LA TROBE UNIVERSITY • AUSTRALIA

Living with Disability Research Centre

SUMMER FOUNDATION

Extended Rehabilitation Services for People with Severe Acquired Brain Injury

Professor Jacinta Douglas and Dr Lucy Knox

Annual National Acquired Brain Injury Conference

8 November 2016

Background

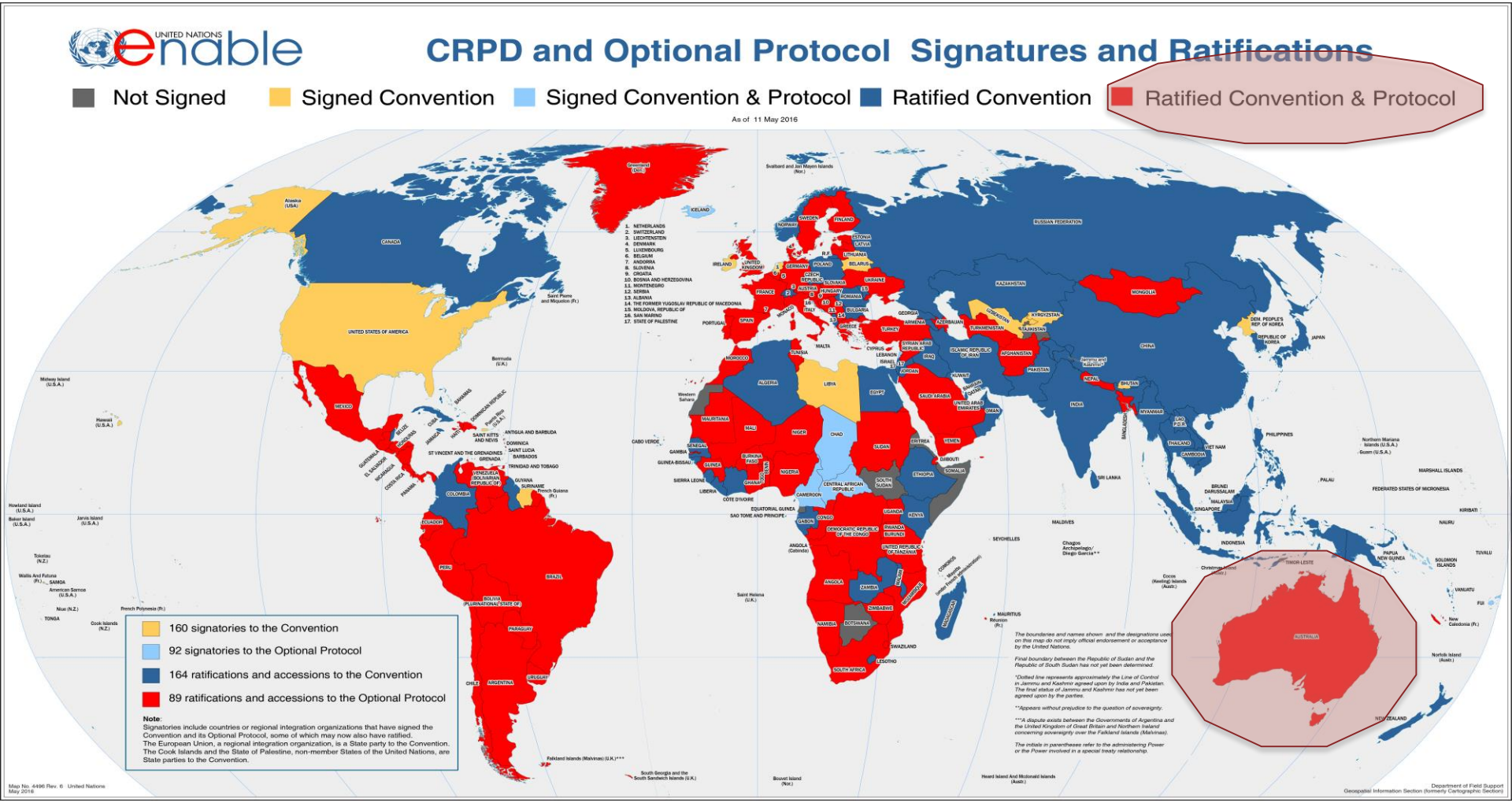
A matter of rights

Young people in residential aged care: An unmet need

Senate Standing Committee Report (June, 2015)

Expertise born of experience

A matter of rights: UN Convention on the Rights of Persons with Disabilities (2006)



CONVENTION on the RIGHTS of PERSONS with DISABILITIES

2006 (2008)

Article 19

- live in the community and enjoy full inclusion and participation in the community
- choose their place of residence and where and with whom they live
- access a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community

Article 26

- attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life

Young People in Nursing Homes

February 2016

Key statistics about permanent residents in and admissions of young people into nursing homes:

Permanent residents as at 30 June 2015

States & Territories	Under 50	50-64	Under 65
NSW	201	2059	2260
VIC	138	1431	1569
QLD	119	1086	1205
WA	42	471	513
SA	39	402	441
TAS	12	139	151
ACT	-	62	62
NT	4	47	51
Australia	**555**	**5,697**	**6,252**

Extended Rehabilitation Services

Senate Inquiry into Adequacy of RAC for young people (<65 years age) (March - May 2015)

Recommendations were released (June 2015)

Recommendation 8

"development and implementation of a national rehabilitation strategy including a **framework for the delivery of slow stream rehabilitation in all jurisdictions**"

Insights from the Senate Inquiry

'How could you send her to a nursing home? What about rehab?' We really fought hard. We pleaded. But the neurologist said, 'No, not unless she responds.' *(Mother, verbal submission)*

Young people may end up in RAC due to difficulties accessing appropriate rehabilitation

I was told that I "couldn't take up a bed any longer". The only alternative to aged care that was presented to me was living with family (but) the home environment was not suitable. *(Person with ABI, written submission)*

From hospital, I was told I was going to a nursing home. I wanted to go to rehab. Rehab is so important to me because I want to get better, I want to talk and walk again *(Person with ABI, written submission)*

Insights from the Senate Inquiry

For 20 months he sat in a wheelchair with no meaningful effort at rehabilitation. *(Father, verbal submission)*

> It was devastating to see the small gains Michelle had made in rehabilitation vanish in her time living in the nursing home. She lay motionless in a bed, all day everyday. *(Mother, written submission)*

There is no sense of rehabilitation or getting better, there is no support for recovery or even to maintain my skills. *(Person with ABI, written submission)*

RAC acts as a barrier to moving to a more appropriate environment

> I am supposed to receive rehab a couple of times a week. I am lucky if they come once a week… a nursing home isn't somewhere people go to be rehabilitated. I need to be living somewhere that encourages regaining of skills. *(Person with ABI, written submission)*

Extended Rehabilitation Services

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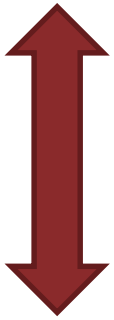


RAC acts as a barrier to moving to a more appropriate environment

Exploring the Evidence for Extended Rehabilitation - Results from a Scoping Review

Aim of Scoping Review

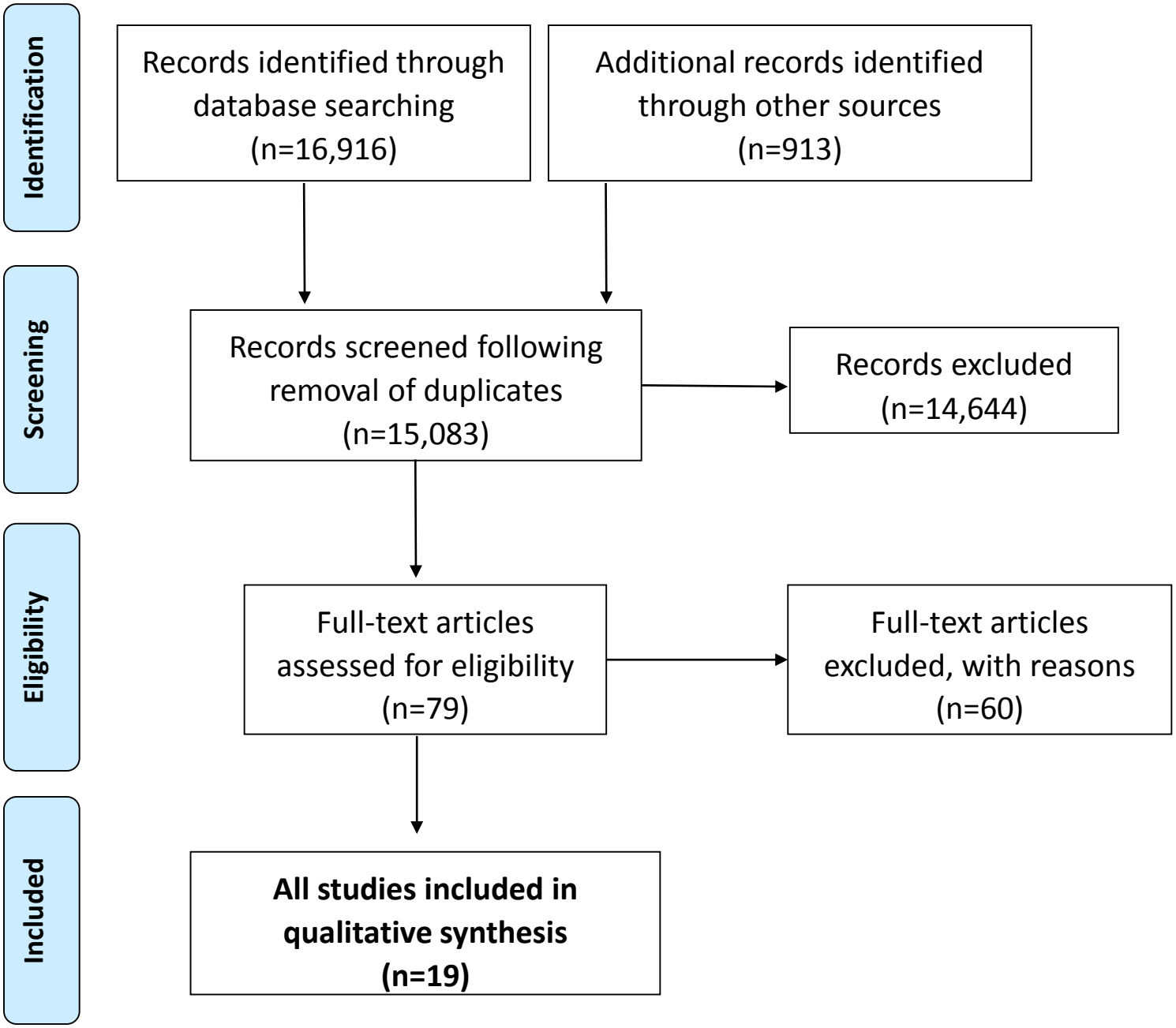
- To identify the extent, nature and range of literature about existing *extended rehabilitation* services and programs for adults after *very severe ABI*

  - What extended rehabilitation programs have been developed for adults with extremely severe ABI?
  - What common characteristics do participants share?
  - How has the effectiveness of these programs been evaluated?

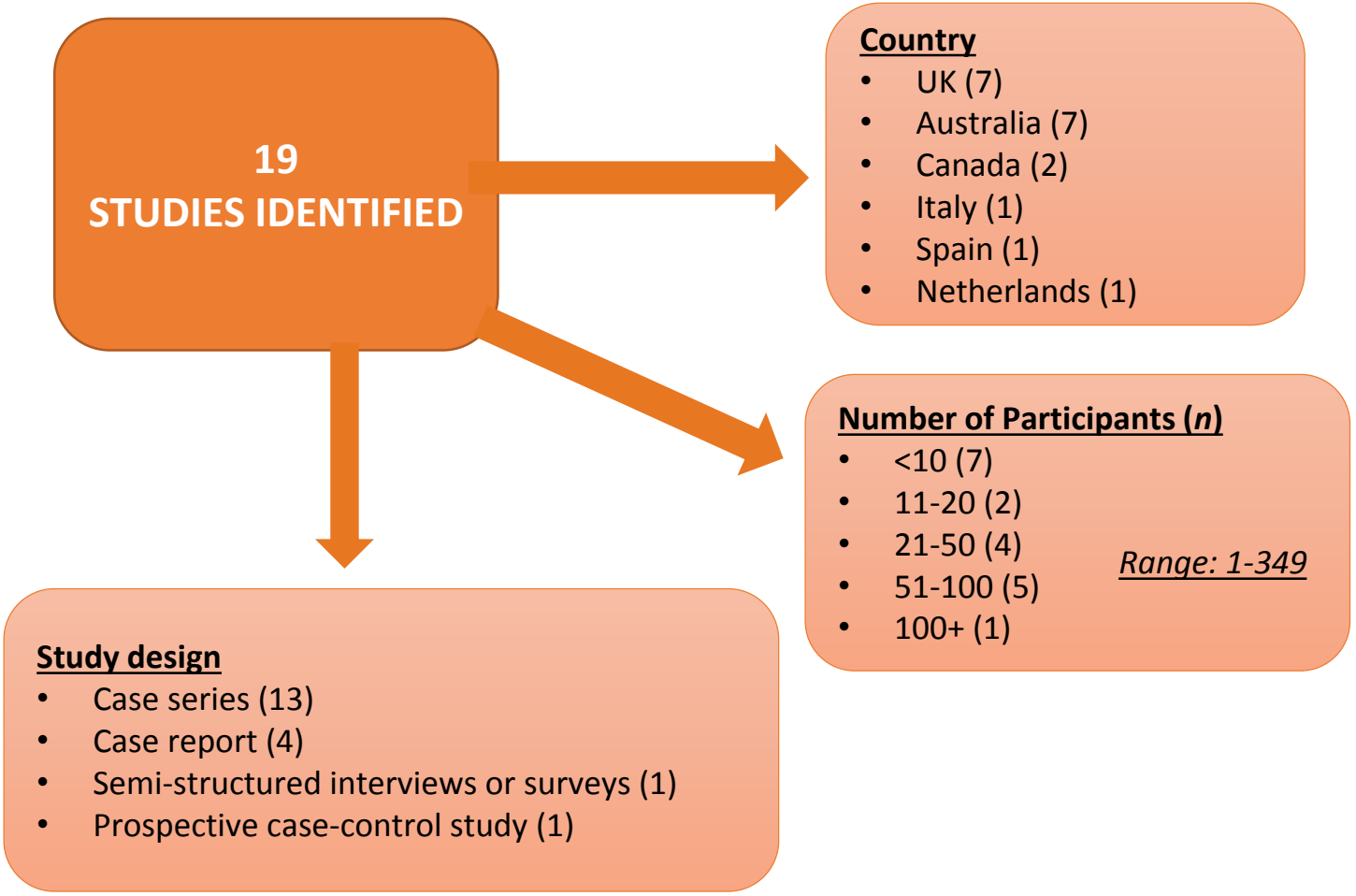
Search terms and locations

Search concepts	Terms used in database
Severe brain injury	traumatic brain injur*, acquired brain injur*, ABI, TBI, brain injuries (MeSH medline) severe vegetative state, unconscious, coma
Long-term rehabilitation interventions	rehabilitation, intervention slow to recover, slow stream, long-term, enhanced

Search locations	
Databases	MEDLINE, CINAHL, PsycINFO, AMED, Web of Science
Grey literature	Google, Google Scholar, PubMed
Key journals (hand search)	Brain Injury, Neurorehabilitation, Archives of Physical Medicine and Rehabilitation, Journal of Neurorehabilitation, Journal of Head Trauma Rehabilitation


Identification
Screening
Eligibility
Included
Records identified through database searching (n=16,916)
Additional records identified through other sources (n=913)
Records screened following removal of duplicates (n=15,083)
Records excluded (n=14,644)
Full-text articles assessed for eligibility (n=79)
Full-text articles excluded, with reasons (n=60)
All studies included in qualitative synthesis (n=19)

Overview of Included Studies



Findings

Participant Characteristics	• Injury severity • Time post-injury • Exclusion criteria
Models of Service	• Aims • Location • Team members • Program length
Program Effectiveness	• Outcome measures • Evidence

Participant Characteristics: Injury Severity

- Descriptors
  - *"Very severe", "extremely severe"* or *"catastrophic"* ABI
  - *"Slow-to-recover", "extremely poor"* prognosis
  - *"Persisting neurobehavioural disability"*
  - Complex physical, health and social support needs
- Clinical Classifications
  - Glasgow Coma Scale: <8
  - Length of PTA: >7 days (generally 1mth++)
  - Coma duration: 3 days > 16 weeks

Participant Characteristics

- Time post-injury: significant range
  - 14 studies: chronic injury (> 1yr)
  - 3 studies included participants in the year following injury (but intervention was long-term)
  - Parish & Oddy (2007): Participants between 11-36 years post-injury
- Exclusion criteria reported in 11/19 studies
  - Eligible for standard / “fast-stream” rehabilitation (5)
  - Progressive neurological conditions (4)
  - “Severe” drug and alcohol issues (2)

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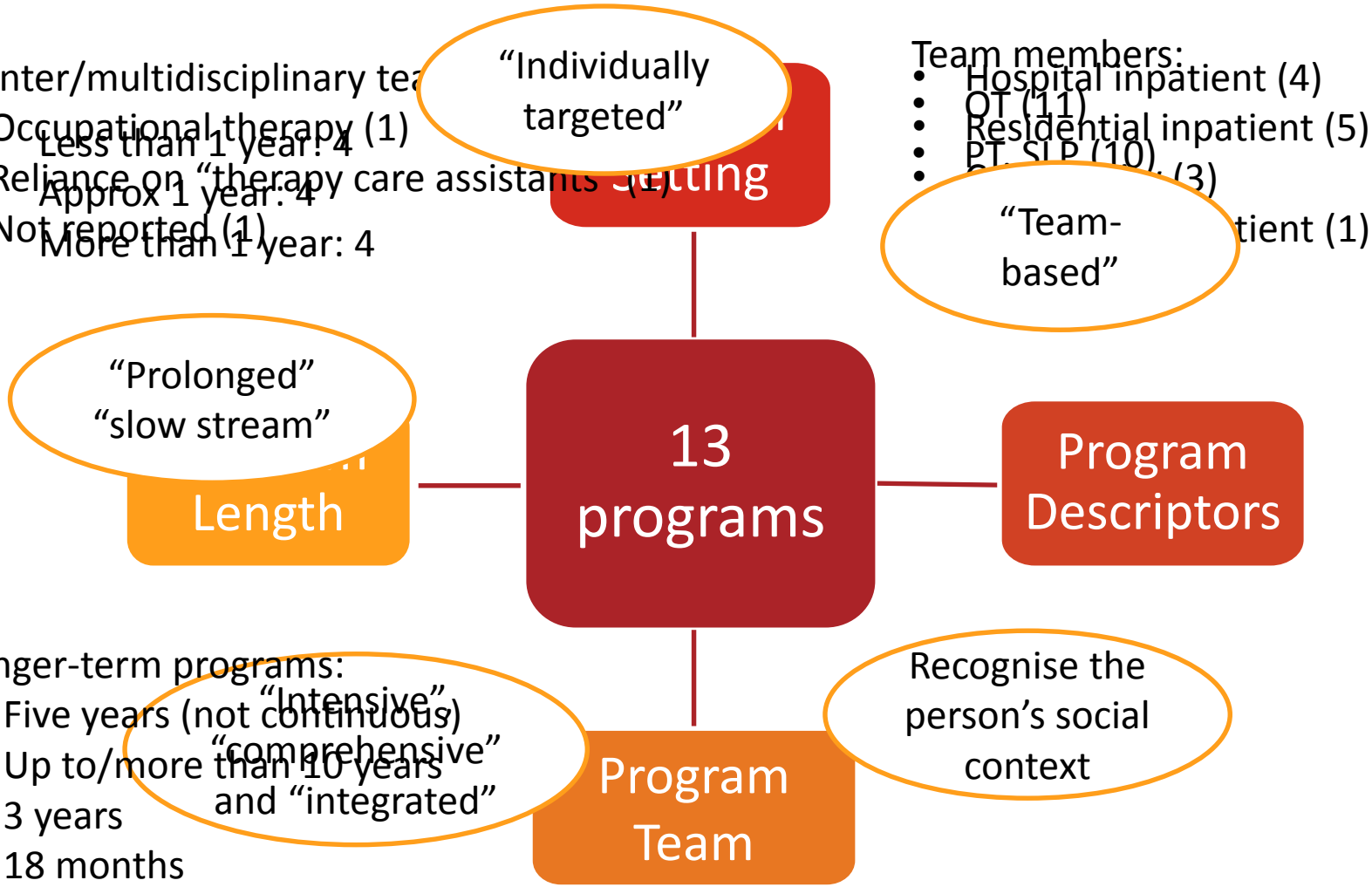
Models of Service



- Inter/multidisciplinary tea
- Occupational therapy (1)
- Reliance on "therapy care assistants
- Not reported (1)

- Less than 1 year: 4
- Approx 1 year: 4
- More than 1 year: 4

Team members:

- Hospital inpatient (4)
- OT (11)
- Residential inpatient (5)
- PT, SLP (10)
- (3)
- tient (1)

Longer-term programs:

- Five years (not continuous)
- Up to/more than 10 years
- 3 years
- 18 months

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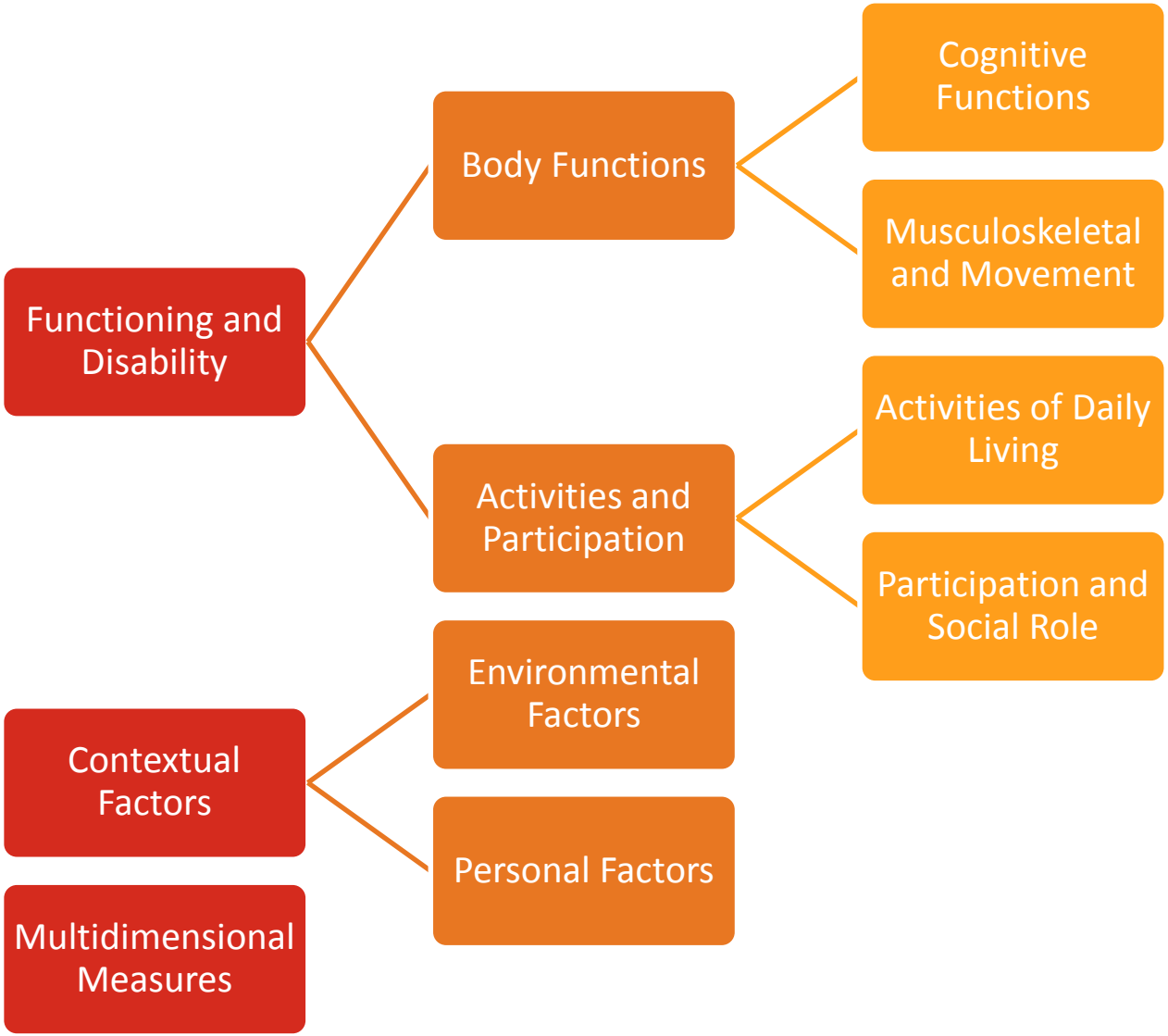
Effectiveness: Outcome Measures



Effectiveness: Outcome Measures

Activities of Daily Living

- Functional Independence Measure (FIM) +/-Functional Assessment Measure (FAM)
- Percentage independence on targeted tasks (e.g. meal preparation, laundry, showering)

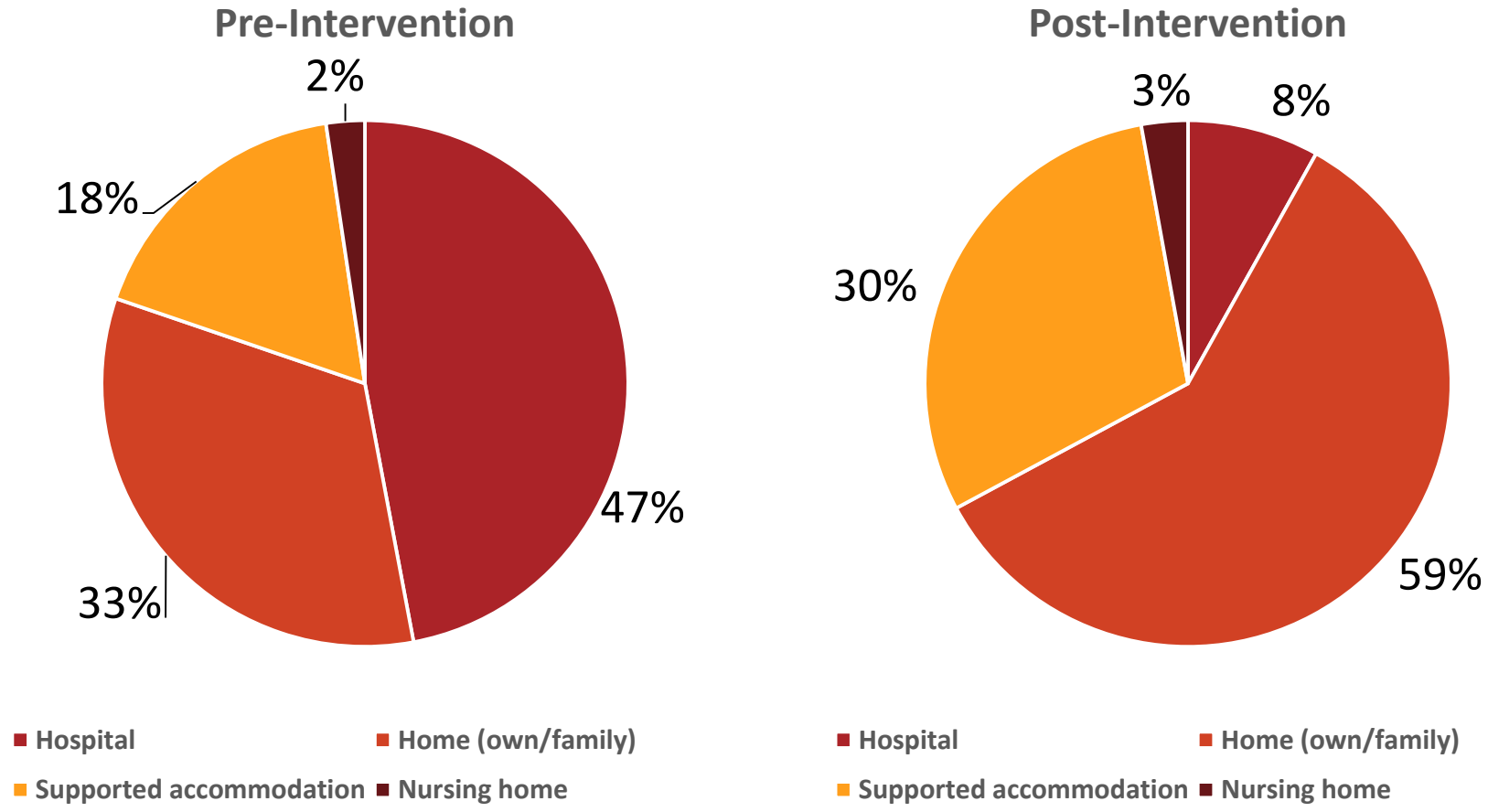
Participation and Social Role

- Community integration questionnaire
- Change in social participation (self or other report)
- Employment (participation in, hours worked)

Environmental Factors

- Change in living environment
- Change in hours or cost of care

Effectiveness: Living Environment



Effectiveness: Hours / Costs of Care

Study	*n*	Hours or costs of care (per week)	
		Pre-Intervention	***Post-Intervention***
Bellisario (2015)	1	£2768	£1100 ↓
Sloan et al. (2004)	1	50 hrs attendant care support	11 hrs attendant care support ↓
Sloan et al. (2009)	43	$2585.77 M (group): 85.85hrs (paid); 33.10hrs (gratuitous)	$2260.93 ↓ M (group): 75.06hrs (paid); 28.24hrs (gratuitous) ↓
Sloan et al. (2012)	43	*Home-like group (28)*: 40.84hrs (paid); 50.62hrs (gratuitous) *Disability-specific group (12)*:170.33hrs (paid); 0.5hrs (gratuitous)	*Home-like group (28)*: 32.88hrs(paid); 38.09hrs (gratuitous) ↓ *Disability-specific group (12)*: 171.08 hrs (paid); 2.0hrs (gratuitous)
Wall, Turner & Clarke (2013)	1	15 hours of care in individualised budget (projected care costs £50,000 pre-admission)	Only funded support provided by mother (hours unknown) ↓
Wood et al. (1999)	76	22.80 hrs/wk (0-2yrs TPI) 19.88 hrs/wk (2-5 yrs TPI) 21.25 hrs/wk (5+ yrs TPI)	15.98 hrs/wk (0-2yrs TPI) ↓ 16.33 hrs/wk (2-5 yrs TPI) ↓ 18.58 hrs/wk (5+ yrs TPI) ↓

Summary and Future Directions

Summary

- Few published studies
- Participants
  - very severe ABI with complex physical, health and support needs
- Outcomes
  - ✓ Fewer living in hospital more living at home
  - ✓ Increased independence
  - ✓ Increased inclusion in the community
  - ✓ Lower costs/hours of care
  - ✓ Life is better*: I'm very proud that I live in my apartment independently, with a continual reduction of support from carers.*

Challenges

- Take effective and appropriate measures to maximise the right of persons with severe ABI and complex physical, health and support needs to live in the community, with choices equal to others, and full inclusion and participation in the community
- Develop a framework for the delivery of extended rehabilitation
  - ✓ Evidence
  - ✓ Principles
  - ✓ Practice guidelines
  - ✓ Evaluation
- Implement of a national rehabilitation strategy that includes a the delivery of extended rehabilitation in all jurisdictions

Thank you

Acknowledgements

Participants in the LTU-SF partnership workshop (2015) and roundtable (2016)

For further information

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