



Exceptional Case History Registry

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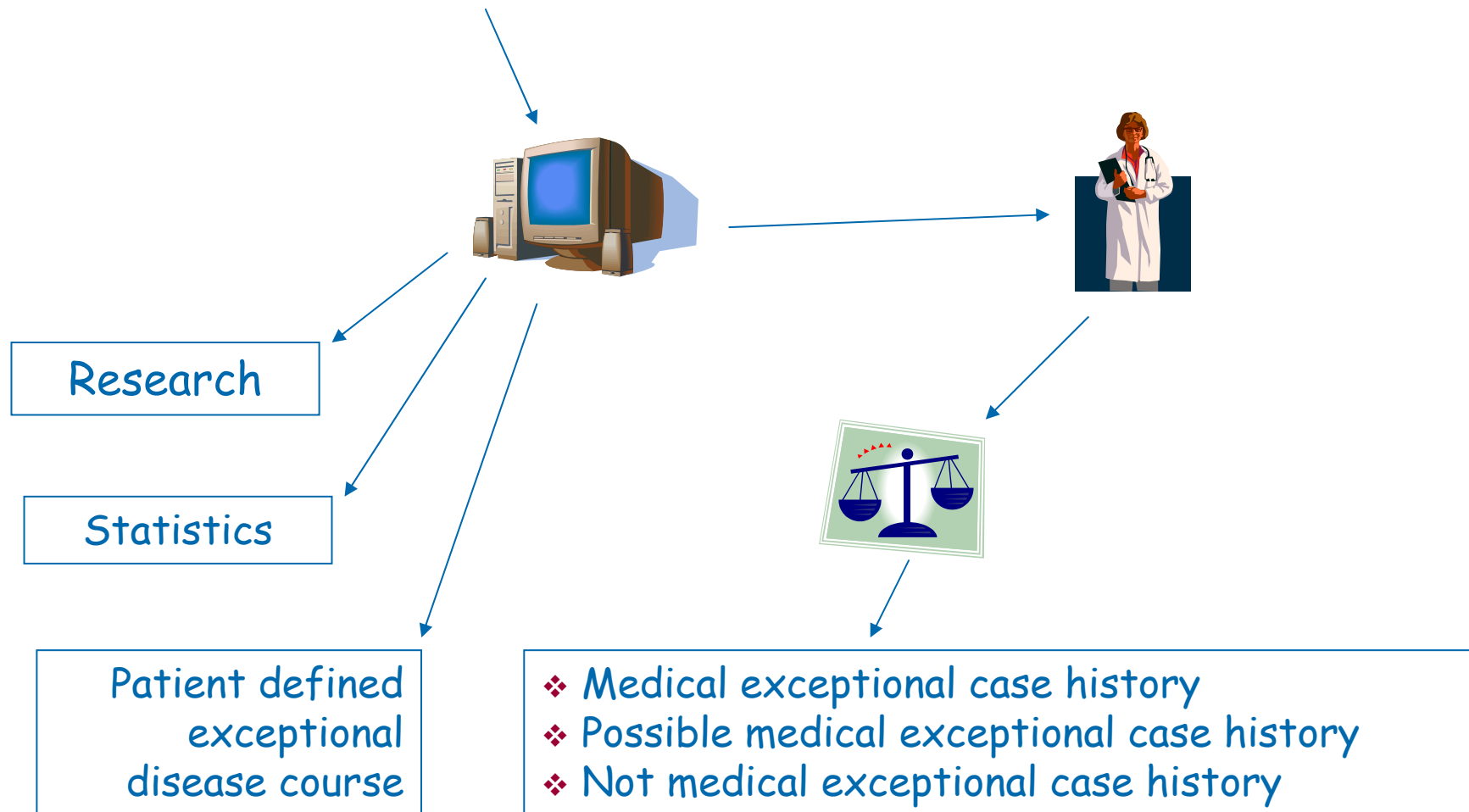
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Exceptional Case History Registry

Primary Program Goal

To establish a registry serving as a base for research on exceptional disease courses.

Exceptional Case History Registry



Exceptional Case History Registry

Internationally there are four approaches to collecting case histories

1. An open invitation to CAM practitioners to submit their best cases for review
2. Individual invitations to CAM providers to submit their best cases
3. Referral by a private foundation of a clinic selected for best-case series review
4. Inviting patients to present their own exceptional case histories

NAFKAM's
approach

What is an exceptional case history?

- ❖ An exceptionally good course of disease
 - ❖ No symptoms or fewer/weaker symptoms
 - ❖ Completely healed

- ❖ An exceptionally bad course of disease
 - ❖ Worsening of symptoms
 - ❖ Unqualified advice to stop taking medication
 - ❖ Encouraged not to see a doctor when this is needed

Exceptional Case History Registry

In an exceptional case history
the use of alternative treatment
gives other results than
the use of conventional medicine.

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Criteria for inclusion of an exceptional case history are that the patient

1. Has defined her/his case history as exceptional
2. Has experienced unusual treatment results after the use of alternative treatment
3. Had a medical diagnosis before she/he started the alternative treatment which gave the exceptional treatment results

Registration packet to patient

- ❖ Letter to the patient
- ❖ Information folder
- ❖ Declaration of consent
- ❖ Registration form
 - ❖ Personal information
 - ❖ Demographic data
 - ❖ Disease history
 - ❖ (Conventional) Medical treatment
 - ❖ Alternative treatment
 - ❖ Self assessment
- ❖ Pre-paid return envelope

The Next Steps

- ❖ Registration of patient information into database
- ❖ Requests for medical records
- ❖ Medical evaluation by MD at NAFKAM
- ❖ Medical evaluation by external expert

Medical evaluations

- ❖ Screening in order to decide whether or not a medical evaluation can be made.
- ❖ If an evaluation can be made, NAFKAM's doctor classifies the case history as possible medical exceptional or not medical exceptional.
- ❖ Review by External MD specialist for classifying the case history as exceptional or possibly exceptional.

The role of the treatment provider

- ❖ Give information about RESF to clients and encourage them to contact NAFKAM
- ❖ Ask clients if they are willing to participate in RESF and whether the provider may give the client's contact information to NAFKAM
- ❖ Send medical records to RESF when receiving an enquiry

Challenges

- ❖ Getting the registration papers back from the patients
- ❖ Receiving medical records upon request
- ❖ Getting exceptionally bad case histories

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