Inequalities in access to children and young peoples mental health services

Midlands Decision Support Network Webinar

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The Strategy Unit.

NHS
Midlands and Lancashire
Commissioning Support Unit

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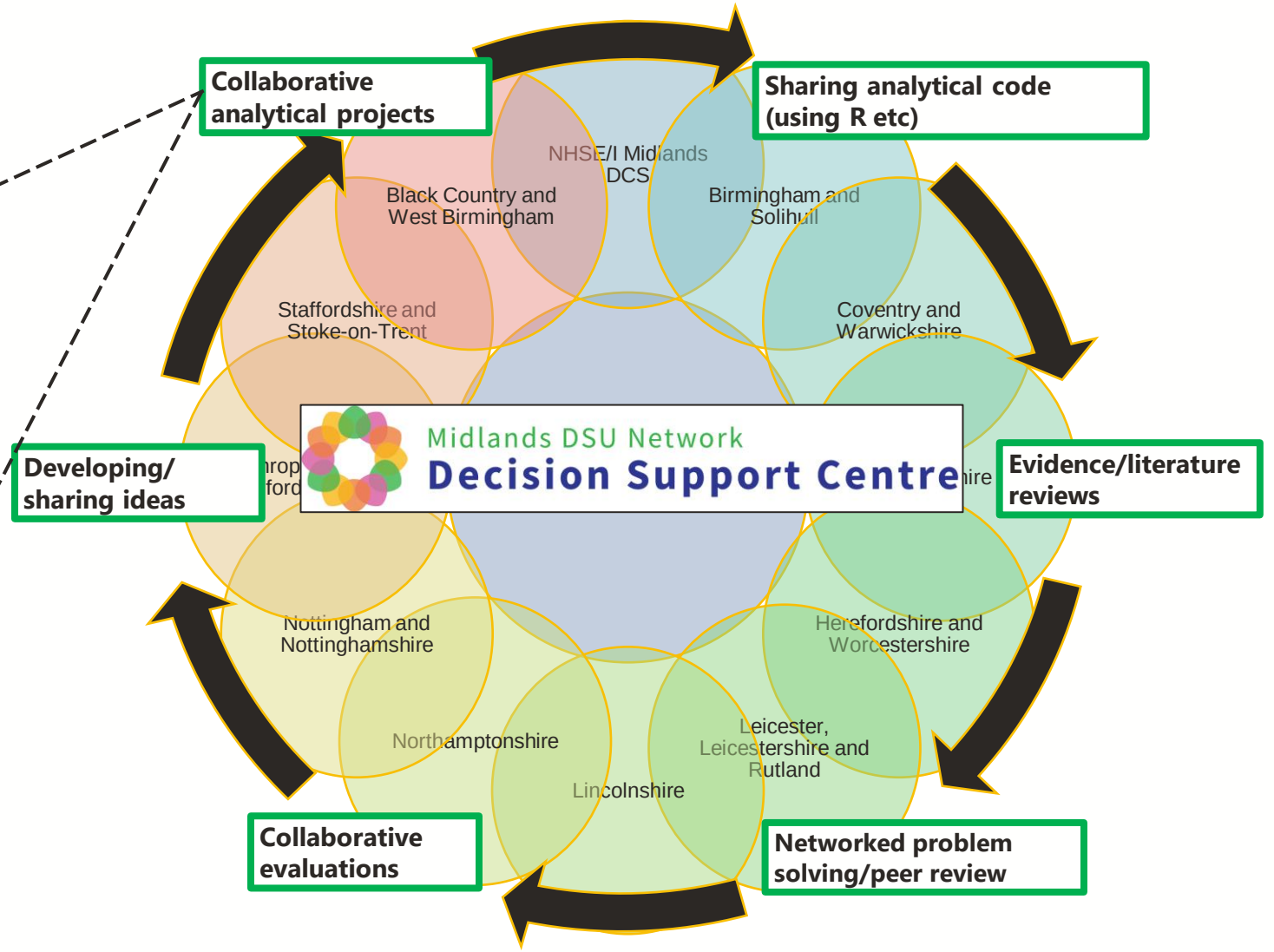
Introduction and Background

The Midlands systems have collaborated to form the Decision Support Network, supported by the Strategy Unit.

20/21 projects
- Inequalities in access to planned care
- Inequalities in access to CYP MH services
- Classifying outpatient activity by function

21/22 projects
- Strategies to reduce health inequalities in planned hospital care
- Patterns of healthcare use amongst people with learning difficulties
- Impact of COVID-19 on the management of long-term conditions



Children and young people living in the Midlands

The Midlands region is home to over 10.5 million people. **Around 2.6 million are aged 5-24.**

There are different circumstances and challenges for these young people depending on where they live:

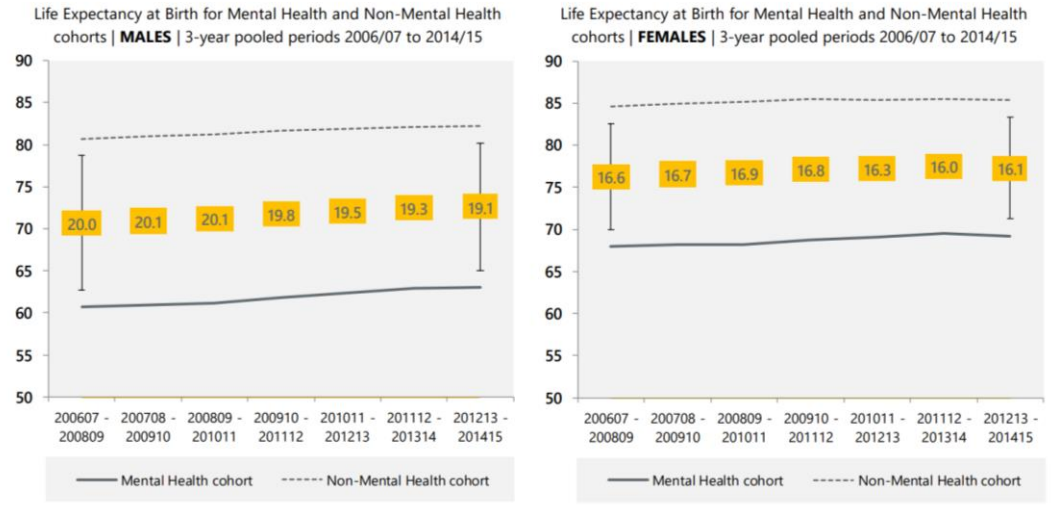
- **Ethnic diversity ranges**
  - low = 11.8% in Herefordshire and Worcestershire (H&W)
  - high = 45.8% in Birmingham and Solihull (BSOL)
- **Social and material deprivation varies**
  - most deprived IMD deciles H&W = 3.8%
  - most deprived IMD deciles BSOL = 35%
- **Access to community/public services varies**
  - Poor housing and education for some
  - Lower access to green areas for some
- **Provision of health and care differs**
  - Lincolnshire has fewer GPs per head of population
  - Shires have less flexible access to acute services and beds

It is no surprise therefore that children and young people have very different experiences of both mental health and the availability of services to support them.

There can be severe implications of slow or no action to support CYP mental health

- Mental illness in childhood affects the experience of education and ultimately life chances.
- Affects resilience to stress and trauma as adults

Trends in life expectancy

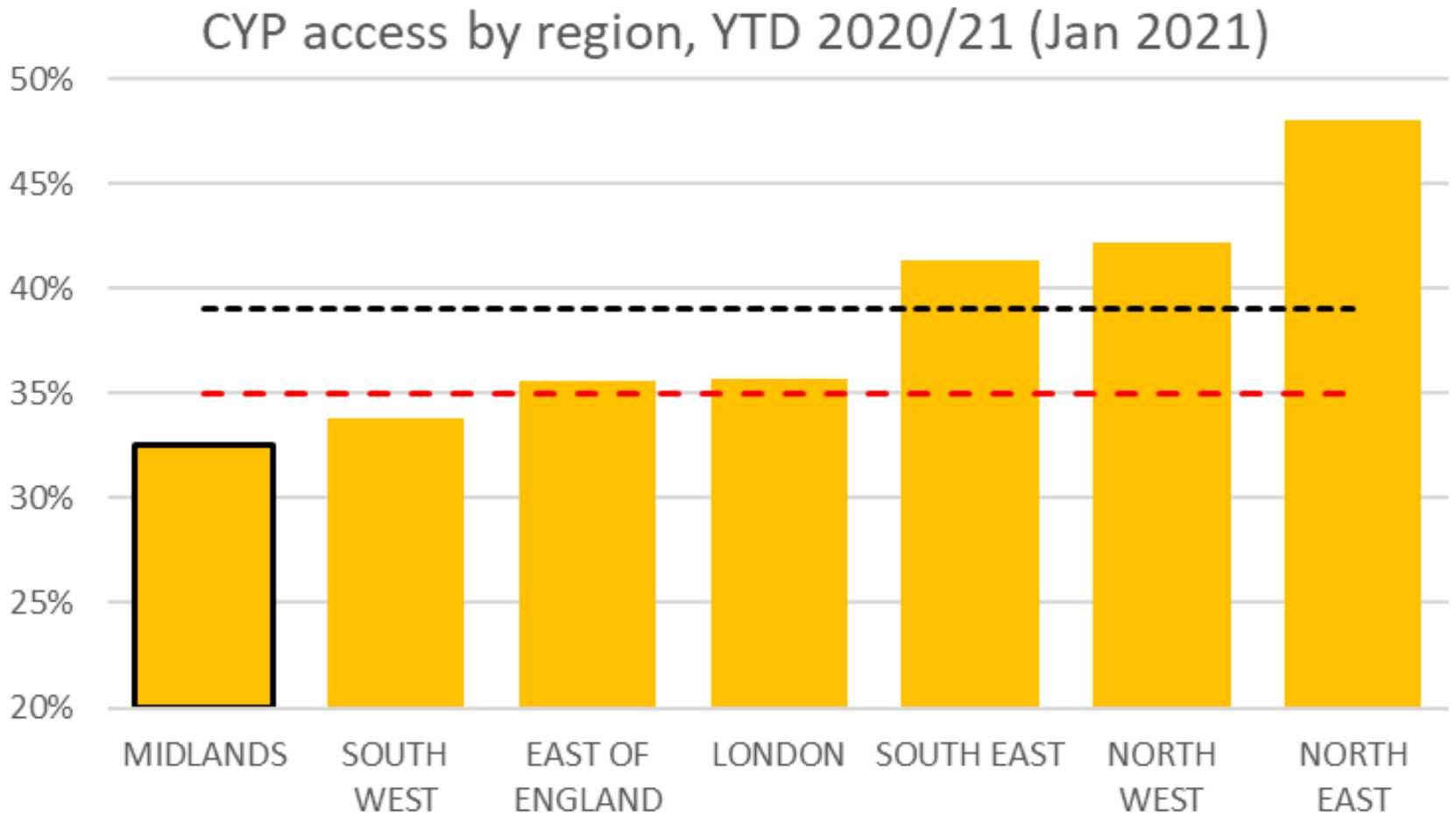


Consequences of not supporting CYP:

- Self-harm
- Substance misuse
- Suicide
- Criminal Justice involvement
- Poor physical health

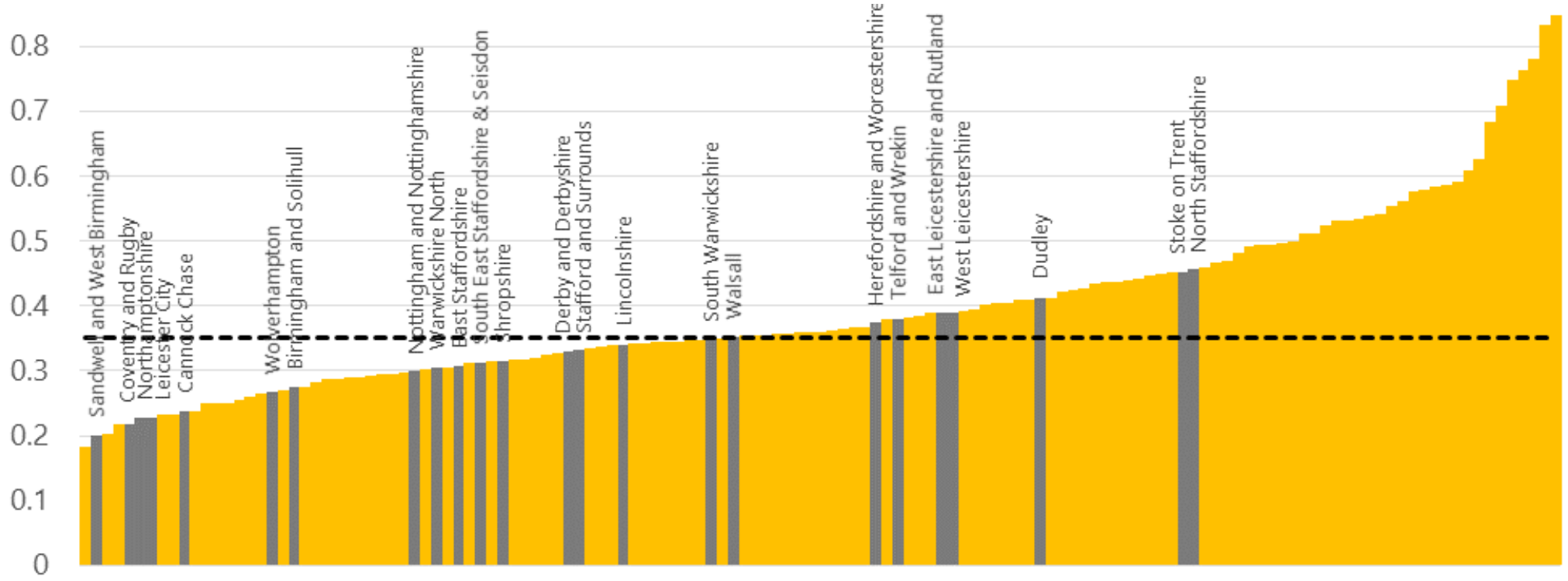
Economic costs of poor mental health in England alone > £100bn **each year** however; the benefit-cost-ratio of early intervention programmes could be 3:1 (£).

The Midlands has the lowest level of CYP access in the country and does not meet the national ambition of 35% receiving support.



* Support as defined by national metric as 2+ contacts post referral within the annual reporting period

The Midlands has the lowest level of CYP access in the country and does not meet the national ambition of 35% receiving support*.



There is significant variation in CYP receiving support* within the region:

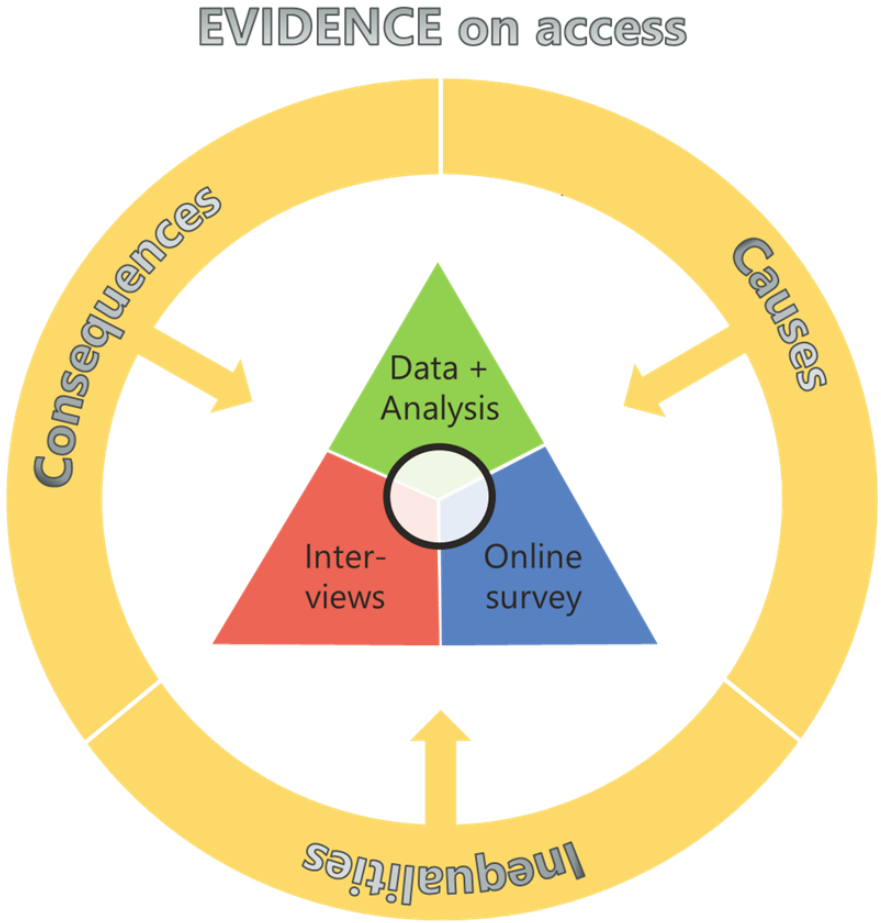
- 1 in 5 Sandwell
- 1 in 2 in North Staffordshire and Stoke-on-Trent

* Support as defined by national metric as 2+ contacts post referral within the annual reporting period

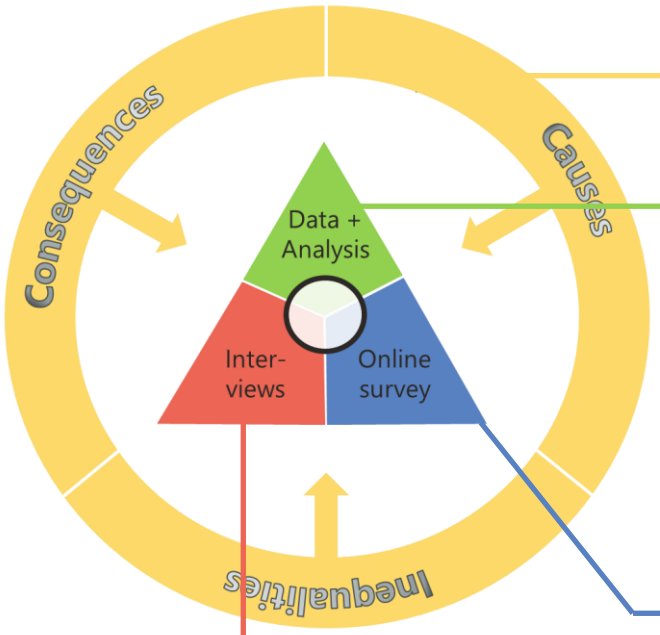
So what is our approach to adding insight to this issue?

This project is aiming to support systems to address the following type of questions:

- Which groups are most affected by poor access to MH services and how do we improve this?
- Are there differences in perspectives around access between patients and the systems?
- What are the consequences of poor access and how might we mitigate them?
- Which factors determine the demand / need for acute support into adulthood?



EVIDENCE on access



- Quantifying unmet needs
  - Acute 'pathway' inequalities
  - Cohort analysis and future needs

700+ articles and reviews.

PROGRESS framework used to categorise the evidence:

Place, **R**ace, **O**ccupation, **G**ender, **R**eligion, **E**ducation, **S**ocial status, **S**ocial capital

Further categorized into: causes, consequences and interventions

37 interviews with clinicians, commissioners and providers across all 11 Midlands ICS areas.

Key areas explored: co-production, performance and measurement, commissioning, service perceptions, data, communications, service provision, workforce

Online survey, 80+ responses.

Key areas explored: information to access services, mode of referral, transition to adult services, maintaining contact with services

Key Findings

1. The complexity of navigating CYP MH services is a barrier to access

This inequity in access is more pronounced for CYP who are:

a) Classified as belonging to lower socio-economic groups
b) Black and Black-British
c) Transitioning to adult MH services
d) Users of LD and/or autism services

Why is this important?

Inequities in access to CYPMH services may exacerbate existing health inequalities, disadvantage or adversity and impact on mental health throughout the life-course.

2. Access to some CYP MH services is poorer than others

Focusing on eating disorders, this inequity in access is:

a) **Known** – long average waiting times. 30% urgent referrals not seen within 1 week.
b) **Growing** in some groups of CYP such as minority ethnic and male
c) In part due to **CYP delaying** seeking support
d) Being addressed in **some systems**

Why is this important?

The demand for, and severity of mental health needs continues to rise. Lockdown and pandemic are expected to accelerate this trend.

3. Improving equity in access to CYPMH services is not a priority for systems

Inequities in access to CYPMH services persist due to:

a) A low performance 'ambition' for access
b) No national requirement to address inequities
c) Limited engagement or involvement of CYP in design of services
d) Lack of dedicated analytical capability to explore inequities

Why is this important?

More focus on improving equity in access has the potential to improve overall performance of CYPMH services

4. The provision of CYPMH services is not distributed according to need

The mismatch in supply and demand is due to:

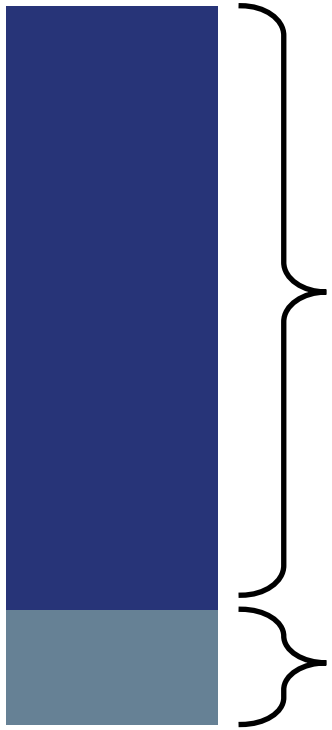
a) An over-reliance on CAMHS
b) Inconsistent utilisation of non-NHS services but limited understanding of why some services are more in demand
c) Workforce challenges, with high competition for qualified clinical practitioners
d) Reactive investment in services

Why is this important?

Rhetoric of improving preventative and early intervention services (see 5YFV, LTP) has not yet translated into a better experience for CYP and MH professionals

Unmet need for different mental health sub-groups is a significant issue

345,593 CYP across Midlands predicted to have a diagnosable condition.



303,343 with unmet needs

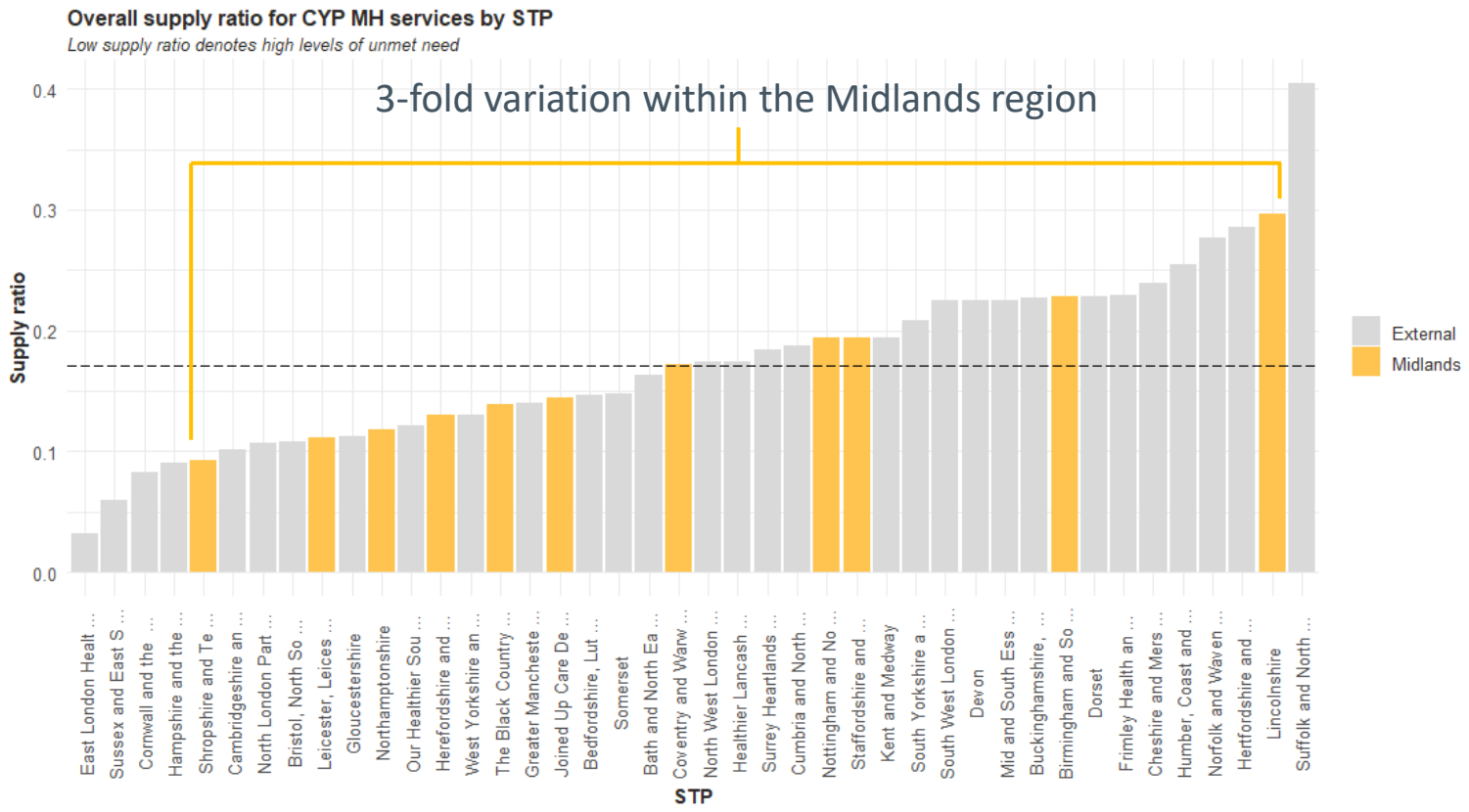
43,250 (12.5%) in contact with services

Condition	Estimate of 'need' [1]	Population 'demands' [2]	Supply ratio (low = bad!)
Looked after children with emotional wellbeing issues	2,755	1,784	0.65
Self harm	22,139	8,960	0.40
Emotional disorders	53,342	19,465	0.36
Hyperkinetic disorders	22,635	4,853	0.21
Conduct disorders	84,092	5,003	0.05
Eating disorders	160,631	3,185	0.02

[1] PHE fingertips data on prevalence of mental health in CYP (various years)
[2] Derived from patients in contact with services, MHSDS data (2019)

There is also significant variation in unmet need

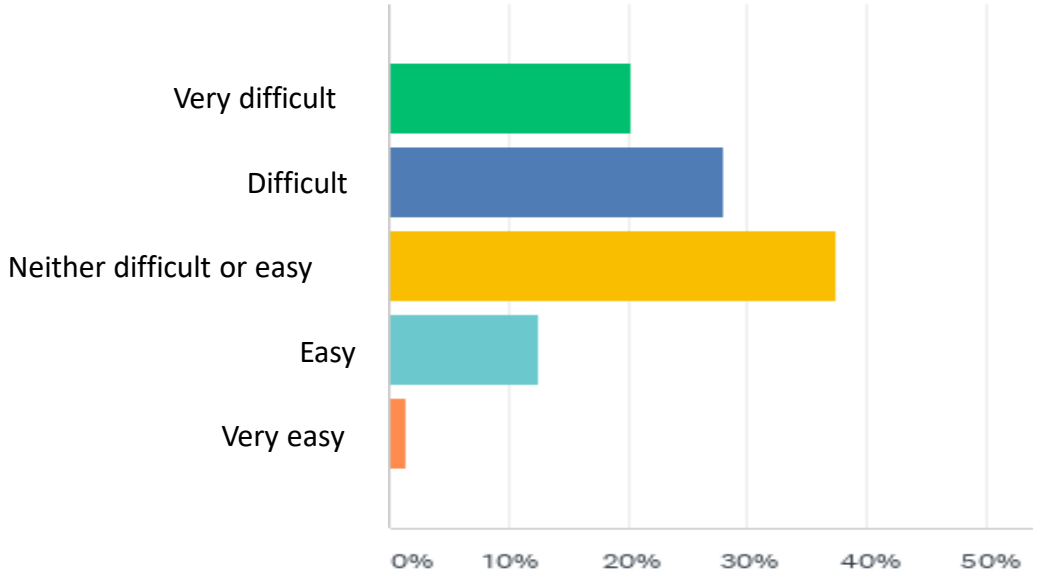
STP	Estimated CYP Population with a diagnosable MH condition	CYP Population in contact with services	Supply Ratio
Lincolnshire	20,736	6,148	0.30
Birmingham and Solihull	47,282	10,800	0.23
Staffordshire and Stoke…	33,921	6,587	0.19
Nottingham and Notting…	36,065	6,992	0.19
Coventry and Warwickshire	28,701	4,951	0.17
Joined Up Care Derbyshire	30,701	4,448	0.14
The Black Country & West…	43,911	6,086	0.14
Herefordshire and Worces…	20,921	2,724	0.13
Northamptonshire	21,695	2,550	0.12
Leicester, Leicestershire &…	34,474	3,840	0.11
Shropshire and Telford &…	14,008	1,303	0.09



1. The complexity of navigating CYP MH services is a barrier to access

This is experienced more acutely by certain groups

Children and young people find MH services difficult to navigate



How easy was is it to find the information you needed to access services?

*"It was possible to find information, **but the information itself wasn't very accessible**. **The language used wasn't easy to understand.** I came across different organisations and didn't know which one I should be using, **this made it overwhelming**....they just kept telling me to refer myself instead of answering my questions, which I felt I needed the answers to before I could make the decision whether to refer myself or not."*

Data source: CYP survey

CYP MH services provide better access to those more advantaged

More disadvantages in access:

- When poverty and rurality combine
- Services operate 9-5
- Multiple appointments that require travel

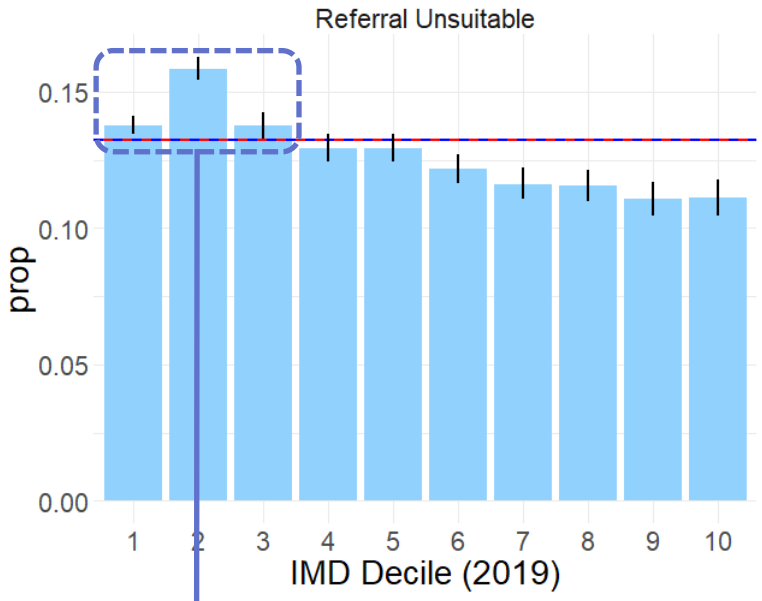
Virtual treatments can be effective in overcoming these access barriers

*"I think there's inequalities there because **those that know how to access [services] will** and those that don't never seem to be successful."*

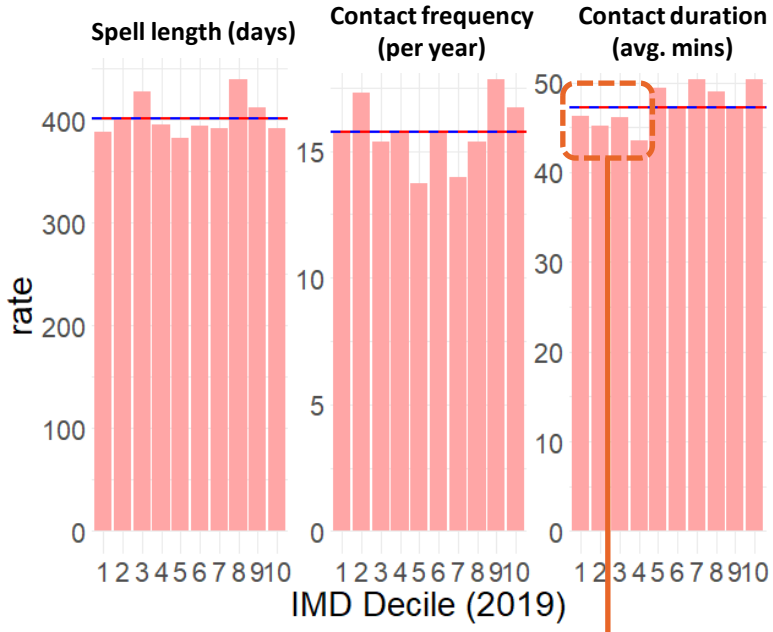
*"So yes, I think we're very good as services predominantly run and driven by middle class people in professional roles, at **developing systems that are right to help people who are middle class**.., [but] we're not necessarily very good at thinking outside of that without it being paternalistic and a little bit pejorative and condescending."*

Data source: literature review and stakeholder interviews

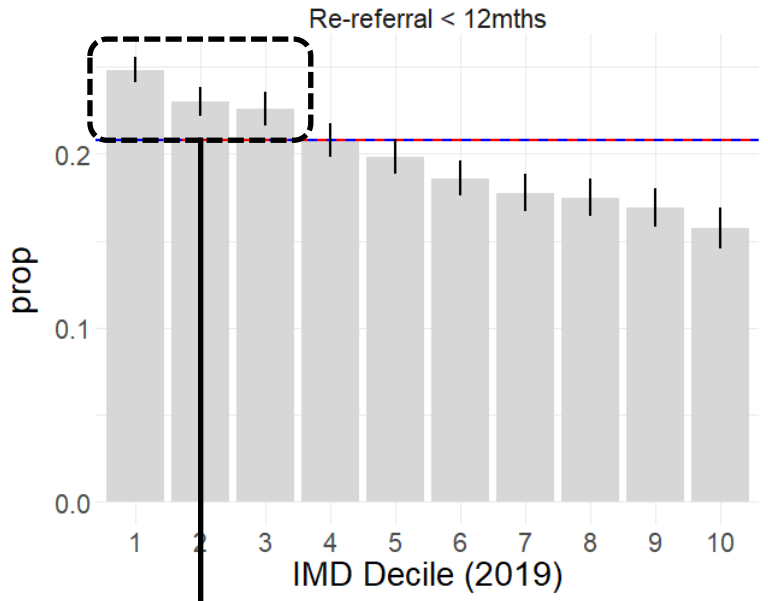
Services may not be as suitable or effective for more disadvantaged patients



Most deprived groups less likely to receive treatment after referral



Most deprived groups typically have shorter contact time during appointments



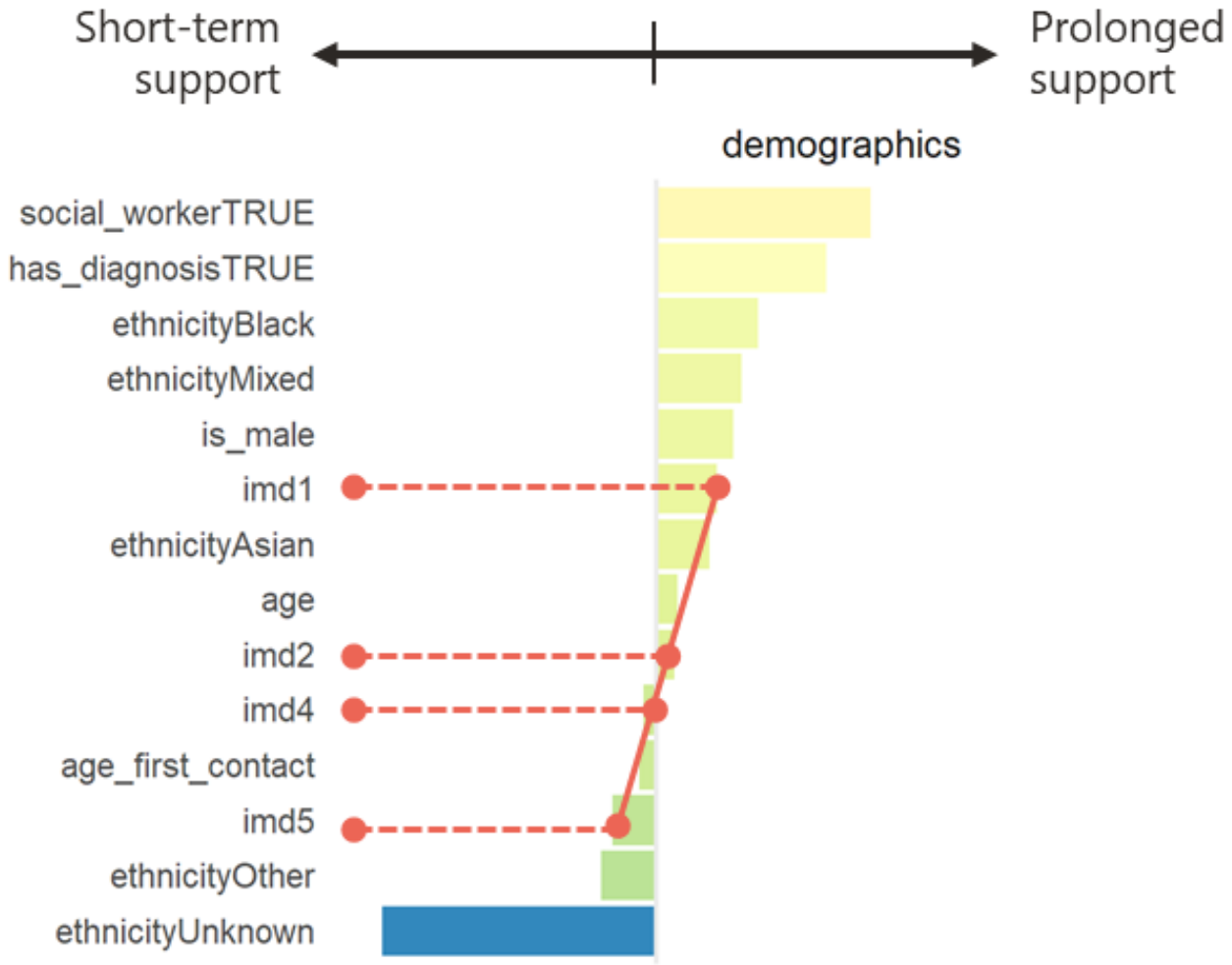
Most deprived groups significantly more likely to refer back into services < 12 months despite lower 'drop-out' rates.

IMD decile

1 2 3 4 5 6 7 8 9 10

MOST deprived — **LEAST** deprived

There is a clear gradient in support needs across the deprivation spectrum



Cohort analysis of adolescents over a 10 year period (2008/09 to 2018/19) suggests there is a clear gradient across the IMD quintiles where more deprived groups tend towards longer acute support needs and more affluent groups tend towards short support needs.

Multiple co-occurring factors may exacerbate this relationship.

CYP from minority ethnic groups experience and use services differently

Compared to other ethnicities

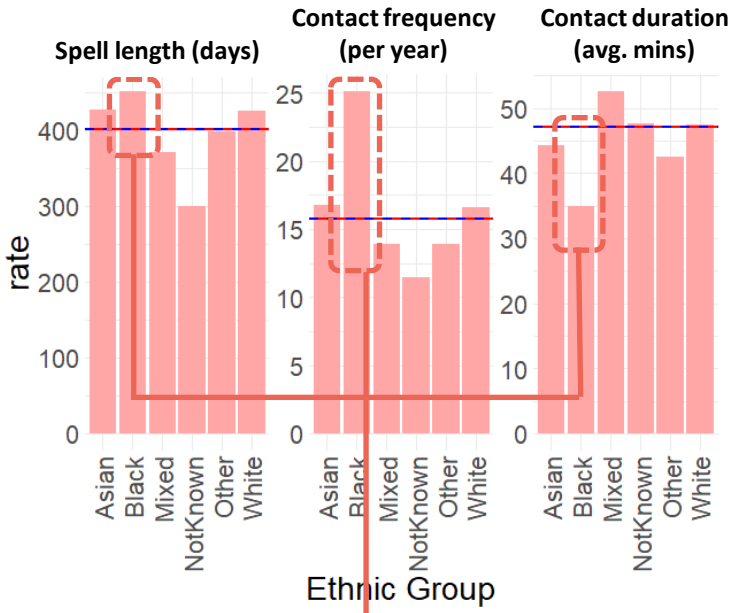
- Black and Black-British groups are higher users of CAMHS
- Asian females have much lower referral rates to eating disorder services
- South Asian CYP with intellectual disabilities have lower use of mental health services

*"I live in a very tight-knit Indian community where **mental health is never discussed**, and when it is it's always portrayed negatively and passed off as being crazy. I found it incredibly hard to talk to my parents about it. I found it hard to even talk about it with my siblings and close friends around me."*

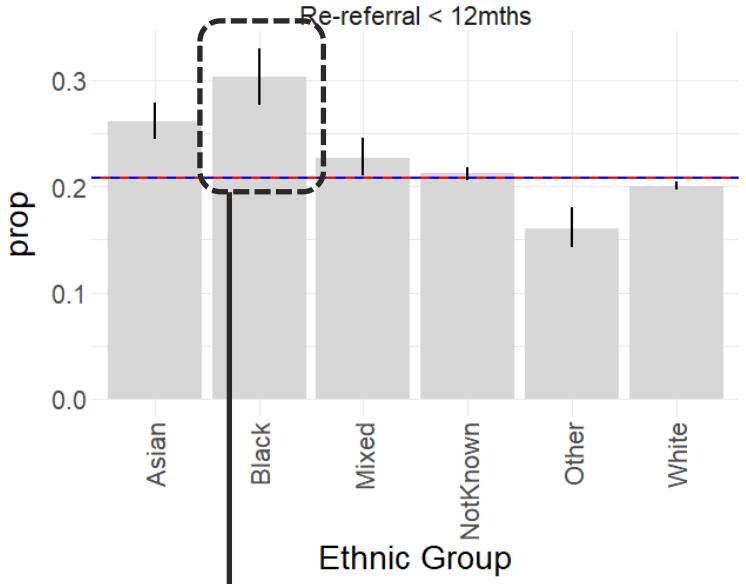
*"I think the Afro Caribbean [and] Sudanese group have challenges because **I think there is inadvertent discrimination**. I think that is a group of children who people - just the way that those children and families tend to deal with things and present – often they are maligned I think – and **that's just a problem of lack of experience dealing with that particular group of people**."*

Data source: literature review, CYP survey and stakeholder interviews

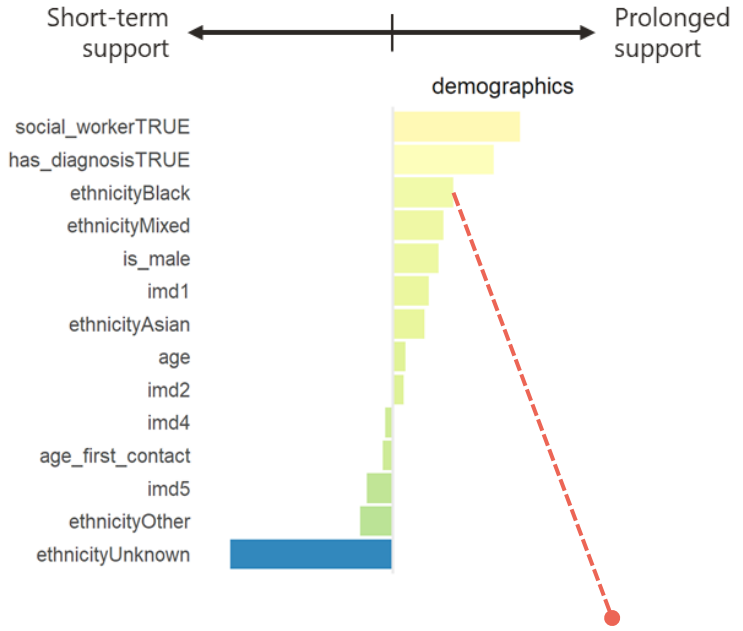
CYP from Black ethnic groups have different experiences of care and longer-term needs



Black groups tend to have longer care spells, more frequent contact but shorter contact time with services.



Black groups have the highest re-referral rates suggesting recurrent problems and/or unsuccessful service provision.



CYP from black ethnic backgrounds are more likely than any other to have prolonged service needs. This could also be compounded by any involvement with care services, being male and living in socio-economically deprived areas.

Older CYP are disadvantaged when their MH needs are treated within adult services

Adult mental health services are:

- more catered towards chronically unwell and don't consider broader issues facing young people
- not as good at involving parents.

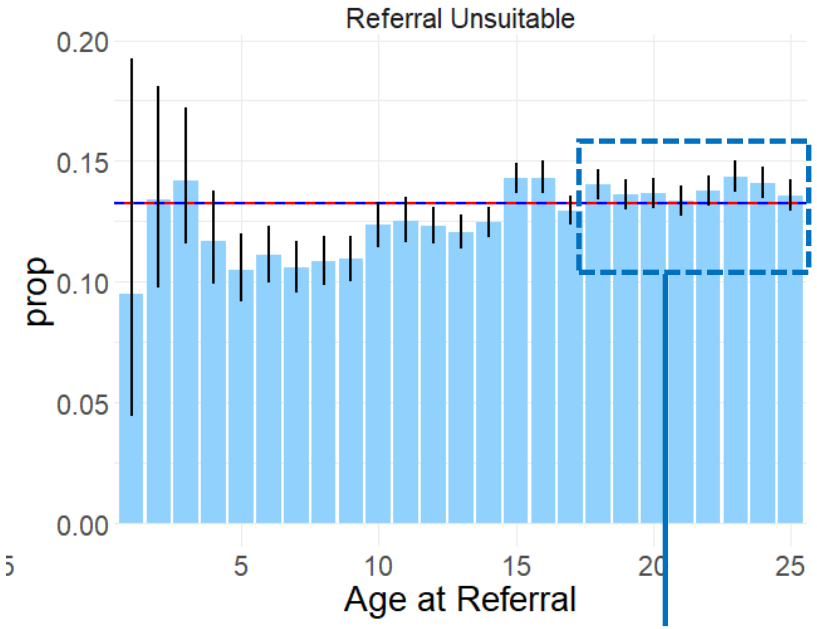
Transition services not subject to the scrutiny of evaluation

"Although [the service] is 0-25, when I was 18 I had to move to an adult psychiatrist in the same building. I wasn't told until my birthday."

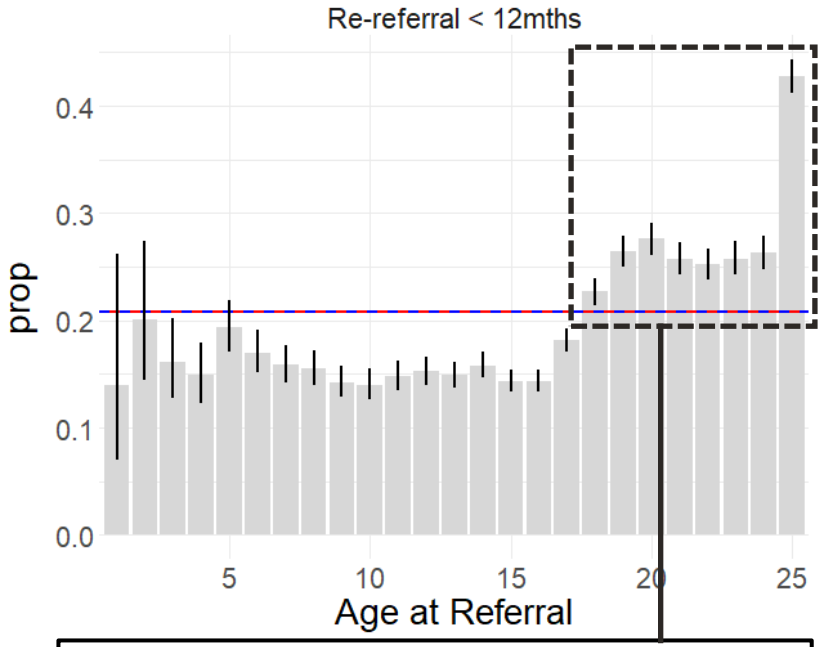
"Under the guidelines we're supposed to be able to treat children, up until the age of twenty five. But all too often ***when somebody gets to 18 or 17 even, they're discharged from CAMH specialist supervision*** *and they end up hitting adult services, if they need any help,* ***and the adult services are not geared up particularly well for that first five years*** *– 18 to 25."*

Data source: literature review, CYP survey and stakeholder interviews

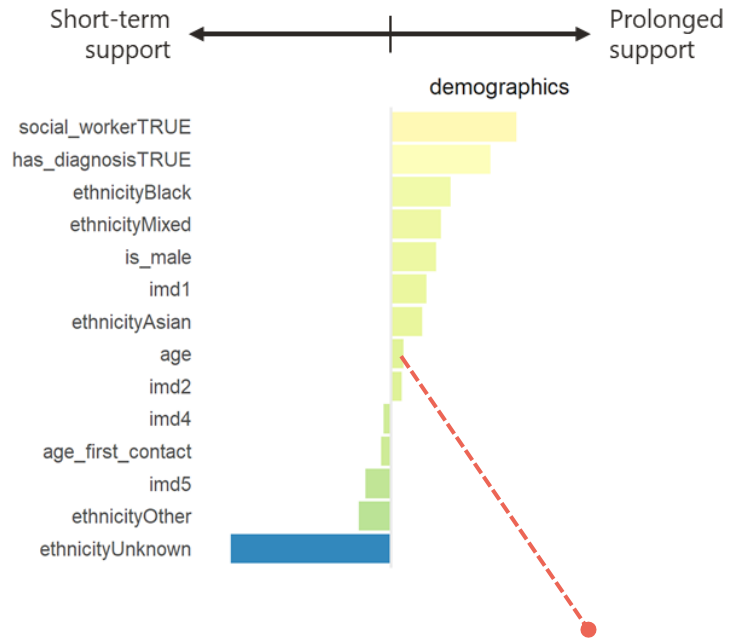
Discharge from services for young adults is premature for many



Generally speaking, those aged 18-25 are less likely to receive support after referral than other CYP – 1 in 7 patients.



Over a quarter of 18+ patients are re-referred back into services within a year of discharge and almost half of those aged 25.



Increasing age at discharge indicates slightly higher likelihood of prolonged service needs.

CYP with LD and/or autism face more barriers when accessing MH services

CYP with intellectual disabilities are particularly susceptible to mental ill health when:

- Transitioning from adolescence to adult
- Moving from one service structure to another

"[Services need a] better understanding of autism. Not dismissing my mental health needs because of my autism diagnosis and realising that CBT will not work for me. Being able to spend time to build a trusting relationship with someone do I feel I can talk to them before they start asking questions"

"You might have someone that's got strong autistic tendencies […] but they can't get into CAMHS to get the holy grail of a diagnosis, until they get the diagnosis they can't access other [specialist autistic] services [..], because they haven't got the magic diagnosis."

Data source: literature review, CYP survey and stakeholder interviews

2. Access to some CYP MH services is poorer than others

The needs of those with eating disorders are not being met

The evidence and stakeholders suggest there are a variety of challenges facing CYP with eating disorders, and COVID has increased demand

- Pre-pandemic the average time to treatment nationally, for eating disorders is over 3 years. Capacity a persistent issue re: time to treatment.
- Stigma, waiting times and poor access in general for adolescents may be causing this.
- Known to be a particular issue with CYP from minority ethnic groups.

*"I think the cohort of young people with eating disorders accessing late is a big issue. I think what's been identified by the eating disorder team is not really so much about the families accessing late, but **GPs referring late is an issue**."*

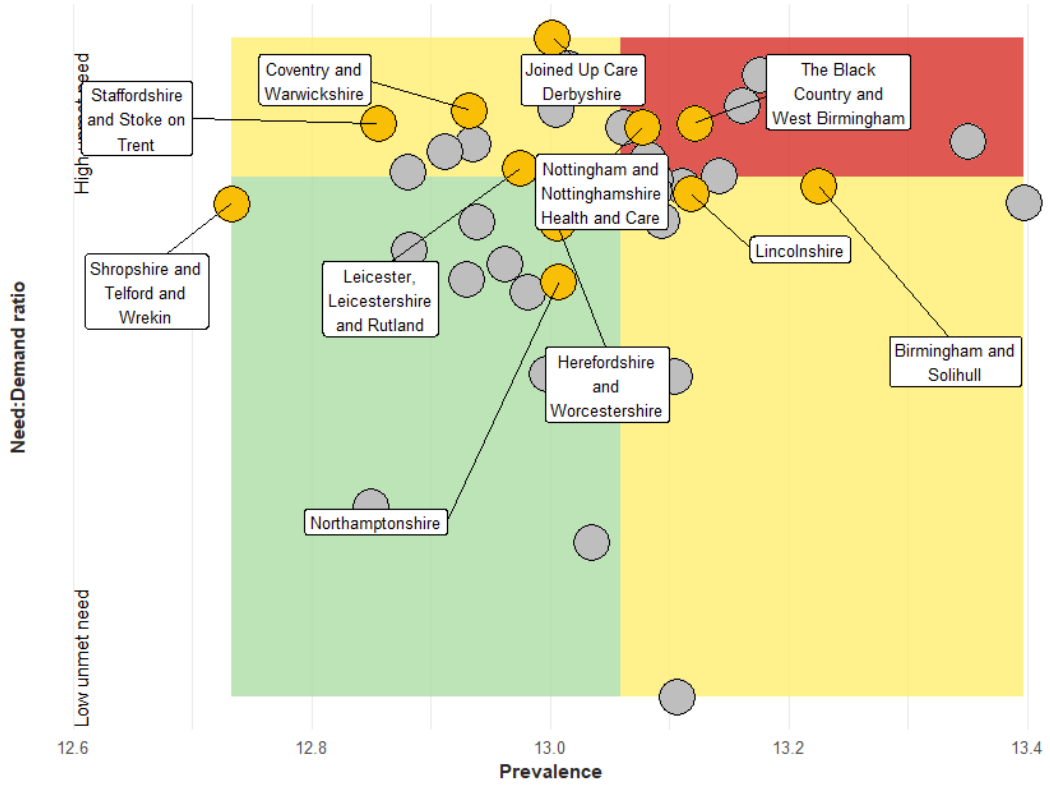
*"So we're seeing, during the pandemic **a much younger profile coming through**, with disordered eating and eating disorders"*

Data source: literature review and stakeholder interviews

This is a universal issue for services and their potential users

Condition	Estimate of 'need'	Population 'demands'	Supply ratio (low = bad!)
Looked after children with emotional wellbeing issues	2,755	1,784	0.65
Self harm	22,139	8,960	0.40
Emotional disorders	53,342	19,465	0.36
Hyperkinetic disorders	22,635	4,853	0.21
Conduct disorders	84,092	5,003	0.05
Eating disorders	**160,631**	**3,185**	**0.02**

Greatest levels of unmet need are in Derbyshire, Cov & Warks, Staffordshire, Black Country and Nottinghamshire – latter 2 areas also have higher prevalence.



3. Improving equity in access to CYPMH services is not a priority for systems

Collection and analysis of data related to equity is not common practice

Key points raised:

- Activity data is inadequately recorded and submitted, there is much variation by system and provider
- Providers are not asked to report on inequity of access. The national requirement to report on general access rates maintains focus on that measure
- Limited awareness on how to appropriately record demographic data in local systems
- No dedicated resource for data collection and analysis around inequity

4. The provision of CYPMH services is not distributed according to need

Where is resource being directed to improve access?

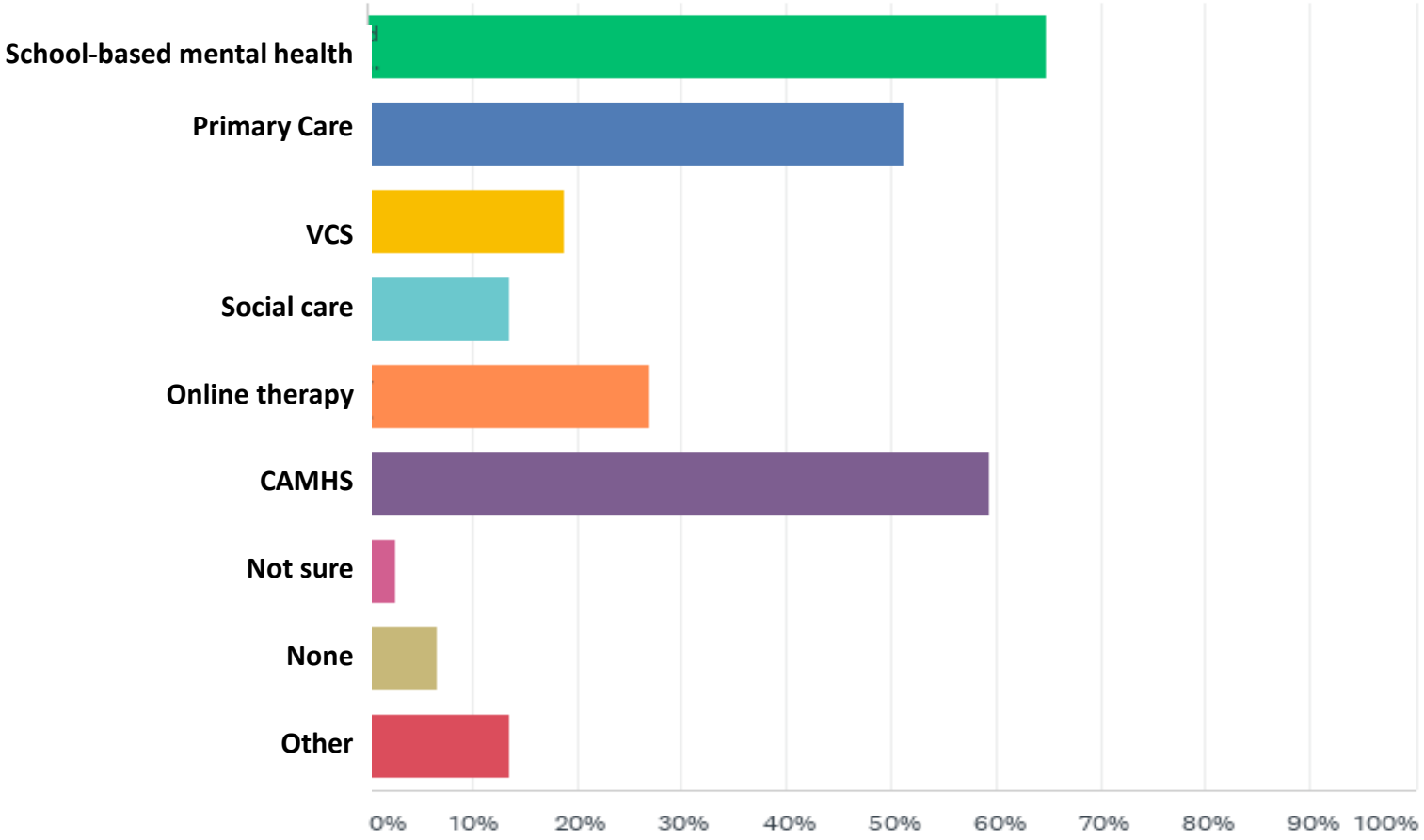
What is already being done to help CYP navigate services?

Intervention type	SPA	MHST	NHS 111	Online offer - Kooth	Online offer - other	Self-referral	ED triage	CAMHS liaison	Social prescribing	Crisis café (drop-in)	Initial Assessment Team	24/7 crisis resolution
BCWB	✓	✓	✓	✓	✓	Partial		✓		✓	✓	✓
BSol	✓	✓	✓	✓	✓	✓			✓	✓		
C&W	✓	✓	✓	✓	✓	Partial						✓
Derbyshire	✓	✓	✓	✓	✓	✓		✓				
H&W	✓	✓	✓	✓		✓		Partial				✓
Leics	✓	✓	✓	✓			✓					
Lincs	✓	✓	✓	✓		✓						
Northants	✓	✓	✓							✓		
Notts	✓	✓	✓	✓		✓						
STW	✓	✓	✓	✓	✓							✓
Staffs	In train	✓	✓		✓	Partial						

Note: This table is based on descriptive accounts of services and therefore limited by stakeholder accounts

Which services are CYP ‘choosing’ to access?

Evidence from the survey



Preliminary Recommendations

The challenge	Recommendations or considerations for action
1. Promoting access to all	**Regionally:** There are limited but creative examples for service user involvement in co-designing CYPMH services. Collate, share and build on these examples across the Midlands to co-produce equitable CYPMH services. **Systems**: Simplify access. Proactively learn from other areas where access is working well. Invest in communication and engagement activity via involvement of the voluntary and community sector to **outreach as appropriate** to target groups of CYP.
1a. Increasing support and access for deprived groups	**Regionally:** Develop 'Psychological profile' of deprived populations in order to develop preventative strategies in education/primary care settings. Multi-disciplinary teams including social care/education where app. **System**: Move the narrative away from 'population group x are less likely to access services' to 'we will do more to provide improved access to population group x'
1b. Meeting the needs of black ethnic groups	**Regionally**: Work with **service user groups** to share understanding of wider needs (both social and cultural) to inform MH and partner agencies service provision. **System**: Consider **investment in digital** offer (Kooth) where this is not already offered & undertake work to understand what it is about this that is more accessible for Black YP.
1c. Better support for those with needs moving to adulthood	**Regionally**: Provide a regional steer and benchmark for young adults MH service provision using evidence-based guidelines, best practice and expert opinion which includes service users. **System**: Incorporate quality improvement approaches to improve equity in access for young adults with a focus on discharge and transition between services. Hold providers accountable.

The challenge	Recommendations or considerations for action
1d. Supporting additional needs of those with LD or Autism	**System:** Training across health **and** care system for LDA 'sensitive' workforce. Ensure services sensitive to specific needs and not offered generic psychological interventions.
2. Insufficient capacity to support those with eating disorders	**Regional:** Eating Disorder workforce strategy. Lobby for / secure additional funding for range of interventions. **System:** Full health needs assessment of eating disorders. Review referral pathways and service model in light of HNA.
3. Data and analysis is poor around MH outcomes and inequalities	**Regional:** Centralised reporting of access and outcome measures by inequality groups. Continued push for data quality improvement from providers. **System:** Facilitate data exchange and linkage so local planning can account for population sub-group and geographical variation.
4. Resource is not distributed according to need	**Regional**: Fully assess the extent of regional inequity and inequality, for example in admissions and detentions, self-harm, mortality, system-wide service use. **System:** Before designing or implementing an inequalities strategy, each ICS should • Assess the mental health needs of their CYP population • Review service and workforce suitability • Engage, involve and coproduce service improvements with relevant CYP

Advancing mental health inequality https://www.rcpsych.ac.uk/improving-care/nccmh/care-pathways/advancing-mental-health-equality

Accessing and utilising the project outputs – next steps

The outputs:

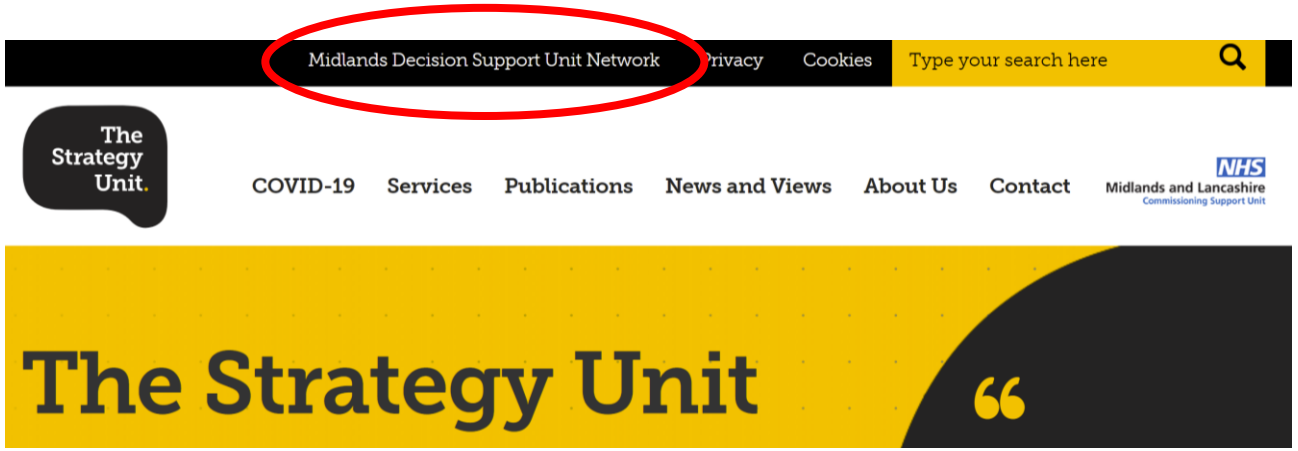
- Publish regional report
- Data packs with ICS data available
  - Unmet needs
  - Pathway analysis
- Other supporting materials
  - evidence map
  - cohort analysis
  - Summary survey report

Supporting the ICS:

The DSU/SU will

- Facilitate action-planning workshop (or alternative) for each area

DSU website currently under (re) construction; temporarily resources will be uploaded to a section of the Strategy Unit website:



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