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Living with Disability Research Centre

A Prospective Study of Hospital Encounters by People with Intellectual and Developmental Disability and a Comparison Group

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Hospital Encounters for People with Intellectual and Developmental Disability

- Higher rates in terms of emergency department presentations (ED) and re-presentations (Balogh et al., 2010; Dunn et al., 2017; Glover et al., 2019; Reppermund et al., 2017)
- Longer hospital stays (Glover et al., 2017)
- Reasons include conditions that can be prevented or managed in primary care (Balogh et al., 2010; Dunn et al., 2017; McDermott et al., 2018; Skorpen et al., 2016)
- Concerns about poor quality care, failure to conduct diagnostic assessments, diagnostic over-shadowing, failure to implement reasonable adjustments (Iacono et al., 2014; Tuffrey-Wijne et al., 2014)
  - Listen to family or paid carers
  - Adapt communication
  - Allowing more time

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Aims

- Prospectively document hospital encounters of people with IDD
  - Contrastive data for people with a previous Traumatic Brain Injury (TBI)
- Explore potential indicators of care quality
- Obtain data for Australia

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Participants

- 60 Primary Participants
  - Adults with Cognitive Disability who had a hospital encounter (mostly Emergency Department) during Nov 2014 – Oct 2017 (35 months)
  - 50 IDD; 35 male; aged 18-74 (mean = 42.9, SD = 14.5)
  - 10 TBI; 9 male; 25-84 years (mean = 50, SD = 18.3)
  - 85% at least 1 chronic health condition (mostly epilepsy for IDD, mental health for TBI)
  - Living situation
    - 27 (45%) with family
    - 24 (40%) in supported accommodation
    - 8 (13%) Independently or semi-independently
    - 1 (2%) missing data

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Frequency of Encounters

- 186 across participants within 35 months
  - Range = 1-16 (median = 2)
- 114 encounters (62%) within first 3 months of being in the study
  - Range 1-9 for IDD; 1-3 TBI

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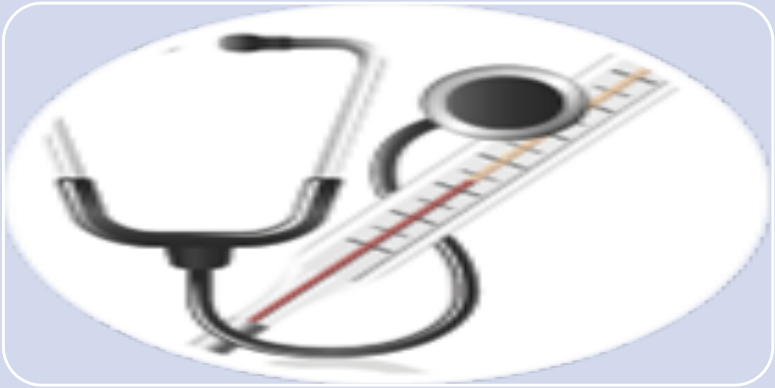
179 Hospital Encounters via Emergency Department

Comparisons with National Hospital Performance Data

AIHW, 2013-14



Getting there:

IDD: 59% ambulance; 36% private car

TBI: 76% ambulance; 17% private car

National Data: 24% ambulance

Emergency Department (ED)

62% > 4 hours

General Patient Data (2013)

H1: 38-46%

H2: 24%

H3: 44%

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Initial Triage Codes

1. Resuscitation: immediate (within seconds) *n* = 4 (2%)
2. Emergency: within 10 minutes *n* = 21 (12%)
3. Urgent: within 30 minutes *n* = 92 (51%)
4. Semi-urgent: within 60 minutes *n* = 58 (32%)
5. Non-urgent: within 120 minutes *n* = 2 (1%)

Not recorded *n* = 2 (1%)

83% vs 79%
AIHW, 2014

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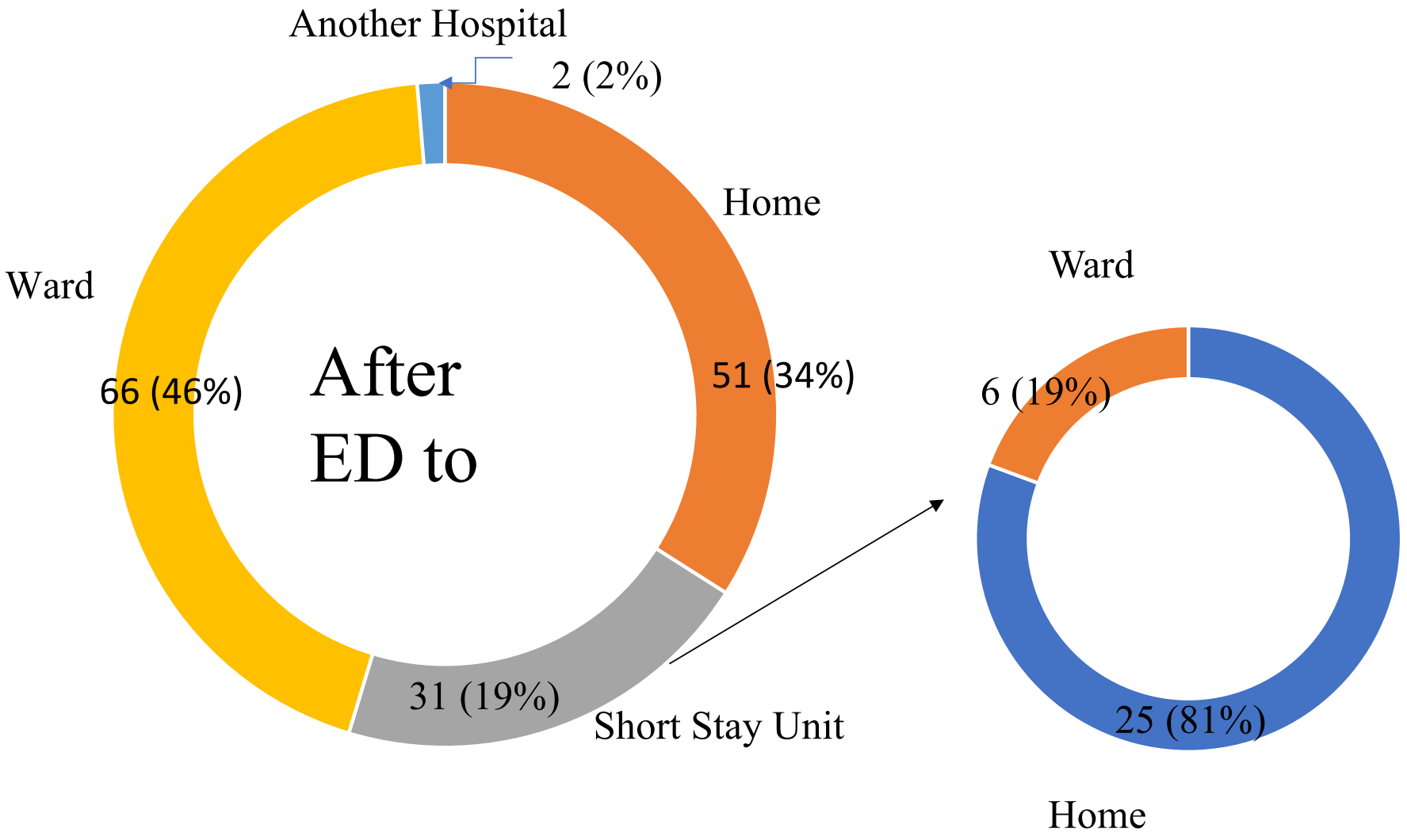

IDD

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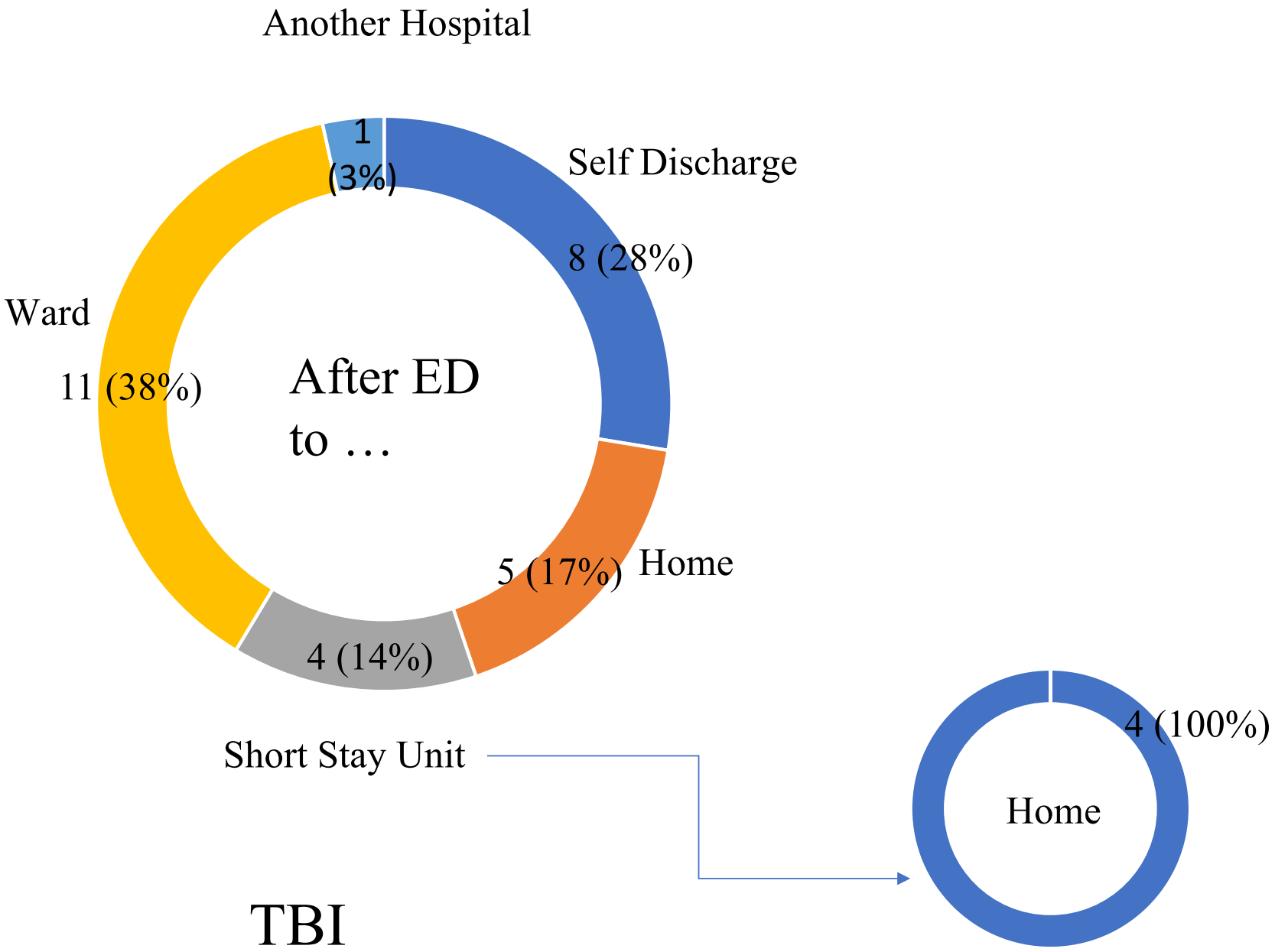

TBI

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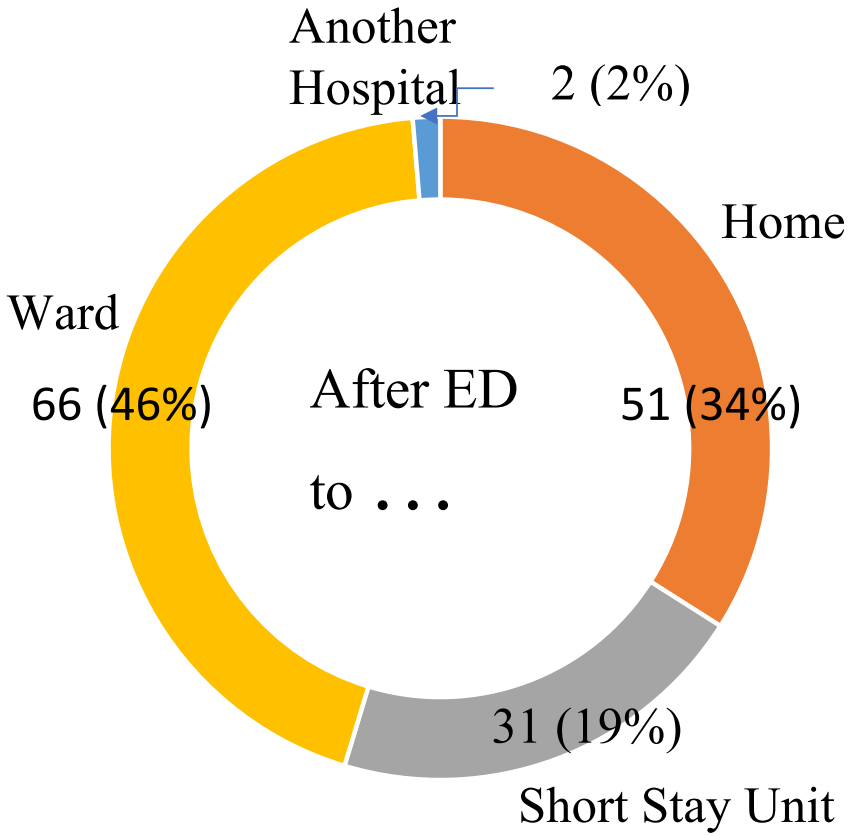
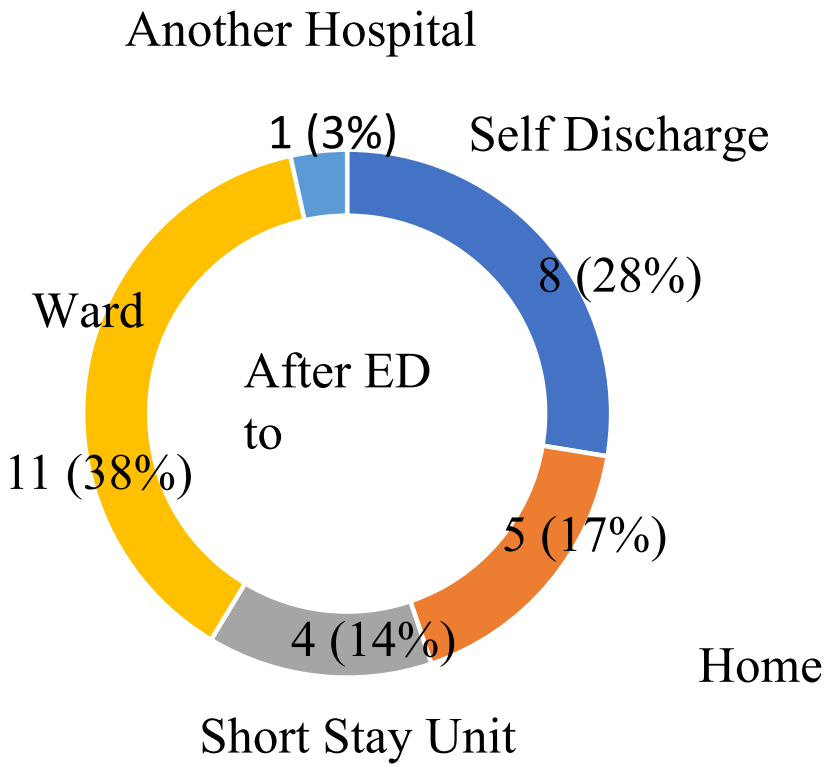


IDD



TBI

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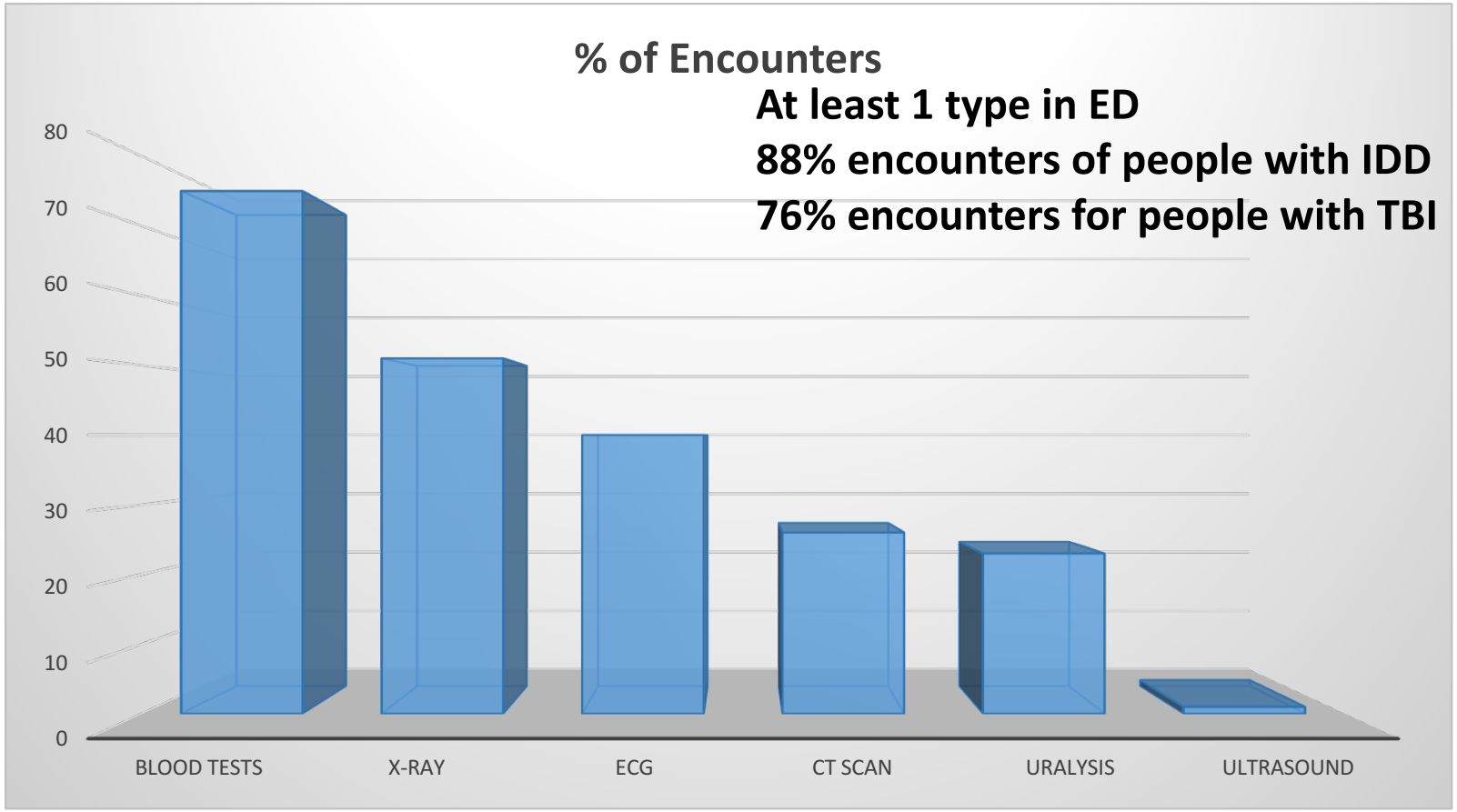
Diagnostic Tests



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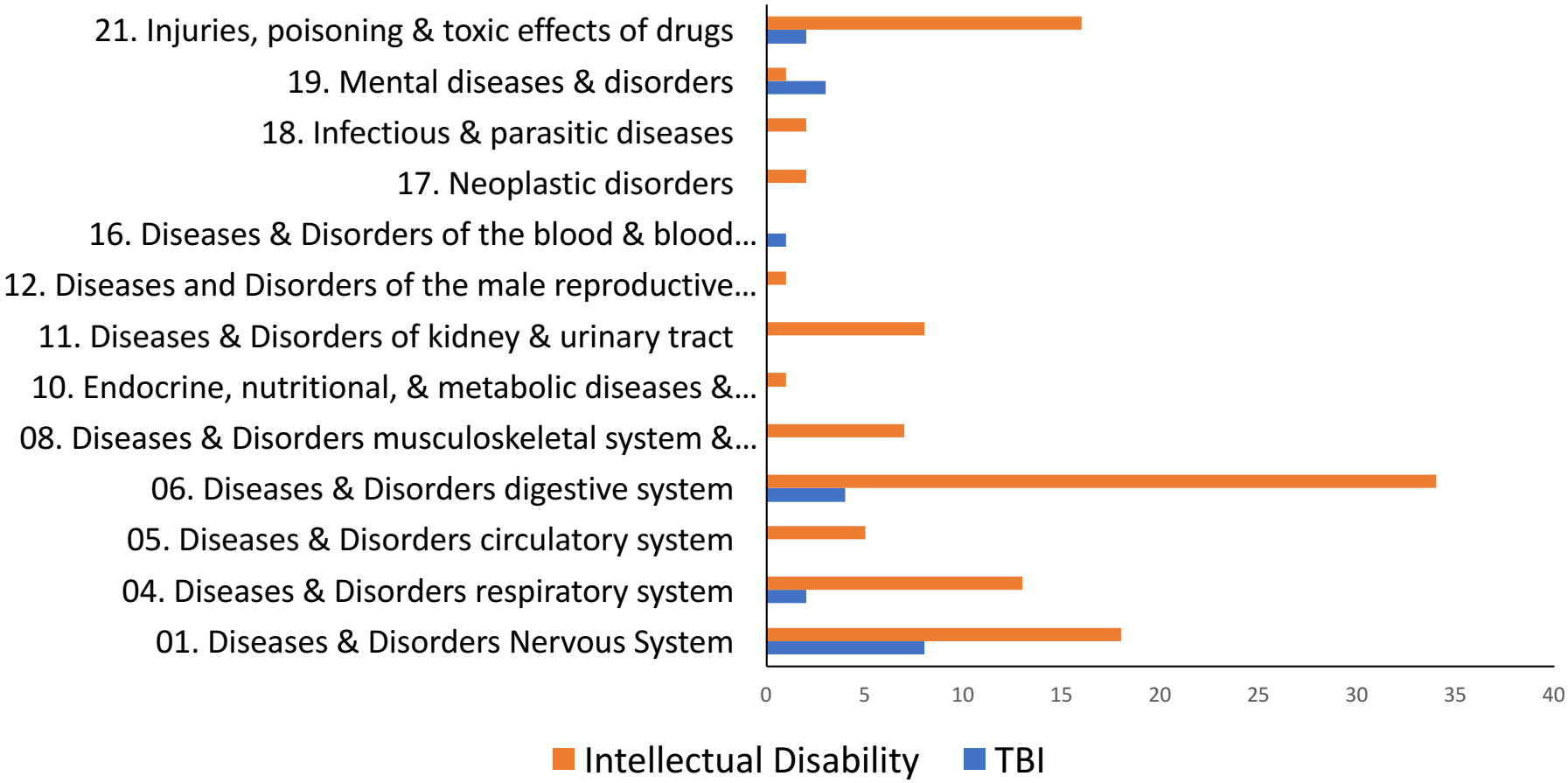
Australian Refined Diagnostic-Related Groups



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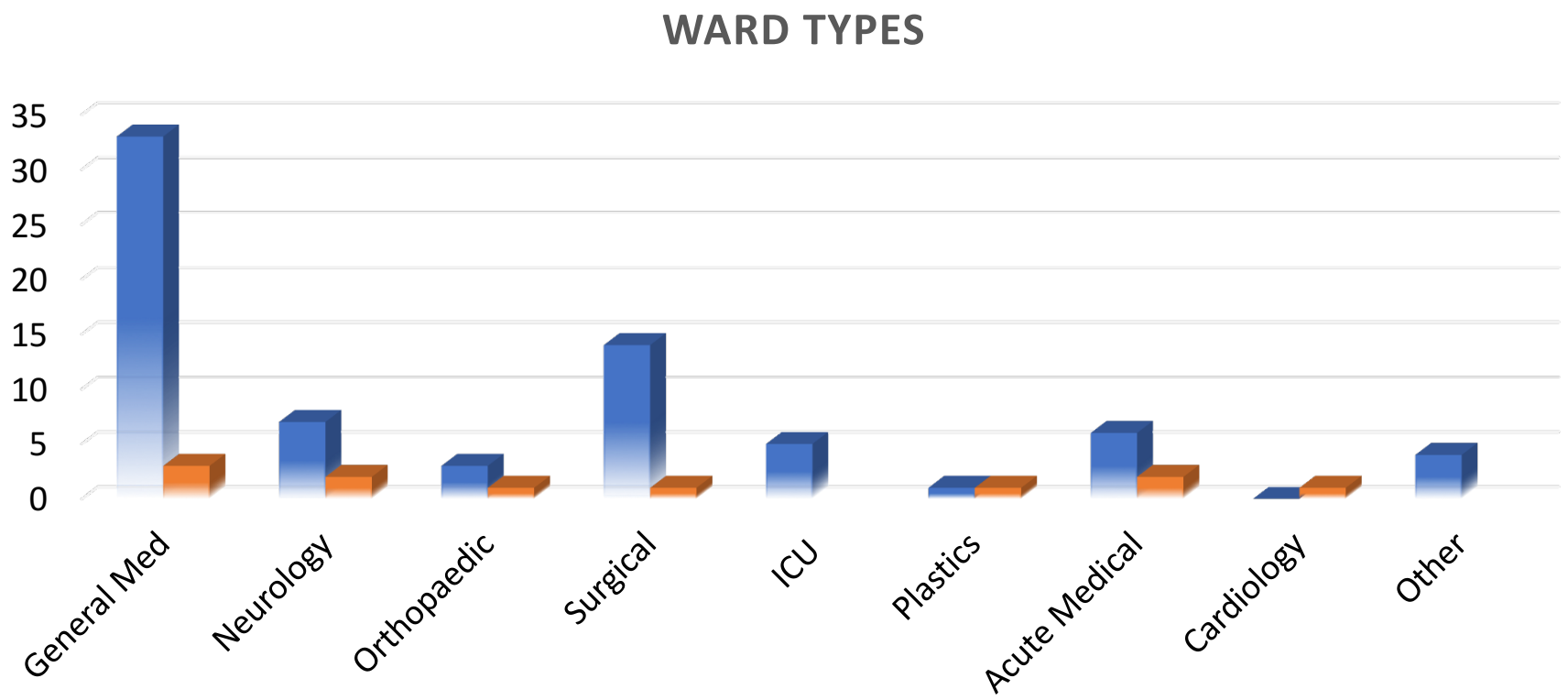

Time in Wards
0.2-35 days
Mean = 5.4 (SD=7)
Median = 3.1

n=73 *n*=10

Time in Wards
0.2-11 days
Mean = 3.7 (SD=3.6)
Median = 3.4

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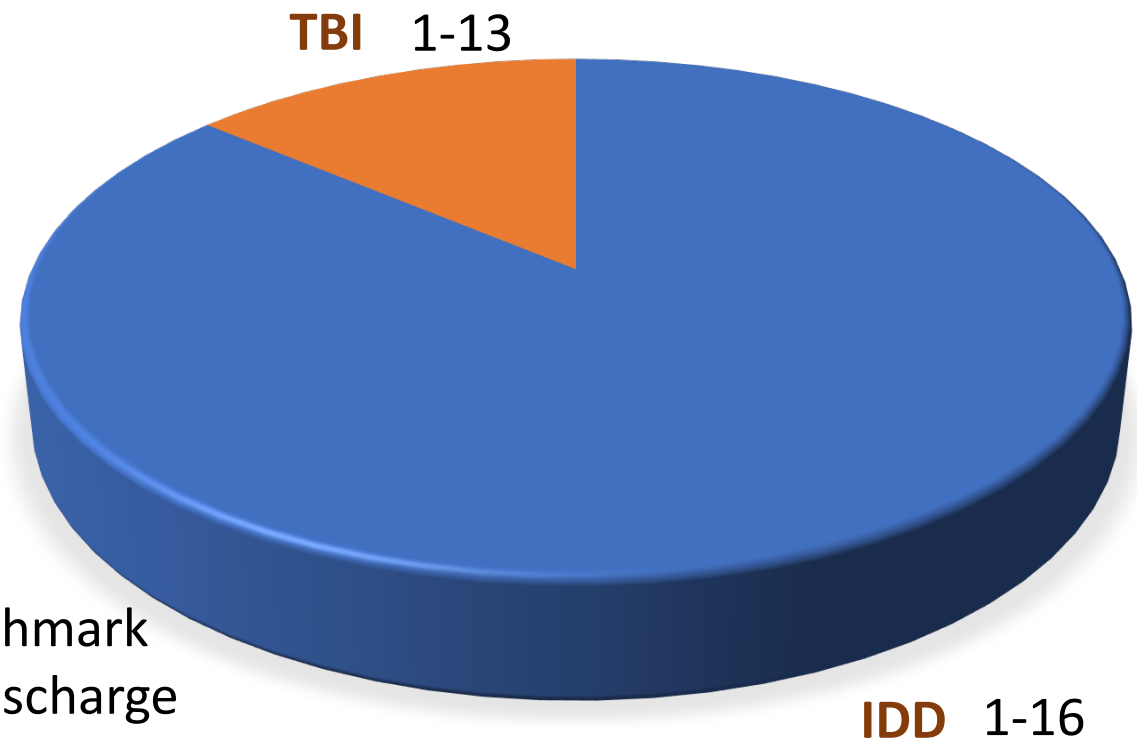
RE-PRESENTATIONS



Exceeding the benchmark of 72 hours since discharge
n= 24 IDD (16%)
n=2 TBI (7%)
Time between presentations <1 – 364 days (M=50; SD = 68; Median = 21)

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Frequent ED Presentations

- 5 or more presentations in 1 year (benchmark, Fuda & Immekus, 2006)
  - 8 (16%) people with IDD
  - 1 (10%) people with TBI

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Trends

- Indicators of high hospital usage?
  - 179 encounters across 60 participants
  - Only 16% of IDD and 10% of TBI met benchmark for frequent ED presentations in 1 year
  - Few re-presentations within 72 hours
- Both IDD and TBI more likely to get to ED by ambulance compared to national data
- Most receive urgent or semi-urgent triage codes ~ national data

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Trends

- Most receive at least one, but often multiple diagnostic assessments
- Diagnoses reflect findings from other studies for people with IDD (Skorpen et al., 2014)
  - Often for chronic health problems with high occurrence in this group– e.g., epilepsy, gastrointestinal problems
  - Reflect findings from Ambulatory Care Sensitive Conditions research
- Lengthy stays?
  - Except for some extreme examples in IDD group, stays in wards were relatively short (medians ~ 3 days)
  - Use of ED and SSU to complete diagnostics and observations, resulting in ~ half encounters going home rather than a ward

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Discussion

- Did not find evidence of high usage or long stays in general (exceptions)
  - Further data needed for TBI group (more likely to have mental health problems)
- General indications were for good care (some exceptions)
  - Outcome of patient-centred focus in training of medical and nursing staff?
  - No evidence of diagnostic overshadowing
- Reasonable adjustments
  - Short stay units may provide the means by which hospitals can provide the additional time needed by people with cognitive disability
  - Other indicators explored in companion qualitative study
- Direct comparisons with other studies and with national data (other than benchmarks) difficult
- TBI and IDD comparisons are indicative only

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