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.
Messy Data: some surveys represent multiple clinics

25 responses

General

Neuropsychopharmacology
Autism
Epilepsy Surgery
Monogenetic
Epilepsy
Genetic
Women's issues
DEEs

Disorder Specific

Leukodystrophy
Hemimegalencephaly
RASopathies
Batten - ND
MECP2-related
Neurogenetic:
8p, Ring 14,
STXBP1, SLC6A1
Angelman/Dup15q
KCNQ2/ ion channel NDD

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

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurology</td>
<td>25/25</td>
</tr>
<tr>
<td>Genetics/Counselor</td>
<td>23/25</td>
</tr>
<tr>
<td>Neuropsychology/Psychiatry</td>
<td>20/25</td>
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<tr>
<td>Gastroenterology</td>
<td>17/25</td>
</tr>
<tr>
<td>Developmental Pediatrics</td>
<td>16/25</td>
</tr>
<tr>
<td>Endocrinology/Metabolism</td>
<td>15/25</td>
</tr>
<tr>
<td>PT/OT</td>
<td>17/25</td>
</tr>
<tr>
<td>SL/Communication</td>
<td>16/25</td>
</tr>
<tr>
<td>Respiratory</td>
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</tr>
<tr>
<td>Neurosurgery</td>
<td>12/25</td>
</tr>
<tr>
<td>Orthopedics</td>
<td>12/25</td>
</tr>
<tr>
<td>Cardiology</td>
<td>3/25</td>
</tr>
<tr>
<td>Gynecology</td>
<td>2/25</td>
</tr>
<tr>
<td>Transition Expert</td>
<td>2/25</td>
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</tbody>
</table>

General

Disorder Specific

[Image: Rare Epilepsy Network]
How are the MDC clinic visits physically managed (initial visit)?

- Open Shop (Multiple visits; patient travels to different rooms) 36%
- Flow Shop (Multiple visits in one day; patient stays in one room) 40%
- Mix Shop (Hybrid) 20%
- Different Locations
- Telehealth
- Different Days

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

- Yes 64%
- No 20%
- Maybe 16%
What is an estimate of how many patients you currently see (per year) under the MDC model?

25 responses

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.
Is there anticipated regular cadence post initial visit?
25 responses

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

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

Patient Care 100%

Clinical/Translational Research 80%

Who funds your MDC? (select all that apply)
25 responses

- Grants: 3 (12%)
- My institution: 17 (68%)
- Patient Advocacy Groups: 8 (32%)
- Biopharma: 0 (0%)

Other funding sources mentioned:
- Philanthropic donation
- Insurance
- Patient fees

Natural History
Improve Quality of Care
Clinical Trials
What are the roles/responsibilities of Hospitals?

17 responses

- Providing infrastructure:
  - Space
  - Staff: Non-reimbursed staff
  - Clinical/behavioral health resources
- Be Supportive of MDC model, assistance with billing/reimburse
- Responsive to family and clinician needs
- Funding, Alternative Funding Models
- Maintain survival functions

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%)
How do YOU measure the success of your MDC?

Success has to be quantified, tracked, and then communicated to MDC, Institute, and communities.
## Barriers in ESTABLISHING your MDC

25 responses

<table>
<thead>
<tr>
<th>Composite Score</th>
<th>5's</th>
<th>4's</th>
<th>3's</th>
<th>2's</th>
<th>1's</th>
<th>AVG</th>
<th>General</th>
<th>Disorder</th>
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<tr>
<td>Funding/Cost</td>
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<td>14</td>
<td>3</td>
<td>7</td>
<td>1</td>
<td>0</td>
<td>4.2</td>
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<td>10</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>3.52</td>
<td>2.14</td>
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<tr>
<td>Scheduling</td>
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<td>6</td>
<td>5</td>
<td>9</td>
<td>3</td>
<td>2</td>
<td>3.4</td>
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<td>Institutional Barriers</td>
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<td>5</td>
<td>5</td>
<td>11</td>
<td>2</td>
<td>2</td>
<td>3.36</td>
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<td>Identifying Leaders</td>
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<td>3</td>
<td>7</td>
<td>5</td>
<td>6</td>
<td>4</td>
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<td>Administrative Billing</td>
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<td>3</td>
<td>4</td>
<td>8</td>
<td>8</td>
<td>2</td>
<td>2.92</td>
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<td>Telehealth licensing barriers</td>
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<td>5</td>
<td>8</td>
<td>5</td>
<td>5</td>
<td>2.76</td>
<td>3.00</td>
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<td>Support Staff</td>
<td>68</td>
<td>3</td>
<td>3</td>
<td>9</td>
<td>4</td>
<td>6</td>
<td>2.72</td>
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<tr>
<td>Referrals and Resources beyond clinic</td>
<td>67</td>
<td>2</td>
<td>6</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>2.68</td>
<td>2.71</td>
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<tr>
<td>Finding patients</td>
<td>56</td>
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<td>4</td>
<td>5</td>
<td>9</td>
<td>7</td>
<td>2.24</td>
<td>1.86</td>
</tr>
</tbody>
</table>

5 being large barrier and 1 being small barrier

Rare Epilepsy Network
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.
Audience Q&A Session

Start presenting to display the audience questions on this slide.
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

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

Based on Caregiver Survey Results circulated in Fall 2022
What Diseases/Disorders are treated?
25 responses

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
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

- EEG: 17 (68%)
- MRI: 16 (64%)
- Biosamples (blood, saliva, urine): 6 (24%)
- Quality of Life/Burden of Illness: 13 (52%)
- Natural History Style data: 19 (76%)

Other clinical testing/data collected:
Genetic report
Do you have a set of standard of care assessments that are done based upon patient type?

25 responses

- **Yes**: 68%
- **No**: 24%
- **This is what we are planning**: 8%
- **For some**: 1%
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: 40%
- 2-3 months: 44%
- 4-6 months: 12%
- 6-9 months
- 9-12 months
- 12+ months
How important is an MDC to create standards of care

25 responses

- 0 (0%)
- 1 (4%)
- 2 (8%)
- 8 (32%)
- 14 (56%)
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”
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
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 sustainability plan for your MDC? If you do not have one, please indicate.

24 responses

- N/A (12.5%)
- No (41.7%)
- Yes (45.8%)

What’s to sustain?
- Reimbursement

- Grants (2)
  - PAG is responsible
  - Ideally endowment
  - Continuous Process Improvement
  - Teach other practitioners
  - Private donation to cover loses

Patient Recruitment (4)
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