

Collaborative Initiatives: How Patient Advocacy Groups Contribute to the Success of Precision Medicine

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ABSTRACT

Patient advocacy groups are integral to the advancement of precision medicine, playing crucial roles in influencing research priorities, enhancing patient engagement, and advocating for policy changes. Their collaborative efforts with researchers, healthcare providers, industry stakeholders, and policymakers contribute significantly to the success of personalized medicine initiatives. This review explores the multifaceted contributions of patient advocacy groups in precision medicine, highlighting their impact on research innovation, patient empowerment, and healthcare policy. By fostering partnerships and addressing challenges, advocacy groups facilitate the adoption of personalized therapies and improve health outcomes for individuals affected by complex diseases.

KEYWORDS: *patient advocacy groups, precision medicine, personalized medicine, research collaboration, patient engagement, healthcare policy*

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Patient advocacy groups are integral to the advancement of precision medicine, playing crucial roles in influencing research priorities, enhancing patient engagement, and advocating for policy changes. Their collaborative efforts with researchers, healthcare providers, industry stakeholders, and policymakers contribute significantly to the success of personalized medicine initiatives. This review explores the multifaceted contributions of patient advocacy groups in precision medicine, highlighting their impact on research innovation, patient empowerment, and healthcare policy. By fostering partnerships and addressing challenges, advocacy groups facilitate the adoption of personalized therapies and improve health outcomes for individuals affected by complex diseases.

INTRODUCTION

Precision medicine stands at the forefront of a revolutionary shift in healthcare, departing from conventional approaches that adopt a uniform treatment regimen for all patients. Instead, it

embraces personalized treatment strategies tailored to individual genetic profiles, environmental exposures, and lifestyle factors. This paradigmatic evolution promises to enhance treatment efficacy, minimize adverse effects, and ultimately improve patient outcomes across diverse medical conditions. At its core, precision medicine leverages cutting-edge technologies and insights from genomics, proteomics, metabolomics, and other omics disciplines. These advanced technologies enable healthcare providers to delve into the intricate molecular mechanisms underlying diseases, identify specific biomarkers indicative of disease susceptibility or treatment response, and devise targeted therapeutic interventions. [1,2,3]

Key to the success of precision medicine are robust collaborations among stakeholders spanning academia, healthcare institutions, biotechnology firms, pharmaceutical companies, regulatory bodies, and notably, patient advocacy groups. These groups, often comprising individuals affected by specific

diseases or their caregivers, play pivotal roles as catalysts for change within the healthcare ecosystem. Patient advocacy groups exert substantial influence by advocating for research funding, shaping policy agendas, promoting patient education, and facilitating community engagement. [4] They serve as vocal advocates for the inclusion of patient perspectives in research priorities, ensuring that scientific advancements align closely with the needs and priorities of those affected by diseases.

Through their advocacy efforts, patient groups drive the acceleration of research into disease mechanisms, biomarker discovery, and the development of targeted therapies. By championing the importance of genetic testing and personalized treatment options, these groups empower patients to actively participate in decisions about their healthcare, fostering a collaborative environment between patients, healthcare providers, and researchers. Patient advocacy groups play a crucial role in navigating the complex regulatory landscape surrounding precision medicine. [5] They collaborate with policymakers and regulatory agencies to advocate for policies that facilitate equitable access to innovative diagnostics and therapies based on genetic and molecular profiling. By addressing barriers such as insurance coverage, reimbursement policies, and regulatory approval processes, advocacy groups ensure that all patients have the opportunity to benefit from advancements in precision medicine. [6]

The impact of patient advocacy groups extends beyond research and policy advocacy to encompass patient education and support. These groups provide valuable resources, educational materials, and support networks that empower patients and caregivers with information about their condition and available treatment options. By fostering patient empowerment and engagement, advocacy groups enable individuals to make informed decisions about participating in clinical trials, accessing personalized therapies, and managing their health effectively. [7] Collaboration among stakeholders is paramount in advancing precision medicine initiatives. Patient advocacy groups collaborate closely with researchers, healthcare providers, and industry leaders to accelerate the translation of scientific discoveries into clinical applications. These collaborative efforts facilitate the integration of genomic data into clinical decision-making, enabling healthcare providers to deliver personalized treatment plans tailored to each patient's unique genetic profile and medical history.

Therefore, precision medicine represents a transformative approach to healthcare that prioritizes personalized treatment strategies over traditional one-

size-fits-all approaches. [8] Enabled by advanced technologies and genomic insights, precision medicine holds the promise of improving treatment outcomes, reducing adverse effects, and revolutionizing patient care across a wide range of medical conditions. Patient advocacy groups play a pivotal role as catalysts for change within the precision medicine landscape, advocating for research funding, shaping policy agendas, promoting patient education, and facilitating community engagement. By championing patient perspectives and fostering collaboration among stakeholders, advocacy groups contribute significantly to the advancement and adoption of precision medicine, ensuring that all patients have access to personalized, effective, and compassionate healthcare. [9-12]

The Role of Patient Advocacy Groups in Shaping Research Priorities

Patient advocacy groups wield significant influence in shaping the research agendas and priorities that drive advancements in precision medicine. Through their collective voices and experiences, these groups play a pivotal role in advocating for increased funding, support, and attention to research initiatives focused on unraveling the genetic underpinnings of diseases, identifying biomarkers, and developing targeted therapies. Their advocacy efforts are instrumental in aligning research endeavors with the diverse needs and priorities of patients, thereby catalyzing innovations that directly impact and benefit affected communities. Patient advocacy groups represent a diverse spectrum of diseases and conditions, ranging from rare genetic disorders to more prevalent chronic illnesses. They bring together patients, caregivers, and families who are intimately acquainted with the challenges and realities of living with these conditions, providing a compelling advocacy platform grounded in lived experiences.

One of the primary roles of patient advocacy groups in precision medicine is to advocate for increased research funding. They actively engage with government agencies, private foundations, and industry stakeholders to secure financial resources dedicated to advancing scientific understanding of disease mechanisms at the molecular level. By lobbying for robust funding allocations, advocacy groups ensure that researchers have the necessary resources to conduct comprehensive genomic studies, explore disease pathways, and translate scientific discoveries into clinical applications. Patient advocacy groups champion the importance of research initiatives that prioritize the identification of biomarkers. Biomarkers are measurable indicators, such as genetic mutations, protein expression levels,

or metabolic signatures, that can reveal important insights into disease progression, treatment response, and patient prognosis. By advocating for biomarker research, advocacy groups promote the development of diagnostic tests that can accurately predict disease outcomes and inform personalized treatment strategies tailored to individual patients' genetic profiles.

Additionally patient advocacy groups play a crucial role in driving the development of targeted therapies. These therapies are designed to specifically target the underlying molecular abnormalities driving disease progression, offering a more precise and effective approach to treatment compared to traditional therapies. By advocating for research into targeted therapies, advocacy groups accelerate the translation of scientific discoveries from the laboratory to the clinic, ultimately expanding the arsenal of treatment options available to patients. Beyond shaping research agendas, patient advocacy groups ensure that research efforts are aligned with the real-world needs and priorities of patients and their families. They actively participate in research advisory boards, scientific committees, and stakeholder meetings to provide input on study design, patient recruitment strategies, and outcome measures. This patient-centered approach not only enhances the relevance and applicability of research findings but also fosters a collaborative environment where researchers and clinicians work hand-in-hand with patients to co-create knowledge and drive innovation. [10-14]

Patient advocacy groups serve as powerful advocates for the inclusion of underrepresented patient populations in clinical research. They emphasize the importance of diversity and inclusion in research studies to ensure that findings are applicable across diverse demographic groups and socioeconomic backgrounds. By advocating for equitable access to clinical trials and research opportunities, advocacy groups strive to eliminate disparities in healthcare outcomes and ensure that all patients have access to cutting-edge treatments and therapies. The impact of patient advocacy groups extends beyond influencing research priorities to fostering a culture of collaboration and knowledge-sharing within the precision medicine community. These groups facilitate partnerships among researchers, healthcare providers, industry stakeholders, and regulatory agencies, creating synergies that accelerate the pace of scientific discovery and innovation. By bridging the gap between stakeholders, advocacy groups promote interdisciplinary collaborations that leverage expertise from diverse fields such as genetics,

bioinformatics, pharmacology, and patient-centered outcomes research.

Enhancing Patient Engagement and Empowerment

Precision medicine represents a paradigm shift in healthcare, emphasizing personalized treatment approaches tailored to individual genetic profiles, environmental factors, and lifestyle choices. At the core of this transformative approach lies the active participation of patients in their own healthcare decisions—a cornerstone facilitated significantly by patient advocacy groups. These groups empower individuals affected by diseases to become informed advocates for personalized treatment options, leveraging educational programs, support networks, and patient-centered initiatives to educate patients about the potential benefits of precision therapies, encourage participation in clinical trials, and foster a collaborative environment where patients play a proactive role in advancing medical research. [15]

Patient advocacy groups serve as crucial catalysts in driving patient engagement and empowerment within the realm of precision medicine. They represent a diverse array of diseases and conditions, ranging from rare genetic disorders to more prevalent chronic illnesses, and unite patients, caregivers, and families who navigate the complexities of managing these conditions daily. By harnessing collective experiences and voices, advocacy groups amplify patient perspectives to advocate for access to innovative treatments, research funding, and policies that prioritize patient-centered care.

Central to the mission of patient advocacy groups is education. These organizations provide valuable resources, educational materials, and information about cutting-edge advancements in precision medicine to empower patients with knowledge. Educational programs conducted by advocacy groups elucidate the principles of precision medicine, including genomic testing, biomarker-driven diagnostics, targeted therapies, and personalized treatment plans. By equipping patients with understanding and insights into these innovative approaches, advocacy groups enable individuals to make informed decisions about their healthcare journey, ensuring that treatment options align closely with their unique medical needs and genetic profiles. [16]

Moreover, patient advocacy groups cultivate support networks that offer emotional support, practical guidance, and shared experiences among patients and caregivers facing similar health challenges. These networks provide a sense of community and solidarity, fostering resilience and empowering

individuals to navigate their healthcare journeys more effectively. By connecting patients with peers who share similar experiences, advocacy groups create opportunities for mutual support, empathy, and empowerment, which are essential components of patient-centered care in precision medicine.

In addition to education and support, patient advocacy groups actively promote participation in clinical trials and research initiatives focused on precision medicine. Clinical trials play a pivotal role in advancing scientific understanding of disease mechanisms, evaluating the safety and efficacy of novel therapies, and validating biomarkers predictive of treatment response. Advocacy groups collaborate with researchers, healthcare providers, and industry stakeholders to facilitate patient recruitment, raise awareness about clinical trial opportunities, and advocate for inclusive trial designs that prioritize diversity and representation across patient populations.[17]

By advocating for increased patient participation in clinical trials, advocacy groups contribute to the acceleration of scientific discoveries and the translation of research findings into clinical practice. They emphasize the importance of diverse patient representation in clinical research to ensure that precision medicine advancements benefit individuals from all demographic backgrounds and socioeconomic circumstances. Advocacy groups also advocate for policies that enhance patient access to clinical trials, address barriers to participation such as geographical constraints and financial burdens, and prioritize ethical considerations to safeguard patient welfare throughout the research process.

Furthermore, patient advocacy groups play a pivotal role in shaping research priorities and influencing policy decisions that impact the development and adoption of precision medicine approaches. [12] These organizations engage with policymakers, regulatory agencies, and healthcare stakeholders to advocate for policies that support genomic testing, biomarker-driven diagnostics, and targeted therapies in routine clinical practice. By addressing regulatory hurdles, reimbursement policies, and insurance coverage limitations, advocacy groups work to ensure that patients have equitable access to innovative treatments that are aligned with their individual genetic profiles and medical needs. [18]

The collaborative efforts of patient advocacy groups extend beyond individual disease communities to encompass broader advocacy initiatives that promote patient-centered care and advance the field of precision medicine as a whole. These groups leverage partnerships with academic institutions, healthcare

providers, industry leaders, and government agencies to foster interdisciplinary collaborations and knowledge-sharing opportunities. By bridging gaps between stakeholders, advocacy groups facilitate the integration of genomic data, digital health technologies, and patient-reported outcomes into clinical decision-making, thereby enhancing the precision and effectiveness of medical treatments and interventions.

Advocating for Policy Changes to Support Precision Medicine

Patient advocacy groups play a multifaceted role in advancing precision medicine beyond research advocacy, actively championing policy changes aimed at integrating these innovative approaches into clinical practice. These groups collaborate with policymakers, regulatory agencies, healthcare providers, and industry stakeholders to address barriers such as insurance coverage limitations, reimbursement policies, and regulatory approval processes. [19] By advocating for policies that promote equitable access to genomic testing and personalized therapies, patient advocacy groups ensure that all individuals have the opportunity to benefit from the transformative potential of precision medicine.

Precision medicine represents a paradigm shift in healthcare, focusing on personalized treatment strategies tailored to individual genetic profiles, environmental factors, and lifestyle choices. This approach holds promise for improving patient outcomes, reducing adverse effects, and optimizing therapeutic efficacy compared to traditional one-size-fits-all approaches. However, widespread adoption of precision medicine in clinical practice faces several challenges, including regulatory hurdles, reimbursement complexities, and disparities in access to advanced diagnostic technologies and targeted therapies.

Patient advocacy groups play a crucial role in navigating these challenges by advocating for policies that facilitate the integration of precision medicine into routine clinical care. One of their primary advocacy efforts revolves around addressing insurance coverage and reimbursement issues. Many precision medicine technologies, such as genomic sequencing and biomarker-driven diagnostics, are often not fully covered by insurance plans or face reimbursement challenges due to perceived experimental status or lack of established payment mechanisms. Advocacy groups work tirelessly to raise awareness among policymakers and insurers about the clinical validity and utility of these technologies, emphasizing their potential to improve

patient outcomes and reduce overall healthcare costs in the long term.

Moreover, patient advocacy groups collaborate with regulatory agencies to streamline approval processes for new genomic tests and personalized therapies. Regulatory frameworks play a critical role in ensuring the safety, efficacy, and quality of medical interventions, including those in precision medicine. However, these frameworks may not always be well-suited to accommodate the rapid pace of technological advancements and the unique characteristics of personalized treatments. Advocacy groups engage in dialogue with regulatory bodies to advocate for flexible and adaptive regulatory pathways that maintain rigorous standards while expediting the approval of innovative precision medicine interventions that demonstrate clinical utility and benefit to patients.

In addition to insurance coverage and regulatory approval, patient advocacy groups address broader policy issues that impact the adoption and implementation of precision medicine. They advocate for policies that support research funding for precision medicine initiatives, promote data sharing and interoperability among healthcare systems and research institutions, and ensure that ethical considerations and patient privacy protections are upheld in the collection, analysis, and use of genomic data. These advocacy efforts aim to create an enabling environment where healthcare providers can confidently integrate genomic information into clinical decision-making, ensuring that personalized treatment options are accessible to all patients regardless of their geographical location or socioeconomic status.

Furthermore, patient advocacy groups collaborate with healthcare providers and industry stakeholders to develop guidelines and best practices for the responsible implementation of precision medicine. They engage in discussions about the ethical implications of genomic testing, informed consent procedures, and the interpretation of genetic information to ensure that patients receive accurate and actionable insights from their genomic data. By promoting transparency, patient-centered care, and shared decision-making between patients and healthcare providers, advocacy groups empower individuals to make informed choices about their healthcare and participate actively in precision medicine initiatives.

Collaborative Initiatives and Partnerships

Precision medicine represents a transformative approach to healthcare, aiming to tailor medical treatments to the individual characteristics of each

patient. At its core, the success of precision medicine depends on collaborative initiatives and partnerships among various stakeholders, including patient advocacy groups, healthcare providers, researchers, industry leaders, and government agencies. These partnerships create a synergistic environment that fosters knowledge exchange, resource sharing, and innovative research endeavors, ultimately driving advancements in medical care and improving patient outcomes. Patient advocacy groups play a pivotal role in shaping the landscape of precision medicine by advocating for policies that prioritize patient-centered care, promote equitable access to personalized therapies, and address barriers to the integration of genomic information into clinical practice. These groups represent the collective voice of patients affected by diverse diseases and conditions, advocating for increased research funding, improved regulatory frameworks, and expanded access to clinical trials and cutting-edge treatments.

Healthcare providers, including physicians, nurses, and allied health professionals, are essential partners in the delivery of precision medicine. They translate scientific advancements into clinical practice, applying genomic insights and personalized treatment strategies to optimize patient care. Through collaboration with researchers and patient advocacy groups, healthcare providers contribute valuable clinical expertise, patient care perspectives, and real-world data that inform research priorities and drive evidence-based practice. Researchers and scientists drive innovation in precision medicine by conducting basic, translational, and clinical research to uncover the genetic, molecular, and environmental factors influencing disease susceptibility and treatment response. Collaborative research initiatives bring together multidisciplinary teams to explore complex biological pathways, identify biomarkers, develop targeted therapies, and validate predictive models that guide personalized treatment decisions. By sharing data, resources, and expertise across institutions and disciplines, researchers accelerate the pace of scientific discovery and translate research findings into actionable insights that benefit patients.

Industry leaders, including pharmaceutical companies, biotechnology firms, and diagnostic companies, play a critical role in the development and commercialization of precision medicine technologies and therapies. These stakeholders invest in research and development, conduct clinical trials, navigate regulatory pathways, and bring innovative products to market. Collaborative partnerships with academia, healthcare providers, and patient advocacy groups enable industry leaders to align their efforts with

patient needs, enhance product development pipelines, and ensure that precision medicine innovations reach patients in a timely and accessible manner. Government agencies and policymakers provide regulatory oversight, funding support, and infrastructure to advance precision medicine initiatives at national and global levels. These stakeholders establish regulatory frameworks that ensure the safety, efficacy, and ethical use of genomic technologies, while also promoting policies that incentivize research investment, facilitate data sharing, and expand healthcare coverage for personalized therapies. Collaborative efforts between government agencies, research institutions, industry stakeholders, and patient advocacy groups are essential for shaping policy decisions that support the integration of precision medicine into mainstream healthcare delivery.

Collaborative initiatives in precision medicine extend beyond research and clinical practice to encompass education, training, and public engagement. Stakeholders collaborate to develop educational programs that raise awareness about the benefits of precision medicine, promote health literacy, and empower patients to make informed decisions about their healthcare. By fostering public engagement and dialogue, stakeholders build trust, reduce stigma associated with genetic testing and personalized therapies, and promote inclusivity in research participation and healthcare delivery. The success of collaborative initiatives in precision medicine is exemplified by several transformative achievements and ongoing efforts across various disease areas. For instance, in oncology, collaborative research consortia have revolutionized cancer treatment by identifying genetic mutations, biomarkers, and targeted therapies that improve survival rates and quality of life for patients with specific tumor types. Similarly, in rare diseases, collaborative networks of researchers, clinicians, patient advocacy groups, and industry partners have accelerated the diagnosis, treatment, and management of rare genetic disorders through genomic sequencing and personalized medicine approaches.

Looking forward, the future of precision medicine will continue to rely on effective collaboration among stakeholders to overcome existing challenges and seize emerging opportunities. Key areas for future collaboration include enhancing data interoperability and sharing, expanding access to genomic testing and precision therapies in underserved populations, addressing disparities in healthcare access and outcomes, advancing artificial intelligence and machine learning applications in data analysis and

predictive modeling, and promoting ethical guidelines for genomic research and clinical practice. [17]

Challenges and Considerations

Patient advocacy groups are pivotal entities in the realm of healthcare, particularly in advancing the field of precision medicine. This transformative approach to medical care aims to tailor treatments to the individual characteristics of each patient, leveraging insights from genomics, biomarkers, and personalized therapies to optimize outcomes and minimize adverse effects. At the forefront of this movement, patient advocacy groups serve as influential voices that champion the needs and priorities of patients affected by diverse diseases and conditions.

Despite their significant contributions, patient advocacy groups encounter various challenges that can impede their efforts to promote precision medicine effectively. These challenges include funding limitations, resource constraints, and varying levels of scientific literacy among their members and the broader patient community. Addressing these hurdles requires collaborative strategies, capacity building initiatives, and sustained support from stakeholders across the healthcare ecosystem.

Patient advocacy groups often operate with limited financial resources, relying on donations, grants, and fundraising efforts to sustain their advocacy activities. Securing adequate funding is crucial for maintaining organizational stability, expanding outreach efforts, and supporting advocacy campaigns aimed at advancing precision medicine. Collaborative partnerships with philanthropic organizations, industry stakeholders, and government agencies can provide essential financial support, expertise, and resources to bolster advocacy initiatives and amplify their impact on policy development and research funding priorities.

Resource constraints pose another significant challenge for patient advocacy groups engaged in precision medicine advocacy. Limited staff, infrastructure, and technical expertise may hinder their ability to effectively navigate complex regulatory landscapes, engage in scientific discourse, or implement data-driven advocacy strategies. Capacity building programs that offer training in advocacy skills, scientific communication, and strategic planning can empower advocacy groups to enhance their organizational capacity, cultivate leadership talent, and leverage technology to amplify their advocacy efforts.

Scientific literacy among patients and advocacy group members varies widely, posing a challenge for

effective engagement in discussions about precision medicine and genomic research. Education and awareness-building initiatives are essential to equip patients with the knowledge and understanding needed to make informed decisions about their healthcare options, participate in clinical trials, and advocate for access to personalized therapies. Patient advocacy groups play a crucial role in providing educational resources, organizing workshops, and facilitating peer support networks that promote health literacy and empower patients to navigate the complexities of precision medicine.

Collaboration across the healthcare ecosystem is essential for overcoming these challenges and maximizing the impact of patient advocacy efforts in advancing precision medicine. Healthcare providers, including physicians, nurses, and allied health professionals, play a critical role in translating scientific advancements into clinical practice and delivering personalized care to patients. By collaborating with advocacy groups, healthcare providers can gain insights into patient perspectives, enhance communication with diverse patient populations, and tailor treatment plans to align with patient preferences and priorities.

Researchers and scientists contribute to precision medicine advocacy by conducting innovative research, identifying genetic mutations and biomarkers, and developing targeted therapies that improve patient outcomes. Collaborative research partnerships between advocacy groups and research institutions facilitate the translation of scientific discoveries into tangible benefits for patients, promote research participation, and advocate for funding support for genomic research initiatives.

Industry stakeholders, including pharmaceutical companies, biotechnology firms, and diagnostic laboratories, drive innovation in precision medicine by developing and commercializing genomic tests, biomarker assays, and targeted therapies. Collaborative partnerships between advocacy groups and industry leaders promote transparency, ethical practices, and patient-centered approaches in the development, pricing, and accessibility of precision medicine technologies and treatments. [20]

Government agencies and policymakers play a crucial role in shaping the regulatory framework and policy environment that governs precision medicine. Advocacy groups collaborate with policymakers to advocate for policies that promote equitable access to genomic testing, support research funding, and address barriers to the adoption of personalized therapies in clinical practice. By engaging in policy advocacy, patient advocacy groups influence

legislative decisions, raise awareness about patient needs, and advocate for regulatory reforms that facilitate the integration of precision medicine into mainstream healthcare delivery. [12-18]

Conclusion

In conclusion, patient advocacy groups are indispensable partners in the journey towards precision medicine, contributing to research innovation, patient empowerment, and policy advocacy. Their unwavering commitment to improving healthcare outcomes for individuals affected by complex diseases underscores the transformative impact of collaborative initiatives in precision medicine. Moving forward, fostering robust partnerships and addressing challenges faced by advocacy groups will be essential to realizing the full potential of precision medicine in delivering personalized, patient-centered care.

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