CHEAT SHEET

for entire health care ecosystem

Neurodegenerative disease stakeholder priorities in 2022

Discover the top three neurodegenerative disease-related priorities of each stakeholder Published – July 2022 • 10-min read

Stakeholders included

- Providers
- Payers
- Life sciences companies
- Digital health companies
- Consumers



Providers

TOP PRIORITIES

CONVERSATION STARTERS

Safely and effectively incorporating telehealth into care

Providers are working toward safe and effective integration of telehealth into care pathways. The pandemic forced providers to use telehealth to protect patients from Covid-19 exposure, but its benefits, such as increased accessibility and convenience of care, have led to provider realization that long-term incorporation of telehealth is a necessary effort. Providers specifically want to identify safe and effective ways to use this modality of care. This includes provider engagement in training about incorporating telehealth in an equitable and effective manner. For example, providers may identify barriers to access and utilization of telemedicine platforms within their communities, in order to address the disparities that could arise as telehealth use increases.

Improving communication between providers

Providers are improving communication among those that care for the various aspects of neurodegenerative conditions. Patients often have several symptoms that may map to multiple specialists, and their providers often include primary care physicians, neurologists, psychologists, physical therapists, and nutritionists. Due to the number of providers involved, providers are increasingly focusing on improving communication between specialists to improve quality of care and reduce inefficient care overlap. Communication between specialists addresses patient health holistically and creates more effective diagnosis and treatment pathways for patients.

Understanding payer coverage of relevant treatments

Providers are increasingly prioritizing staying aware of coverage variability of different services and treatments. This is a priority because of the amount of media attention and buzz about potential new breakthrough treatments, but many won't be covered by health plans in the near future. Providers try to stay up to date on the coverage (or lack thereof) of new treatment options, keeping in mind that some patients may not be able to access these new treatments, depending on their insurance coverage or ability to pay out-of-pocket. This allows providers to make informed choices about what to recommend for their patients, based on key medical and economic factors. What have your biggest challenges been when attempting to introduce telehealth into your day-to-day practice? What are your ongoing concerns?

What support do you need in order to improve the virtual delivery of care to patients with neurodegenerative diseases?

- How do you currently communicate, if at all, with other providers who care for patients (other specialists or therapists)?
- How might your patients benefit if you were able to more easily access their other medical information and discuss it with their other providers?
- How does payer coverage of relevant services affect your ability to provide patient-centered care?
- Are most health plans covering the relevant tests and treatments for these diseases, or are there gaps in coverage that need more attention?
- What support do you need to continuously stay apace with treatment coverage for your patients?
 Source: Advisory Board Interviews and Analysis.



Payers

TOP PRIORITIES

CONVERSATION STARTERS

What strategies do you have in

of new treatment options?

What support do you need to

properly decipher clinical

relevance?

place to ensure a fair clinical review



Deciphering clinical relevance of new treatment options

There is a low success rate for disease modifying therapies that target the underlying mechanism of disease, as most drugs that make it to market provide mainly symptomatic relief for patients. However, as more symptomatic-based specialty medications come to market (and at higher prices), pharmacy benefit managers and health plans are responding by using methods like step therapy, prior authorization, and formulary restrictions to encourage use of value-based therapies and to control unnecessary costs.

Developing inter-industry collaborations in response to higher costs of specialty treatments

As of 2019, although only 1-2% of the population take specialty medications, these medications account for more than half of new drugs in development, and more than half of payer spending on prescriptions. This trend is expected to intensify in response to an older population and the increasing prevalence of chronic conditions. To address rising costs, vertical integrations are increasing in prevalence across insurers, specialty pharmacies, and pharmacy benefit managers. Such partnerships reduce price mark-ups and reimbursement rate negotiation of specialty treatments for payers and streamline patient access to life saving therapies.

Evaluating continued coverage options for telehealth

Because the variety of telehealth services has grown, payers are presented with more choices of services to cover. However, as the benefits of telehealth have grown and become evident (particularly in the area of mental health), health plans have more consistently provided reimbursement for telehealth services at the same rate as in-person services. For example, there have been legislative developments in several states that have established, extended, or expanded telehealth coverage. As use cases for telehealth in providing neurodegenerative disease care increase (both for patients and caregivers), the evaluation of coverage for members will also continue.

- In response to the influx of expensive, infusion-based treatments, how are you approaching site-of-care steerage?
- How are you working with other stakeholders, if at all, to bridge the gap between containing costs and providing patients access to treatments?
- What do you look for in an ideal partnership to address this priority?
- What metrics do you use to evaluate the efficacy of telehealth in comparison to in-person care?
- What support do you need in determining conditions that are suitable for virtual care vs. those that are not?



Life sciences companies

TOP PRIORITIES

Responding to demands for more standardized, accurate, accessible, and timely methods of diagnosis

Diagnostic procedures like MRIs and lumbar taps are costly and poor at identifying early-stage neurodegenerative diseases. As a result, payer coverage is variable and consumer follow-through is low, impacting demand and revenue for diagnostic stakeholders.

- *Diagnostics:* Manufacturers are developing new blood-based diagnostics to address concerns around cost and invasiveness.
- *MedTech*: Medical device companies are developing technologies that improve the precision of current diagnostic procedures to streamline patients' diagnostic experience.

Monitoring diagnostic and treatment regulatory outlook

Industry members are investing in AI companies to improve diagnosis and expedite pharmacological discoveries. However, the submission process for diagnostics and MedTech companies is very complex, particularly for companies developing neuro-based AI software, as regulatory bodies have struggled to keep up with evolving technology.

But the FDA has recently shown their willingness to work with life sciences companies and help them navigate the approval process.

Developing real-world evidence of treatment effectiveness

Historically, drug and device companies have struggled to prove long-term clinical benefits that justify high prices. Additionally, in the aftermath of the pandemic, providers and payers are even more interested in using real-world evidence when choosing and supporting treatments. Driven in large part by CMS's refusal to cover Biogen's Aduhelm, pharma companies are now focused on conducting large-scale trials to prove the long-term clinical efficacy of their drug candidates before applying for FDA approval. CONVERSATION STARTERS



- How do you evaluate consumer priorities and preferences for different methods of diagnosis and their administration?
- How are you taking these different priorities into account when structuring your product portfolio?
- What support do you need in developing more standardized and accurate diagnostics?
- Are there any ways in which other stakeholders could support your navigation of regulatory procedures around AI-based platforms?
- How are you minimizing the unintended consequence of bias in AI-based applications?
- What workflows do you have in place to share and obtain cost, utilization, and clinical data from other stakeholders?
- How are you factoring in other stakeholder priorities when developing treatments?



Digital health companies

TOP PRIORITIES

Designing accessible products for entire patient population

As competition grows in the digital health space of neurodegenerative disease care, it's increasingly important for companies to focus on approachable user experience design, such as designing easy-to-use platforms that patients can use through their own devices. There is also a growing focus on improving patient ability to properly use new wearable devices, especially to ensure that patients can safely and accurately use remote tracking and assistive devices at home. A potential area of growth for digital health companies is creating infrastructure to educate and support users of their devices and programs, including practicing cultural humility when it comes to accessibility, which means meeting patients 'where they are' in order to provide them with the best care possible.

Developing better systems for provider communication

The neurologist shortage has left many areas of the U.S. lacking in sub-specialized provider access, meaning a general neurologist or PCP may need to interact via telehealth with a specialist who can support and guide them through a treatment plan for a patient. This demand for easier provider-provider communication plus the increased recognition of the multispecialty components of neurodegenerative disease care means that digital health companies are now required to develop improved systems for communicating between the various providers. While this is true for digital health across health care, it is especially important in order to facilitate the necessary, often complex, multi-disciplinary neurodegenerative disease care.

Designing platforms for caregiver-provider communication Digital health companies are creating platforms that allow caregivers and providers to communicate with one another. This

is an area of opportunity for digital health since it addresses the large burden that caregivers of patients with neurodegenerative diseases experience. These platforms allow caregivers to provide optimal care, access provider recommendations, and learn from educational resources, while still allowing the patient to retain some independence and confidentiality. CONVERSATION STARTERS



- What are patients' main barriers to accessing your products?
- How can we help you expand the accessibility and user-friendliness of your products so that they can be used by a wider population?
- How can providers and patients make introduction of communication products as effective as possible?
- Are you able to create products that abide by patient confidentiality standards?
- How can we work together to incorporate information from patient EMR, remote monitoring devices, and various providers?
- What areas do caregivers need the most support in, and how can we provide that content to fill out the digital health platforms that you will create?
- How can we support you in creating a platform that allows for caregiver input without jeopardizing patient privacy or independence?



Consumers

TOP PRIORITIES

Navigating different diagnostic options

Consumers have several diagnostic options but have challenges discerning which modalities are covered by their health plan. In addition to cost, the invasive and rule-out versus confirmatory nature of current diagnostics act as a further deterrent to consumers in pursuing follow-up diagnostic options. Due to these challenges, many consumers opt not to pursue all the diagnostic options available to them, resulting in a low number of patients diagnosed in the early stages of disease, when there are the greatest number of treatments available.

Accessing new treatment options

Lack of evidence around the clinical efficacy of many pharmacological and next-generation therapies, particularly those passed through expedited approval pathways, means that payers have predicated conditional insurance mandates for these therapies on confirmatory research by life science companies. Again, this leaves consumers unable to readily access many innovative treatments.

In response to this, consumers are joining forces with other stakeholder groups to advocate for access to novel treatments, particularly as a means of a "last resort" for conditions with few or no available treatment options. Patient advocates are also fighting for reductions in premiums for high-cost treatments.

Taking advantage of digital health use cases

Neurodegenerative diseases require interdisciplinary care spanning several specialties. However, the loss of cognitive and/or motor function among these patients makes it difficult to travel to appointments and to keep on top of care regimens.

• *Patients:* Increased adoption of telemedicine is providing more convenient alternatives to in-person care models, including methods for cognitive assessments and monitoring clinical symptoms and disease progression.

 Caregivers: Caregivers are taking advantage of telehealth interventions that provide educational and emotional support, improving their competence. CONVERSATION STARTERS



- What strategies do you use to navigate the cost and efficacy of different diagnostic methods?
- What support do you need to ensure easier access to these procedures?
- What support would you need in determining next steps following a positive diagnosis?
- What is your thought process when deciding whether to avail of experimental "last resort" treatments?
- What support do you need in navigating the variety of innovative, next-generation therapies that are coming to the market?
- What about digital health care makes you more or less likely to engage in virtual treatment pathways?
- What are the limitations of virtual care in comparison to in-person care?
- Which of your symptoms or types of visits do you think are best suited for virtual care?

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