

Patient advocates play an important role in influencing patient care and health policy by forging reciprocal relationships with stakeholders across the health care landscape. Through “Outlining Our Paths to Impact and Change,” Dr. Rachel Giles of the International Kidney Cancer Coalition (IKCC) shared key insights from relationships between governmental organizations, health care providers and patient advocacy organizations in Europe. You can view her keynote presentation [here](#). Our working groups also met to identify those who are most impacted in each of their focus areas as well as the necessary stakeholders to engage to create and sustain meaningful change.

Featured Speakers



Rachel Giles, M.D., Ph.D.
Chair, International Kidney Cancer Coalition



Neil Bertelsen
Health Technology Assessment International (HTAi) Patient and Citizen Involvement Group



Brad Love, Ph.D.
Co-Founder and Chief Culture Officer, GRYT Health



Gary Nolan
Independent Advisor



Sheila Thorne
President and CEO, Multicultural Healthcare Marketing Group, LLC

Outlining Our Paths to Impact and Change

Key Points and Resources

Learning from Patient Advocacy in Europe

- Patient advocacy groups are publicly funded by the European Union. They provide patient support, increasingly help shape health and regulatory policy, and support and direct research on local, national, regional and global levels.
- European patient advocacy groups navigate challenges that come with supporting multinational disease communities. Examples include:
 - 80+ languages used across disease communities
 - 512 million people impacted by disease
 - 27+ different health systems and associated rules and regulations
- **Evidence-based advocacy** is practiced by most European advocacy groups and involves making policy decisions based on data vs. opinions. This is accomplished through targeted advocacy, robust data and tailored messaging.
- **Patient involvement** plays a valuable role throughout the lifecycle of a clinical trial. [This paper](#) provides a roadmap for how to engage patients in clinical trial development and describes the beneficial outcomes of patient involvement.

Skill Building Opportunities

- [The IKCC](#) is a global umbrella organization that consists of 46 national organizations that collectively reach over 1.2 million kidney cancer patients. The IKCC hosts an annual [Global Kidney Cancer Summit](#) for patient advocacy groups as well health care providers and researchers to share important information with the kidney cancer community.
- [EUPATI](#) provides [comprehensive on-demand training](#) for patient advocates to gain the level of expertise needed to provide expert patient insight. The [EUPATI Toolbox](#) also offers a collection of accessible, virtual resources focused on pharmaceutical research and development.
- [The European Society for Medical Oncology \(ESMO\)](#) offers a [Patient Advocate Track](#) during its annual congress for cross-collaboration between medical experts and patient advocates.
- [The European School of Oncology \(ESO\)](#) offers virtual five-day masterclasses on patient advocacy. In partnership with ESMO and Rare Cancers Europe, they held a [virtual training course for rare cancer patient advocates](#) in early 2021.
- [WeCan](#) is an EU funded, informal workgroup and think tank of leaders from 20 pan - European cancer patient umbrella organizations that develops patient-centered health industry standards and policy.