



**Calvary**

# Research Overview June 2017

Continuing the Mission of the Sisters of the Little Company of Mary



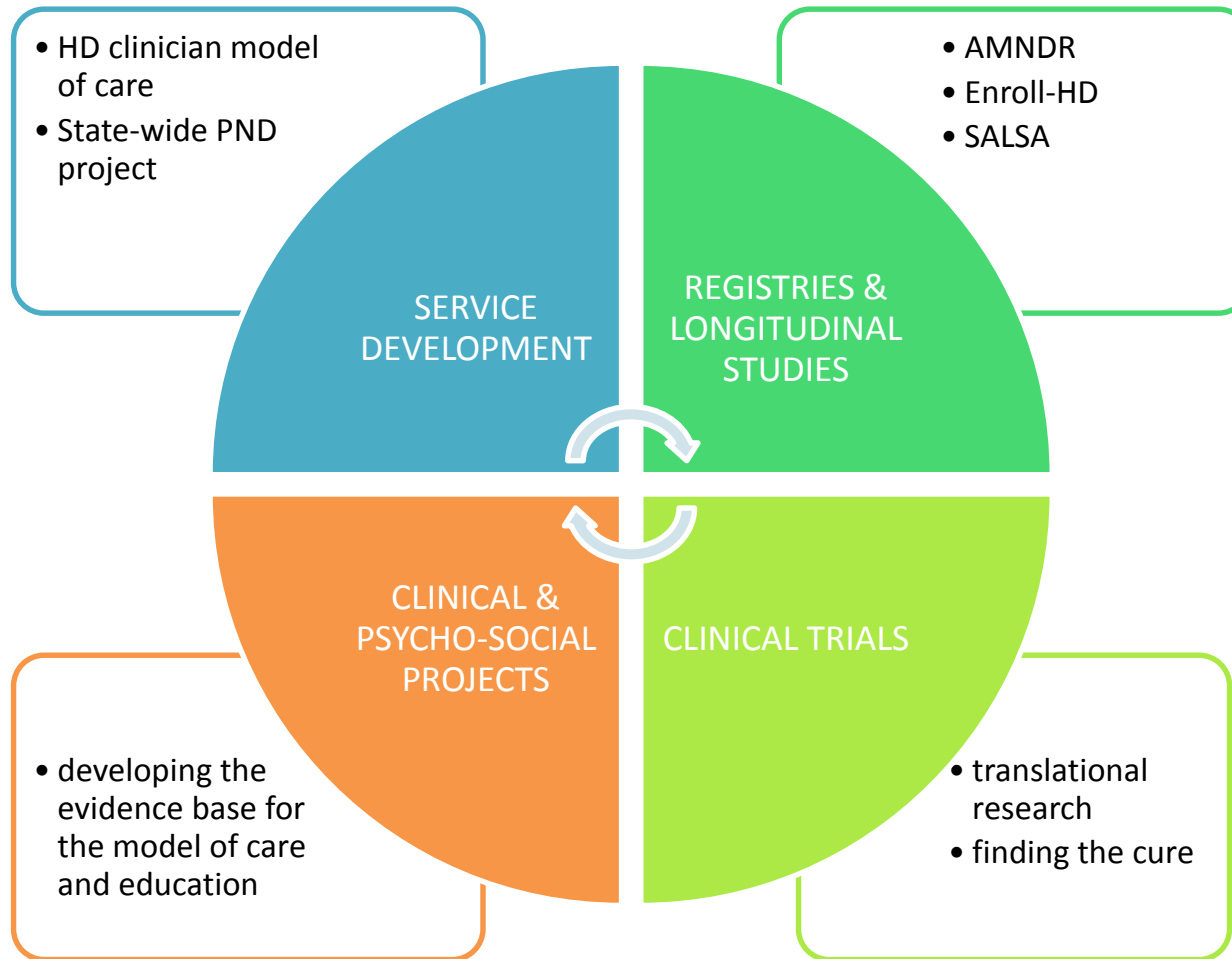
# Calvary

Statewide Progressive  
Neurological Disease  
Service (SPNDS)

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Continuing the Mission of the Sisters of the Little Company of Mary

# Research



# Victoria-wide survey

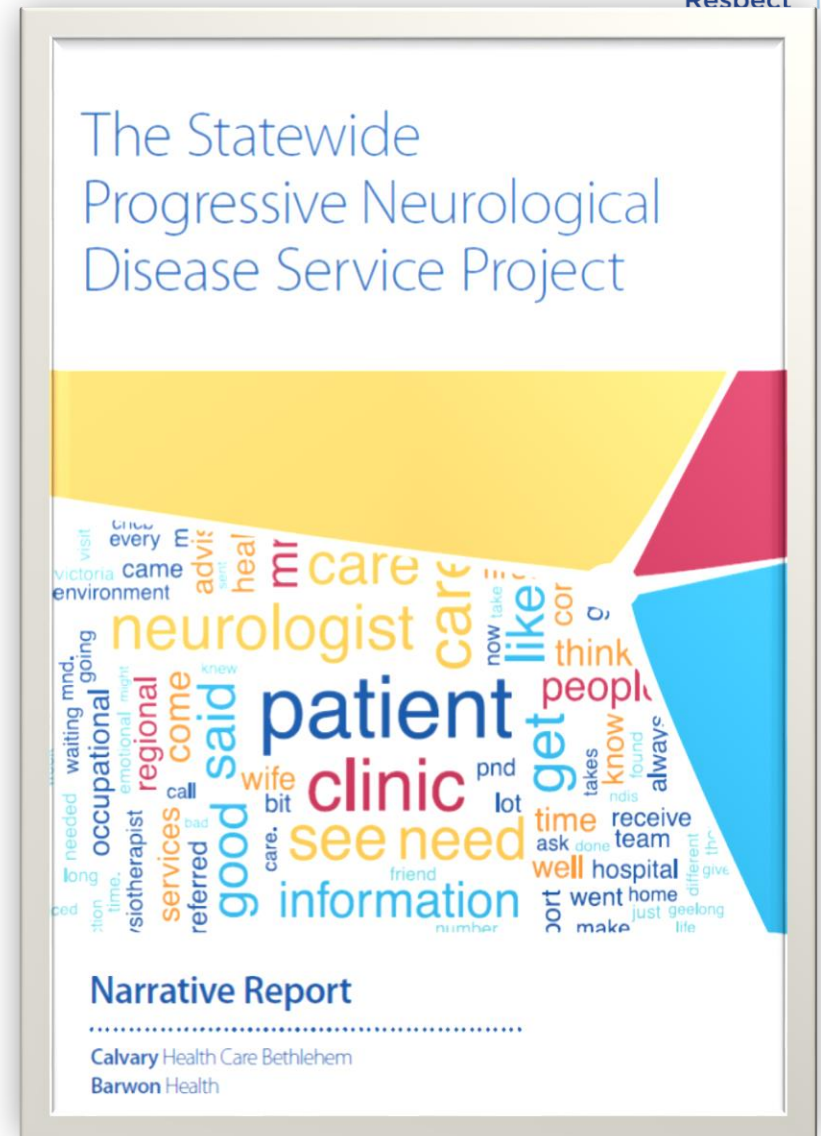


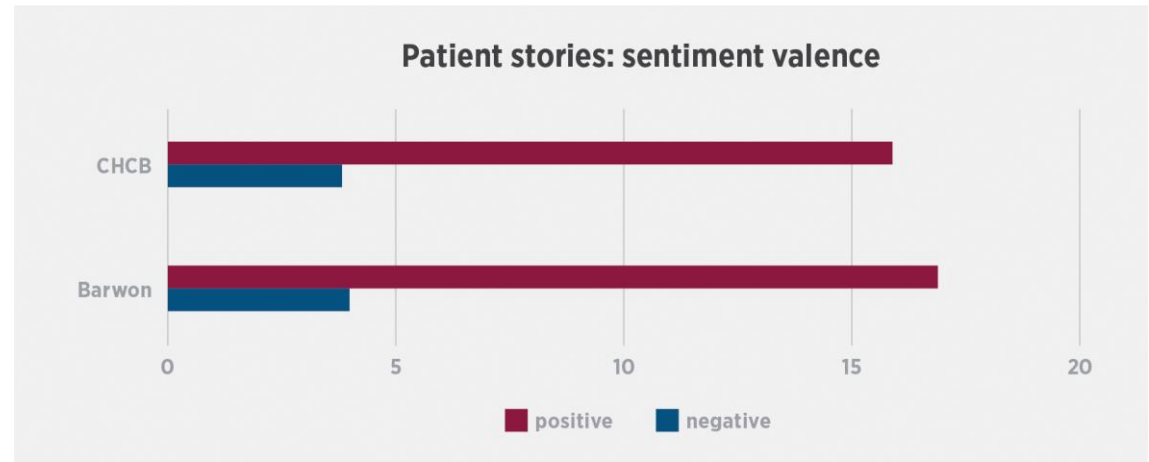
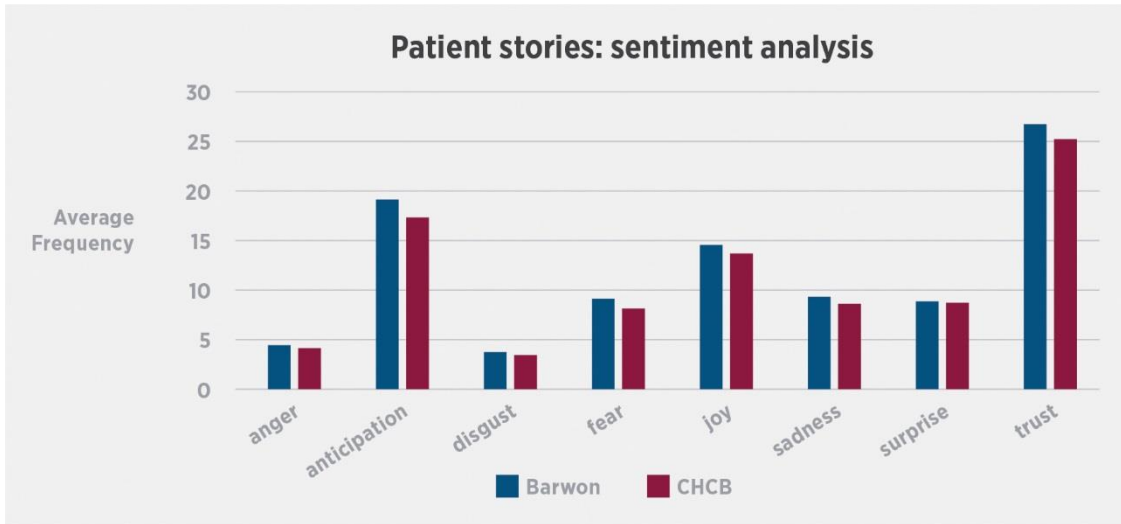
■ Important for the quality of my care

■ I need better access to -

# SPNDS report

- 70% reduction in travel
- Increased referral patterns
- Enhanced clinical pathways
- High levels of palliative care involvement
- High levels of ACP
- Comparable outcome measures





# Other clinical projects

## Collaborative studies

- Functional MRI
- Respiratory management and ventilation

## Enhancing clinical care

- ‘Red Flags’ tool
- Behaviour management training in residential care
- Family life study
- Emotional well-being
  - In early HD
  - For carers
- Communication (Photo-voice study)

# Registries and observational studies

- Australian MND Registry (AMNDR)
  - Opt-out consent
  - Linkage to NZ and Malaysia
- **Enroll-HD**
  - Prospective registry in global Huntington's Disease
  - CHDI Foundation
- **Sporadic ALS Australian Systems Genomics Consortium (SALSA)**
  - Linkage to project MINE in Europe



# Advantages

Large cohorts of patients  
High participation rates  
Expanded research staff  
Trial ready

Clinical phenotyping  
Longitudinal assessments  
Consent to share research data with treating clinicians

- Research integrated with care
- Economical use of resources and time

# Clinical trials

- 4 current drug trials in MND/HD, all multi-site
- ‘Drug pipeline’
- Patient-led research and funding



# The future

- Meeting the needs of modern consumers
- Improving health literacy
- Pathways for translational research
  - right research environment for trials?
  - ethics and logistics of unapproved and unfunded therapies?