



In transition with ADHD

How to get it *right*.

Experiences of young people with ADHD, their parents / carers

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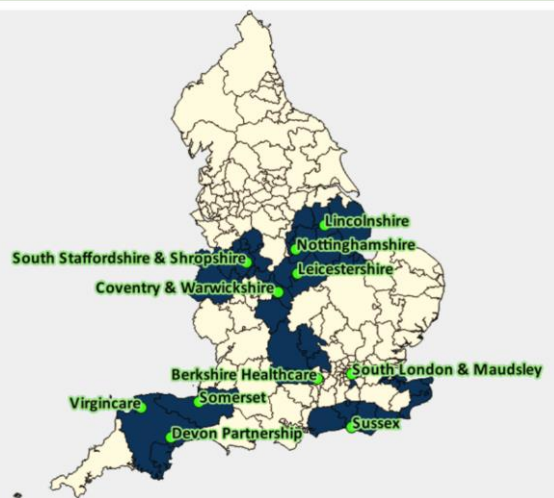
Disclaimer: Early findings as presented at
IACAPAP July 2018
Details may change



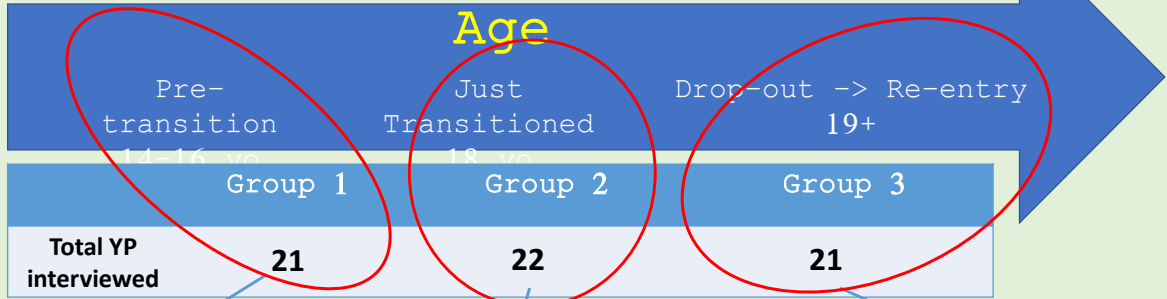


Qualitative study: Recruitment

- Young people and parents (n=100) :
14 NHS Trusts in England
- Child and adult clinicians (n=34)
Surveillance study, across UK
- General Practitioners (n=13)
Social media, emails +
snowball effect



Multiple cross-sectional studies: 3 key informants on transition



- M:F ratio (16:5)
- All in education
- High proportion with comorbidity

- M:F ratio (14:8)
- Hard to recruit
- All living at home

- M:F ratio (14:7)
- Range of (un)employment / educational status
- High proportion with comorbidity
- Hard to engage & recruit

Framework Analysis

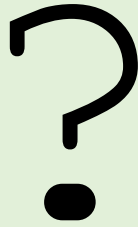
WHAT	WHO?
Indexing (4 interviews; 2p / interv)	● ● ● ● ●
Developing coding framework	● ● ● ● ●
Coding (4 interv. double coded)	● ● ● ● ●
Framework Summaries (double summ's)	● ● ● ● ●
Column Summaries + Reorganising subthemes	● ● ● ● ●
Categorising and Classifying (Typologies/models)	● ● ● ● ●

● A. Stimson ● H. Eke ● T. Newlove-Delgado ● A. Price ● A. Woodley

Pre-transition, 14-16 yo



I have not thought about ADHD when growing up.

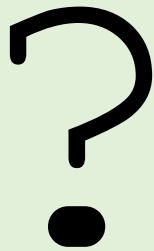


I have never met an adult with ADHD - I don't know what that's like

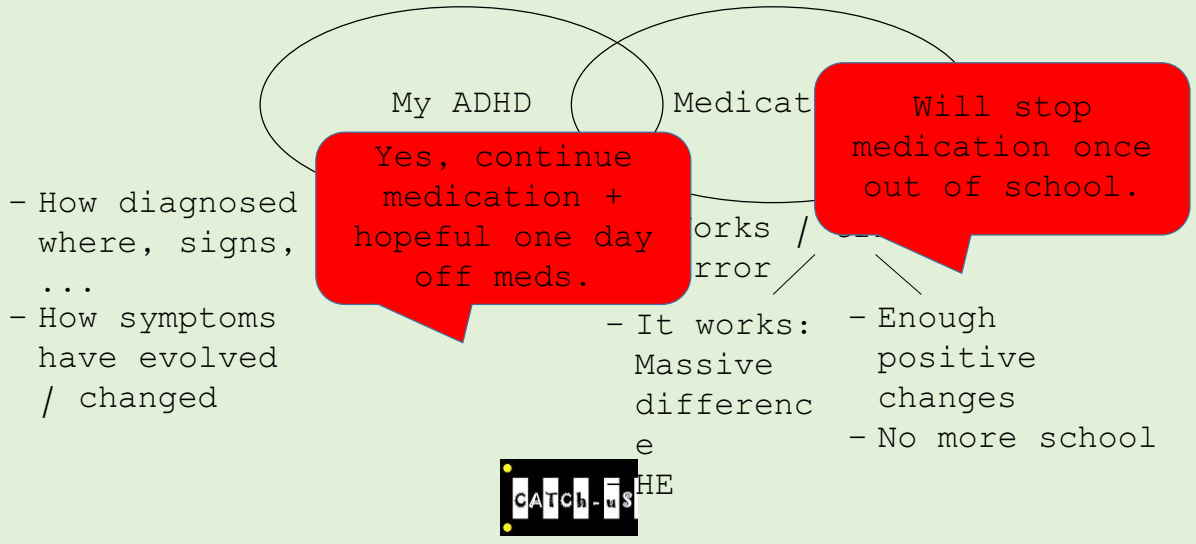
I'm not worried, I'm not sure what will change



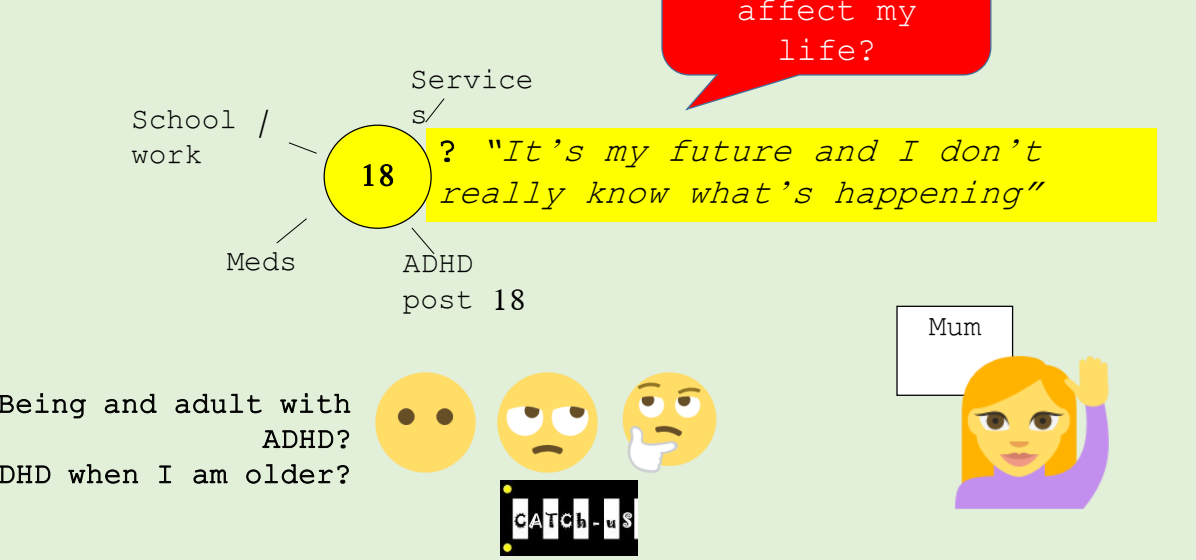
Pre-transition, 14-16 yo



Pre-Transition: ADHD = Medication



Life post 18?



Post-Transition: 18 yo

It's a big jump

I felt like the Doctor didn't know enough about me



It wasn't too bad



I was worried about what would happen

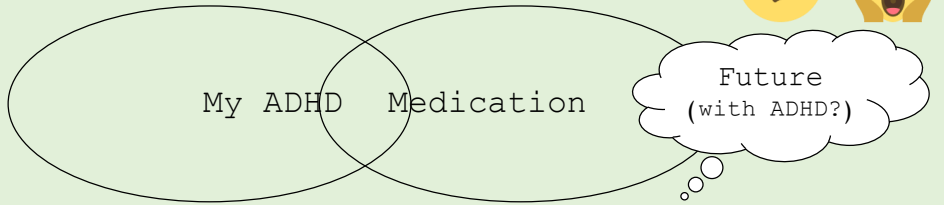
I didn't know what to expect; that was really annoying and scary



Mixed emotions



Post-transition: One day...



Change over time:
"Symptoms mid twenties? It's an issue in some ways and in some ways not."

Good (for now -> hopeful 1 day - near future - can stop):
"I'm hoping that when I'm 25 I won't be even thinking of it as a problem anymore"

Dealing w. ADHD (self-care vs support):
*"I'm worried about planning work and every detail of life and hope to get some support."
"I'm hopeful that one day I will be able to manage my own care."*



Mixed emotions

I wished they took initiative in deciding what's best.

You have to figure it out yourself - that's hard; it's harder being an adult with ADHD - 'cause you still need that degree of care.

Change of level of support is dangerous: you might get off the rails

You need to know what you need and dare to ask for help. That's hard and I didn't know that was going to happen.

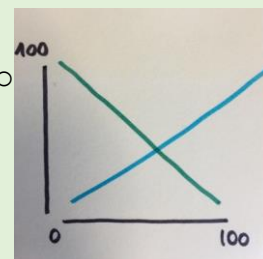
You're not allowed to be a child anymore and that's scary.



Post-Transition: typology

- Ownership

Take charge of treatment, make decisions, manage ADHD-care, accept ADHD or identify as being someone with ADHD



- Preparedness

Information about adult services, what will happen post 18, how will adult services help me?, what does that mean going to adult services and how does that work (for me?), what will adult life with ADHD look like?



Re-entering services: 19+yo - If only...

- BY CHOICE...
 - Is this an informed decision? -> Young Adult:
No!
More info about ADHD = LT condition
 - Clinician should push harder
- How to re-enter?
- NOT BY CHOICE
Drift off, drop out, sliding process (DNA, no follow-up services ...)



Food for thought

Most transition literature (guidelines, support documents):
development of autonomy = fundamental goal of transitional care.

However, and in particular in the context of ADHD, this goal should be approached keeping in mind that *"adolescents should be engaged in decisions regarding their health in an **age- and developmentally appropriate manner**"*.





The stories behind the data

He asked me, *"Will I be able to still see somebody if I want to?"*

He said, *"I might need somebody."*

And I said, *"Well hopefully we will get that right for you"*

(How) do / will you prepare your patients for 'the Big Jump'?

Let's make sure they 'transition' into adult services...



Something magical might just happen



“What if we don't change at all ...
and something magical just happens?”

What can you do?

- Assess YP's Ownership

Makes decisions, engages during consultation, identifies as YP with ADHD, takes charge of treatment, manage ADHD-care

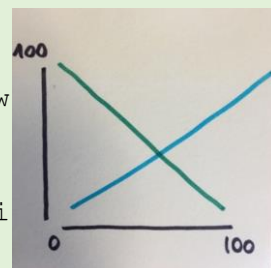
- Adapt preparation accordingly

✓ADHD = long-term condition: You might still show symptoms of ADHD post 18.

Q&A: What will adult life with ADHD look like?

✓Service provision: Information about adult servi

Q&A: What will happen post 18 & how will adult services help me? What if I want to return to services?



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PenCRU for Childhood Disability Research

PenCHORD
The Peninsula Collaboration for Health Operational Research & Development

Berkshire Healthcare NHS
NHS Foundation Trust

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#catchusADHD



THE

TAKE-HOME MESSAGE

- Evidence that 25% successfully complete transition (= attending appointment in adult services). Even then, not optimal.
- Dichotomy between specialist and other services where young people end up.
No (online) resource available to find out about these services.
- The majority of YP feel unprepared when approaching or going through transition.
Those who successfully completed transition have very mixed emotions / experiences. What defines a smooth transition is

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