



Community expectations

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Outline

1. What are the expectations of our bleeding disorders communities?
2. What is our relationship to health services?
3. What can our community teach others about delivering *partnership* in engaging with health services?





Then...



Now...

- Re-definition of the clinician/patient relationship
- From “doing to” to “working with”
- Patient/client/consumer



What does the community expect
when engaging with health
services?



We expect some challenges



- The needs of the bleeding disorders community sit alongside:
 - Ageing population
 - Increasing needs and less money
 - Concerns about quality and safety
 - Care disparities
 - Waiting (waiting times/waiting lists)



Expectations

- A supply of safe and effective products for the treatment of haemophilia
- Comprehensive care
- Ease of access
- Ability to involve family
- Representation



Expectations

- Longevity
- Prophylaxis
- Mobility and independence
- Genetic testing options
- Scientific advances leading to increased half life? A cure?
- Information



EXPECTATIONS

Please don't disappoint

Patient responsibilities

- With rights come responsibilities
- Accurate information from patient
- Treatment record, bleeds, treatment regimens, activities, personal circumstances...



Partnership

- What does this really mean?
- Partnership is a term in contrast to a paternalistic, top-down approach
- In the care of bleeding disorders , partnership is needed for care plans to be successful
- Tends to be a patient-centered concept



Partnering with patients

- “Australian healthcare organisations are becoming increasingly interested in patient-centered care. Most organisations can readily put patient charters and informed consent policies in place, but many find it hard to actively change the way care is delivered, and **many struggle to involve patients, families, carers and consumers** and learn from their experience”
(Groene et al 2009, in Australian Commission on Safety and Quality in Healthcare 2011)



Consumers?

- Prescribe for the good of *patients*
- What are we buying and what is being sold?



Representation

- Whatever you call us, as long as we have a voice in the hospital setting and beyond we are happy.
- Australasia – we are fortunate: NMO, Bleeding Disorders Registry Steering Committee, NBA
- If you haven't included us you will hear about it anyway!



Partnering

- Expectations on both sides to achieve optimal treatment
- Opportunity to lead the way in understanding and implementing true patient partnership and engagement



The future...

- Partnership and representation will continue to be important
- We need you and you need us
- Through partnership as our community understands it, optimal care can be achieved.

