

MDC - Professional Intake

The Rare Epilepsy Network (REN) is creating a roadmap for Patient Advocacy Organizations to establish their own Multidisciplinary Center (MDC). Through this survey, we will identify barriers towards establishing an MDC. REN wants to ensure that Patient Advocacy Organizations understand the needs of similar rare disease families and can market their MDC in an effective and efficient manner. This is one of several surveys that REN has created to gather the experience of an MDC. REN will also seek input from clinicians and Patient Advocacy Organizations. We appreciate your time and can be reached at info@rareepilepsynetwork.com.

* Indicates required question

1. Email *

Privacy Statement

We will be asking you a series of questions about your or your institution's operation of your medical specialty clinic so that we can collect information about the importance of multi-disciplinary clinics to all stakeholders (clinicians, patients, institutions, biopharma, etc). Your privacy is very important to us, so we make every effort to keep your information safe and secure. All this information will be securely stored.

2. Phone number *

3. Best method of contact for you? *

Mark only one oval.

Email

Phone

Other:

4. What is your institution? *

5. What was the impetus for creating the MDC?

Check all that apply.

PAG driven

Clinician driven

Institution Driven

Grant funding

Other: _____

6. What was, if any, the institutional oversight towards starting an MDC? *

Check all that apply.

My institution required sign off

I was able to start informally

CLINIC FOCUS, MODEL & GOALS

7. What Diseases/Disorders are treated?

Check all that apply.

Single Disease

Multiple Diseases/Disorders

Other: _____

8. Please list the disorder(s) treated (or if its a group/type of disorders) *

9. How are the MDC clinic visits physically managed (initial visit)?

Check all that apply.

- Flow shop (seeing multiple docs one day) Team comes to patient (Patient stays in one room)
- Open Shop (Pts seen via a different sequence, can be a different day) Patient comes to team (Patient travels to different room)
- Mix Shop (Hybrid)
- Other: _____

10. Is this your preferred clinic visit structure if there were no constraints? *

Mark only one oval.

- Yes
- No
- Other: _____

11. Is there coordinated care meeting for each patient towards care plan? *

Mark only one oval.

- Yes
- No
- Maybe

12. Check all Clinic Goals that apply. ****If Clinical/Translational Research is selected, please use Other to describe objectives (improve quality of care, national history studies, disperse knowledge, etc.)****

Check all that apply.

- Focus on Patient Care
- Focus on Clinical/Translational Research
- Hybrid
- Other: _____

13. Clinic is 'medical home' or 'consultancy.' (****If consultancy, use OTHER to describe relationship to home team regarding aftercare, emergencies, and ongoing advice/guidance.****)

Check all that apply.

- Medical "home" for patient
- Serves as "consultancy"
- Other: _____

14. Is there anticipated regular cadence post initial visit? *

Mark only one oval.

- Annual
- Bi-Annual
- As needed
- Other: _____

CLINIC OPERATIONS & LOGISTICS

15. Who leads & staffs the clinic?

Check all that apply.

- Clinical Champion(s)
- Administrator/Coordinator/Scheduler
- Research Coordinator
- Genetic Counselor
- Multi-Disciplinary Specialists
- LSW/Navigator
- Nurse
- Other: _____

16. Who is the point person for the families? Not their name, their role *

17. What specialties are included/have ability to refer as needed

Check all that apply.

- Neurology
- Neuropsychology/Psychiatry
- Genetics/Counselor
- Transition Expert
- Gastroenterology
- Respiratory
- Developmental Peds
- Neurosurgery
- Endocrinology/Metabolism
- PT/OT
- SL/Communication
- Orthopedics
- Other: _____

18. How frequently is the clinic offered?

Check all that apply.

- Weekly
- Monthly
- Quarterly
- Annually
- As needed
- Other: _____

19. Are the clinic days in group, meaning do families meet each other? *

Mark only one oval.

- Yes
- No
- Maybe
- Other: _____

20. How do you communicate back to the local providers? *

Mark only one oval.

- 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

21. Prior to seeing a new patient, what records do you request they bring or that you access?
(Check all that apply)

Check all that apply.

- Previous EEGs/imaging
- General med history
- Genetic testing results
- Medication and medication history
- Intake Survey
- Nothing
- Other: _____

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

Mark only one oval.

- 1 month
- 2-3 months
- 4-6 months
- 6-9 months
- 9-12 months
- 12+ months

23. Do patients whose disorders are served in your MDC get preferential scheduling with your providers? On average do you think that they are seen more quickly due to the time being set aside.

Mark only one oval.

- Yes
- No
- Maybe

24. What is an estimate of how many patients do you currently see under the MDC model? (Per Year)

25. Do you anticipate that number increasing/do you have the capacity to see more? *

Mark only one oval.

Yes

No

Maybe

26. Who coordinates the schedules and assessments that are done at the MDC visits? *

27. Is Pre-Authorization/insurance a requirement to be seen in your clinic? *

Mark only one oval.

Yes

No

Other: _____

FUNDING

28. Who funds your MDC? (select all that apply) *

Check all that apply.

- Grants
- My institution
- Patient Advocacy Groups
- Biopharma
- Other: _____

METRICS

29. To whom do you report the number of patients you see? *

Check all that apply.

- Your institutional leadership
- Biopharma
- Patient Advocacy Groups
- No one
- Other: _____

30. How is your success measured by your institution? *

Check all that apply.

- It's not
- Patient number
- Referrals to ancillary services
- Revenue

CLINICAL DATA COLLECTION/ RESEARCH

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

Mark only one oval.

- Yes
- No
- Other: _____

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

Mark only one oval.

- Yes
- No
- Other: _____

33. What type of clinical testing/data do you collect? *

Check all that apply.

- EEG
- MRI
- Biosamples (blood, saliva urine, etc)
- Quality of Life/Burden of Illness
- Natural History Style data
- Other: _____

CHALLENGES/BARRIERS

34. Please rank the barriers in ESTABLISHING your MDC (5 being a large barrier and 1 being a low barrier)

Mark only one oval per row.

| | 1 | 2 | 3 | 4 | 5 |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Funding/Cost | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Space | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding patients; small #; family buy in | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Scheduling | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Institutional Barriers/Buy In/ Burecracy | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Identifying Leaders/Champions | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Administrative Billing | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support Staff; Buy in | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Referrals and Resources beyond clinic | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Teleheath licensing barriers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

35. Please rank the barriers in MAINTAINING your MDC. *

Mark only one oval per row.

| | 1 | 2 | 3 | 4 | 5 |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Funding/Cost | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Space | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding patients; small #; family buy in | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Scheduling | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Institutional Barriers/Buy In/ Burecracy | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Identifying Leaders/Champions | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Administrative Billing | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support Staff; Buy in | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Referrals and Resources beyond clinic | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Teleheath licensing barriers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

36. How important is an MDC to create standards of care *

Mark only one oval.

1 2 3 4 5

Not Very important

37. According to you, multidisciplinary clinics have value because *

We appreciate your time. If you would be open to a future call or email from a member of the team please leave your email below. We understand if you prefer to keep your answers limited to this survey and thank you for completing this survey.

38. Would you be open to a follow call/email if we have additional questions? *

Mark only one oval.

Yes

No

Other: _____

INTERVIEW: ROLES & RESPONSIBILITIES

39. What is your process for creation of standards of care? Do you need more than one clinic to develop standards of care?

40. What are the roles/responsibilities of PAGS (including any MAB/SAB roles)

41. What are the roles/responsibilities of Clinicians

42. What are the roles/responsibilities of Hospitals

43. What are the roles/responsibilities of the Patients/Caregivers

44. How can PAGs/REN support MDCs more effectively?

Interview Questions

45. What is your sustainability plan for your MDC? If you do not have one, please indicate. *

46. How do YOU measure the success of your MDC? *

47. What is your biggest lesson learned in establishing your MDC? *

This content is neither created nor endorsed by Google.

Google Forms

