

The Future of Advocacy

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The Future of Advocacy

Different types of advocacy and how COVID has positively and negatively impacted these areas

- Care
- Empowerment
- Access
- Awareness

We need to add two new types as well:

- Research
- Policy

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Care

Problems we've seen:

- Patients feel dissociated from providers due to lack of communication; this leads to patients feeling isolated and a lack of confidence
- Some patients took their care into their own hands and avoided hospital visits
- Providers, researchers and advocates also lacked clarity throughout the pandemic

Solutions:

- Identifying and embracing preferred communication channels of patients and loved ones
- Increase in virtual programming, new avenues such as podcasts to distribute information
- Offer programming that does **not** relate to COVID, such as trivia, virtual pub night, practical and hobby-based activities because patients wanted a break from the pandemic

“If we have beneficial information for patients, we need to find many ways to communicate and get this information out as much possible.”

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Care

Key highlights:

- In a post COVID world, care is personal and “one size does not fit all,” we need to embrace new communication approaches and approaches to care, but remember to utilise established and proven approaches
- Over communicate at times of difficulty, especially when credible information is scarce
- Care goes beyond the disease, and often a distraction from a disease or COVID is “care”

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Empowerment

How have you helped patients and caregivers feel more empowered to advocate for themselves?

- Hybrid programming and open access to information
- How-to videos and resources – “How to tell your family about your diagnosis”

Over-empowerment has become an issue:

- Virtual programming and care is good, but we need to make sure we are not asking patients to do too much on their own; if *too* much is on their shoulders, this can create a burden or feel overwhelming
- Online appointments and registrations are creating a burden – each “click” on a website is a potential roadblock for patients

We are at risk of over empowering patients and creating unnecessary burdens for patients. In an attempt to reduce an impact or burden on a healthcare system, we are now moving the burden to the patients.

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Access

- Increase in home delivery of medications, at home or in car blood draws
- We must also remember that some patients **need** to be seen by a provider for certain conditions; sometimes, you **cannot** replace face-to-face care (safety of a full physical examination, and the reassurance patients feel)
- Access to care must be driven by patient preference
- COVID has proven that care can be convenient and available physically, virtually or at home

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Awareness

- The world has been educated on the drug discovery and drug development process
- We now have greater public awareness of clinical trials and what is involved; let's keep these conversations going to increase awareness and education on clinical trials

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Research

What COVID has demonstrated in drug discovery:

- We have seen a positive impact on clinical trials; we're finally bringing clinical trial *to* patients, rather than bringing patients to trials
- If we look at drug discovery and distribution, COVID has taught us that yes, we **can** generate drugs quicker and generate greater access to larger populations

What we have learnt from COVID – Pros:

- We can develop “drugs” very quickly
- We can give access to new therapies in “days” and globally
- The distribution networks are there

What we have learnt from COVID – Cons:

- Proper testing isn't always feasible in accelerated drug development
- The patient voice can't be included in accelerated drug development

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Policy

- We have seen quicker approvals that positively impact all areas of advocacy
 - Example: government approvals allowing medication deliveries and at home blood draws
 - Laws, regulations, policy and guidelines have been amended to support care during COVID, this should not stop after COVID

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Moving Forward

- We have seen an increase in collaboration across all parts of healthcare and this needs to continue
- We need to define what “our” advocacy organizations do well and don't do well
 - Advocacy groups need to be very clear on what they do and don't do
 - Advocacy groups might need to better define their mission statements
- Groups that participate in one type of advocacy can lean on, collaborate with and learn from groups that are focused in the other areas

Join Us for the Next Working Group Session

Thursday, May 13, 2021
12:00-1:30pm ET