

Surveillance Study

Estimating and describing the incidence of
transition for young people with
ADHD

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Disclaimer: Early findings as presented
at IACAPAP July 2018
Details may change



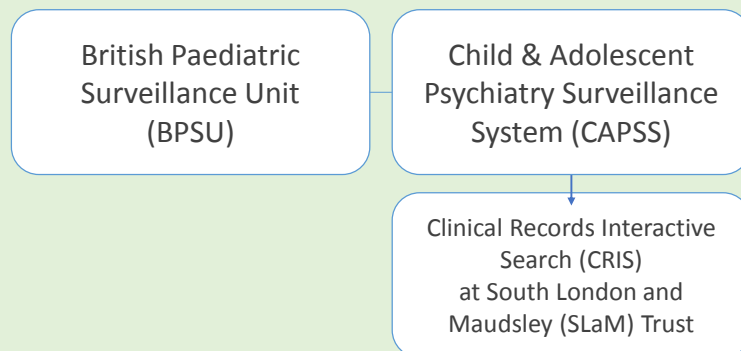
What is Surveillance?

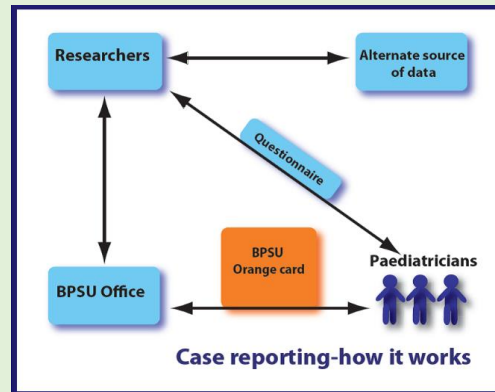
The ongoing systematic collection, recording, analysis, interpretation and dissemination of data...

Dictionary of Epidemiology, 2018

Methodology

Aim: Estimate the need and describe the group





Methodology

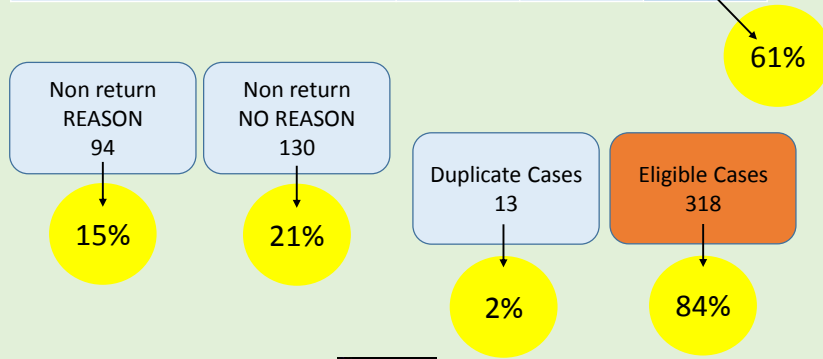
Case definition:

- Young person with clinical diagnosis of ADHD
- On medication for ADHD
- Requiring transfer to an adult service for continued treatment
- Within 6 months of the age boundary of children's services
- Only reported once



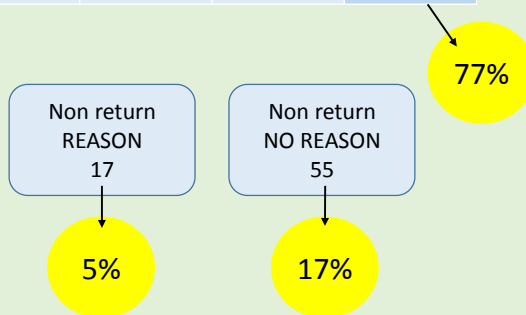
Findings at baseline

November 2015-November 2016			
	BPSU	CAPSS	Combined
Notifications	314	300	614
Returned baseline questionnaire	238	139	377

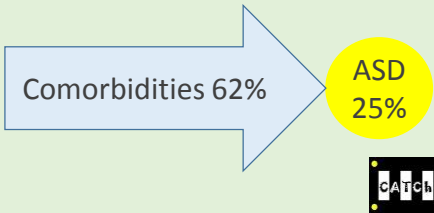
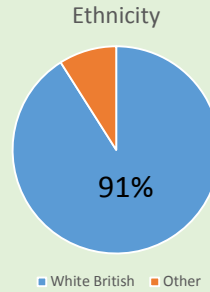
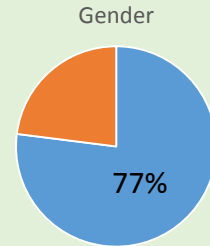
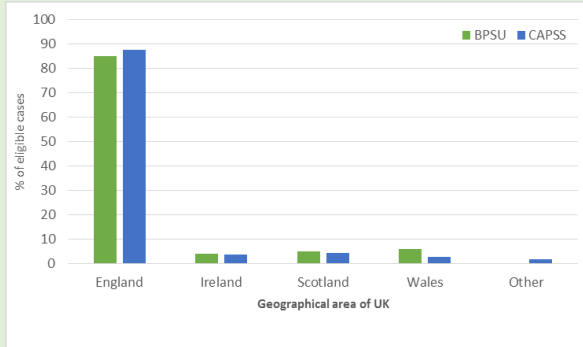


Findings at 9 month follow up

August 2016-August 2017			
	BPSU	CAPSS	Combined
Sent	205	113	318
Returned	161	85	246

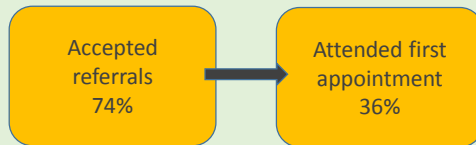
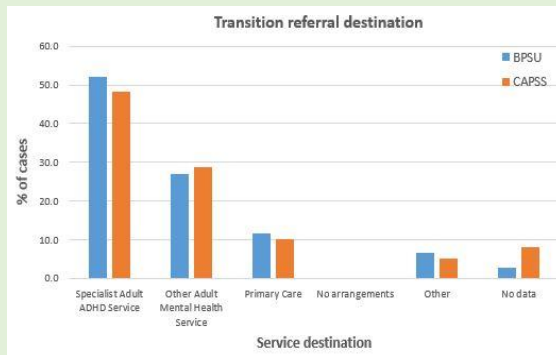


Demographic findings



Findings about transition referral

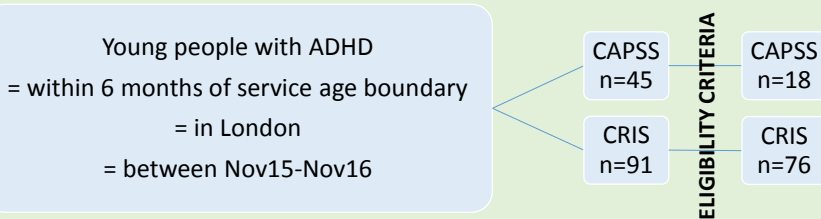
Age boundary of child service	BPSU %	CAPS S %
14 - 14yrs 11m	0	1
15 - 15yrs 11m	0.4	0
16 - 16yrs 11m	12	0
17 - 17yrs 11m	17	12
18 - 18yrs 11m	63	83
19 - 19yrs 11m	3	1
Variable	3	0
Unknown / no data data	2	3



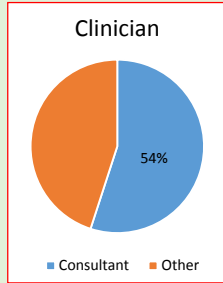
Findings about transition planning

<i>Pre transition</i>	BPSU %	CAPSS %	<i>Post transition</i>	BPSU %	CAPSS %
Information sharing	87	82	User/carer involvement	71	64
Young person involvement	80	86	Information sharing	66	75
Planning meeting	11	26	Care plan agreed	22	51
Plan & agree care plan	24	40	Joint working before transfer	8	17
Patient involvement 93%	28	22	Alignment of assessment procedures	6	14
Transition Protocol 60%			Continuity of care	22	48
Using Protocol 51%			Consistency of care	9	42
			Consideration of appropriate	50	57
			Clarity of funding & eligibility	39	61

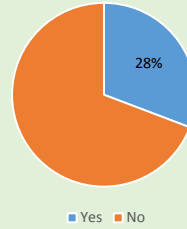
Findings from the Clinical Records Interactive Search (CRIS)



Findings from the Clinical Records Interactive Search (CRIS)



Completed transition?



Incidence of transition



Conclusions

- Surveillance methodology is successful
 - high engagement and return rates
 - geographical spread of data is national
 - reporting incidence of event or process
- Underestimation of actual need but currently best data available
- Transition is happening
 - completed for 1/4 of cases
 - not in line with NICE guidelines



References

- Paul, M., Ford, T., Kramer, T., Islam, Z., Harley, K., & Singh, S. P. (2013). Transfers and transitions between child and adult mental health services. *Br J Psychiatry Suppl*, 54, s36-40. doi:10.1192/bjp.bp.112.119198
- Lynn, R., Avis, J., & Reading, R. (2016). *The British Paediatric Surveillance Unit 30th anniversary report: Facilitating childhood rare disease research for over 30 years*. Retrieved from London: https://www.rcpch.ac.uk/system/files/protected/page/30YrReport_07102016.pdf
- Ford, Janssens, A., Asherson, P., Beresford, B., Paul, M., Ani, C., Sayal, K., Hollis, C., Elliott, T., Young, S., Newlove-Delgado, T., Shotton, C., Logan, S. (2015) CATCH-uS: Children with ADHD in transition from children's services to adult services.

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