We've been working in concert with Rev. Rosemary Lloyd (The Conversation Project), Rev. Gloria White-Hammond (Bethel A.M.E. Church), and leadership at the Boston Theological Interreligious Consortium (BTI) on this effort. As an initial initiative, we helped plan and support a major event on April 2 entitled "Dying Well: Multi-Religious End of Life Conversations." This sold out conference attracted faith leaders and



## Notes on Current Coalition Activities

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divinity students from the region to share perspectives on religious components of serious illness and ACP, with an emphasis on practical ideas that attendees could take back to their places of worship. Presenters also shared perspectives on how various denominations support congregants with the spiritual dimensions of end of life.

### Other Activities

- **Community Health Centers (CHCs)** – In partnership with the Mass. League of Community Health Centers, we've been working to explore opportunities and challenges for CHCs looking to expand efforts related to palliative care, serious illness communication, and advance care planning. Soon we'll be hosting focus groups with CHC clinical and administrative staff to learn more about the most promising areas of activity.
- **Palliative Care for the Underserved** – Dr. Suzanne Mitchell (Boston Medical Center) is dedicated to improving ACP and palliative care for traditionally underserved populations. Last November, we collaborated with her on a conference called Project TRIO: Transforming Risk into Opportunity – Redesigning Palliative Care for the Underserved. Attendees explored ways to adapt and implement best practices to fit the life experiences of people who have a social vulnerability that affects their ability to access care.
- **Webinar on Advance Care Planning and Serious Illness Care** – We partnered with the Health Policy Commission to co-host a webinar in January about the work of our state's accountable care organizations (ACOs) with respect to palliative care and advance care planning.

*For more information about these and other Coalition initiatives, please contact Richard Averbuch at [richard.averbuch@bcbsma.com](mailto:richard.averbuch@bcbsma.com) or 617-246-3788.*

*May 2019*



MASSACHUSETTS COALITION FOR  
SERIOUS ILLNESS CARE

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## Coalition Members

Alzheimer's Association,  
Massachusetts/New Hampshire Chapter

American Cancer Society and  
the ACS Cancer Action Network

American Nurses Association Massachusetts

Archdiocese of Boston - Initiative for  
Palliative Care and Advance Care Planning

Ariadne Labs

Ascend Hospice and Home Health

Association for Behavioral Healthcare

Association of Independent Colleges  
and Universities in Massachusetts

Atrius Health

Baystate Health

Beacon Patient Advocates

Beth Israel Deaconess Medical Center

Bethel A.M.E. Church

Betsy Lehman Center for Patient Safety

Blue Cross Blue Shield of Massachusetts

Boston Bar Association

Boston Center for Independent Living

Boston Senior Home Care

Cake ([joincake.com](http://joincake.com))

Cape Cod Health Care

Care Dimensions

Care4ward

Caregiver Homes / Seniorlink

Commonwealth Care Alliance

Conference of Boston Teaching Hospitals

Cooley Dickinson Hospital

Courageous Parents Network

Disability Law Center of Massachusetts

Disability Policy Consortium

Eden Home Health Care, LLC

End With Care

Fallon Health

Gerontology Institute  
at the University of Massachusetts Boston

Good Shepherd Community Care

Greater Boston Interfaith Organization

GVNA HealthCare, Inc.

Hallmark Health VNA and Hospice

Harmony House of Western MA

*Coalition Members...continued*



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| Harvard Pilgrim Health Care                           | Massachusetts Ambulance Association   |
| Health Care for All                                   | Massachusetts Assisted Living Association                                   |
| Health New England                                    | Massachusetts Association for Mental Health                                 |
| Health Story Collaborative                            | Massachusetts Association of Health Plans                                   |
| Healthy Aging Martha's Vineyard                       | Massachusetts Association of Physician Assistants                           |
| Hebrew Senior Life                                    | Massachusetts Bar Association   |
| Home Care Aid Council                                 | Massachusetts Chapter of National Academy of Elder Law Attorneys (MassNELA) |
| Home Care Alliance of Massachusetts                   | Massachusetts Coalition for the Prevention of Medical Errors                |
| Honoring Choices Massachusetts                        | Massachusetts Council of Community Hospitals                                |
| HopeHealth  | Massachusetts Department of Public Health                                   |
| Hospice & Palliative Care Federation of Massachusetts | Massachusetts eHealth Institute   |
| Indian Circle for Caring USA, Inc.                    | Massachusetts General Hospital  |
| Informed Medical Decisions Foundation                 | Massachusetts Group Insurance Commission                                    |
| Institute for Healthcare Improvement                  | Massachusetts Health and Hospital Association                               |
| Lahey Health  | Massachusetts Guardianship Policy Institute (MGPI)                          |
| Landmark Healthcare                                   | Massachusetts Executive Office of Elder Affairs                             |
| LeadingAge Massachusetts                              | Massachusetts Health Policy Commission                                      |
| Living Wisely, Dying Well                             | Massachusetts League of Community Health Centers                            |
| Lowell General Hospital                               | Massachusetts Medical Society   |
| Lown Cardiovascular Group                             | Massachusetts Psychiatric Society   |
| Lundberg Health Advocates                             |   |
| Mass Home Care  |   |

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Massachusetts Senior Care Association	Southeastern Massachusetts EMS Council
MassPACE, Inc.	Spaulding Hospital Cambridge
Metropolitan Boston Emergency Medical Service Council	The Bucket.com
Mount Auburn Cambridge Independent Practice Association	The Conversation Project
National Alliance on Mental Illness – Massachusetts	The Project on Advanced Care and Health Policy, a collaboration between the Petrie Flom Center at Harvard Law School and the Coalition to Transform Advanced Care
National Association of Social Workers – Massachusetts Chapter	The Schwartz Center for Compassionate Healthcare
New England Quality Innovation Network-Quality Improvement Organization	Tribute Home Care
Newton Wellesley Hospital	Tufts Health Plan
Nina Rosenberg Consulting	Tufts University School of Medicine
Northeast Emergency Medical Services, Inc.	UMass Medical School Graduate School of Nursing
NVNA and Hospice	UMassMemorial Health Care
Old Colony Hospice & Palliative Care	University of Massachusetts Boston Department of Nursing, College of Nursing, College of Nursing and Health Sciences
Regis College Young School of Nursing	Valley Medical Group
Saint Vincent Hospital	VNACare
Seasons Hospice & Palliative Care of Massachusetts	Vynca
Simmons College School of Nursing	YMCA of Greater Boston
Sirona Health Advocates	
Solomont School of Nursing, Zuckerberg College of Health Sciences, University of Massachusetts, Lowell	



## Speaker Biographies

*In alphabetical order*

### ZAMAWA ARENAS

Five-time Emmy award winner, Zamawa is a marketing strategist and entrepreneur intent on making a difference. She is the Founder and CEO of Flowetik, a brand marketing consultancy that helps mission-driven organizations to achieve impact.

For over 20 years, Zamawa has led public health/social norms marketing efforts on a broad range of issues, including tobacco control, drunk driving prevention, seat belt use, healthcare access, among others.

Active in Greater Boston's business and nonprofit community, she currently serves on the boards of several organizations including the Boston Foundation, Boston Chamber of Commerce and Eastern Bank. Since 2006 Zamawa has served as a Trustee of the Boston Public Library. Most recently Massachusetts Governor Charlie Baker appointed her to the state's Workforce Development Board.

Zamawa is the recipient of the Pinnacle Award from the Boston Chamber of Commerce and was inducted into the YWCA Academy of Women Achievers. She was also named by the Boston Business Journal as a "Hispanic on the Move" an award for Hispanic professionals making a difference in Boston.

### MAUREEN BISOGNANO

Maureen is President Emerita and Senior Fellow, Institute for Healthcare Improvement (IHI), and previously served as IHI's President and CEO for five years, after serving as Executive Vice President and COO for 15 years. She is a prominent authority on improving health care systems, whose expertise has been recognized by her elected membership to the National Academy of Medicine (IOM), among other distinctions.

Ms. Bisognano advises health care leaders around the world, is a frequent speaker at major health care conferences on quality improvement and is a tireless advocate for change. She is also an Instructor of Medicine at Harvard Medical School, a Research Associate in the Brigham and Women's Hospital Division of Social Medicine and Health Inequalities.

Additionally, she chairs the Advisory Board of the Well Being Trust, co-chairs the Massachusetts Coalition for Serious Illness Care with Dr. Atul Gawande, and serves on the boards of the Commonwealth Fund, Cincinnati Children's Hospital Medical Center, Indiana University Health and Nursing Now. Prior to joining IHI, she served as CEO of the Massachusetts Respiratory Hospital and Senior Vice President of The Juran Institute.

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## **ANDREW DREYFUS**

Andrew is President and Chief Executive Officer for Blue Cross Blue Shield of Massachusetts (BCBSMA), one of the largest independent Blue Cross Blue Shield plans in the country with over \$8 billion in revenue and nearly 3 million members. During his tenure, BCBSMA has consistently been recognized as one of the nation's best health plans for member satisfaction and quality. The company has also received many awards for community involvement and leadership in promoting diverse, healthy and environmentally-friendly work places. Mr. Dreyfus assumed the role of CEO in September 2010.

Mr. Dreyfus joined BCBSMA in 2005 as Executive Vice President, Health Care Services. During his tenure, BCBSMA created the Alternative Quality Contract, one of the largest commercial payment reform initiatives in the nation.

Previously Mr. Dreyfus served as founding President of the Blue Cross Blue Shield of Massachusetts Foundation, where he developed the "Roadmap to Coverage," a multi-year initiative which led to the passage of the state's landmark 2006 Health Reform Law.

Prior to his appointment at Blue Cross, Mr. Dreyfus was Executive Vice President of the Massachusetts Hospital Association (MHA), and held a number of senior health and regulatory positions in Massachusetts state government.

Mr. Dreyfus sits on the boards of Ironwood Pharmaceuticals, Boys and Girls Clubs of Boston, Jobs for Massachusetts, RIZE Massachusetts, and the New England Chapter of the National Association of Corporate Directors (NACD). He is a member of the Massachusetts Digital Health Council and the advisory boards of Ariadne Labs and the Leonard D. Schaeffer Center for Health Policy and Economics at the University of Southern California (USC). Andrew is a founding member of the Massachusetts Coalition for Serious Illness Care and a member of the National Academies of Sciences, Engineering, and Medicine's Roundtable on Quality Care for People with Serious Illness.

Mr. Dreyfus graduated from Connecticut College with a B.A. in English.

## **ATUL GAWANDE MD, MPH**

Atul is CEO of Haven, the Amazon, Berkshire Hathaway, and JPMorgan Chase health care venture and a globally recognized surgeon, writer, and public health leader.

He practices general and endocrine surgery at Brigham and Women's Hospital. He is a professor at the Harvard T.H. Chan School of Public Health and the Samuel O. Thayer Professor of Surgery at Harvard Medical School.

In addition, he is the founder and chairman of Ariadne Labs, a joint center for health systems innovation, and chairman of Lifebox, a nonprofit organization making surgery safer globally. Dr. Gawande has also been a staff writer for *The New Yorker* magazine since 1998 and has written four *New York Times* Bestselling books: *Complications*, *Better*, *The Checklist Manifesto*, and *Being Mortal*.

### **ELLEN GOODMAN**

Ellen is the co-founder and Director of The Conversation Project. She has spent most of her life chronicling social change and its impact on American life. She was one of the first women to write for the op-ed pages where she became, according to Media Watch, the most widely syndicated progressive columnist in the country. In 1980, she won the Pulitzer Prize for Distinguished Commentary. Ms. Goodman founded The Conversation Project in 2012, which is dedicated to helping people talk about their wishes for end-of-life care. The Conversation Project has the audacious goal of changing our nation's culture so that everyone's wishes for end-of-life care are both expressed and respected.

### **MARIAN GRANT, DNP, ACNP-BC, ACHPN, FPCN, RN**

Marian is Senior Regulatory Advisor for the Coalition to Transform Advanced Care (C-TAC), a consultant for the Center to Advance Palliative Care (CAPC), the Community Health Accreditation Partners (CHAP), and the Cambia Foundation and Health Solutions, and a palliative care nurse practitioner at the University of Maryland Medical Center. She is adjunct faculty at the University of Maryland and Johns Hopkins Schools of Nursing. In 2014, she was selected as a Robert Wood Johnson Health Policy Fellow. Dr. Grant has served on the board of the Hospice and Palliative Nurses Association, been faculty for ELNEC, the End-of-Life Nursing Education Consortium, and speaks nationally and internationally on palliative care. Before becoming a nurse, she had a career in marketing at the Procter & Gamble Company and worked on the Max Factor and Cover Girl cosmetics brands.

### **SUSAN LYSAGHT HURLEY, PHD, RN**

As Director of Research at Care Dimensions, Dr. Hurley oversees and coordinates all aspects of grant implementation including serving as site coordinator for multiple National Institutes of Health (NIH) funded studies. She works closely with external research and education leaders to enhance and promote quality end-of-life care within Care Dimensions, and at the state, regional and national level. She is helping to lead the Mass Coalition effort in bringing together leadership from nursing schools and clinical settings across the commonwealth incorporating serious illness content into nursing curriculum. Susan is a member of the Palliative Care Research Cooperative Group (PCRC), and her research has received funding from the John A. Hartford

Foundation and the NIH. She also continues to coordinate a grant-developed Hospice Nurse Residency. Prior to her research role, Susan was a hospice and palliative care nurse practitioner for 14 years providing community-based palliative care consults and supporting hospice patients and interdisciplinary care teams.

## **PEGGY MAGUIRE**

As president of Cambia Health Foundation, Peggy works with a wide range of stakeholders to drive health care transformation that results in better experiences for people and families. Sojourns<sup>®</sup>, the Foundation's signature program, promotes palliative care to help people with serious illness and their caregivers live well. Through Healthy People, Healthy Communities, the Foundation addresses social determinants of health, improves health equity, and empowers consumers to take charge of their health and wellbeing.

Under Peggy's leadership, the Foundation has evolved from a regional grant-making organization to a purposeful investor in person-centered, economically sustainable solutions. In 2016, the American Academy of Hospice and Palliative Medicine recognized the Cambia Health Foundation with its highest honor, a Presidential Citation.

Peggy also oversees Corporate Social Responsibility, Ethics, Compliance and Palliative Care Solutions for Cambia Health Solutions, the Foundation's parent company. Peggy provides leadership and strategic direction over Cambia's "Personalized Care Support" program, which includes regional health insurance benefits for palliative care services, as well as specialized case management and resources for family caregivers. Peggy also advises the company on strategic investments that address aging, caregiving and coordination of care.

Peggy joined the company in 1997 as an associate general counsel and has held several posts, including chief of staff to the CEO, vice president of Legal Services, and director of Litigation & Risk Management. Previously, Peggy worked as an attorney at Garvey Schubert & Barer.

Peggy is very active in the philanthropic community. She chairs the board of directors of Doernbecher Children's Hospital Foundation. She also serves as a member of the leadership advisory bodies for All Hands Raised, Dress for Success and Habitat for Humanity. Peggy is a senior fellow of the American Leadership Forum of Oregon. In 2017, Peggy chaired the American Heart Association's Go Red for Women campaign in Oregon and used that platform to promote health equity and palliative care awareness for people living with heart disease. She is the immediate past chair of the national board of Friends of the Children and the Oregon-based Start Making a Reader Today (SMART).

Peggy was recognized by *Portland Monthly* magazine as an Extraordinary Board Member in 2017 for her service to the community and leadership of the Cambia Health Foundation.

She was honored by Dress for Success Oregon with its Athena Award in 2016, by the Girl Scouts of Oregon and Southwest Washington as a Woman of Distinction in 2015, and by the *Portland Business Journal* as a Woman of Influence in 2014.

She received her bachelor's degree in philosophy and anthropology from Lawrence University and her law degree from Northwestern School of Law of Lewis and Clark College. She has also completed the Stanford Executive Program and is a member of the Stanford Graduate School of Business Alumni Association.

### **SHOSHANA UNGERLEIDER, MD**

Shoshana is a physician, philanthropist, founder and speaker. She works as an internist practicing hospital medicine at California Pacific Medical Center in San Francisco. She also created End Well Foundation and the End Well Symposium, an annual convening to improve the end of life experience, encouraging thought to action through the human-centered intersection of healthcare, policy, design, technology, science, society, culture and art. Shoshana received her medical degree from Oregon Health & Science University in Portland, OR and completed residency at California Pacific Medical Center where she is on the teaching faculty and serves on the Executive Board of the Foundation Board of Trustees. Shoshana has also executive produced Oscar-nominated films including *End Game*, a short documentary on hospice and palliative care by Academy Award winning directors Rob Epstein and Jeffrey Friedman. Shoshana's other film, *Extremis*, a short documentary about end of life decision making in the intensive care unit premiered at the Tribeca Film Festival in April 2016 and won Best Documentary Short, it was also nominated for a 2017 Academy Award and two Emmy Awards.

### **REV. GLORIA E. WHITE-HAMMOND, MD**

Gloria is Co-Pastor of Bethel AME Church ([www.bethelame.org](http://www.bethelame.org)) and the Swartz Resident Practitioner in Ministry Studies at Harvard Divinity School. She retired from the South End Community Health Center in 2008 after serving 27 years as a dedicated pediatrician to families from some of Boston's most challenged communities. Currently, Gloria's work includes the "Planning Ahead" ministry at Bethel AME Church to encourage congregants to begin conversations about and document their advance care wishes. Along with a team of clergy, palliative care clinicians and hospital chaplains, Gloria has organized Sacred Conversations colloquia to equip multi-faith community-based clergy persons to engage in more effective conversations with their seriously ill members. Gloria co-directs the joint Harvard Medical School and Harvard Divinity school course "Spirituality and Healing in Medicine." She is a graduate of Boston University, Tufts University School of Medicine and Harvard Divinity School.