

The Future of Advocacy - Update

8 April 2021

The Future of Advocacy

Background to the Future of Advocacy – Summary

This working group was designed in response to observations and questions from the 2020 COVID Advocacy Exchange sessions:

- The role of patient advocacy organizations is changing
- There are increased demands and new challenges
- What are the emerging opportunities for creating meaningful change within healthcare systems?

The Meaning of Advocacy

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The Meaning of Advocacy – Summary

Attendees identified six themes that define what their collective definition of Patient Advocacy is:

- **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 disease to support earlier diagnosis, new treatment approaches and social acceptance
- **Research** – Support continued research into new treatment options for patients
- **Policy** – Ensure health care policies reflect the needs of patients

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The Meaning of Advocacy – Summary

Advocacy means something different to all stakeholders and personal perspectives are important. Not all Patient Organizations (PO) will advocate or provide the associated support around:

- Care
- Empowerment
- Access
- Awareness
- Research
- Policy

Advocacy is what groups decide it **is** and **isn't**. POs that are limited by resource and bandwidth should consider communicating clearly what they **do** and **don't** do to avoid being distracted from their Vision and Mission.

The Future of Advocacy – What We Have Learnt

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Care Summary – What We Have Learnt

- Patients are feeling disconnected from their health providers due to fewer appointments and access to information and Patient Organizations (PO) are having to bridge these communication gaps
- Some patients are taking care into their own hands e.g., cancelling hospital appointments or taking treatment holidays and PO are having to manage these situations with limited access to information
- PO are having to embrace new and preferred communication channels of patients to deliver ‘care’
- Alongside COVID information, PO are still having to focus on their mission and vision as PO
- Care is personal and “one size does not fit all” - we must not forget established and proven approaches
- Over-communicating to patients when credible information is scarce is better than not communicating
- Caring for patients goes beyond the disease especially during COVID

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Empowerment Summary – What We Have Learnt

- Providing access to information through a patient's preferred channels is empowering
- Provide basic “how to” information supporting patients on how to reintegrate into society alongside managing their own disease and self advocating
- We need to be mindful that we are asking a lot of patients. Online appointments can create a burden; each click on a website is a potential roadblock
- Ensuring we don't move a burden from an under-resourced healthcare system or PO onto a patient must always be front of mind with any PO; we run the risk of over-empowering patients

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Access Summary – What We Have Learnt

- We have seen that we can have an impact on access to care, e.g., at home or in car blood draws
- Telemedicine and online services open new opportunities and access to care
- Online approaches are not for every patient and disparities in age and economic status present new challenges around access to care
- Patient preference and their desired access to care is paramount
- COVID has proven that care can be convenient and available physically, virtually or at home

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Awareness Summary – What We Have Learnt

- COVID has educated the world on the drug discovery, development and access process; including the challenges
- We have never discussed so openly the importance of research, clinical trials, side effects, efficacy and access to these ‘services’
- Awareness and alignment on a single global challenge has resulted in international collaborations never seen before from governments, NGOs and the pharmaceutical industry

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Research Summary – What We Have Learnt

- COVID has identified positive and negatives in research and drug discovery
- What we have learnt from COVID – Positives:
 - An appreciation for the importance of access to regular testing and diagnostics – *if we collaborate*
 - We can discover and develop “drugs” quickly – *if we collaborate*
 - We can grant access to new therapies in “days” and globally – *if we collaborate*
 - Distribution and manufacturing networks are established and available – *if we collaborate*
- What we have learnt from COVID – Negatives:
 - Accelerated drug development does not allow for rigorous long-term studies focused on safety
 - The patient voice can't be included, where required in accelerated drug development

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Policy Summary – What We Have Learnt

- As a result of collaboration, we have have changed policies to support:
 - **Care** – Providing personalized, individual or group care/support to a patient or loved one along their journey
 - **Access** – Advocating for patients to ensure they have access to the latest treatment options and a minimum standard of care for them
 - **Research** – Support continued research into new treatment options for patients
- Approval of new therapies that relieve a burden on a healthcare system have been granted

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Summary

Through collaboration, achieving our definition of Patient Advocacy is very possible. COVID has proven that when all the stakeholders affected by a therapy area work collaboratively on a single purpose, we can:

- Improve patient care
- Empower patients to advocate for themselves
- Allow access to personalized care
- Drive greater awareness and lift level of knowledge in unmet needs
- Accelerate drug discovery and research and
- Change policies that make meaningful differences to patients

The future of Advocacy may require Patient Organizations (PO) positioning themselves as the “*collaborator*” working to align all stakeholders on a single vision, remove competitive advantage and any personal objectives for the greater good of patients.

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Working Group Attendees

