

# ENGAGING PATIENT ADVOCACY GROUPS

Strategic Insights from the Digital Therapeutics Alliance and Medlive



## Executive Summary

In the rapidly evolving digital health landscape, engaging with Patient Advocacy Groups (PAGs) is essential for digital therapeutic manufacturers to ensure the development of patient-centered solutions that meet real-world needs. PAGs represent the voices of patients and caregivers, providing critical insights into their experiences, challenges, and unmet needs. Collaborating with these groups helps refine product design and enhance patient outcomes and plays a pivotal role in gaining commercial traction with payors and driving adoption by healthcare providers.

By forming meaningful partnerships with PAGs, digital therapeutics companies can raise awareness of their products, build trust within patient communities, and demonstrate the value of their therapies in improving quality of life. Engaging early and consistently allows PAGs to contribute insights during product development, ensuring that digital therapeutics are aligned with patient needs from the outset. Additionally, PAGs can advocate for the inclusion of digital therapeutics in treatment protocols and payor policies, increasing the likelihood of reimbursement and wider adoption.

This white paper, developed in collaboration between the Digital Therapeutics Alliance (DTA) and Medlive, outlines strategic approaches for digital health manufacturers to engage with PAGs effectively. By leveraging insights from leading advocacy organizations and digital therapeutics stakeholders, it offers practical guidance on how to foster trust-based relationships, align product development with patient needs, and navigate the complex landscape of healthcare reimbursement and provider adoption.

The Digital Therapeutics Alliance (DTA), an international association focused on advancing the adoption of clinically-validated digital therapeutics (DTx), collaborated with Medlive, a leader in developing educational initiatives and partnerships with Patient Advocacy Groups (PAGs). Together, they created strategic guidance to help DTA member companies and other digital therapeutics manufacturers engage more effectively with PAGs. This guidance draws from a detailed survey and qualitative input from key stakeholders, including DTA, Medlive, the Depression and Bipolar Support Alliance (DBSA), Diabetes Sisters, the Coalition for Headache and Migraine Patients (Champ), Freemira, MedRhythms, and 21 advocacy organizations. Data presented at the 2024 Digital Therapeutics Alliance Summit, emphasized the importance of raising awareness about digital therapeutics, fostering early and sustained engagement, customizing interactions, and offering meaningful financial support. These strategies aim to strengthen collaborations between manufacturers and advocacy groups, fostering broader acceptance and integration of digital therapeutics in healthcare.



## Introduction

**Context & Purpose:** Patient advocacy groups (PAGs) are vital partners in the healthcare ecosystem, offering trusted information, support, and advocacy for patients and caregivers. They play a key role in the adoption of new therapies, including digital therapeutics. However, engaging with PAGs requires a nuanced approach because these organizations have varied priorities, missions, and operational frameworks. This whitepaper equips DTA members with strategies to build and sustain meaningful, mutually beneficial relationships with PAGs.

**Design and Distribution:** DTA and Medlive, in collaboration with DBSA, Freespira, and MedRhythms, developed a survey to understand how digital therapeutics companies can effectively engage with patient advocacy groups (PAGs). Stakeholder discussions guided the creation of carefully crafted questions designed to elicit detailed, actionable insights. Distributed to 150 PAGs across various therapeutic areas, the survey focused on assessing familiarity with digital therapeutics, preferred engagement strategies, and challenges in existing models.

Participants were asked questions such as, *“What do the most successful advocacy group-industry relationships look like for your organization?”*, *“Are there things companies should avoid?”*, *“What type of data is important for your organization to engage with emerging digital therapeutics?”*, and *“How can digital therapeutics companies best help further your mission and support your community?”*

In addition to survey responses, DTA, Medlive, DBSA, Freespira, and MedRhythms provided qualitative insights to further inform strategies for engaging with PAGs. **Participants and Insights:** The survey received 21 responses from PAGs representing diverse therapeutic areas, including oncology, cardiovascular disease, infectious disease, migraine and diabetes, among others. A follow-up meeting to discuss the survey results with representatives from DTA, Medlive, and Freespira provided additional insights and context.

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## Key Findings

**Familiarity with Digital Therapeutics:** The International Standardization Organization (ISO) defines Digital Therapeutics as health software intended to treat or alleviate a disease, disorder, condition, or injury by generating and delivering a medical intervention that has a demonstrable positive therapeutic impact on a patient's health. The survey revealed that many advocacy groups have limited familiarity with digital therapeutics, which is understandable given the emerging nature of the field. Stakeholders emphasized the need for educational initiatives to raise awareness and understanding, particularly among PAGs that may not yet recognize the impact of digital therapeutics on their patient populations.

**Importance to Populations Served:** Responses varied regarding the relevance of digital therapeutics to the populations served by PAGs. Many groups are still exploring how these therapies fit into their frameworks, underscoring the need for DTA members to clearly communicate the specific benefits tailored to each group's unique needs.

**Current Engagement Practices:** The survey found limited engagement between advocacy groups and digital therapeutics companies, often restricted to event sponsorships or educational partnerships. Stakeholders noted the opportunity to move beyond traditional, transactional models by fostering value-driven, trust-based partnerships. DTx manufacturers can engage more meaningfully by aligning their goals with the needs and priorities of patient communities. By collaborating on shared objectives—such as improving patient outcomes, increasing access to care, and supporting health equity—DTx companies can build trust and create long-lasting, impactful relationships that truly benefit patients and the healthcare ecosystem.

*We do rely on partners to help fuel our operational budgets so that we can reach patients. Also, it is important for us to see that they are 'patient first' and willing to invest in our community - not just leverage our mission. In a true advocacy partnership, we are all investing in the patient experience.*

**Preferred Engagement Strategies:** Advocacy groups value early involvement in product development and regular communication, ensuring patient voices guide decisions. Early and ongoing engagement fosters trust and allows advocacy groups to contribute meaningfully. Tailored strategies, such as patient advisory boards or co-created initiatives, help address each group’s unique needs and prioritize patient-centered outcomes.

**Challenges and Opportunities:** A key challenge identified was the expectation of financial contributions from digital therapeutics companies, like traditional industry models, as many emerging DTAs are running very lean operations, with smaller budgets. While financial support is important, stakeholders stressed that relationships should also be built on education, transparency, and regular communication. Differentiating digital therapeutics is crucial and highlighting the focus on patient-centered outcomes—like quality of life—offers a unique opportunity for digital therapeutics manufacturers, setting them apart in enhancing patient experiences.

### Strategic Recommendations

**Increase Awareness and Education:** Patient centricity is essential for meaningful collaboration between digital therapeutics (DTx) manufacturers and patient advocacy groups (PAGs). Stakeholders emphasized the need for research that prioritizes patient-centered outcomes. For example, diabetes-focused groups may value studies on daily life improvements, while neurological groups prioritize cognitive function data.

DTx manufacturers should share credible, relevant research, such as published studies and long-term data, tailored to each group’s priorities. Collaborative efforts, including involving PAGs in study design and co-developing resources, ensure that research aligns with patient needs and fosters stronger advocacy for DTx solutions.

***On a scale of 1-5 with 5 being of highest importance, PAGs averaged 4.1 on the importance of financial contributions to their organization.***

**Engage Early and Often:** Engaging advocacy groups early in product development establishes a strong foundation for trust and collaboration, ensuring mutual understanding and value exchange. Early involvement allows advocacy groups to provide meaningful feedback, shape priorities, and invest in the product's success. Regular communication and collaboration are essential for building trust-based, long-term relationships.

#### Keys to Successful Advocacy Relationships

- **Consistent Communication:** Align on priorities for both the advocacy group and the industry partner.
- **Patient-Centered Programs:** Develop educational materials and initiatives that support patients, caregivers, and families.

#### Sample Advocacy Group Contributions at Key Stages

- **Ideation and Discovery:** Highlight unmet needs and real-world challenges to shape product concepts.
- **Design and Prototyping:** Provide feedback on user experience, accessibility, and cultural relevance.
- **Clinical Development and Validation:** Participate in trials or pilots to test effectiveness, usability, and adherence strategies.

By involving advocacy groups at these stages, industry partners can ensure their products and initiatives are deeply patient-centered and aligned with real-world needs.

**Tailor Engagement to Community Needs:** DTA members should authentically adapt their strategies to meet the unique needs of each advocacy group, considering the impact on patients, the organization's current priorities, and alignment with their mission. Tailored, mission-aligned engagement strengthens partnerships, ensuring the collaboration is both relevant and impactful.

**Financial Contributions:** Financial support should be part of a broader strategy that includes meaningful value exchanges and support for the advocacy group's mission. Stakeholders recommended educating advocacy groups about the financial realities of digital therapeutics companies, particularly how they differ from traditional pharmaceutical models. Emphasizing the value of non-monetary contributions, such as providing resources, administrative support, or expertise focused on improving the patient experience, can build stronger and more sustainable partnerships.

*While advocacy organizations are always seeking funding from industry partners, the most successful partnerships are ones where there is thought leadership, collaboration on information, consideration of patient perspectives, and then potential financial support for programs/awareness/events*

## Implementation Roadmap

### Steps for DTA Members:

**Educate and Inform:** Share tailored resources with advocacy groups, focusing on the unique benefits of digital therapeutics and their role in patient care, emphasizing patient-centered outcomes

**Early Engagement:** Involve advocacy groups early in product development, using their feedback to shape designs that meet patient needs and emphasize quality-of-life improvements.

**Regular Communication:** Maintain consistent communication to build trust and gather ongoing feedback, ensuring a collaborative relationship throughout the product lifecycle. Tailored Strategies: Customize engagement strategies based on each advocacy group's specific needs to ensure relevant and effective partnerships.

**Strategic Contributions:** Combine financial support with non-monetary contributions like resources or expertise, enhancing the advocacy group's mission and creating sustainable partnerships.

## Metrics for Success

To measure the success of these strategies, DTA members are encouraged to track metrics such as:

- Number of advocacy groups engaged early in product development.
- Frequency and quality of communication with advocacy organizations.
- Feedback from advocacy groups on the engagement's value and impact.
- Increased collaboration and co-development of educational initiatives.
- Positive outcomes for patient communities from these collaborations.

## Conclusion

The findings from the joint survey conducted by the Digital Therapeutics Alliance (DTA) and Medlive, further enriched by qualitative insights from a stakeholder review meeting, offer valuable guidance on how digital therapeutics (DTx) companies can enhance their collaboration with patient advocacy groups (PAGs). This whitepaper serves as a practical resource for both DTA members and advocacy organizations, outlining best practices for fostering meaningful partnerships.

By raising awareness about digital therapeutics, engaging PAGs early in the product lifecycle, tailoring outreach to meet specific community needs, and making thoughtful, strategic contributions, DTx manufacturers can build trust-based relationships that benefit all parties. These insights emphasize that collaboration must be more than transactional—it should reflect a shared commitment to improving patient outcomes and advancing the adoption of digital therapeutics within healthcare. Ultimately, the whitepaper aims to support DTA members and advocacy groups in aligning their efforts for maximum impact and long-term success.

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