



## Patient Data Storytelling and the Learning Healthcare System

Tuesday, April 29<sup>th</sup>, 10:30am

366 West Village H – Breakfast Served

People communicate their health and health care needs through words, stories, feelings and impressions. Coupled with other clinical data like laboratory tests, this information is used by the doctor to diagnose, treat, monitor, and advance health; health care systems are aggregates individual patient experiences, ultimately attempting to advance the lives of populations of people. The plural of story is data. Stories combined with visualizations can communicate complex information to audiences in ways that are psychologically efficient. “Learning health care” reflects the rapidly expanding role of data and technology to iteratively advance health; key features include translation of patient stories into data, understanding points for improvement at the patient or system level, introducing change and monitoring impact. Data stories, visualizations, and infographics can advance doctors' ability to care.



Amy P. Abernethy, MD PhD, a hematologist/oncologist and palliative care physician, is Director of the Duke Center for Learning Health Care (CLHC) in the Duke Clinical Research Institute, and Director of the Duke Cancer Care Research Program (DCCRP) in the Duke Cancer Institute. With over 350 publications, she is an internationally recognized expert in health services research, comparative effectiveness research, clinical informatics and patient-centered care.

Dr. Abernethy is an appointee to the Institute of Medicine’s National Cancer Policy Forum, President of the American Academy of Hospice & Palliative Medicine (AAHPM), Secretary of the Board of Directors for the Personalized Medicine Coalition, Chair of the Advisory Board for the Rapid Learning System for Cancer of the American Society of Clinical Oncology (ASCO’s CancerLinQ), Co-Chair of the National Institutes of Health (NIH)-funded Palliative Care Research Cooperative Group, Co-Chair of the Patient Reported Outcomes (PRO) Core for the NIH Collaboratory Program, Chair of the PRO Task Force for the Patient Centered Outcomes Research Institute National Clinical Research Network, and Principal Investigator of ASCO/AAHPM Virtual Learning Collaborative for Palliative Care. Dr. Abernethy participates integrally in current high-level national and international discussions about reforming the evidence development system, presenting a model for a rapid learning cancer care that coordinates clinical and research functions to better serve patients’ needs in an evidence-driven, cost-effective, and patient-centered manner.



RJ Andrews is a data storyteller for the Duke Center for Learning Health Care and Duke Institute for Health Innovation. He is interested in humanizing information and experiments with this at [infowetrust.com](http://infowetrust.com). Mr. Andrews is a Northeastern University Engineer and MIT MBA.