Clinician Survey

Multidisciplinary Clinics (MDCs)

December 2022

Purpose: Obtain first hand experience from clinicians that run MDCs, capture barriers for initiating and sustaining maintaining MDCs, and identify ways to improve care and conducting research.
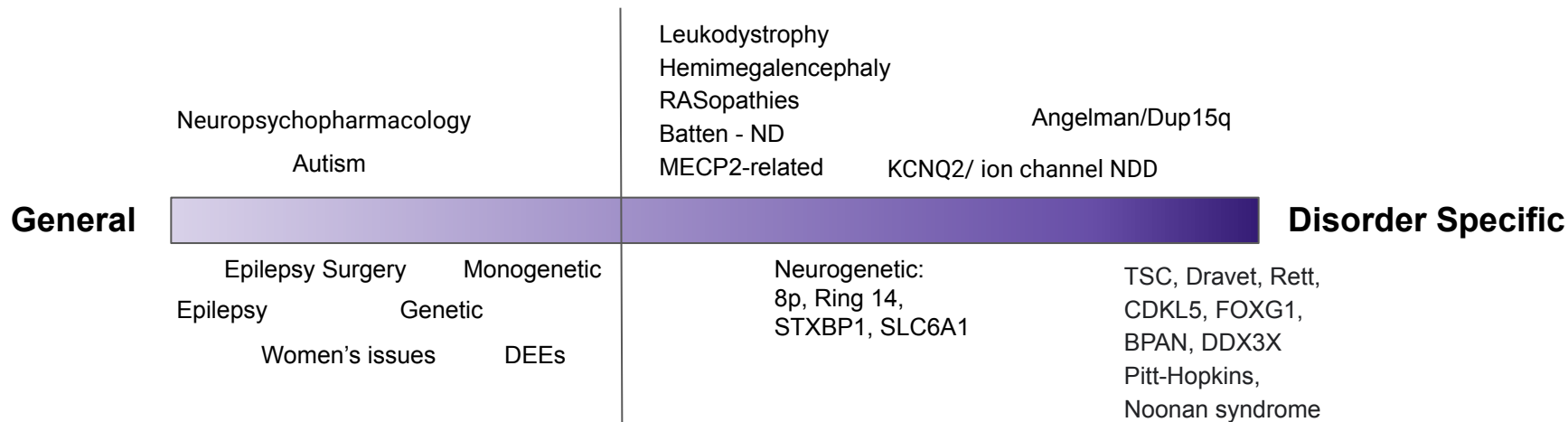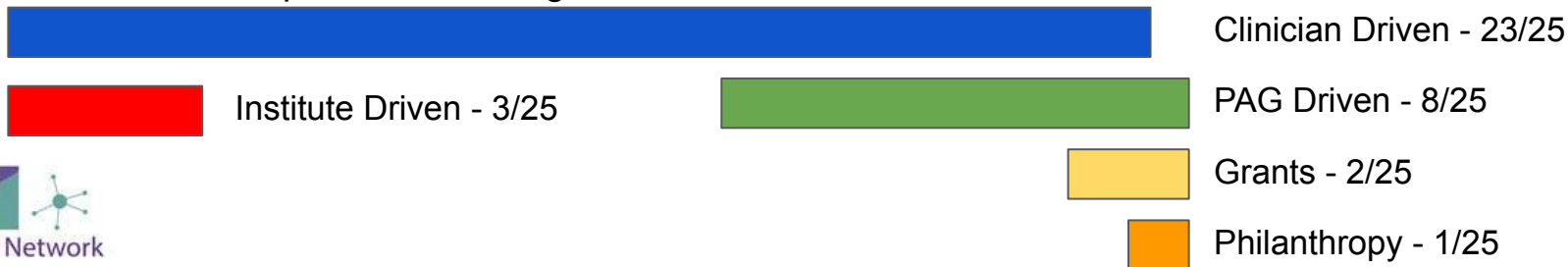
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www.rareepilepsynetwork.org

Messy Data: some surveys represent multiple clinics

25 responses

Leukodystrophy
Hemimegalencephaly
RASopathies
Batten - ND
MECP2-related

Angelman/Dup15q

Neuropsychopharmacology

Autism

KCNQ2/ ion channel NDD

General ── **Disorder Specific**

Epilepsy Surgery   Monogenetic

Epilepsy   Genetic

Women's issues   DEEs

Neurogenetic:
8p, Ring 14,
STXBP1, SLC6A1

TSC, Dravet, Rett,
CDKL5, FOXG1,
BPAN, DDX3X
Pitt-Hopkins,
Noonan syndrome

What was the impetus for creating the MDC?

Clinician Driven - 23/25

Institute Driven - 3/25

PAG Driven - 8/25

Grants - 2/25

Philanthropy - 1/25

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What specialties are included and/or have ability to refer?
25 responses

General

Disorder Specific
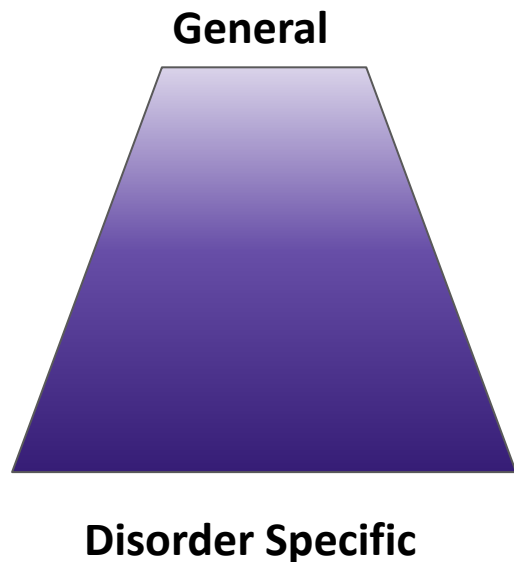
Neurology	25/25
Genetics/Counselor	23/25
Neuropsychology/Psychiatry	20/25
Gastroenterology	17/25
Developmental Pediatrics	16/25
Endocrinology/Metabolism	15/25
PT/OT	17/25
SL/Communication	16/25
Respiratory	13/25
Neurosurgery	12/25
Orthopedics	12/25
Cardiology	3/25
Gynecology	2/25
Transition Expert	2/25

# How are the MDC clinic visits physically managed (initial visit)?
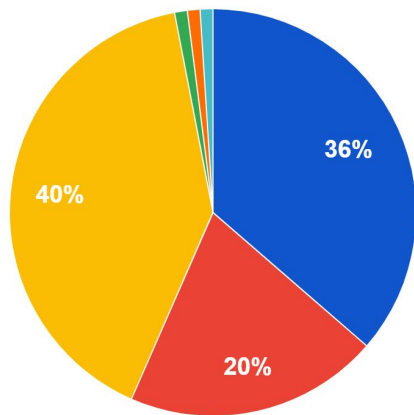
- 🔴 Open Shop (Multiple visits; patient travels to different rooms)
- 🔵 Flow Shop (Multiple visits in one day; patient stays in one room)
- 🟡 Mix Shop (Hybrid)
- 🟠 Different Locations
- 🟢 Telehealth
- 🔵 Different Days

Pie chart values: 36%, 20%, 40%

Is there a coordinated care meeting for each patient towards care plan?

- 🔵 Yes
- 🔴 No
- 🟠 Maybe

Pie chart values: 16%, 20%, 64%

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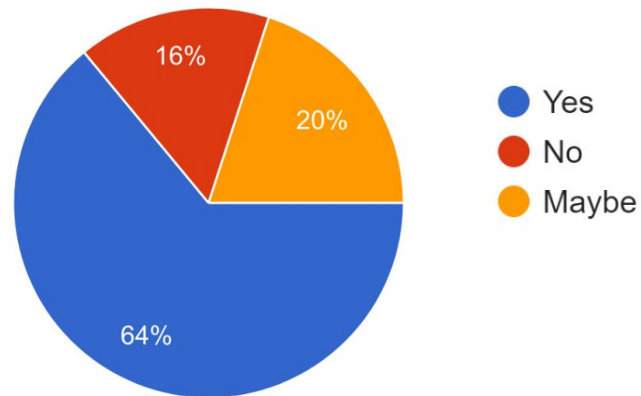
What is an estimate of how many patients you currently see (per year) under the MDC model?
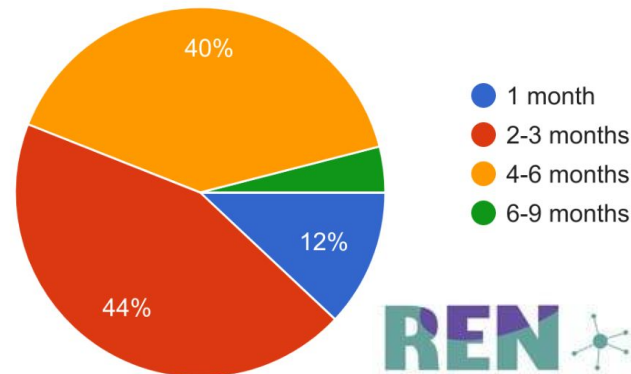25 responses
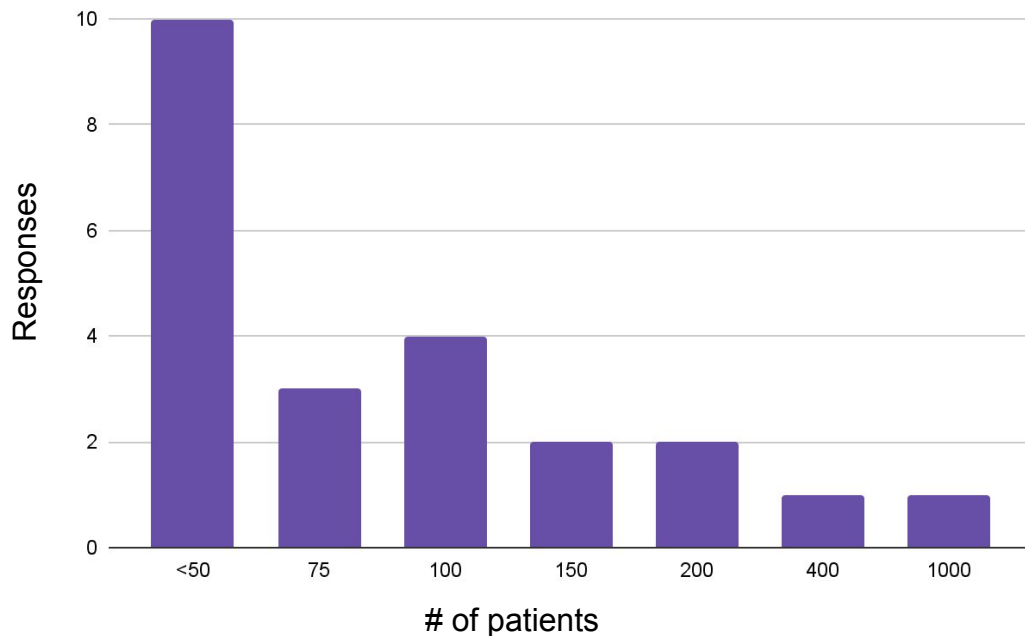
Disorder Specific MDC · · · General MDC

Do you anticipate that number to increase; do you have the capacity to see more?

Yes 76% (19)
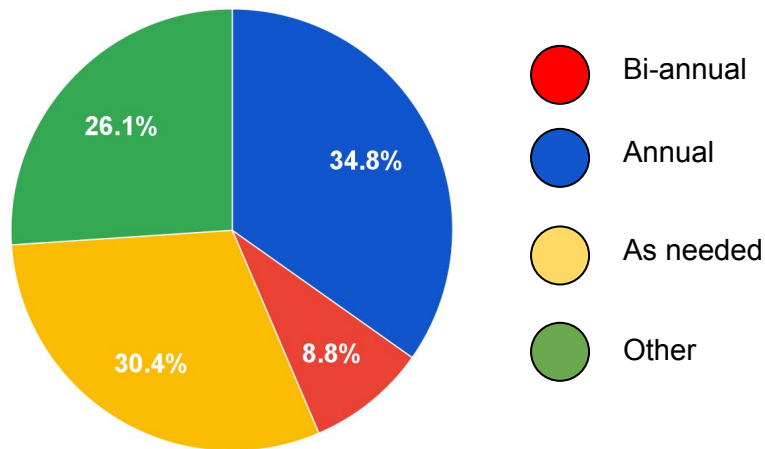No 4% (1)
Maybe 20% (5)

What is the ideal timeline for patients to contact the clinic before being seen? Take into account your waiting list.

- 1 month — 12%
- 2-3 months — 44%
- 4-6 months — 40%
- 6-9 months

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Is there anticipated regular cadence post initial visit?
25 responses

- Bi-annual (red)
- Annual (blue)
- As needed (yellow)
- Other (green)

34.8% — Annual
8.8% — Bi-annual
30.4% — As needed
26.1% — Other

MDC is 'medical home' or 'consultancy'?
25 responses

- Medical home for patients- 56% (14)
- Serves as consultancy- 64% (16)

Do you communicate back with local providers?
25 responses

80% — Send a visit summary with the patient
8% — Directly connect with the local provider to discuss care decisions
12% — There is no direct communication back to local providers
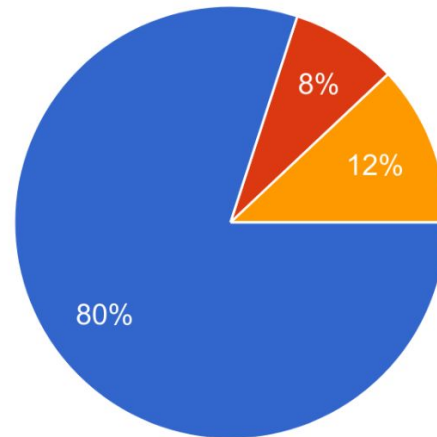
- Send a visit summary with the patient
- Directly connect with the local provider to discuss care decisions
- There is no direct communication back to local providers

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CLINIC GOALS
25 responses

Patient Care
100%

Clinical/Translational Research
80%

Natural History

Improve Quality of Care

Clinical Trials

Who funds your MDC? (select all that apply)

25 responses

Source	Value
Grants	3 (12%)
My institution	17 (68%)
Patient Advocacy Groups	8 (32%)
Biopharma	0 (0%)
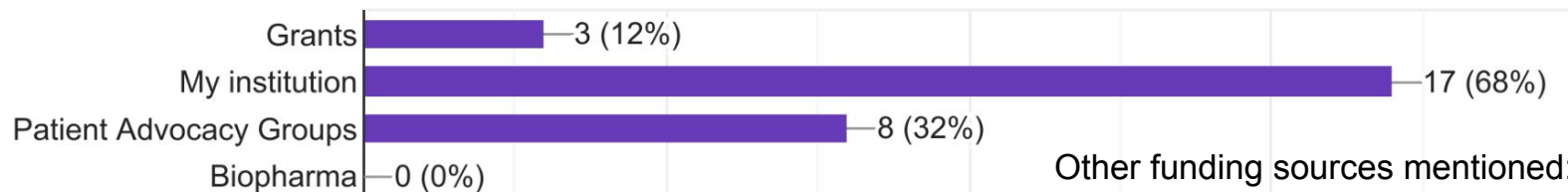
Other funding sources mentioned:
Philanthropic donation
Insurance
Patient fees

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How is your success measured by your institution?

25 responses
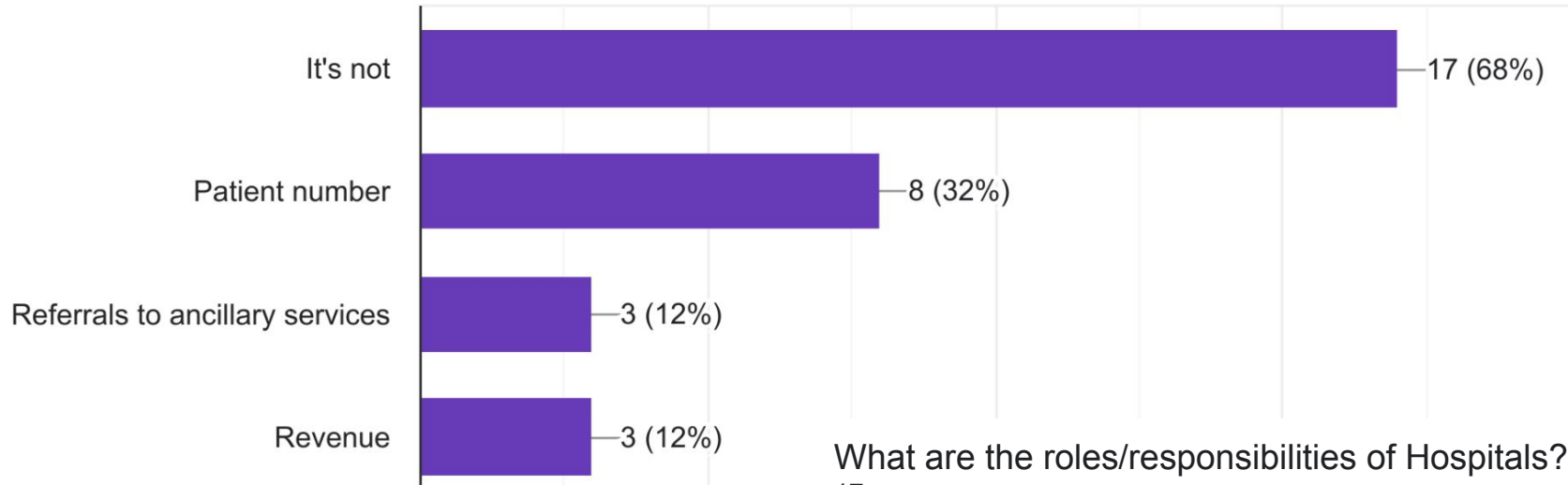
- It's not — 17 (68%)
- Patient number — 8 (32%)
- Referrals to ancillary services — 3 (12%)
- Revenue — 3 (12%)

- Providing infrastructure:
  - Space
  - Staff: Non-reimbursed staff
  - Clinical/behavioral health resources

What are the roles/responsibilities of Hospitals?

17 responses

- Be Supportive of MDC model, assistance with billing/reimburse
- Responsive to family and clinician needs
- Funding, Alternative Funding Models
- Maintain survival functions

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How do YOU measure the success of your MDC?

Success has to be quantified, tracked, and then communicated to MDC, Institute, and communities.

physician/clinical team satisfaction
patient care
patient volume
clinician participation
efforts
research advances
patients/family satisfaction
family satisfaction
patient quality of life
patient care
funding by PAG
engage other physicians
return visits
developed expertise
surveys
publications
progress in understanding
natural history studies
research
access
patient satisfaction
patient
clinical care
grants
patient
coordination of care
grants
communication among stakeholders
volume patients
synergies
synergies
no measures
obtaining
funding
research
grants
patient volume
family satisfaction
synergies
surveys
developed expertise
patient involvement
healthcare outcomes
publications
obtaining
family feedback
clinician participation
clinical outcomes
grants
clinical care
grants
research
clinical trials
publications
grants
patient volume
funding by PAG
progress in understanding
patient involvement
volume patients
clinician participation
quality of care
patient
referrals
new specialty services
clinical outcomes
patient involvement
return visits
surveys
developed expertise
patient quality of life
return visits
natural history studies
access
healthcare outcomes
family feedback
patient quality of life
funding
care revenue
access
progress in understanding
clinical trials
volume patients
clinical care
physician/clinical team satisfaction
clinical trials
new specialty services
patients/family satisfaction
efforts
clinical outcomes
research advances
coordination of care
no measures
patient care
efforts
patients/family satisfaction
quality of care
funding
referrals
family satisfaction
new specialty services
grants
natural history studies
communication among stakeholders
coordination of care
care revenue
physician/clinical team satisfaction
patient satisfaction
family feedback
engage other physicians
quality of care
referrals
patient satisfaction
research advances
care revenue
obtaining
healthcare outcomes
communication among stakeholders

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Barriers in ESTABLISHING your MDC

25 responses

	Composite Score	5's	4's	3's	2's	1's	AVG	General	Disorder
Funding/Cost	105	14	3	7	1	0	4.2	3.28	4.44
Space	88	10	5	3	2	5	3.52	2.14	4.13
Scheduling	85	6	5	9	3	2	3.4	3.57	3.31
Institutional Barriers	84	5	5	11	2	2	3.36	2.14	3.81
Identifying Leaders	74	3	7	5	6	4	2.96	2.71	2.81
Administrative Billing	73	3	4	8	8	2	2.92	2.86	2.81
Telehealth licensing barriers	69	2	5	8	5	5	2.76	3.00	2.69
Support Staff	68	3	3	9	4	6	2.72	2.43	2.81
Referrals and Resources beyond clinic	67	2	6	5	6	6	2.68	2.71	2.38
Finding patients	56	0	4	5	9	7	2.24	1.86	2.25

5 being large barrier and 1 being small barrier

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How can PAGs/REN support MDCs more effectively?

14 responses

- Funding Clinics
  - Seed money for nascent MDCs
  - Combined philanthropy/grant/service model
- Identify academic leaders/disease area experts
- Promote Standards of Care
- Continue to promote and discuss MDCs
- Establish crosscutting REN MDCs and COEs for genetic epilepsies
  - Establishing guidelines for MDCs
  - Take advantage of common needs
  - Assist with data collection in uniform manner
  - Breakdown clinic silos
- Be a presence at and outside the MDC
  - Provide a space to meet/engage new families at visit
  - Creating/sustaining patient/family support groups
  - Educational programming coordinated with medical team

There is a continuing role for PAGs/REN.

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TABLE TALK

For the Next 10 Minutes

Reflect on the survey findings with your table and prepare 2-3 questions for the panel.

**PROMPTS FOR YOUR DISCUSSION
and sharing your ideas in Slido**

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What surprised you?
What do you want to learn more about?
What are some trends of interest to you?

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Detailed Findings

Based on Caregiver Survey Results circulated in Fall 2022

What Diseases/Disorders are treated?

25 responses

Single Disease	8 (32%)
Multiple Diseases/Disorders	19 (76%)
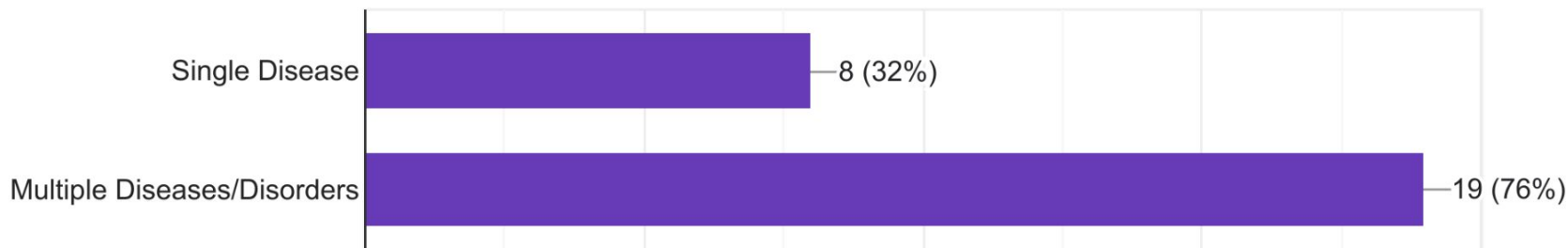
Note: Some professionals have both single (ex: Tuberous Sclerosis Complex) and multiple disease/disorder (ex: DEE) clinics.

Disorders:
Tuberous Sclerosis Complex; Rett, mecp2-related, CDKL5 disorder, FOXG1 disorder, Dravet, Angelman, KCNQ2, Dup15Q, Pitt-Hopkins, DDX3X, RASopathies, Noonan syndrome, Chromosome 8P, Ring 14 disorder, SLC6A1, STXBP1, Leukodystrophy clinic, BPAN, Batten

All monogenic epilepsies, epilepsy genetics clinic, neuropsychopharmacology clinic, Developmental Epileptic Encephalopathies, Neurodegenerative Diseases, Neurogenetic

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CLINIC OPERATIONS AND LOGISTICS
25 responses

Who leads and staffs the clinic?
- Clinical Champions- 10
- Multidisciplinary Specialists- 9
- Nurse- 8
- Administrator/Coordinator/Scheduler- 8
- Genetic Counselor- 5

Who is the point person for the families?
- Nurse- 11
- Administrator/Clinic Coordinator/Scheduler- 8
- Clinician- 5
- Genetic Counselor- 1
- Patient Advocate- 1

How frequently is the clinic offered?
- Weekly- 6
- Monthly- 12
- Quarterly- 5
- Annually- 1
- As needed- 6

Do you collect data in a research record as part of your clinical care?

25 responses

Yes 12 (48%)
No 4 (16%)

Other responses:
-Depends on the condition
-Not yet, but hope to collect data in the future

What type of clinical testing/data do you collect?

25 responses

Category	Count
EEG	17 (68%)
MRI	16 (64%)
Biosamples (blood, salavia urin…	6 (24%)
Quality of Life/Burden of Illness	13 (52%)
Natural History Style data	19 (76%)

Other clinical testing/data collected:
Genetic report

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Do you have a set of standard of care assessments that are done based upon patient type?

25 responses

- Yes
- No
- this is what we are planning
- for some

68%
24%

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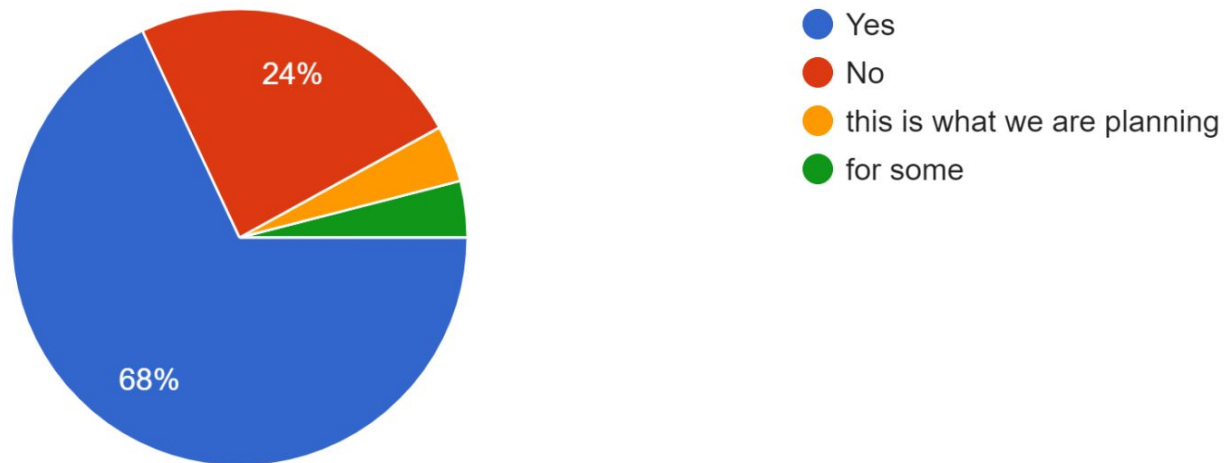
What is the ideal timeline for patients to contact the clinic before being seen? Please take into account your waiting list.

25 responses

- 1 month
- 2-3 months
- 4-6 months
- 6-9 months
- 9-12 months
- 12+ months
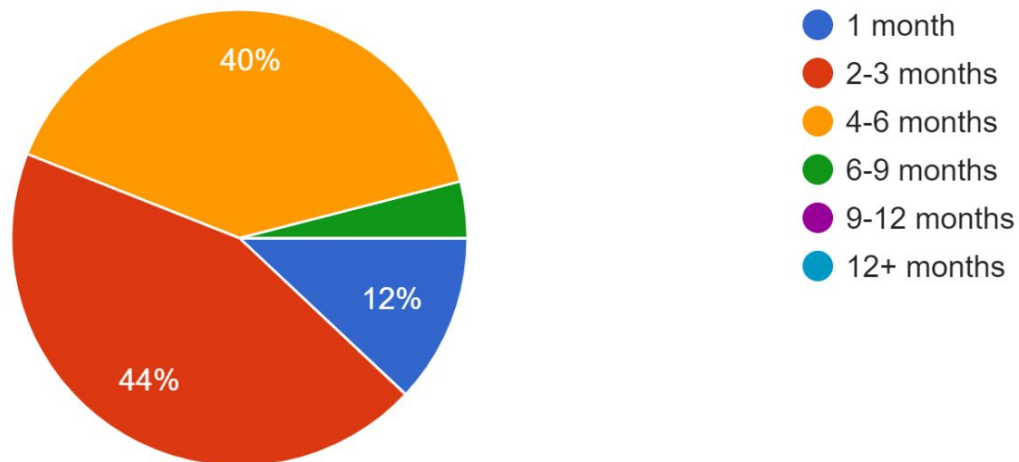
How important is an MDC to create standards of care

25 responses
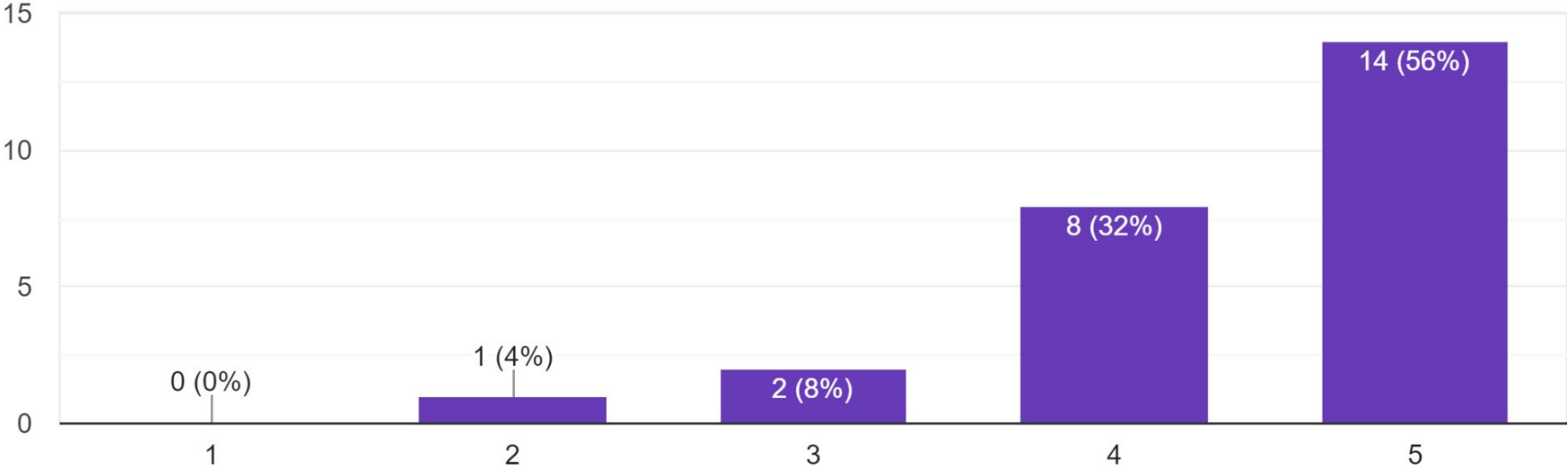
What is your process for creation of standards of care?

- Use published guidelines (AAN, NAEC, …)
- data, consensus, more data, publish
- Clinicians identify standards based on family input and literature
- This is a tiered process based on current evidence and clinical expertise.
- We use published guidelines, adapted to what we think is best care for our population within our local healthcare system, and individualized to the patients needs, and patient/parents goals of care
- currently informal and ad hoc, no protocols

Do you need more than one clinic to develop standards of care? Yes (4 of 4)

What are the roles/responsibilities of Patient Advocacy Groups (including any MAB/SAB roles)?

- Advisory Role
- Fundraising & Supporting the MD
- Vision setting and Strategic Goals
- Liaison to families
- Communication of family priorities
- Collect Data

Ranged from "none/no relationship" all the way to "HUGE - they motivate the whole thing"

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What are the roles/responsibilities of Clinicians?
14 responses

- !!! Patient Care !!!
- Resources and Development
- Acquire Expertise
- Research
  - Data Collection
  - Analysis
  - Development of Guidelines
- Be responsive to the patient/community needs
- Provide consultation to local providers

What are the roles/responsibilities of Hospitals?
17 responses

- Providing infrastructure:
    - Space
    - Staff: Non-reimbursed staff, e.g. Clinical Coordinator
    - Clinical/behavioral health resources

- Be Supportive of MDC model, assistance with billing/reimbursement

- Responsive to family and clinician needs

- Funding, Alternative Funding Models

- Maintain survival functions of the clinic

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What are the roles/responsibilities of the Patients/Caregivers?

17 responses

- Advocate for themselves and the Clinic
- Keep appointments
- Insurance - prior authorization, in-network
- Support PAGs
- Identify needs and outcomes
- Participate in clinical research
- Effectively communicate
    - History
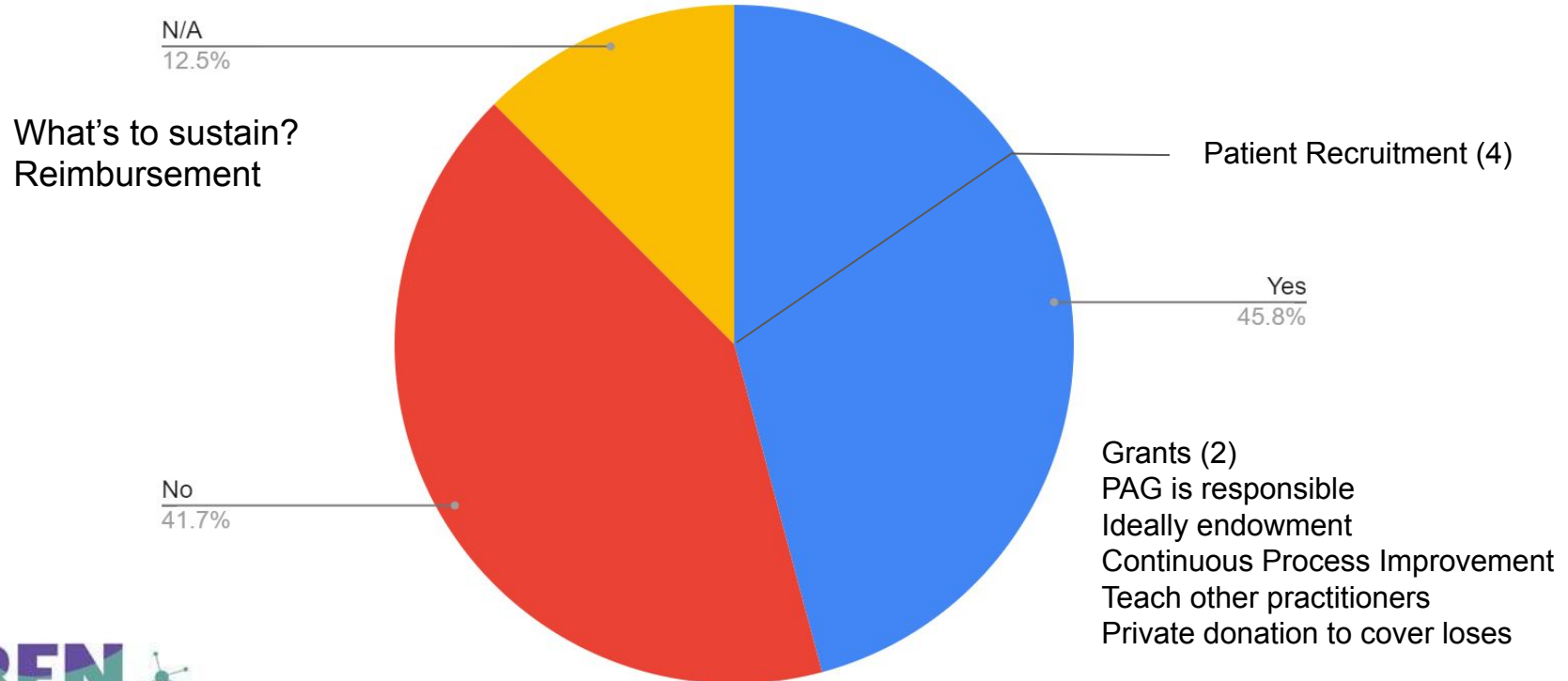   - Shared decision making with clinical team

According to you, multidisciplinary clinics have value because ….

25 responses

What is your biggest lesson learned in establishing your MDC?
26 responses

- If you build it, they will come.
- If there is a will, there is a way. Persistence is key.
- Ensure family input.
- Need a large, academic institution with good infrastructure (insurance & philanthropy)
- Clinical care first with balanced research program
- Planning crucial
- Very challenging (if not impossible) without institutional prioritization
- Finding great coordinator is vital
- So many bureaucratic painpoints…
- HUGE rewards - patient care, research benefits, physician satisfaction