In 2016, the U.S. spent $3.35 trillion, or approximately 18 percent of gross domestic product, on health care (Papanicolas, Woskie, & Jha, 2018). Concerns are particularly acute in oncology where costs have nearly doubled over the last decade (Batty et al., 2014). The costs of cancer care are rising more quickly than the costs of health care in other medical sectors and account for five percent of total U.S. health care spending (Schnipper & Bastian, 2016).

In addition to the societal impact of these costs, patients may also face high out-of-pocket expenses including premiums, co-payments, deductibles, and co-insurance rates. As we celebrate innovations that are improving and extending life, the realities of unsustainable health care costs are leading decision makers to seek answers in utilization management (UM) approaches, among other solutions. Serious discussions and collaborative efforts are needed to improve access to quality health care and to design patient-centered utilization management programs that incentivize cost-efficiency through optimized patient care and outcomes.

Utilization Management is defined by URAC (Utilization Review Accreditation Committee) as “the evaluation of the medical necessity, appropriateness, and efficiency of the use of health care services, procedures, and facilities under the provisions of the applicable health benefits plan,” UM includes approaches such as step therapy, prior authorization, coverage with evidence development, pathways, and general discussions around the concept of value.

UM strategies are common. They can foster cost-effective, seamless care. When implemented appropriately, they can enhance the patient experience. However, UM strategies also can negatively impact patient access to care as well as contribute to provider burden.
The Forum brings patient advocacy organizations together for meaningful conversations across health care sectors with diverse stakeholders such as health care providers, insurance companies, employers, benefit managers, pharmaceutical companies, and others.

By fostering a broader understanding of UM and exploration of areas of common importance, the Forum provides a platform to:

(1) Advance consensus-oriented dialogue between patient communities and a broad range of health care leaders to both learn from each other’s expertise and elevate patient focused solutions.

(2) Engage with stakeholders to address the tough, nuanced questions about the impact of various UM approaches and to identify together when such UM methods are acceptable and when they are harmful.

(3) Identify new ideas and promising practices that optimize patient care based on evidence.
On October 23, 2019, CSC convened a summit including patient organizations, payers, manufacturers, providers, and other stakeholders to gain insights into the future of UM.

The goal was to be challenged by thoughtful conversations among industry and patient organizations, and to contribute to a set of principles that will guide cross-sector collaboration on patient-centered UM practices.

**Important and actionable findings emerging from the Summit include:**

1. Utilization management, while an established approach to managing benefits and improving resource allocation and cost-management, has acknowledged challenges that require updated and more patient-informed policy development.

2. Cross-sector collaboration is vital to achieving the outcomes all stakeholders desire including high-quality and cost-effective patient care.

3. Patient perspectives included early in the development of the UM programs and policies can contribute to a more patient-centered health care system.

4. Continued conversations among patient advocates and a wide range of UM stakeholders are needed to further clarify perspectives and to identify specific actions that can lead to shared success.

5. Full and transparent information needs to be made available to all stakeholders regarding the methods and metrics used to define the “value” of a treatment and how to obtain the data needed to illustrate the impact of UM.
The Guiding Principles serve as a roadmap for the creation, implementation, and evaluation of the strategies.

This includes evidence-based, efficient, transparent processes that drive clinical best practices to support patient health and wellbeing. A patient-centered UM program is created in partnership with patients, patient advocates, and providers along with a host of UM stakeholders*.

A patient-centered UM program uses multiple data sources to evaluate the impact on patient outcomes and incorporates flexibility to address the range of patient needs and situations encountered across the health care system.

These practices should be standardized across health care systems, institutions, and insurance types to ensure patient-centricity. The goals of patient-centered utilization management include:

- Effectively reducing out-of-pocket costs for patients
- Efficiently improving patient health and wellbeing
- Adequately reflecting individual patient needs and preferences
- Supporting timely access to appropriate treatments and services
- Improving adherence

*For purposes of this document “UM stakeholders” includes health care systems, health insurance companies, benefit managers, industry (including pharmaceuticals, diagnostics, and devices), employers, and members of the health care team.

Patients and patient advocates are also key voices throughout all phases of UM program planning, implementation, evaluation, and management.
(1) Collaboration and Partnership
UM stakeholders consistently and meaningfully engage patients and patient advocates to participate in proactive planning, creation, implementation, and evaluation of UM practices.

(2) Evidence-Based, Inclusive Processes
UM practices are informed by clinical evidence and patient input from multiple sources including but not limited to nationally recognized clinical guidelines, claims data, registries, real-world evidence and data, patient experience data, and patient preference information.

(3) Evaluation and Quality Improvement
UM stakeholders update UM practices on (at least) an annual basis, meaningfully and routinely incorporating emerging data and both patient and provider feedback into UM evaluation and refinement. UM stakeholders consider not only administrative, operational, and treatment costs, but also patient impacts as they evaluate and refine UM practices. UM stakeholders communicate how trends in patient evaluation and patient feedback are incorporated in quality improvement.

(4) Transparency and Fairness
UM stakeholders transparently display all UM information (such as medical and pharmacy benefits, clinical evidence, exceptions and appeals processes and required documentation) in clear, understandable language that is easily accessible and understood by patients. UM stakeholders provide patients with timely, understandable decision information and provide options to quickly and easily connect with someone to assist them.

(5) Patient-Centric Practices and Policies
UM stakeholders only use UM practices for patients whose current medications are not working effectively and never for patients in life threatening situations. UM stakeholders do not require patients to undergo UM processes they have previously undergone unsuccessfully. UM stakeholders limit exceptions or appeals decisions to 24 hours on an expedited basis and 48 hours on non-expedited basis. UM processes that are successfully implemented (such as prior authorization) should be valid throughout the duration of treatment as to ease the burden on patients and providers.
The Forum continues to build off the successes achieved in 2019 and delves more deeply into the impact of UM practices on patients living with chronic illness. In 2020, the Forum will:

1. Focus on prior authorization, step therapy, coverage with evidence development, clinical pathways, and other types of review used by payers, hospitals, employers, and institutions to reduce overall costs of care.

2. Seek to understand the impact of utilization management practices in the lives of patients across disease states and amplify their voices to inform policy and practice.

3. Engage in advocacy opportunities and hold round table events to foster dialogue on timely issues, host a summit of thought leaders to advance solutions, and conduct leading-edge research to inform policy.

4. Promote and implement the guiding principles for patient-centered utilization management. By working together, we can lower health care costs while also ensuring enhanced quality of care.

For more information, or to join the Forum, please contact:

action@cancersupportcommunity.org
The Forum on Utilization Management thanks the following organizations for joining us at events throughout 2019:

ADVI Health
Advisory Board
Advocate Good Samaritan Hospital
Alliance for Patient Access
American Academy of Dermatology Association
American Association of Cancer Research
American Cancer Society Cancer Action Network
American Lung Association
American Society for Radiation Oncology
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George Washington University Cancer Center
GlaxoSmithKline
Hogan Lovells
International Myeloma Foundation
Johns Hopkins Kimmel Cancer Center at Sibley Memorial Hospital
Johnson and Johnson/Janssen
Kidney Cancer Association
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National Alliance on Mental Illness
National Cancer Institute
National Comprehensive Cancer Network
National Coalition for Cancer Survivorship
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The Cancer Support Community

As the largest professionally-led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC) is dedicated to ensuring that all people impacted by cancer are:

Empowered by knowledge, strengthened by action, and sustained by community.

CSC’s Cancer Policy Institute (CPI) brings together patient advocates and policy experts to ensure that the voices of cancer patients and their loved ones play a central role in federal and state legislative, regulatory, and executive policymaking.

The CPI works in partnership with patient advocates, the CSC affiliate network of over 170 locations, and numerous allied health care and oncology organizations to work towards a future where 15.5 million cancer survivors have access to comprehensive, high-quality, timely, and affordable medical, social, and emotional care.

The CPI also partners with the Research and Training Institute (RTI) to support policy positions with evidence that is based on the patient experience. Whether CSC is on Capitol Hill or in state legislatures, in discussions with regulators, or working in policy coalitions, the focus is always on the patient and how to work towards a system that is truly centered around the experiences, preferences, and values of cancer patients and their loved ones.

Deficiencies of methods applied in cost effectiveness analysis of hematological malignancies. Journal of Cancer Policy, 2, 40-44.


Health care spending in the United States and other high-income countries. JAMA, 319(10), 1024-1039.
