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Introduction: patients as policy actors / Nancy Tomes and Beatrix Hoffman -- Solitary advocates: the severely brain injured and their surrogates / Joseph Fins and Jennifer Hersh -- Physician-patient communication in the care of vulnerable populations: the patient's voice in interpersonal policy / M. Robin DiMatteo ... [et al.] -- Is it time to push yet? The challenges to advocacy in American childbirth / Elizabeth Mitchell Armstrong and Eugene DeClercq -- A pound of flesh : patient legal action for human research protections in the biotech age / Lori Andrews and Julie Burger -- From outsiders to insiders: the consumer/survivor movement and -- Its impact on American mental health policy / Nancy Tomes -- "Don't scream alone" : the health care activism of poor Americans in the 1970's / Beatrix Hoffman -- The canary in Gemeinschaft: using the public voice of patients to enhance health system performance / Mark Schlesinger -- Patient appeals as policy disputes: individual and collective action in managed care / Marc Rodwin -- The power of us: a new approach to advocacy for rare cancers / Amy Dockser Marcus -- Patients and the rise of the nurse practitioner profession / Julie Fairman -- A house on fire : newborn screening, parents' advocacy, and the discourse of urgency / Rachel Grob -- Measuring success : scientific, institutional, and cultural effects

of patient advocacy / Steven Epstein.

Sommario/riassunto

Patients as Policy Actors offers groundbreaking accounts of one of the health field's most important developments of the last fifty years--the rise of more consciously patient-centered care and policymaking. The authors in this volume illustrate, from multiple disciplinary perspectives, the unexpected ways that patients can matter as both agents and objects of health care policy yet nonetheless too often remain silent, silenced, misrepresented, or ignored.