

# The Future of Advocacy

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Participants' Affiliate Organizations



International Association for the Study of Lung Cancer



International Kidney Cancer Coalition



# The Future of Advocacy

## Key Insights that Inspired Session 1 Conversation

The workshop was primarily broken down into two core sessions, *The meaning of Patient Advocacy* and *The future of Patient Advocacy*.

### **The Meaning of Patient Advocacy:**

All attendees touched on *four* common themes when they were asked to define what their personal and collective definition of Patient Advocacy was:

**Care** - Providing personalized, individual or group care/support to a patient or loved one along their journey

**Empowerment** - Empowering patients and their loved ones to advocate for themselves, seek better care, new treatment options and second opinions

**Access** - Advocating for patients to ensure they have access to the latest treatment options and a minimum standard of care for them

**Awareness** - Raising awareness of a diseases to support earlier diagnosis new treatment approaches and social acceptance

*Consideration* - we may decide to compose a **proposition statement** based on the above to define the meaning of patient advocacy for future workshop attendees to buy into - further thought required.

# The Future of Advocacy

## Key Insights that Inspired Session 1 Conversation

- Advocacy means something different to different stakeholders
- Advocacy could be a group or organization that provides care or support on a personal basis (or to a group) that allows or provides ways to empower patients to advocate for themselves
  - Support side of advocacy: support groups, psychosocial support, helping a patient seek a second opinion, etc.
  - Policy side of advocacy: making sure patients of a specific disease area that advocates represent can access the treatments they need
  - Awareness side of advocacy: helping drive greater awareness of the disease and those important factors associated with it
- COVID has changed the advocacy world, but some of the positive changes to advocacy should be taken into the future
  - A big benefit has been getting information and resources out to a larger population and sometimes earlier than before
  - Organizations can spend less money and time on travel
  - Organizations will probably move towards a hybrid model of advocacy (virtual and in person)

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### ***The future of Patient Advocacy:***

Unsurprisingly, The Future of Advocacy has changed as a result of COVID. From the conversations we had, Advocacy is going to become more personal, more tailored and importantly more accessible when patients are most in need of **Care, Empowerment, Access and Awareness**.

The greatest observation from our conversation was how COVID has provided an opportunity to provide patient care/support earlier in a patient's journey. Our social acceptance of technology and platforms like Zoom has allowed Patient Organizations to support patients "when/where" they were previously unavailable. A great examples of this is when patients are "sick" and hospitalized; technology allows them to speak with a Patient Advocate in their hospital beds and receive the support and reassurance they need **at the point of care** (*this is important not after, but at the point of care*).

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## Key Insights that Inspired Session 1 Conversation

- We will discover, align, cultivate, create and empower; we are trying to CREATE meaningful resources that are tangible deliverables from this platform.
- As conversations progress, we can add more stakeholders that are outside of advocacy if we want to (policy makers, healthcare professionals, etc.) as long as they can help us define the future of advocacy.
- We want to move towards creating a deliverable.

# Join Us for the Next Working Group Session

Thursday, March 11, 2021

12:00 – 1:30pm ET