Transforming the Australian MS Longitudinal Study: Adding value to a beautiful resource

Aims Australian MS Longitudinal Study

– Set up by Rex Simmons, Canberra Hospital, in 2000/01

– Aims
  o To continue to recruit and enrol Australian people with MS into the study and to collect baseline and longitudinal demographic and clinical data on each participant through a self-report questionnaire for the participant and a clinical questionnaire to be completed by the participant’s neurologist;
  o To collect and analyse data on matters of importance to the MS community through the use of well-designed and ethically approved surveys;
  o To provide MS researchers with an established, well-characterised cohort of people with MS for ethically approved, predominantly social-and-applied, collaborative research projects; and
  o To provide data on the issues of practical importance that affect people with MS, their families and carers to MS Australia and the state MS societies to facilitate the provision of services and advocacy for people with MS.
Key achievements

- Electricity usage
  - Nice example how actual data can be powerful for advocacy
  - Outcome: medical electricity rebates negotiated for people with MS in most states

- Health economic surveys
  - Statements on the actual cost of MS have been very powerful for advocates, researchers and other people
    - MS costs Australia $1.04 billion a year.
    - The reduction in quality of life associated with MS is commensurate with other serious conditions, such as stroke and end stage cancer.
    - There is a 20% reduction in utility in MS patients, and this increases to 50% when a person’s condition becomes severe.
    - Nearly half ($494M) of the total MS cost is due to sickness absence and early retirement. Keeping people with MS longer in the workforce and maintaining or increasing productivity (including less absenteeism) could result in a large cost saving to the society.


Key achievements

- Employment surveys
  - Obtain Australian data on employment and determine the reasons for leaving employment.
    - Good to have Australian figures
      - 56% of MS patients had lost employment due to MS and 64% were not in the paid labour force.
      - Over 4 years, the longitudinal loss of employment was 5.4%.
      - Compared to the Australian population, people with MS were less likely to be employed (49.8% vs 59.6%). Of the employed people, people with MS were less likely to be employed full-time (29% vs 40.8), while a similar number was employed part-time (20.8% vs 18.8%).
    - Useful data for designing interventions
      - The most frequently listed symptoms relating to employment loss were:
        - fatique (70%), mobility-related symptoms (44%), arm and hand difficulties (39%), and cognitive deficits (37%).
        - Too stressed by the effort to work (37%), felt they were not doing a good enough job to their own standards (33%).
        - 17% had been asked to leave employment, 19% mentioned the more suitable work was not found in the same organisation, and 12% was not allowed flexible work hours.

Key achievements

– Employment surveys (continued)
  o Key message for people with MS
    • The data suggests that many employees with MS are leaving their planning for effective symptom management, and for appropriate accommodations in the workplace, until it is too late.
    • Accessing Employment Services early, via e.g. MS Societies, can be extremely useful. Considering these employment aspects early in the disease process can possibly keep people in the workforce for longer.
  o Disclose or not disclose
    • 42% reported positive employer attitudes to MS, 27% reported negative employer attitudes leading to discrimination, and 31% were neutral in their response.
    • People who had disclosed their MS status to an employer were more likely to remain in employment!
    • Disclosure was associated with positive employer attitudes, while non-disclosure was strongly related to an expectation of negative attitudes leading to potential discrimination from their employer.
    • This seems to indicate that employees who disclose are receiving more assistance with workplace accommodations, social support and possibly even more effective symptom management than non-disclosing employees.


Key achievements

– Employment surveys (continued)
  o Key message for people with MS on disclosure
    • Those who disclosed their MS to their employer were more likely to be employed longer-term.
    • The majority of employer responses to disclosure are positive and supportive.
    • However, potential discrimination following disclosure may well still occur for a minority of individuals.
  o Future for employment surveys
    • Further prospective analysis
    • Including employment as key outcome measures
What to continue

- Good communication
  - Communication strategy
  - Newsletters
  - Explaining about outcomes
  - Improve the website

- Encourage use of online questionnaires
  - Easier to complete through the use of skip logic
  - Less labour intensive
  - Some participants will find this challenging

New directions – increased tracking

- Increased tracking over time - MS outcomes
  - Disability, patient-reported symptom severity, quality of life, employment outcomes
  - Examine factors that are associated with changes over time
    - E.g. Compare disease modifying drugs in relation to employment outcomes and fatigue
  - Allows for new research questions developed after the data has been collected
New directions – data linkage

- Data linkage
  - Linking AMSLS data with MSBase (enduring linkage)
  - Linking AMSLS data with PBS or MBS use (linkage at discrete points in time)
    - Tracking progression long-term and evaluate predictors of different measures of progression, including (neurologist measured) disability, and relapses.
    - Examining how key clinical disability milestones (EDSS progression) and treatment decisions affect health service utilisation.
    - Evaluating the short-term and long-term effectiveness of different treatment decisions in people with MS.
    - Evaluating service utilisation from the Pharmaceutical Benefit Scheme, Medicare Benefit Scheme and examine whether this utilisation is influencing progression in clinical endpoints.

New directions – spin off projects

- Spin-off projects
  - Use the AMSLS participants as a recruitment base to recruit for other projects
    - PPMS Study – using the AMSLS study to identify people with PPMS
New directions – MS Portal

Vision
- Create a MS Portal that improves patient care, improves services and expands research opportunities.

MS Portal Project
- This project is the development stage of a website portal that links the research data from the Australian MS Longitudinal Study (AMSLS) with other sources.
- In the first instance, link data with the clinical information from neurologists captured by MSBase.

MS Portal - Expected outcomes

- Improve patient care
  - Participants would view research data of choice with their treating health professional, which then can be used to improve the care and treatment decisions.

- Improve service delivery
  - Service providers such as MS Societies and National Disability Insurance Scheme could access grouped data which can be used for the planning and service delivery at a state and national level.
  - Service providers could view personal data with participants, which potentially can be used to improve the care being provided.

- Expand research opportunities
  - Linking data and a higher availability of data
A visualisation of how would it work?

Creating win-wins

- A Portal at the interface of research and patient care/service delivery
- Only when there are clear outcomes
- Carefully examine the drawbacks/weaknesses
  - E.g. Research needs
    - Reliable and valid measures
    - Representative sampling
  - Ensuring buy-in (ongoing)
- Need a highly secure system
- Will do it staged
- Monitor usage when developed
How would it work?

Participants in control

- Participants are in control of their personal information flows
- Similar to MyGov
MS Portal project

This project will:
- Brainstorm about the opportunities that the MS Portal can offer to AMSLS participants, neurologists, MS Nurses, MS Societies, and other allied health professionals.
  - Brief surveys for each stakeholder group
  - Focus groups / workshops
- Establish an ethical and logistical framework
- Trial the set-up of a linkage between the AMSLS and MSBase
- Design and test an MS Portal prototype

Your potential involvement in the MS Portal Project

1. Online survey – 3 minutes
   - Whether you have suggestions for future research of the AMSLS study.
   - What is the likelihood of using such an MS Portal.
   - Whether you have specific suggestions for the MS Portal.

2. Participate in an online focus group or workshop

3. Assist with testing the MS Portal Prototype
2015/16 surveys

1. Larger survey with modules
   - MS Outcome module
   - Medication module
   - Employment module

   – Medication module
   - Update from 2010-now
   - Compare disease modifying treatments in relation to
     - Employment outcomes
     - Disability progression
     - Symptom severity

2015/16 surveys

– Employment module
   - Collaborators from Monash, Department of Management
     - A/Prof Andrea Kirk-Brown / A/Prof Pieter van Dijk
   - Aim
     - Examine the inter-relationships that impact on the intention to quit.
   - Relevant factors
     - Perceptions of the work environment, the ability to work, the difficulties at work and whether or not people have disclosed their MS.
   - Data used for
     - Developing education programs for employees & employers, and work-place interventions.
   - Ultimate aim
     - Improve the management of MS at work
     - Keep people with MS in paid work longer.
2015/16 surveys

2. Health Economic Survey
   - Prof Andrew Palmer (and myself, Prof Bruce Taylor)
   - DEVA project: Development and Validation of a computer simulation tool to identify interventions and treatments of MS that are excellent value for money.
   - Currently, lack of a validated, transparent and widely available health economic model for MS in Australia and internationally.
   - Using a flexible approach to software development, we will build a gold standard, validated, transparent decision analysis tool to identify cost-effective interventions amongst a plethora of existing and future medications and non-pharmaceutical interventions from a variety of perspectives.

3. Comorbidities
   - Myself & Prudence Tettey (post-doc)
   - Examines
     - Association between comorbidities and health-related quality of life
     - Whether the association is stronger for some comorbidities compared to others
     - Association between disease modifying drug use and the risk of developing new comorbidities
Love to hear your feedback

1. Type your questions & comments via the Webinar software

2. Raise your “hand” to speak now in the Webinar forum

3. Online survey – 3 minutes
   - Whether you have suggestions for future research of the AMSLS study.
   - What is the likelihood of using such an MS Portal.
   - Whether you have specific suggestions for the MS Portal.

4. Email or phone
   - Helen Hornsby on AMSLS.info@utas.edu.au, 03 6226 4739
   - Myself on Ingrid.vanderMei@utas.edu.au, 03 6226 7710