

Network of Rare Blood Disorder Organizations

Barriers, Challenges, Shortcomings and Areas to Improve

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Comprehensive Care – Barriers / Challenges (cont'd)

Medical Care

- Many people have no experience with rare blood disorders, no physician interest (communication, IDing experts)
- Lack of follow-up in absence of comprehensive care clinic
- Medical referrals – lack of referral structure (especially adults)
- Pediatric to adult transitions – no adult clinics, different services
- Need dedicated physicians in certain parts of the country
- Need home treatment for rare blood disorders (hemophilia model), chose of treatment (patient input)
- Inconsistent availability and access to treatment by province & region
- Lack of access to diagnostics, expertise and funding
- Confidentiality



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Comprehensive Care – Barriers / Challenges

Funding

- Lack of governmental funding support for NRBDO
- Too low profile/importance among regional health authorities, collaboration
- Rare blood disorder clinics need to be centralized, seen as costly by government
- Provincial disparities in funding, services for rare blood disorders, Federal government needs policy
- Overall lack of funding – resources, nursing, supplies, facilities, admin (records)
- *Rare vs Very Rare Disorders, Orphan Drugs vs Ultra*, definitions not defined in Canada, no legislation, government can rationalize access based on category
- Funding model (non- blood product related), lack of envelope funding

Patient Registries – Barriers / Challenges

Registry design

- National (Pan-Canadian) vs. provincial vs, single disorder with national or international linkage since very rare
- Scope of data, variables, information to be collected, long-term sustainability and maintenance
- Confidentiality of patient info, access

Funding and resources

- Interface design
- Set-up costs, hardware, software, IT support
- Resources for project manager, admin support & data entry (initial and ongoing)

Challenges – Patient Registries (cont'd)

Access, consent privacy and security

- Ownership. Who has access to registry, what is shared? Where is it stored?
- Timeliness – real time? If not, how frequent updates are loaded.
- Recordkeeping inconsistencies, quality of data, how data is interpreted and inputted i.e. aids patient's primary cause of death pneumonia

Areas to Improve

Engage key players

- Decision-makers, physician/medical expert to champion cause and be liaison with other key players
- Transfer of best models and practices (regional, national, international)

Equal access

- Treatment and funding for similar disorders
- Rural areas vs. urban centres (treatment, funding, clinical trials)
- Research – pharmacoeconomics, outcomes, quality of life



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The 4 chosen focus areas

- Development of registries
- NRBDO continuation
- Continue progress of Comprehensive Care clinics and improved communications with and among Health care providers
- Government relationships to improve access to drugs, therapies, care.