The Martin House RESEARCH CENTRE

In partnership with UNIVERSITY of York

Can the categorization of patients with life-limiting conditions help us to provide better care?

Dr Lorna Fraser

Senior Lecturer and Director of the Martin House Research Centre

Outline

- Paediatric Palliative Care Services in the UK
- Martin House Research Centre
- Key Definitions
- ChiSP Study
- PICU; Palliative Care relationship
- Summary

United Kingdom PPC Services

60+ Organisations providing Paediatric Palliative Care Services

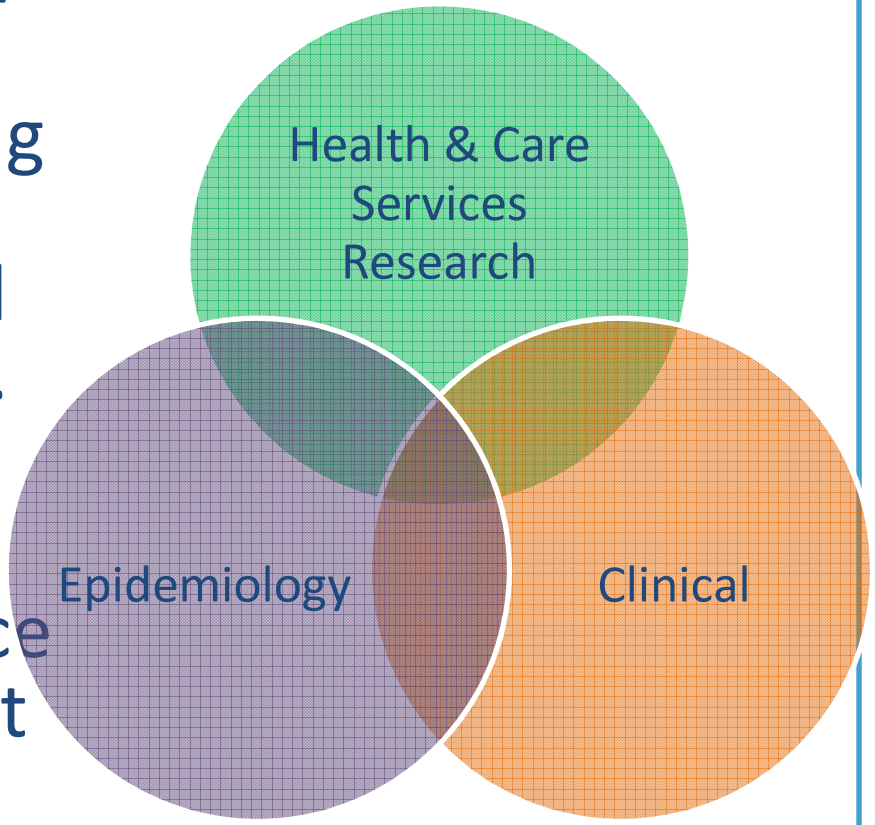
- Children's Hospices (n=53)
  - Charity funding
- Hospital Based Specialist Paediatric Palliative Care Services (n=9)
  - NHS funding
- Community/Outreach Teams

Martin House Children's Hospice

30 years of care

“The Martin House Research Centre”

- a multi-disciplinary centre for research on the care and support of children and young people with life-limiting conditions, their families and the palliative care workforce.
- To undertake high quality research, the outputs of which, should be the evidence which will help to ensure that all children and families receive equitable, high quality care



www.york.ac.uk/mhrc

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The Martin House RESEARCH CENTRE

Martin House Research Centre

The Martin House Research Centre is a partnership between Martin House Children's Hospice, the University of York (Department of Health Sciences and the Social Policy Research Unit) and the University of Leeds. It is a multi-disciplinary centre for research on the care and support of children and young people with palliative care needs, their families and the palliative care workforce. The Centre will be holistic in its scope, recognising that the care and support needs of children and families span clinical/medical, social, parenting/caring, spiritual, financial and practical domains.

Twitter updates

UoYmhrc Retweeted

Jan R. Boehnke
@jrboehnke

#job
#sysreview #cancer #children
#adolescents
@UoYmhrc

Jul 19, 2017

UoYmhrc Retweeted

Lorna Fraser
@lornafraser10

New paper @UoYmhrc Children with life-limiting conditions in

Team

Dr Lorna Fraser

Prof Bryony Beresford

Dr Roger Parslow

Dr Jan Aldridge

- Lecturer
- 3 research fellows
- Administrator
- 1 part time PhD student
- 2 fulltime PhD students

Epidemiological workstream

- All children and young people with Life-Threatening or Life-Limiting Conditions have EQUITABLE access to Paediatric Palliative Care Services when they need them
- ..we need reliable data to structure our services in line with need. To establish who the children are and what are their needs[1]
- Use a population based approach to planning services. Hospices need to engage in a strategic approach to planning their future services. This should take into consideration the current and anticipated future shape of the populations they serve[2]

[1]The Future of Hospice Care; Implications for the children's hospice and palliative care sector. Together for Short Lives, Sept 2013

[2] Future needs and preferences for hospice care: challenges and opportunities for hospices. Help the Hospices Commission into the future of hospice care. April 2013

Definitions (1)

- **The WHO Definition of Children's Palliative Care:** Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):
- **It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.**

Definitions (2)

- **Life-limiting conditions** are those for which there is no reasonable hope of cure and from which children or young people will ultimately die prematurely, e.g., Duchenne muscular dystrophy or neurodegenerative disease.
- **Life-threatening conditions** are those for which curative treatment may be feasible but can fail, e.g. cancer

ACT Categorisation

1. Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment are not included. **Examples: cancer, irreversible organ failures of heart, liver, kidney.**
2. Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. **Example: cystic fibrosis**.
3. Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. **Examples: Batten Disease, muscular dystrophy, mucopolysaccharodosis.**
4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. **Examples: severe cerebral palsy; multiple disabilities, such as follow brain or spinal cord injury**

Children in Scotland requiring Palliative Care (ChiSP Study)

ChiSP Project

- to develop an evidence base to support and inform planning for children's palliative care in Scotland
  - Workstream 1: Quantitative (analyses linked routine datasets)
  - Workstream 2: Qualitative review

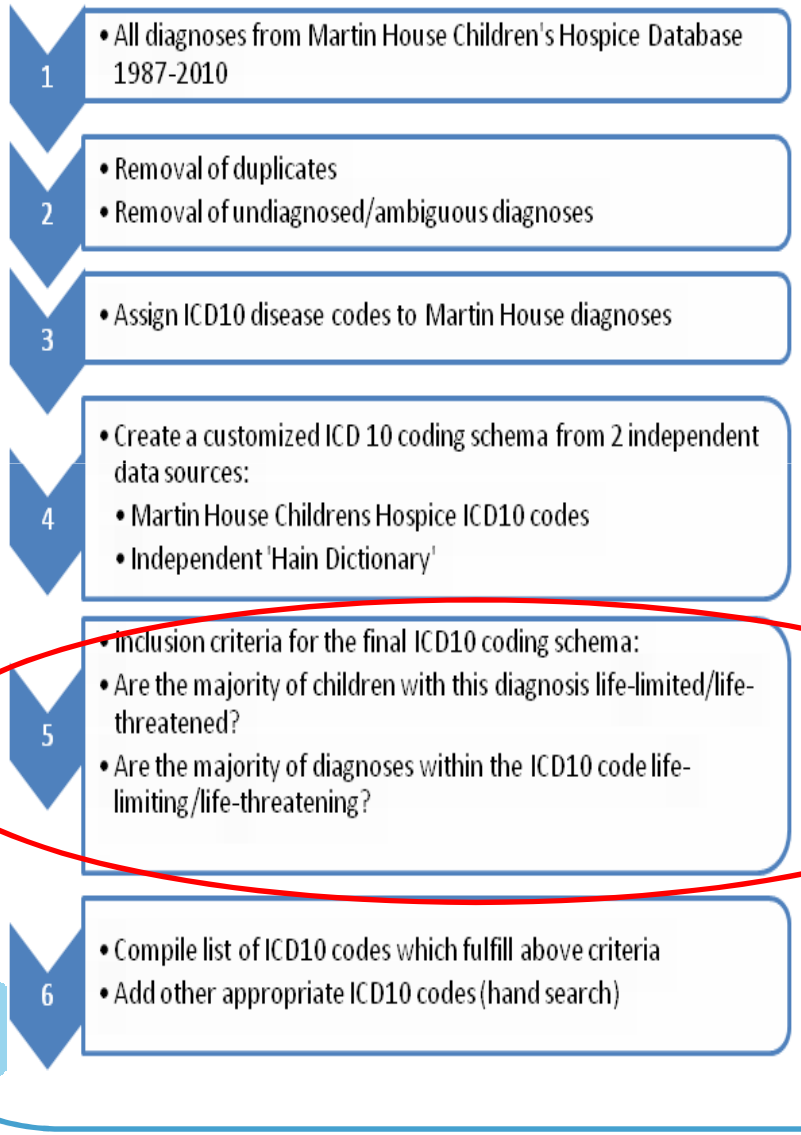
http://www.york.ac.uk/inst/spru/research/pdf/chisp.pdf

Robin House

Workstream1: Aims

- The actual **number** of children and young people with life-limiting or life-threatening conditions in Scotland
- The **number** of children and young people with palliative care needs, as well as their **ages**, any **underlying conditions**, care needs and **geographic locations** and **ethnicity**
- The **stage** of the condition (stable/unstable/deteriorating/dying) of each of these children and young people with palliative care needs

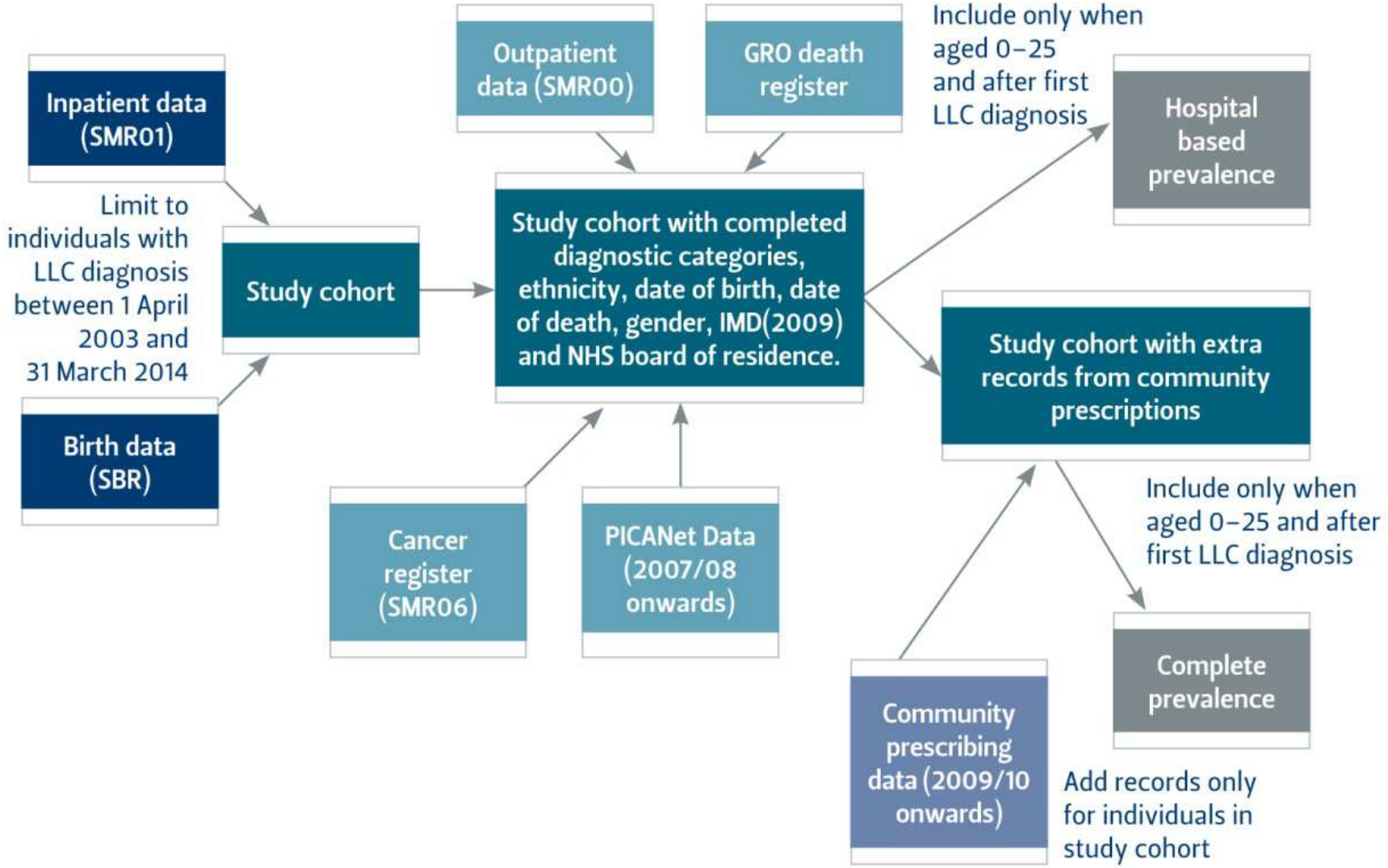
Identification



ICD 10 Coding Framework

Fraser LK, Miller M, Aldridge J, Norman P, Hain R, McKinney PA, Parslow RC. Rising National Prevalence of Life Limiting Conditions in Children in England. Pediatrics 2012 129 (4) e923-e929

Datasets

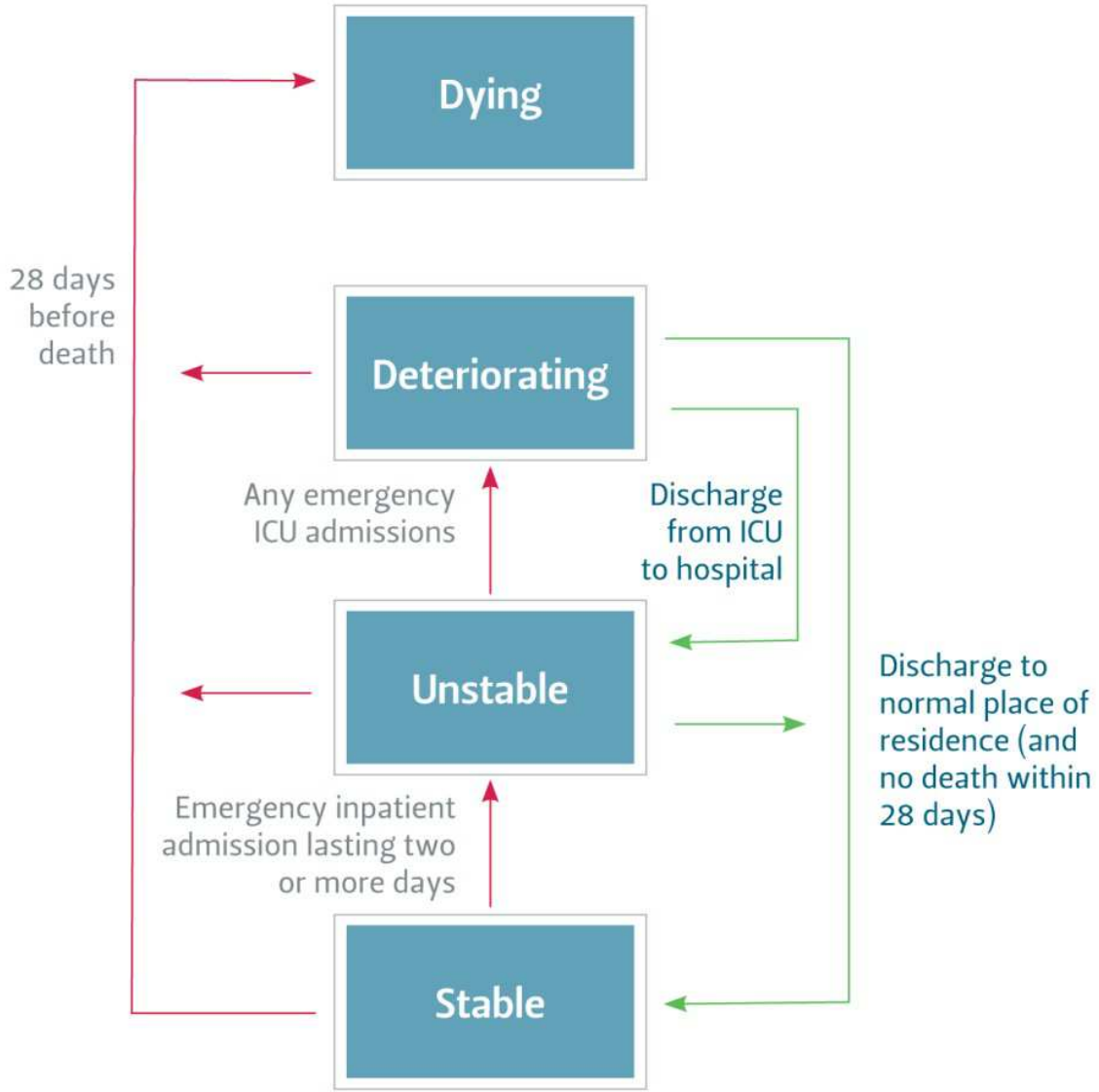

Inpatient data (SMR01)
Outpatient data (SMR00)
GRO death register
Include only when aged 0–25 and after first LLC diagnosis
Hospital based prevalence
Limit to individuals with LLC diagnosis between 1 April 2003 and 31 March 2014
Study cohort
Study cohort with completed diagnostic categories, ethnicity, date of birth, date of death, gender, IMD(2009) and NHS board of residence.
Study cohort with extra records from community prescriptions
Birth data (SBR)
Cancer register (SMR06)
PICANet Data (2007/08 onwards)
Include only when aged 0–25 and after first LLC diagnosis
Complete prevalence
Community prescribing data (2009/10 onwards)
Add records only for individuals in study cohort

Prevalence

$$prevalence = \frac{number\ of\ individuals\ with\ a\ LLC}{population\ at\ risk} \times 10000$$

- Hospital based prevalence
- 'Complete' prevalence
- Deaths/place of death
- Aggregate data from Childrens Hospice Association Scotland

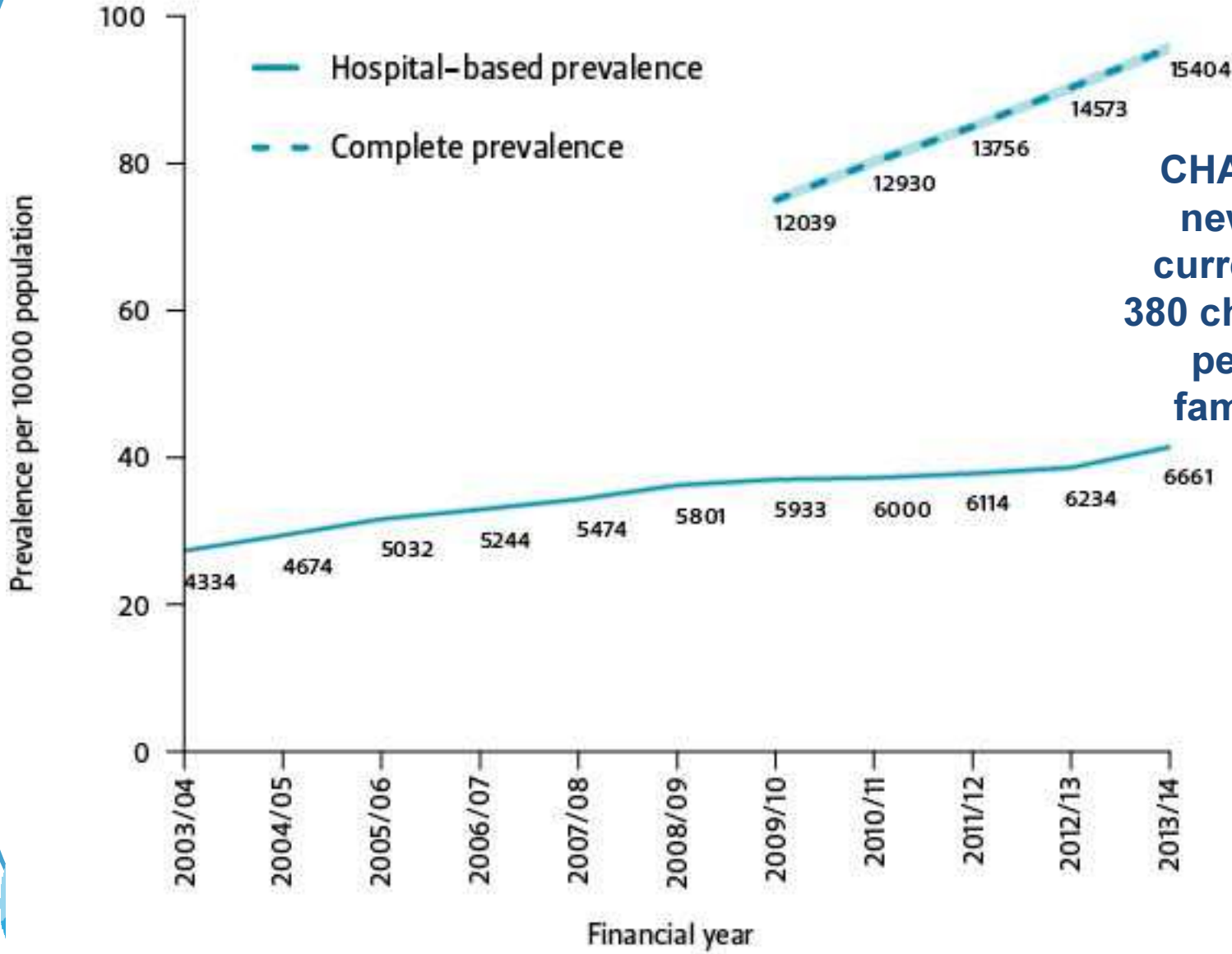
Stage of Condition



Results Part 1

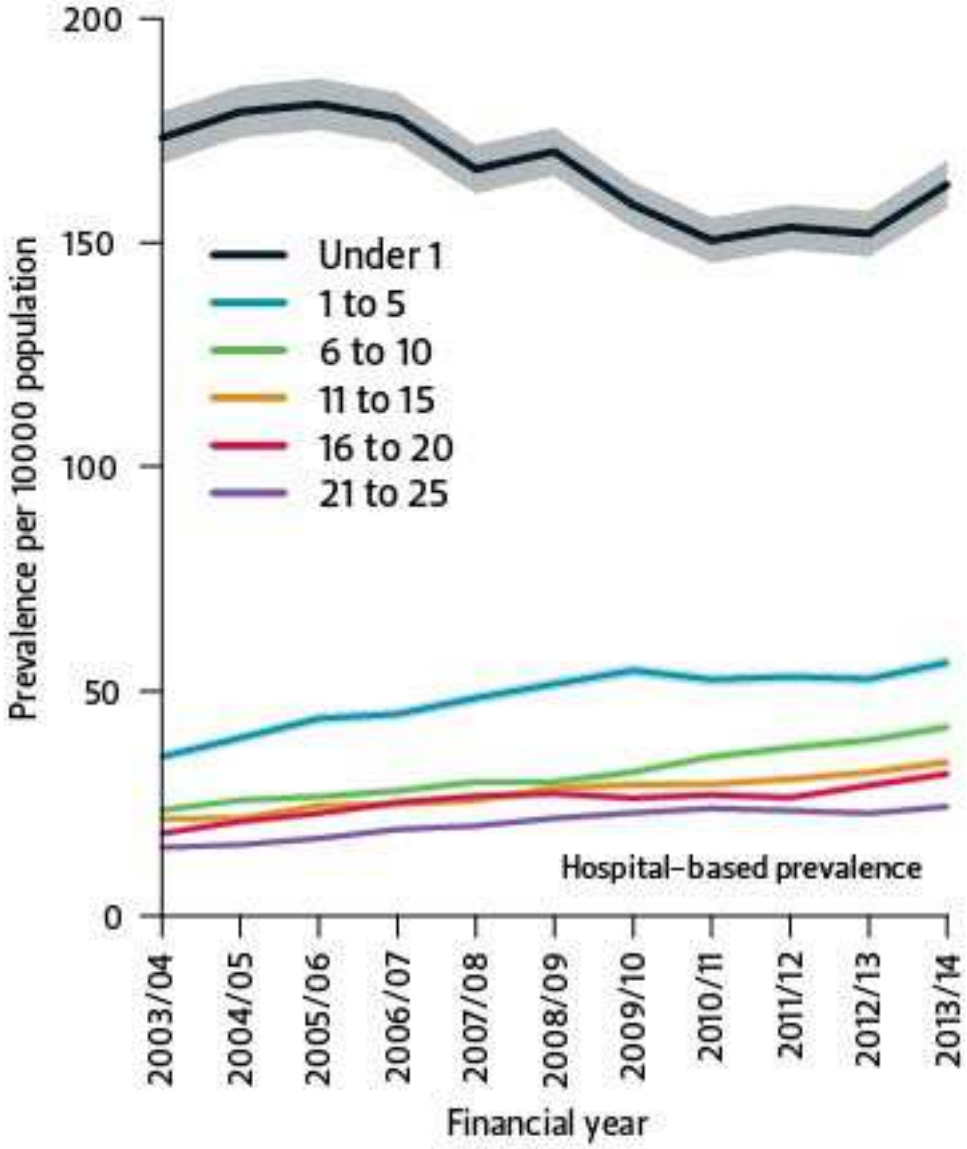
PREVALENCE

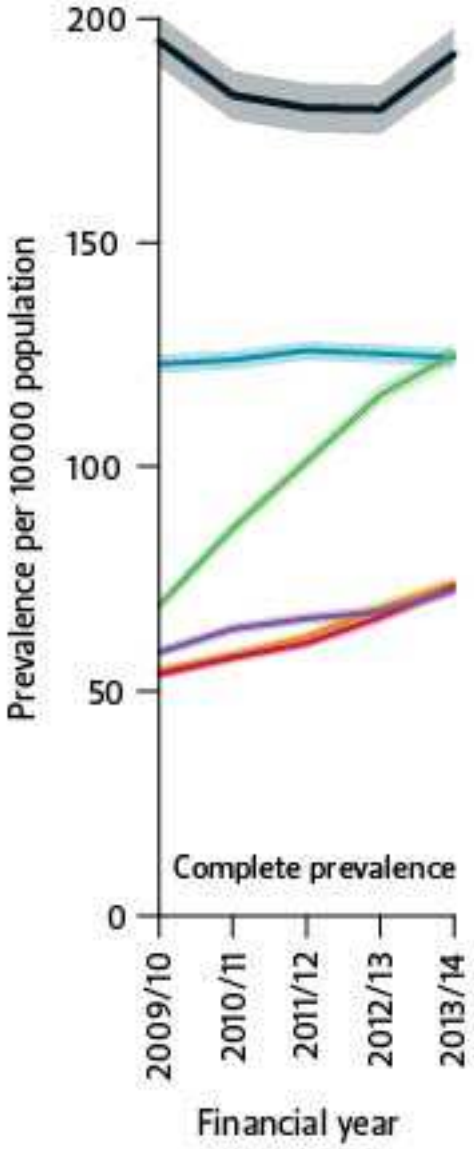
Prevalence



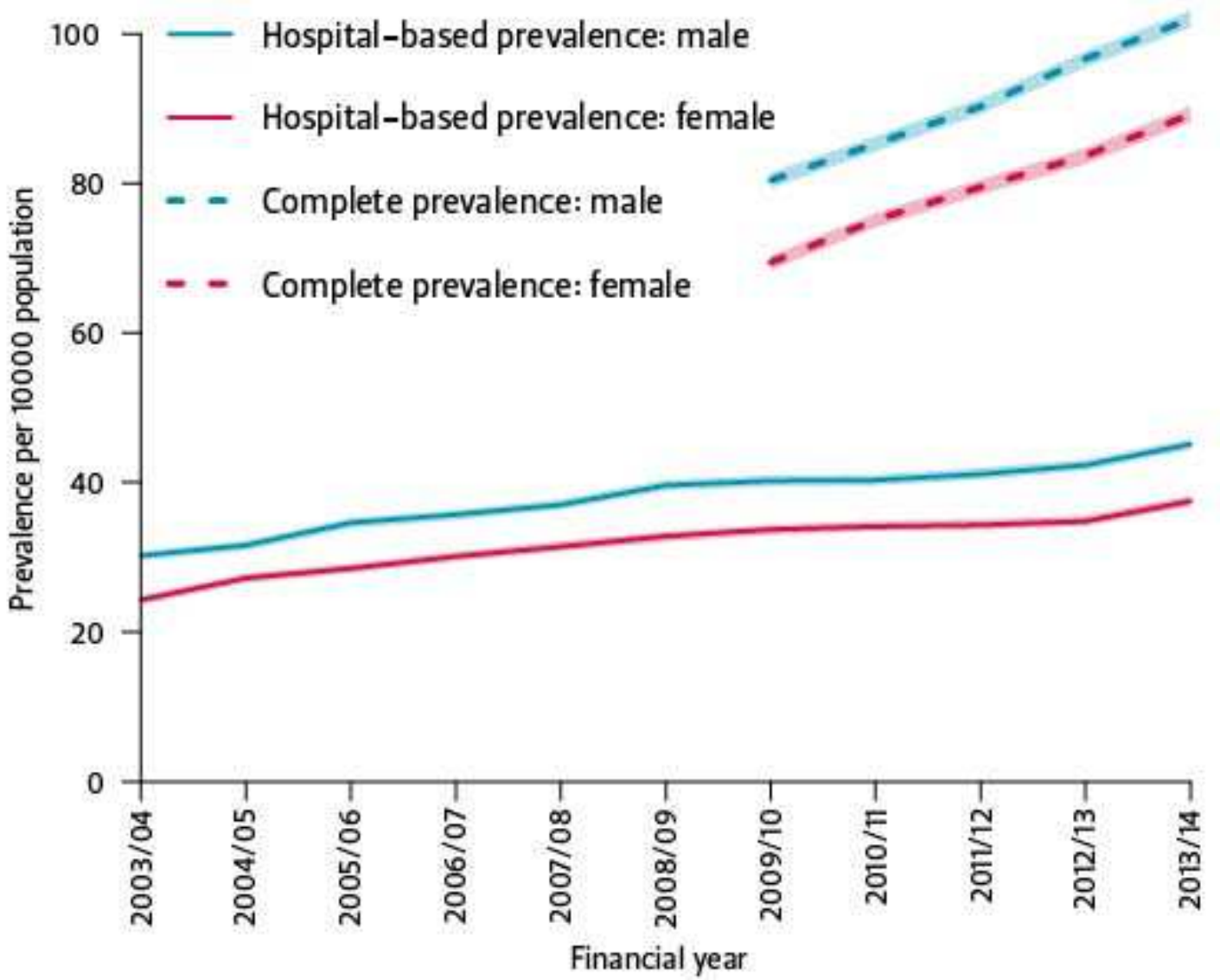
CHAS receive ~ 115 new referrals and currently cares for ~ 380 children and young people and their families each year

Prevalence by Age

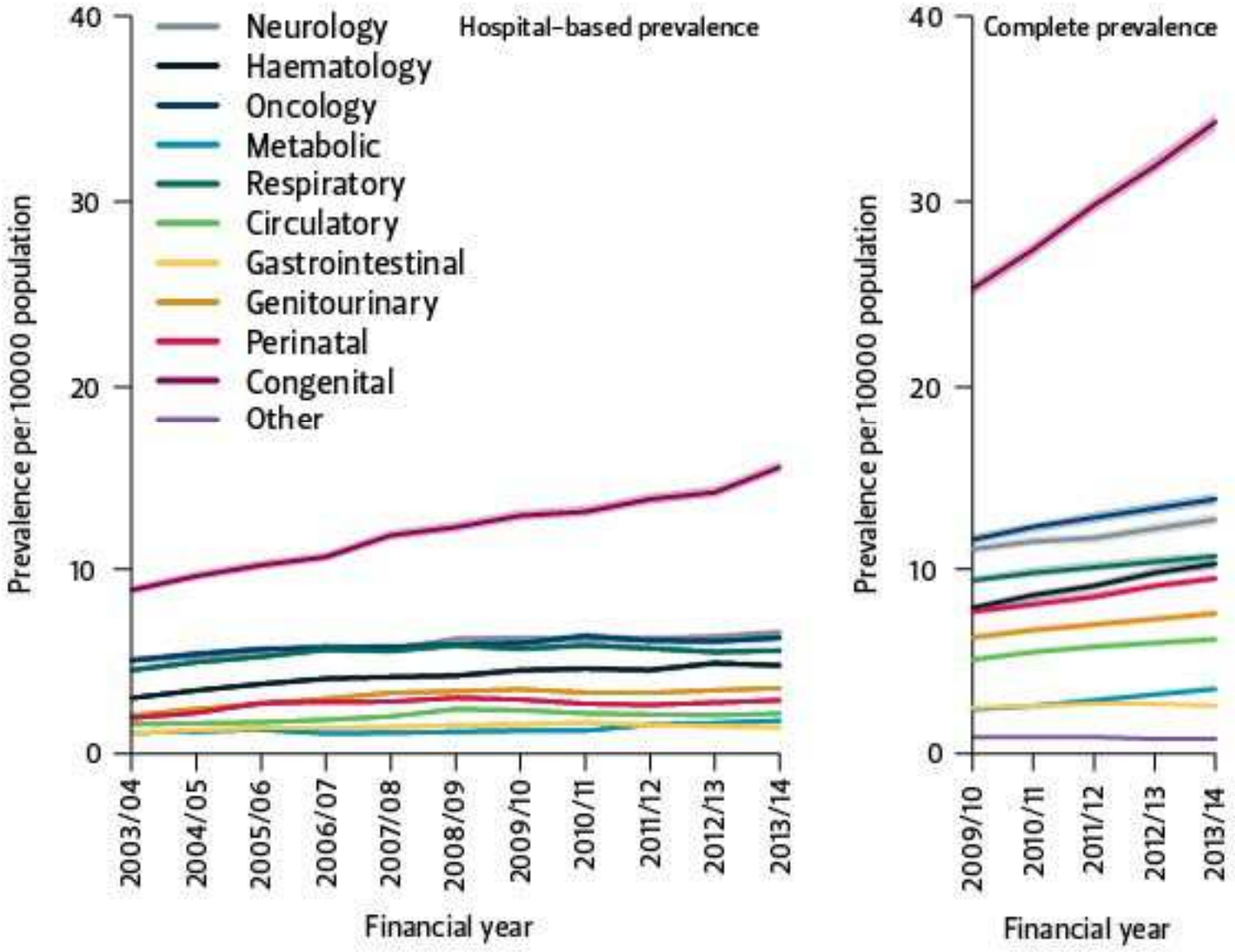




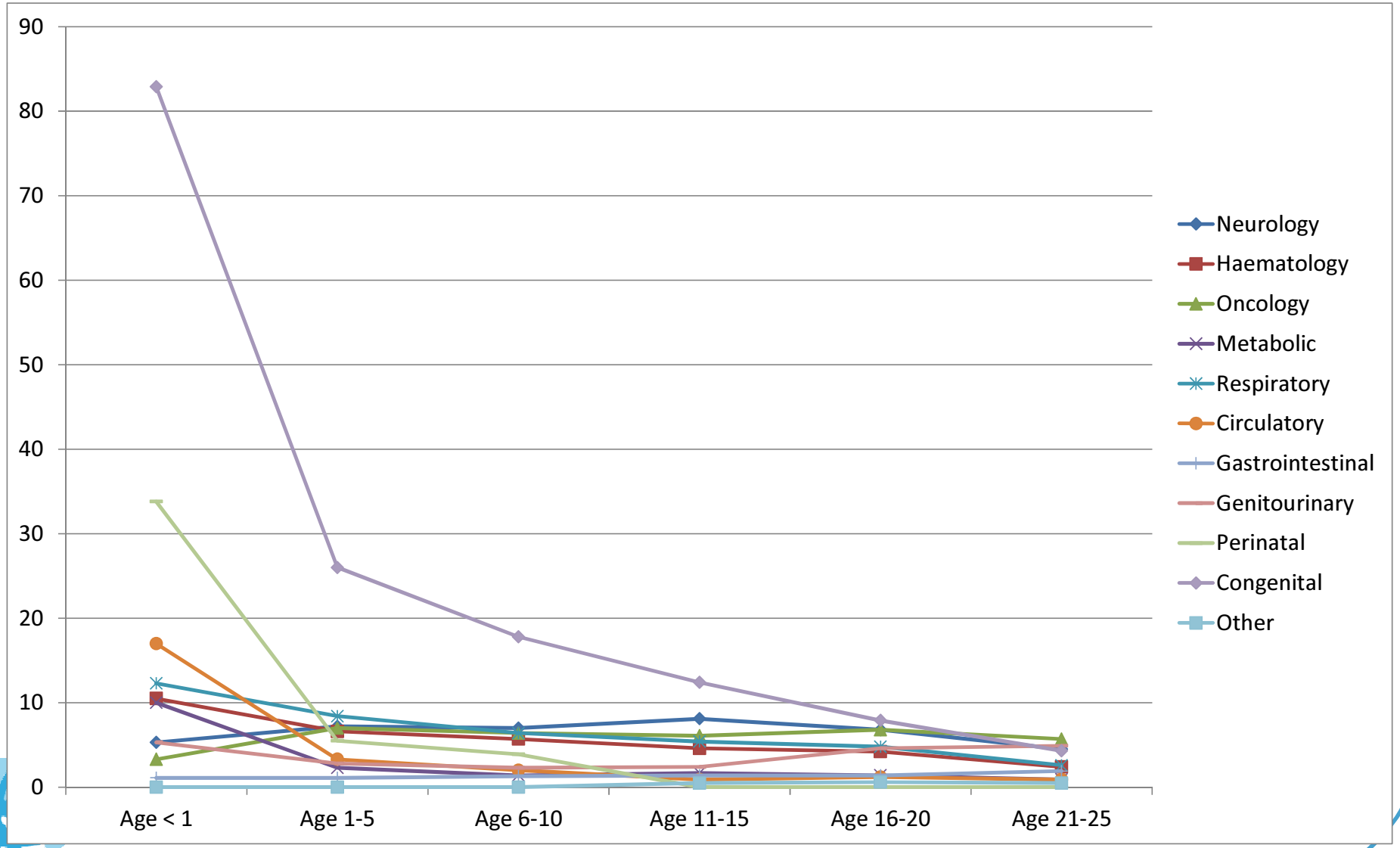
Prevalence by Gender



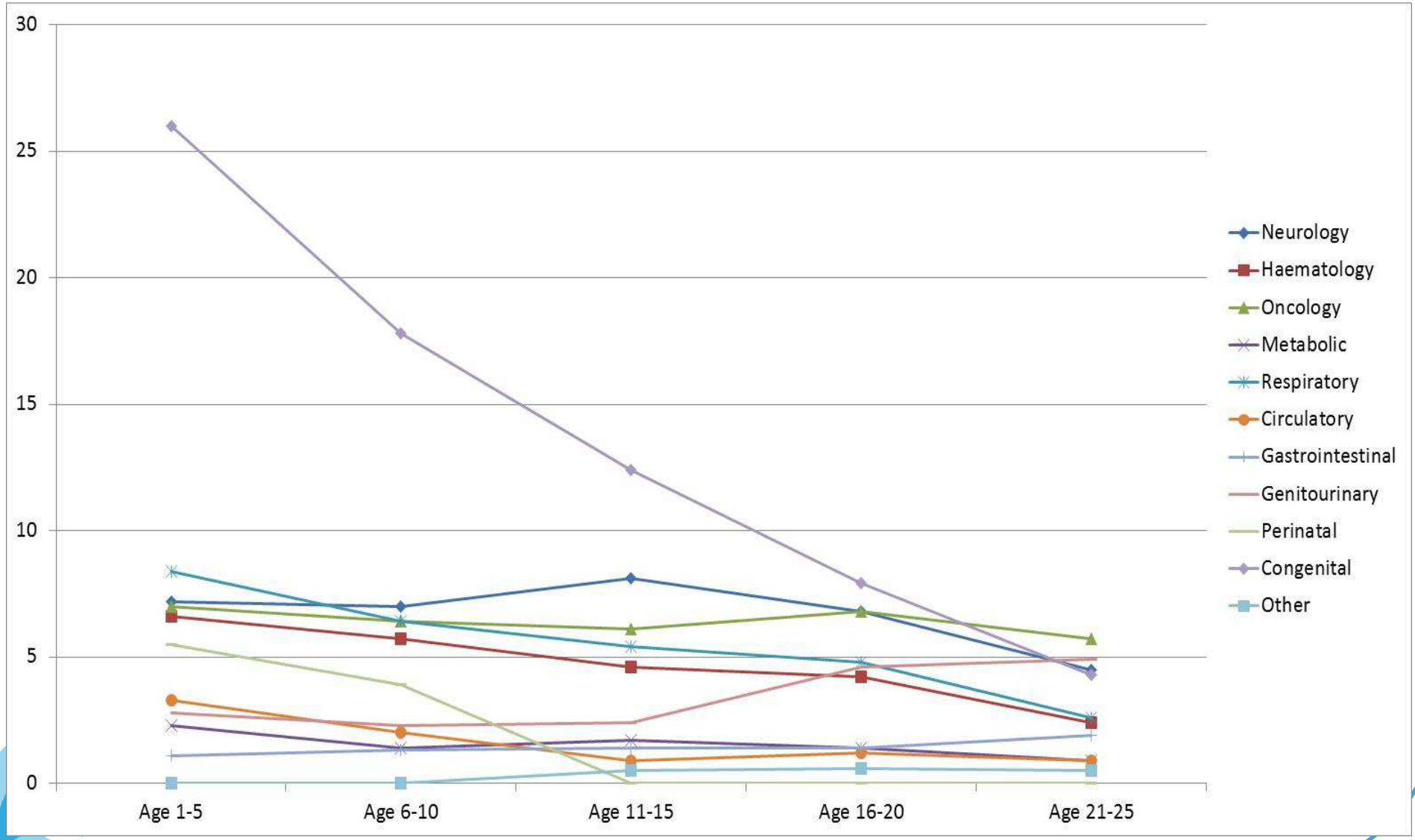
Prevalence by Diagnostic Group



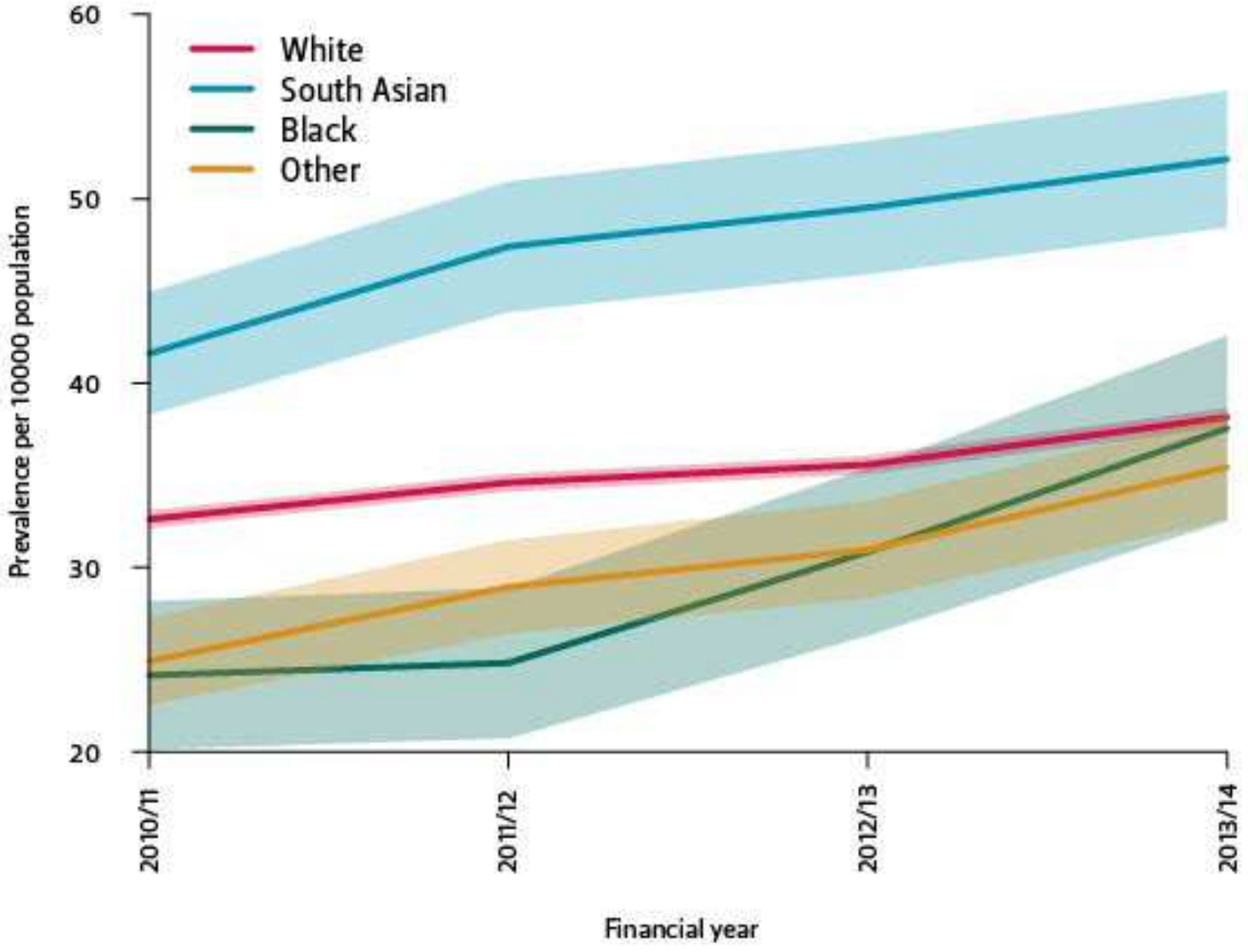
Diagnoses by Age (2013/14)



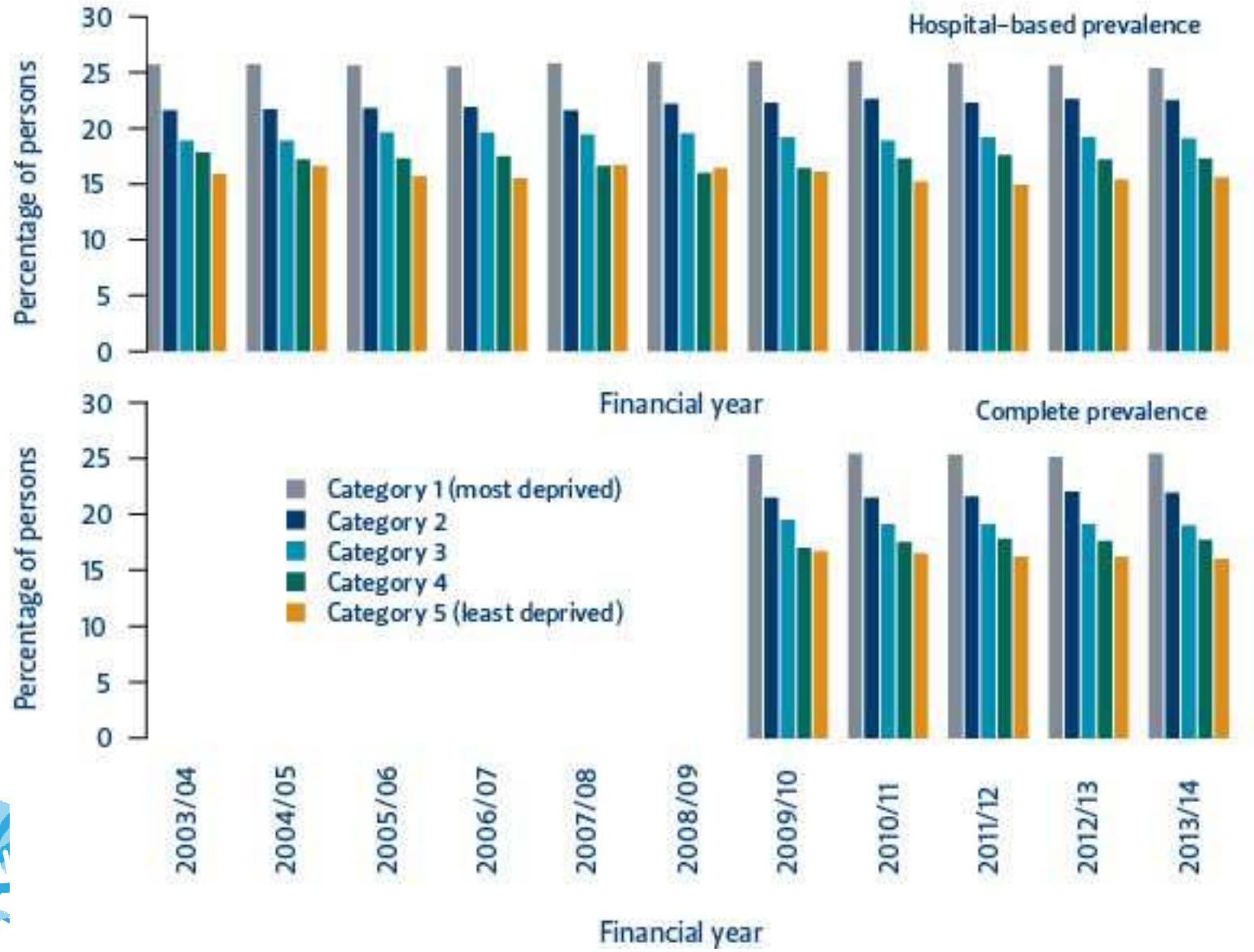
Diagnoses by Age (2013/14)



Prevalence by Ethnicity

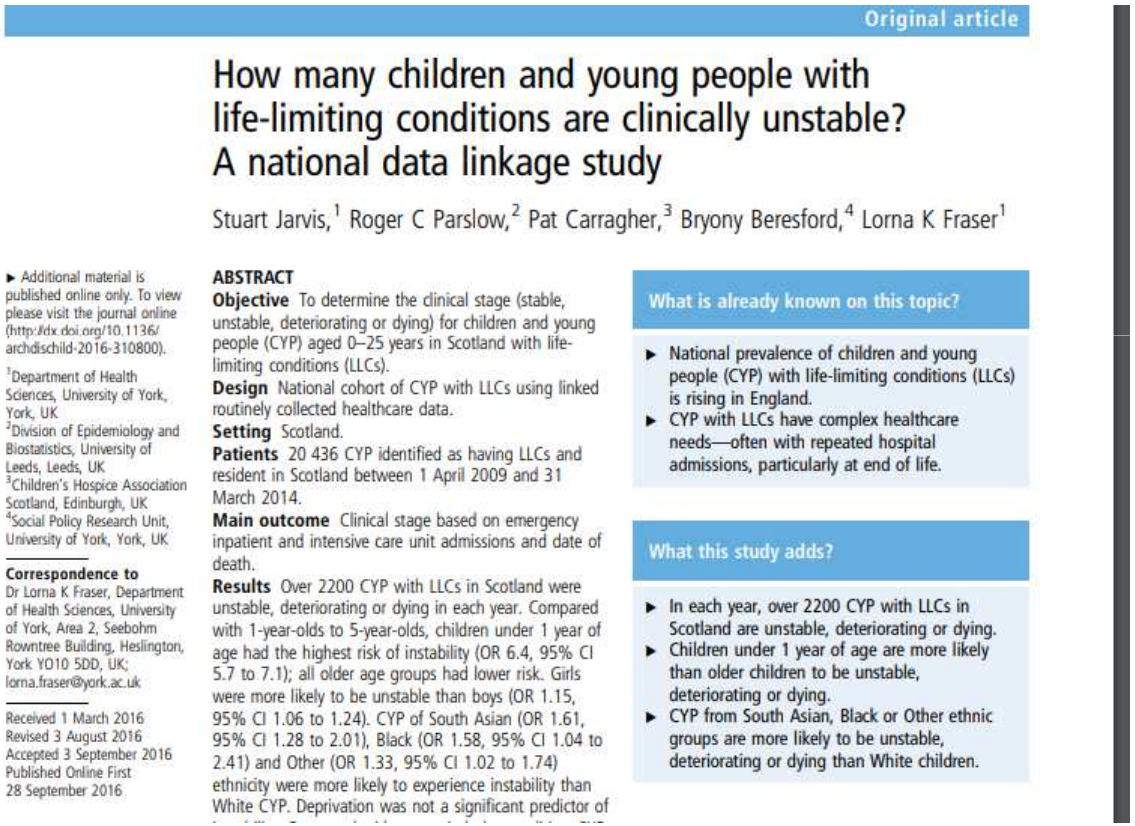


Deprivation Category



Results Part 2

STAGE OF CONDITION



Original article

How many children and young people with life-limiting conditions are clinically unstable? A national data linkage study

Stuart Jarvis,[1] Roger C Parslow,[2] Pat Carragher,[3] Bryony Beresford,[4] Lorna K Fraser[1]

► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/archdischild-2016-310800).

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[3]Children's Hospice Association Scotland, Edinburgh, UK
[4]Social Policy Research Unit, University of York, York, UK

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ABSTRACT
Objective To determine the clinical stage (stable, unstable, deteriorating or dying) for children and young people (CYP) aged 0–25 years in Scotland with life-limiting conditions (LLCs).
Design National cohort of CYP with LLCs using linked routinely collected healthcare data.
Setting Scotland.
Patients 20 436 CYP identified as having LLCs and resident in Scotland between 1 April 2009 and 31 March 2014.
Main outcome Clinical stage based on emergency inpatient and intensive care unit admissions and date of death.
Results Over 2200 CYP with LLCs in Scotland were unstable, deteriorating or dying in each year. Compared with 1-year-olds to 5-year-olds, children under 1 year of age had the highest risk of instability (OR 6.4, 95% CI 5.7 to 7.1); all older age groups had lower risk. Girls were more likely to be unstable than boys (OR 1.15, 95% CI 1.06 to 1.24). CYP of South Asian (OR 1.61, 95% CI 1.28 to 2.01), Black (OR 1.58, 95% CI 1.04 to 2.41) and Other (OR 1.33, 95% CI 1.02 to 1.74) ethnicity were more likely to experience instability than White CYP. Deprivation was not a significant predictor of

What is already known on this topic?

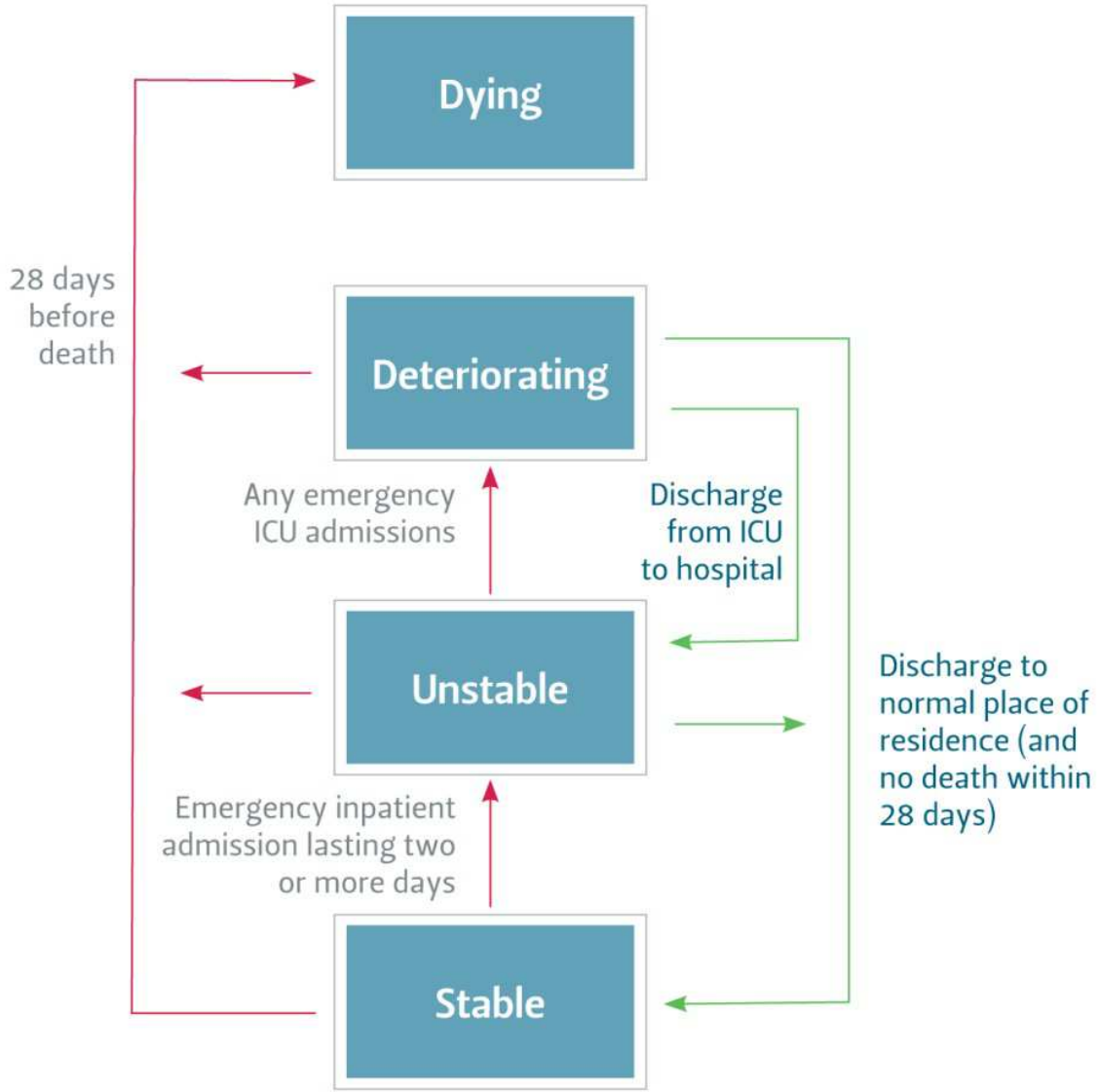
- National prevalence of children and young people (CYP) with life-limiting conditions (LLCs) is rising in England.
- CYP with LLCs have complex healthcare needs—often with repeated hospital admissions, particularly at end of life.

What this study adds?

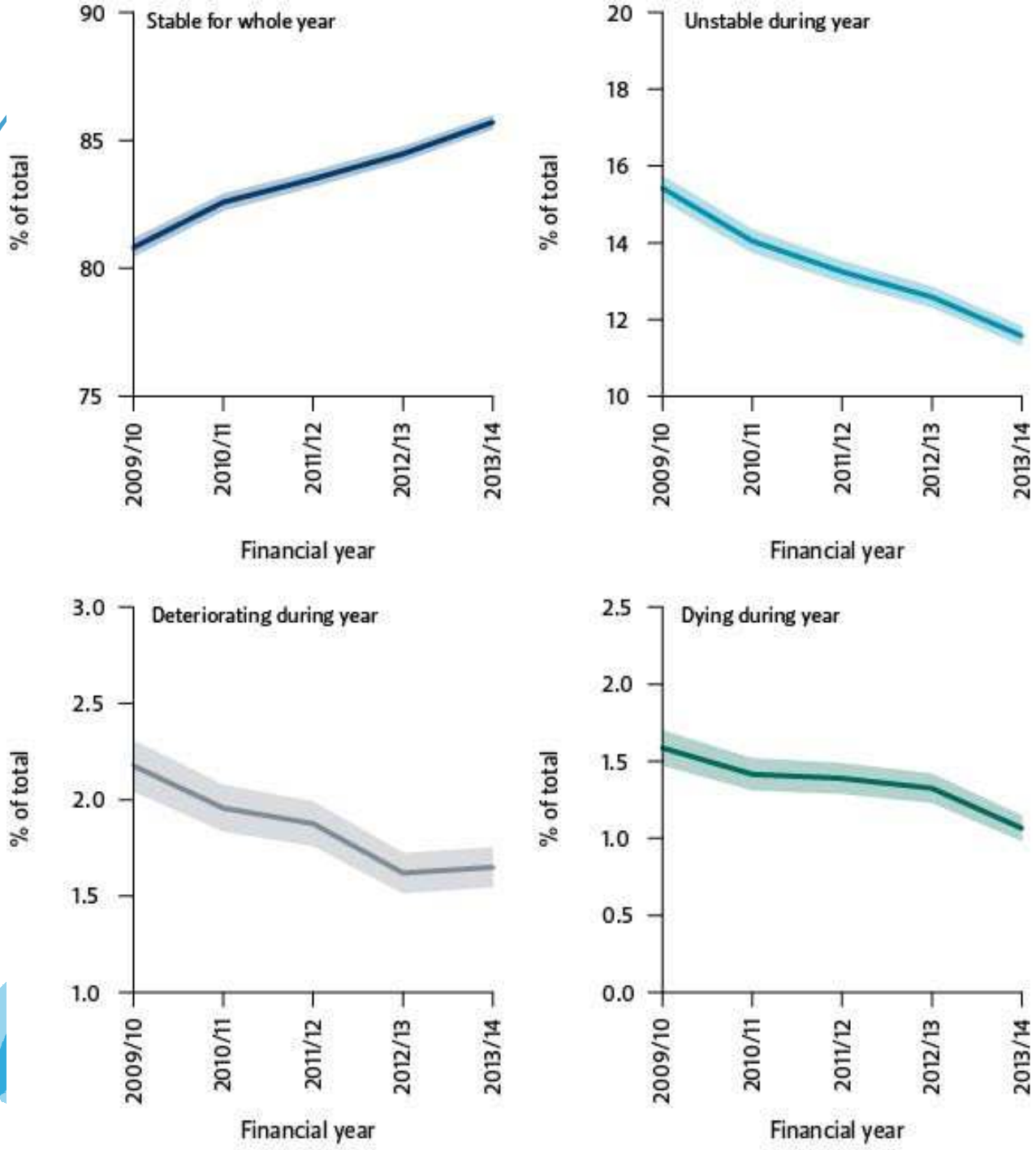
- In each year, over 2200 CYP with LLCs in Scotland are unstable, deteriorating or dying.
- Children under 1 year of age are more likely than older children to be unstable, deteriorating or dying.
- CYP from South Asian, Black or Other ethnic groups are more likely to be unstable, deteriorating or dying than White children.

Jarvis SW, Parslow RC, Carragher P, Beresford BA, Fraser LK. How many Children and Young People with Life Limiting Conditions are clinically unstable?: a National data linkage study. Archives of Disease in Childhood. 2016 Sep 28. Available from, DOI: 10.1136/archdischild-2016-310800

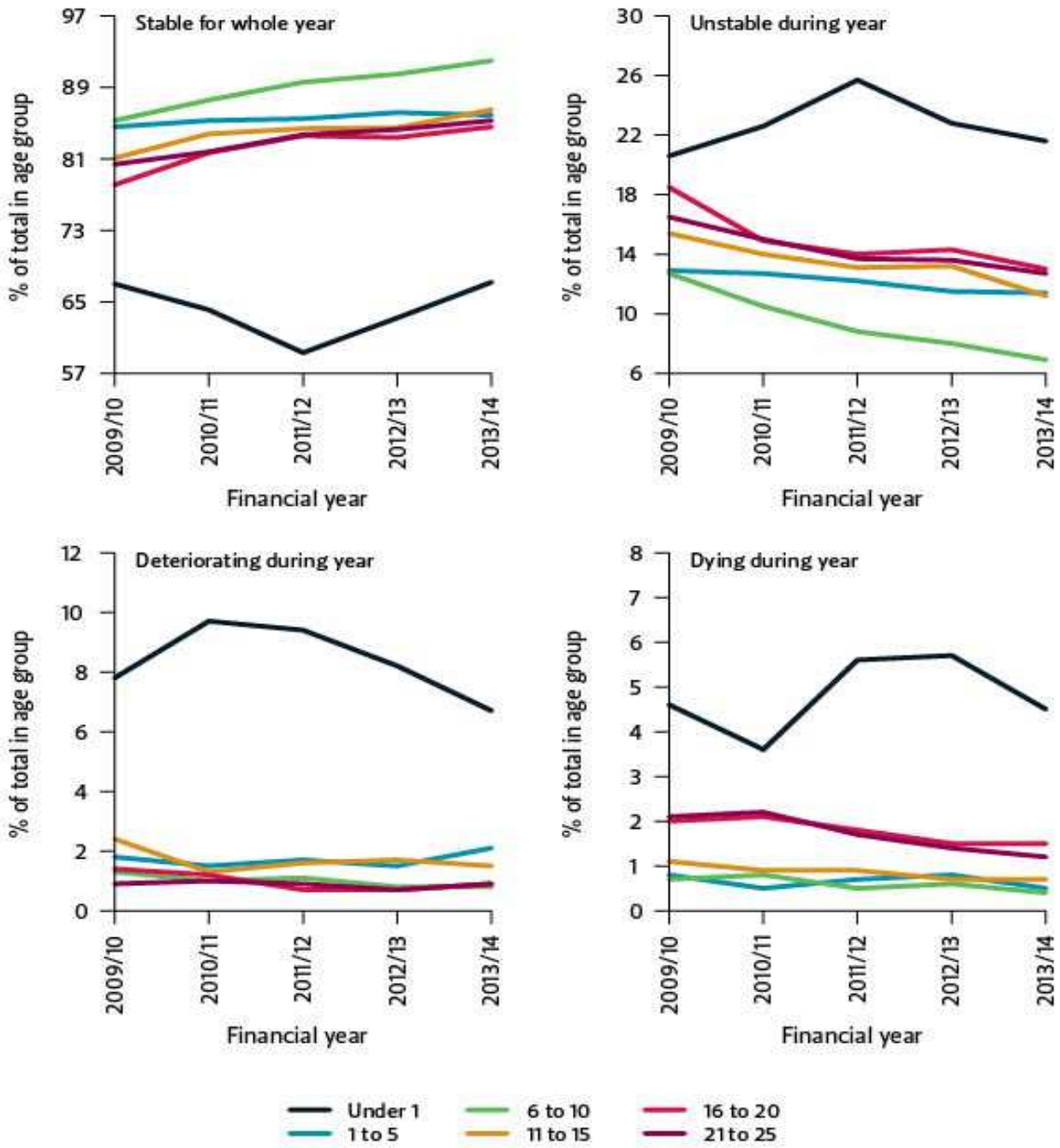
Stage of Condition



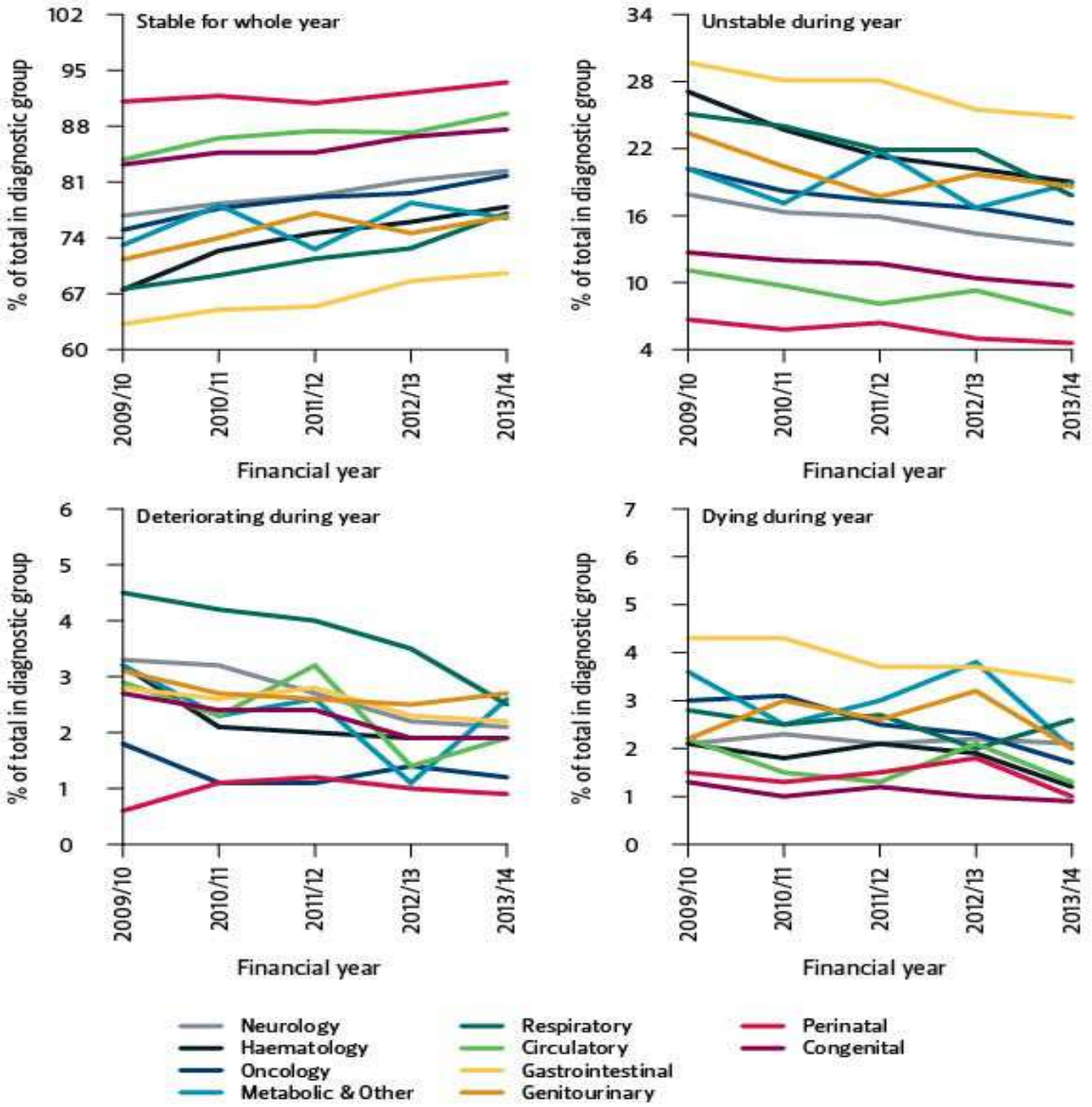
Stage of Condition

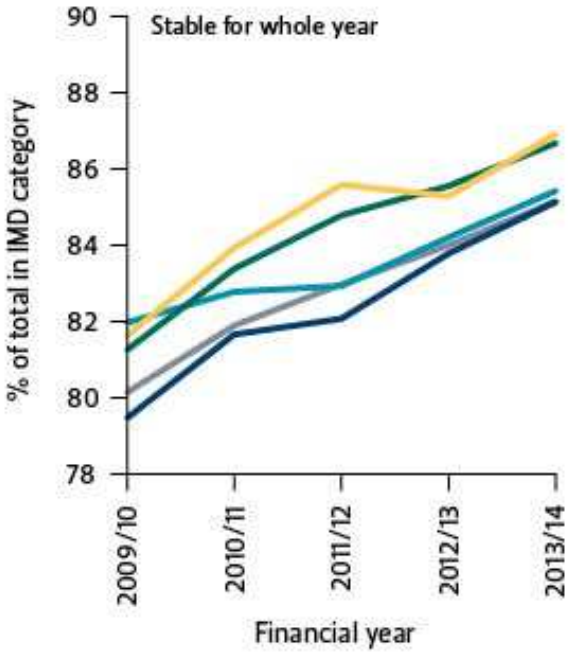


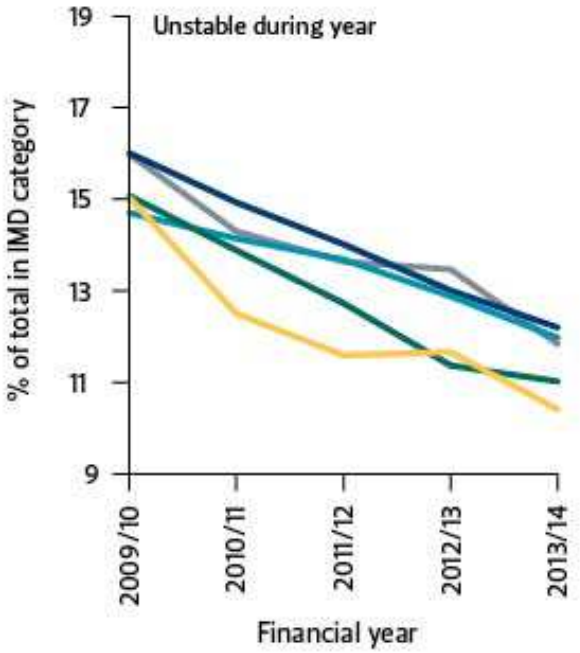
Stage of Condition by Age

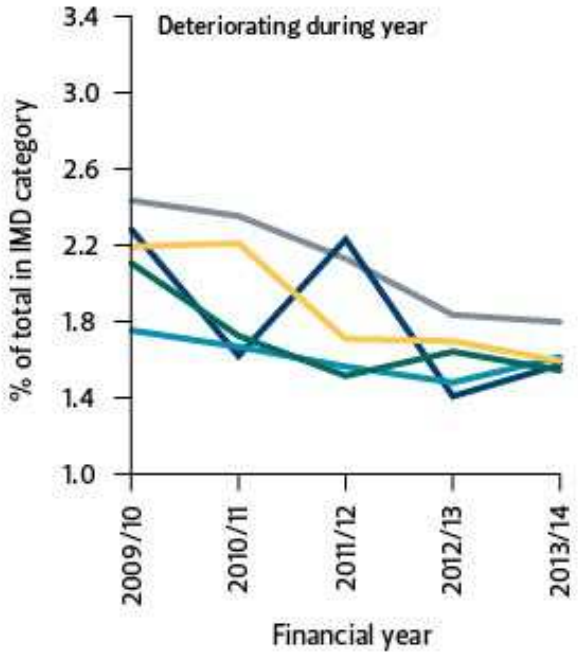


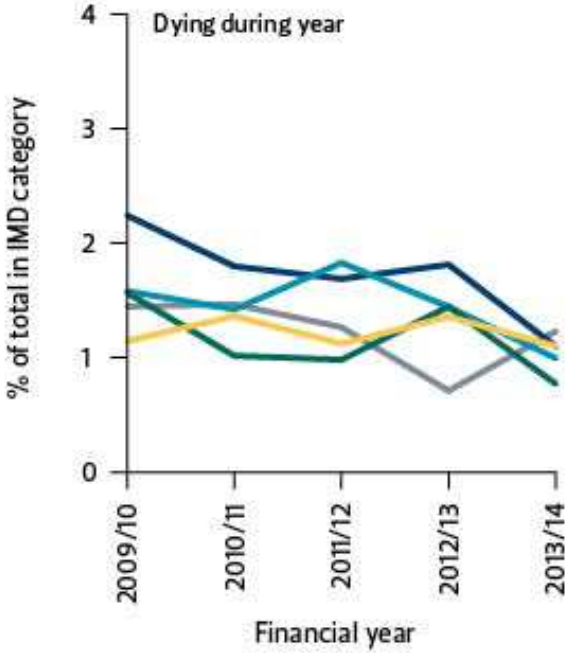
Stage of Condition by Diagnostic Group











Stage of Condition by Deprivation Category

Modelling Instability

- Binary Outcome:
  - Stable (for whole period present in year)
  - Not stable (unstable, deteriorating, dying at any point in year)
- Multilevel logistic regression:
  - Level 1: year
  - Level 2: individual
  - Allows for dependence between years for an individual
- Only ‘primary’ diagnostic group used

Modelling Instability

	OR	95% CI	
Age group (ref: 1-5)			
<1	6.40	5.74	7.15
6-10	0.54	0.49	0.60
11-15	0.73	0.65	0.82
16-20	0.80	0.71	0.90
21-25	0.66	0.59	0.75
Sex (ref: Male)			
Female	1.15	1.06	1.24
Ethnicity (ref: White)			
South Asian	1.61	1.28	2.01
Black	1.58	1.04	2.41
Other	1.33	1.02	1.74
IMD 2009 category (ref: 1 - most deprived)			
2	1.09	0.98	1.21
3	1.04	0.93	1.16
4	0.96	0.86	1.08
5 - least deprived	0.93	0.82	1.05

	OR	95% CI	
Diagnostic category (ref: Congenital)			
Neurological	2.53	2.23	2.88
Haematology	2.41	2.03	2.87
Oncology	3.75	3.31	4.25
Metabolic	2.34	1.88	2.91
Respiratory	3.50	3.06	4.00
Circulatory	0.89	0.72	1.09
Gastro-intestinal	5.22	3.91	6.96
Genitourinary	4.32	3.68	5.07
Perinatal	0.23	0.19	0.29
Other	3.11	1.88	5.12

- OR: odds ratio for risk of instability in a year

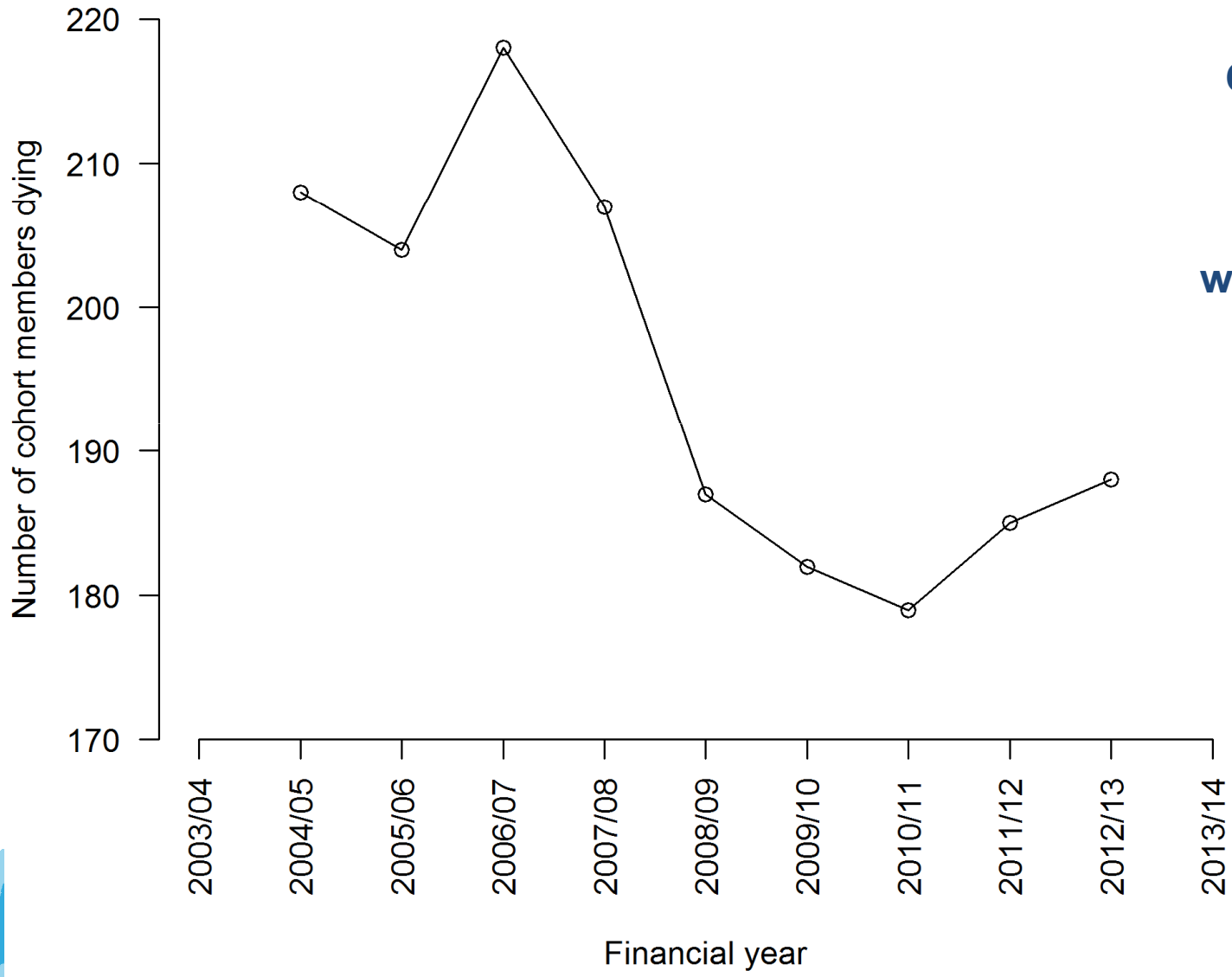
SoC Summary

- up to ~20% of CYP with a LLC experience instability each year
- Higher instability for under 1 age group:
  - ~35-40% not stable each year
- CYP with LLC from ethnic minority groups have significantly higher risk of instability
- Odds of instability varies by diagnostic group

Results Part 3

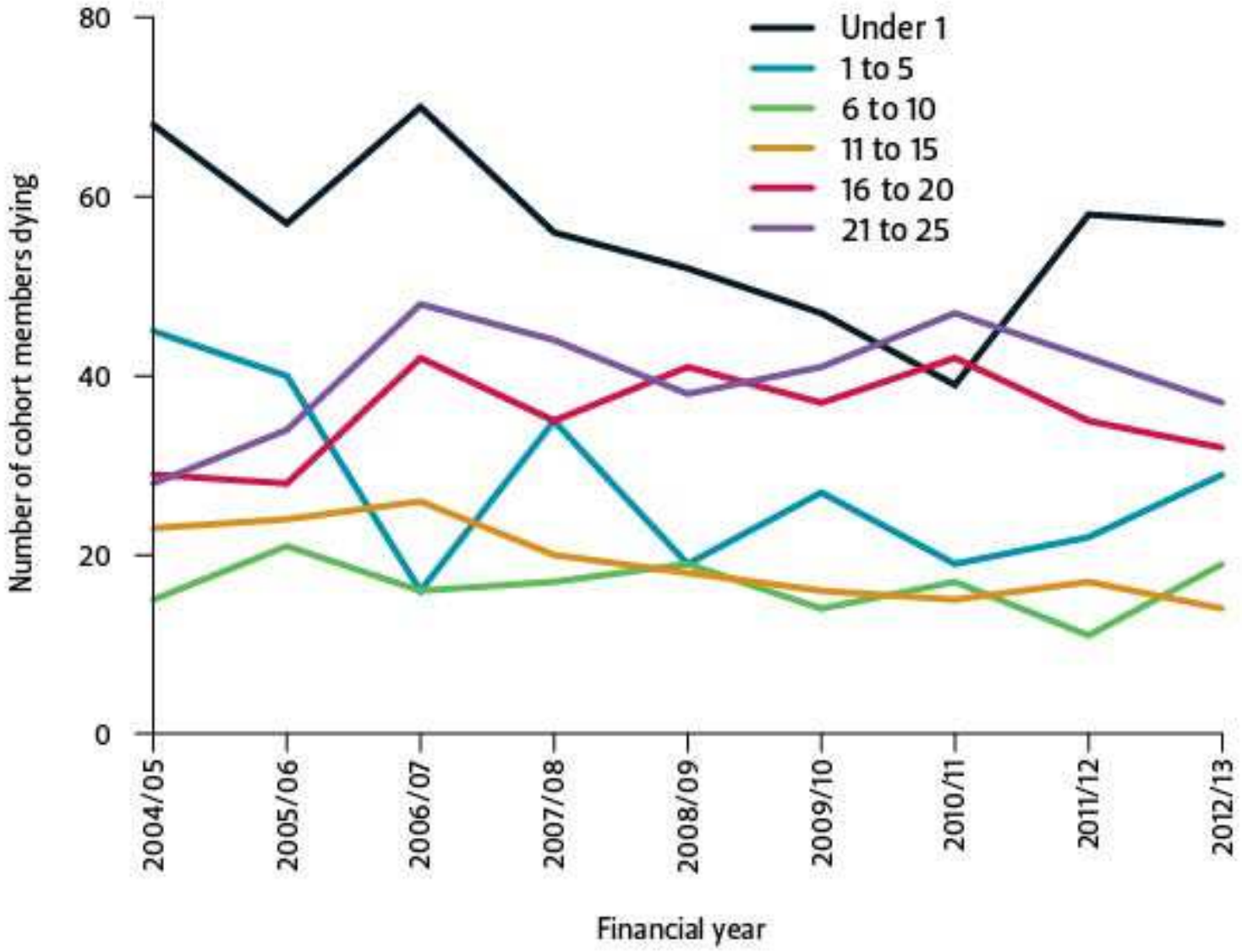
DEATHS

Number of Deaths

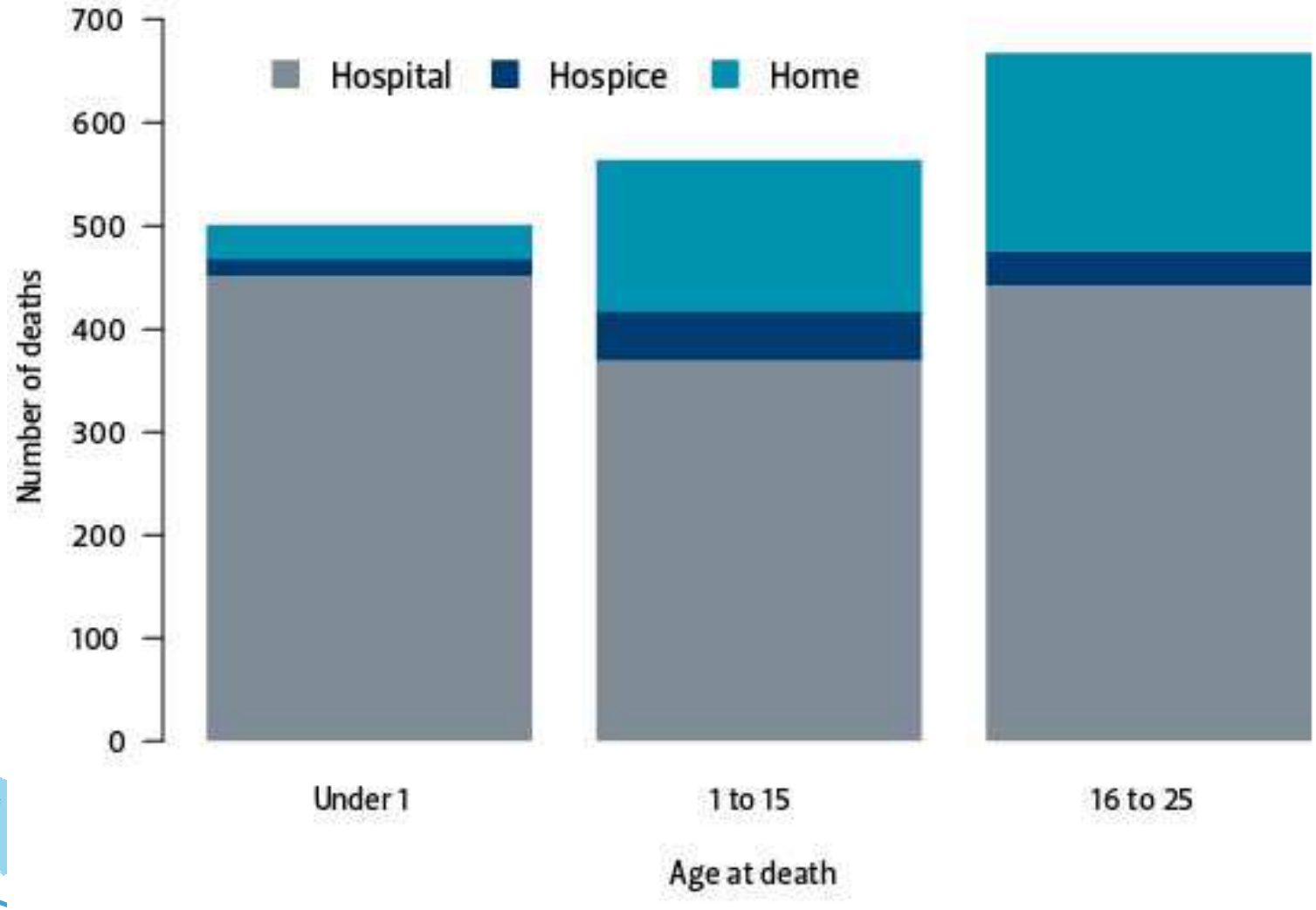


CHAS currently cares for ~ 60 children and young people who die each year

Deaths by Age



Place of Death



Recommendations for Scotland

FIRST 5!

Recommendations

1. More children and young people of ALL AGES in Scotland with life-limiting conditions should have input from palliative care services
2. Children [illegible] year of age should be seen as a priority group for [illegible] palliative care services
3. Age specific palliative care services for young people (aged 16-25 years) with a life-limiting condition in Scotland should be developed
4. Palliative care services should be able to provide culturally competent care to children and young people from ALL ethnic groups.
5. Future development of palliative care services in Scotland should ensure that access to services for children and young people from areas of high deprivation is prioritised

Strengths/Limitations

- Strengths
  - High quality administrative data
  - Refinement of ICD10 coding framework
  - Transparent and repeatable methodology
- Limitations
  - Disclosure control limitations
  - No linkage to CHAS data
  - No data from other PPC providers
  - ICD 10 coding ? Specificity
  - Stage of condition transition definitions

Policy

Strategic Framework for Action on Palliative and End of Life Care

Commitments

The Scottish Government commits to working with stakeholders to:

1. Support Healthcare Improvement Scotland in providing Health and Social Care Partnerships with expertise on testing and implementing improvements in the identification and care co-ordination of those who can benefit from palliative and end of life care.

2. Provide strategic commissioning guidance on palliative and end of life care to Health and Social Care Partnerships.

3. Support the development of a new palliative and end of life care educational framework.

4. Support and promote the further development of holistic palliative care for the 0-25 years age group.

5. Support the establishment of the Scottish Research Forum for Palliative and End of Life Care.

6. Support greater public and personal discussion of bereavement, death, dying and care at the end of life, partly through commissioning work to facilitate this.

7. Seek to ensure that future requirements of e-Health systems support the effective sharing of individual end of life/Anticipatory Care Planning conversations.

8.Support clinical and health economic evaluations of palliative and end of life care models.

9. Support improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care.

10. Establish a new National Implementation Support Group to support the implementation of improvement actions.

Impact

Scottish Government
Riaghaltas na h-Alba
gov.scot

About Topics

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NEWS

Children's palliative care boost

Published: **14 Oct 2016**

Part of: Health and social care

£30 million investment in CHAS.

Health Secretary Shona Robison has announced plans for increased investment in specialist children's palliative care and end of life services.

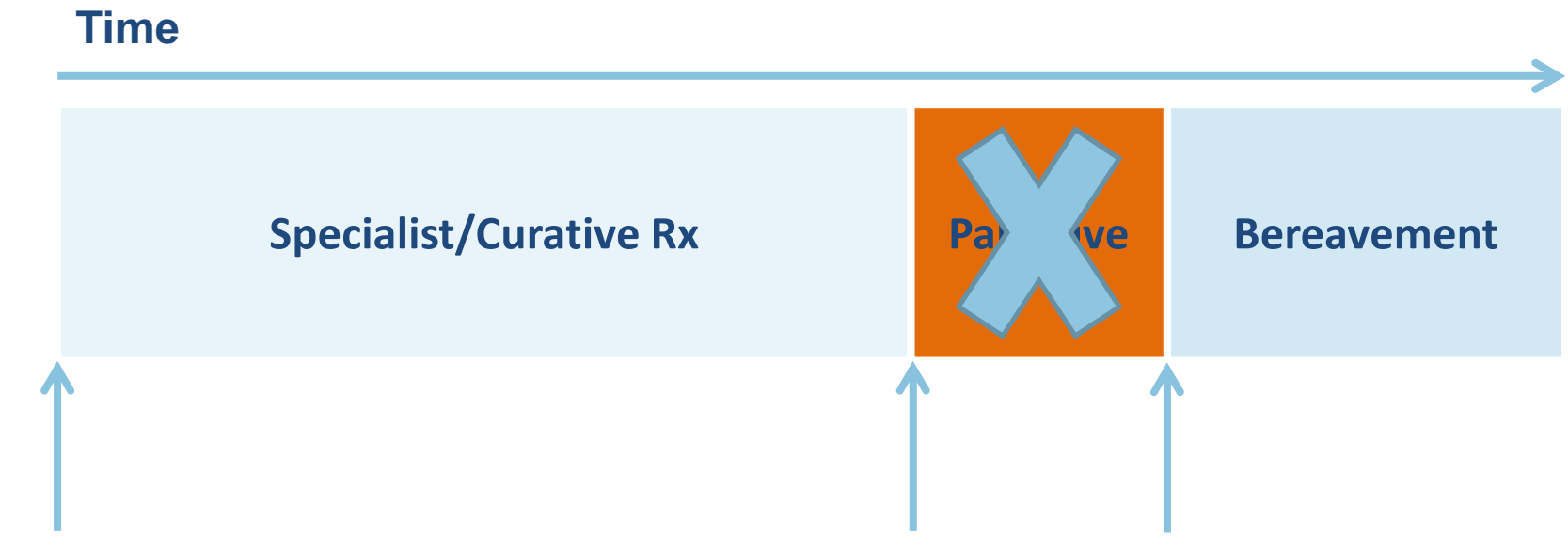
As part of this, the Children's Hospice Association Scotland (CHAS) is to receive approximately £30 million over the next five years to support its vital work with children with life-shortening conditions and their families.

CHAS hospices in Kinross and Balloch offer families short planned breaks, emergency support, end of life care and a range of bereavement services. The charity also provides a home care service, helping families when they need it most.

Ms Robison said:

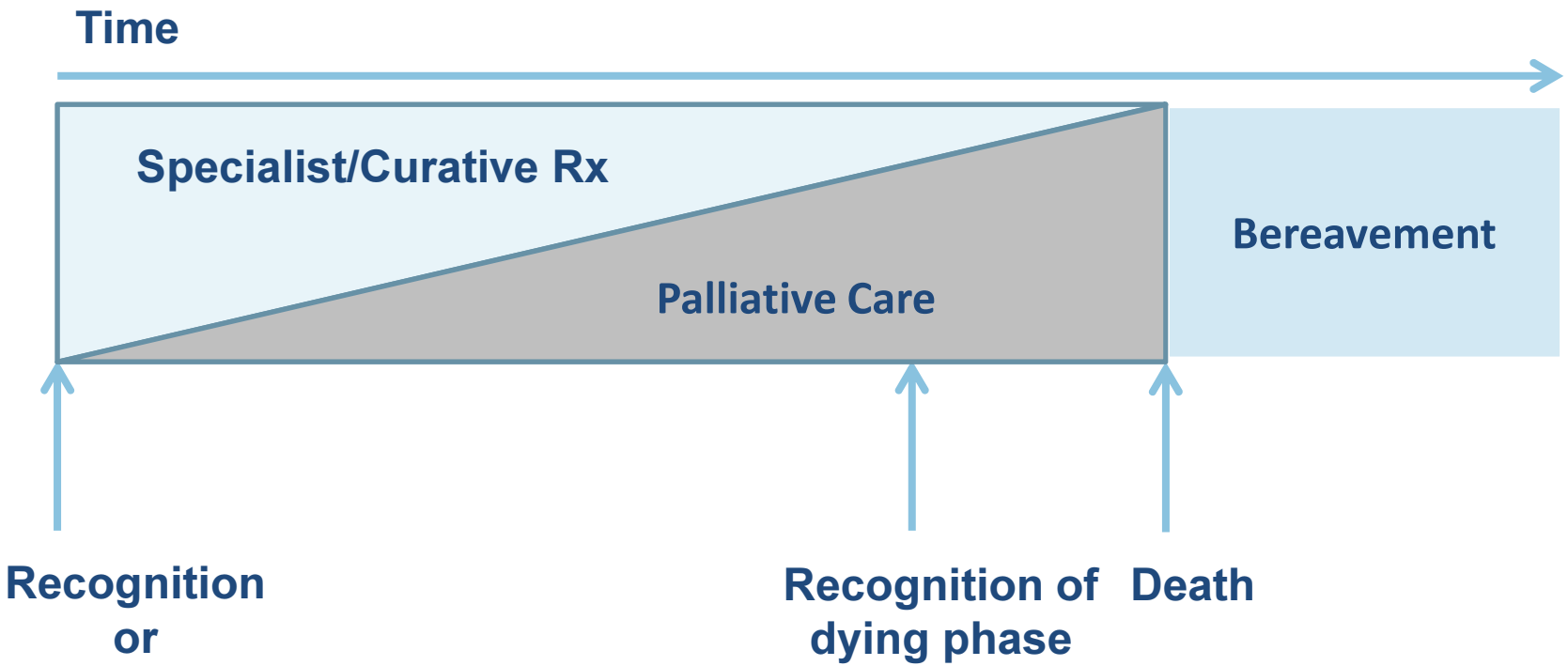
MODELS OF CARE

Recognition



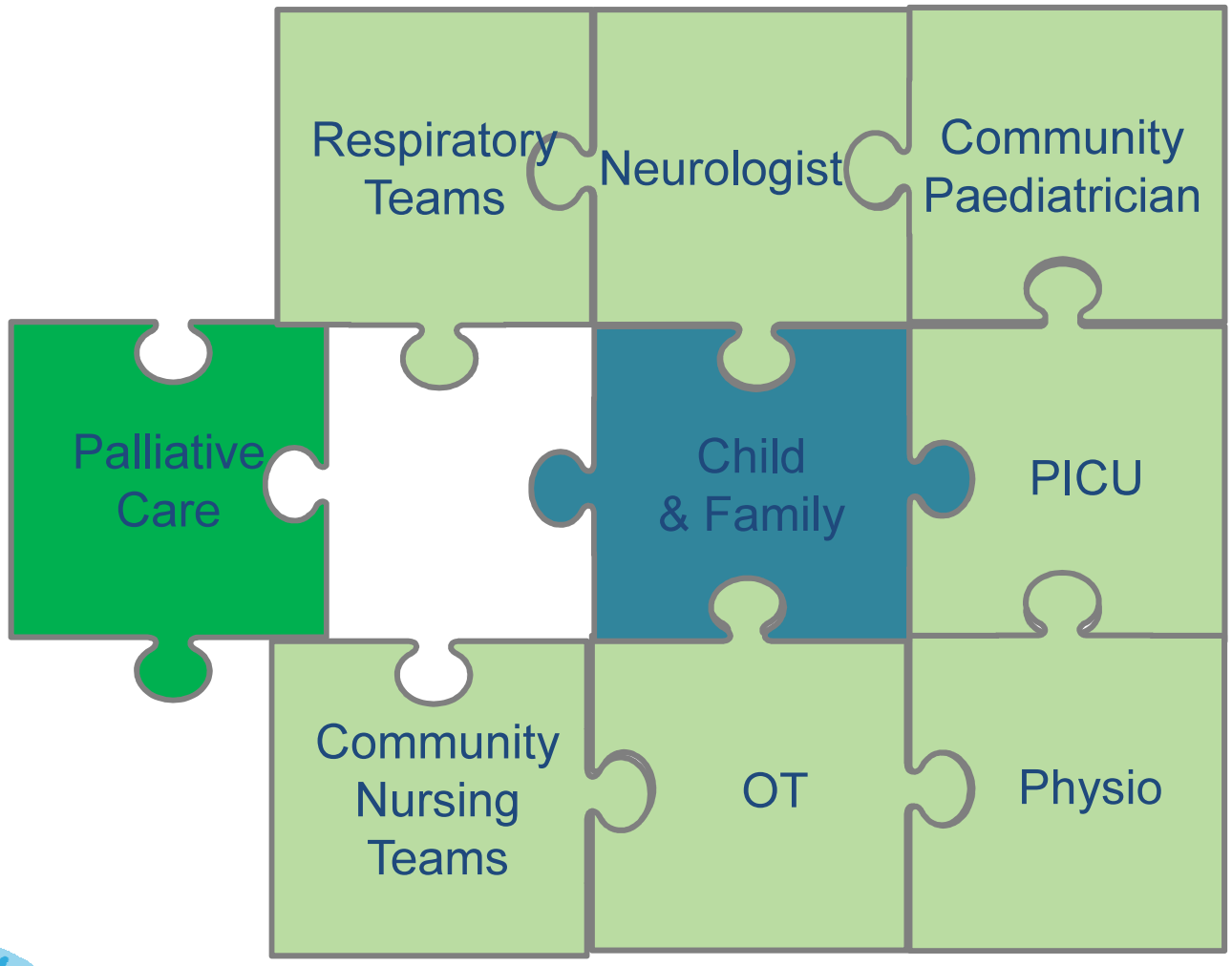
Not ONLY end of life care

Integration 1



Fluid relationship

Parallel planning


Respiratory Teams
Neurologist
Community Paediatrician
Palliative Care
Child & Family
PICU
Community Nursing Teams
OT
Physio

Key Relationships

PICU  **Palliative Care**

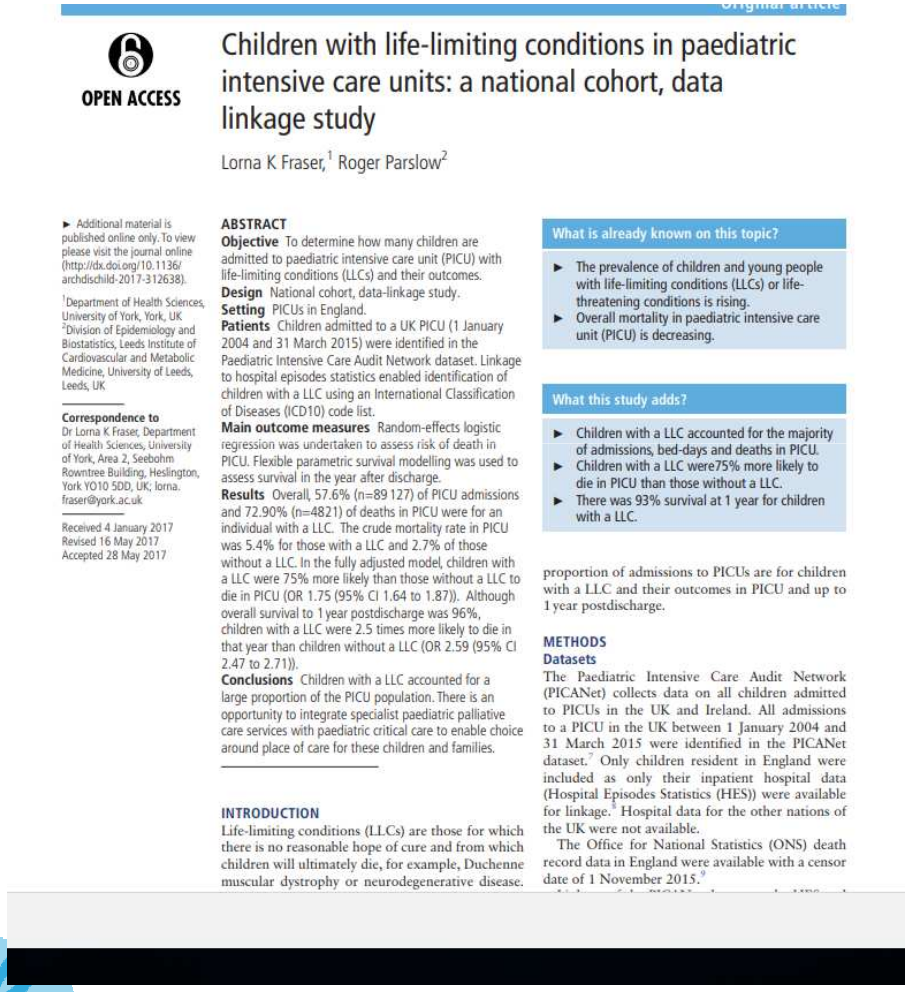
Place of Death after discharge from PICU

- 110,328 children discharged alive PICU 2004- 2014
- 852 children discharged to palliative care.
- 7709 deaths occurred after first discharge from PICU.
- Overall 73.7% deaths in hospital (32.5%PICU), 16.6% home, 8.7% hospice, 1.3 % other/unknown.
- Trends over time ↓ hospital
- For children who died
  - Adjusted OR **8.06** (95%CI 6.50-10.01) of children ever discharged to PALLIATIVE CARE of dying in community (home or hospice) rather than hospital

Fraser LK, Fleming S, Parslow R. Changing Place of Death in Children who died after discharge from Paediatric Intensive Care Units: a national, data linkage study. Palliative Medicine. 2017 May 12;1-10. Available from, DOI: 10.1177/0269216317709711

PICA Net

Children with Life-Limiting Conditions in PICU: a national cohort, data linkage study



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Children with life-limiting conditions in paediatric intensive care units: a national cohort, data linkage study

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ABSTRACT

Objective To determine how many children are admitted to paediatric intensive care unit (PICU) with life-limiting conditions (LLCs) and their outcomes.

Design National cohort, data-linkage study.

Setting PICUs in England.

Patients Children admitted to a UK PICU (1 January 2004 and 31 March 2015) were identified in the Paediatric Intensive Care Audit Network dataset. Linkage to hospital episodes statistics enabled identification of children with a LLC using an International Classification of Diseases (ICD10) code list.

Main outcome measures Random-effects logistic regression was undertaken to assess risk of death in PICU. Flexible parametric survival modelling was used to assess survival in the year after discharge.

Results Overall, 57.6% (n=89 127) of PICU admissions and 72.90% (n=4821) of deaths in PICU were for an individual with a LLC. The crude mortality rate in PICU was 5.4% for those with a LLC and 2.7% of those without a LLC. In the fully adjusted model, children with a LLC were 75% more likely than those without a LLC to die in PICU (OR 1.75 (95% CI 1.64 to 1.87)). Although overall survival to 1 year postdischarge was 96%, children with a LLC were 2.5 times more likely to die in that year than children without a LLC (OR 2.59 (95% CI 2.47 to 2.71)).

Conclusions Children with a LLC accounted for a large proportion of the PICU population. There is an opportunity to integrate specialist paediatric palliative care services with paediatric critical care to enable choice around place of care for these children and families.

What is already known on this topic?

- The prevalence of children and young people with life-limiting conditions (LLCs) or life-threatening conditions is rising.
- Overall mortality in paediatric intensive care unit (PICU) is decreasing.

What this study adds?

- Children with a LLC accounted for the majority of admissions, bed-days and deaths in PICU.
- Children with a LLC were75% more likely to die in PICU than those without a LLC.
- There was 93% survival at 1 year for children with a LLC.

INTRODUCTION

Life-limiting conditions (LLCs) are those for which there is no reasonable hope of cure and from which children will ultimately die, for example, Duchenne muscular dystrophy or neurodegenerative disease. proportion of admissions to PICUs are for children with a LLC and their outcomes in PICU and up to 1 year postdischarge.

METHODS

Datasets

The Paediatric Intensive Care Audit Network (PICANet) collects data on all children admitted to PICUs in the UK and Ireland. All admissions to a PICU in the UK between 1 January 2004 and 31 March 2015 were identified in the PICANet dataset.[7] Only children resident in England were included as only their inpatient hospital data (Hospital Episodes Statistics (HES)) were available for linkage.[8] Hospital data for the other nations of the UK were not available.

The Office for National Statistics (ONS) death record data in England were available with a censor date of 1 November 2015.[9]

Cohort of 154,667 PICU admissions

Children with a LLC accounted for:

- nearly 58% of all admissions to PICU
- 72% of PICU bed-days
- 87.5% of all PICU admissions that lasted >28 days
- 73% of all in PICU deaths
- Children with LLC 2.5 times more likely to die in the year after discharge

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ORIGINAL REPORTS | Pediatric Oncology

Predictors of Specialized Pediatric Palliative Care Involvement and Impact on Patterns of End-of-Life Care in Children With Cancer

Kimberley Widger, Rinku Sutradhar, Adam Rapoport, Christina Vadeboncoeur
Shayna Zelcer, Alisha Kassam...

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https://doi.org/10.1200/JCO.2017.75.6312

Abstract

Purpose

The impact of specialized pediatric palliative care (SPPC) teams on patterns of end-of-life care is unknown. We sought to determine (1) which children with cancer access SPPC and (2) the impact of accessing SPPC on the risk of experiencing high-intensity end-of-life care (intensive care unit admission, mechanical ventilation, or in-hospital death).

Other key relationships

- Obstetrics
- NICU
- Cardiac surgery
- Metabolic
- Neurology
- ……Almost all Paediatric specialities

Summary

- Increasing numbers of children and young people with LLC
- Stage of condition may help target PPC resources
- Key clinical relationships e.g PICU
- More investment in paediatric palliative care services
- Further research & evaluation is needed

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Questions

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