

### **JCPP Advances First Year Anniversary**

Thursday 9 June 2022

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# Will the neurodiversity concept change child psychology and psychiatry research?

ADHD as an example

**JCPP Advances Anniversary Celebration** 

Edmund Sonuga-Barke

King's College London
Aarhus University

### Neuro-diversity as a rights-based concept

- Originating within the autism community.
- New way of thinking about people with neuro-developmental

conditions....

- .... motivated by the pursuit of justice....
- ... valuing & accommodating to different ways of thinking/being ....
- ...promotes their personal dignity/societal acceptance...

### Neuro-diversity as a rights-based concept

- Accepts The neuro-biological reality of "ADHD".
- Rejects "ADHD" as disorder.
- Emphasizes Positive "ADHD" aspects.
- Looks to Accommodate to "ADHD".
- Privileges Personal experience of ADHD.
- Promotes Self determination & solidarity.

### Neurodiversity as a scientific paradigm

These radically different assumptions about the nature of ADHD also have the potential to transform our scientific paradigm.

### History of science and paradigm shifts - Kuhn

- Incremental gains within stable framework a paradigm (DSM/ICD).
- Facilitates and constrains science through assumptions, scientific & non-scientific, about disorder's nature.
- Step change occurs when meta-theory is overturned and paradigm shifts.

  Pre-science

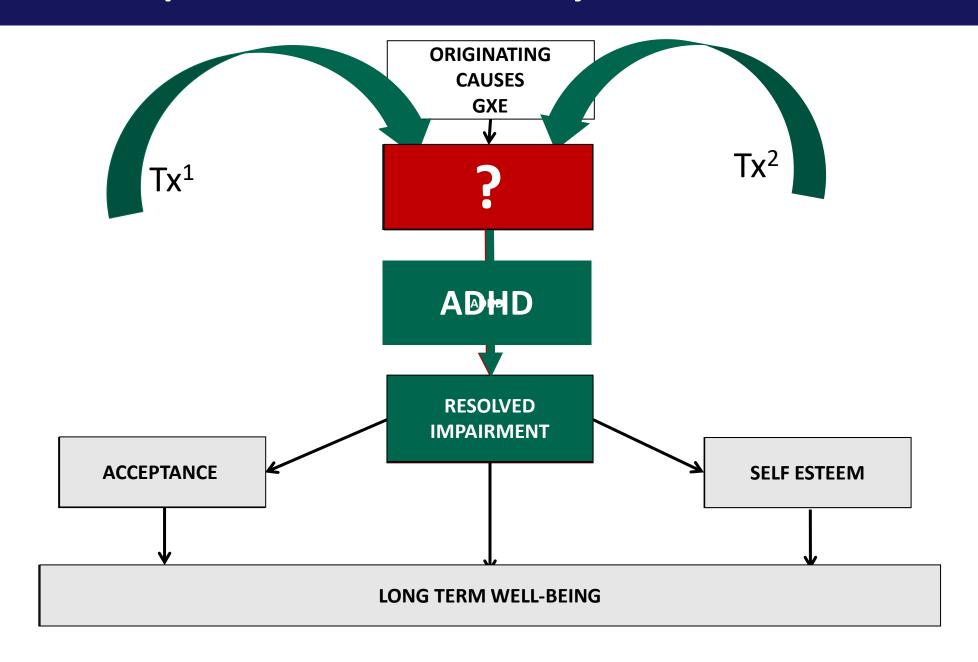
Model

Science

Paradigm رChange

Revolution

### **Key science question – what brain dysfunction causes disorder?**



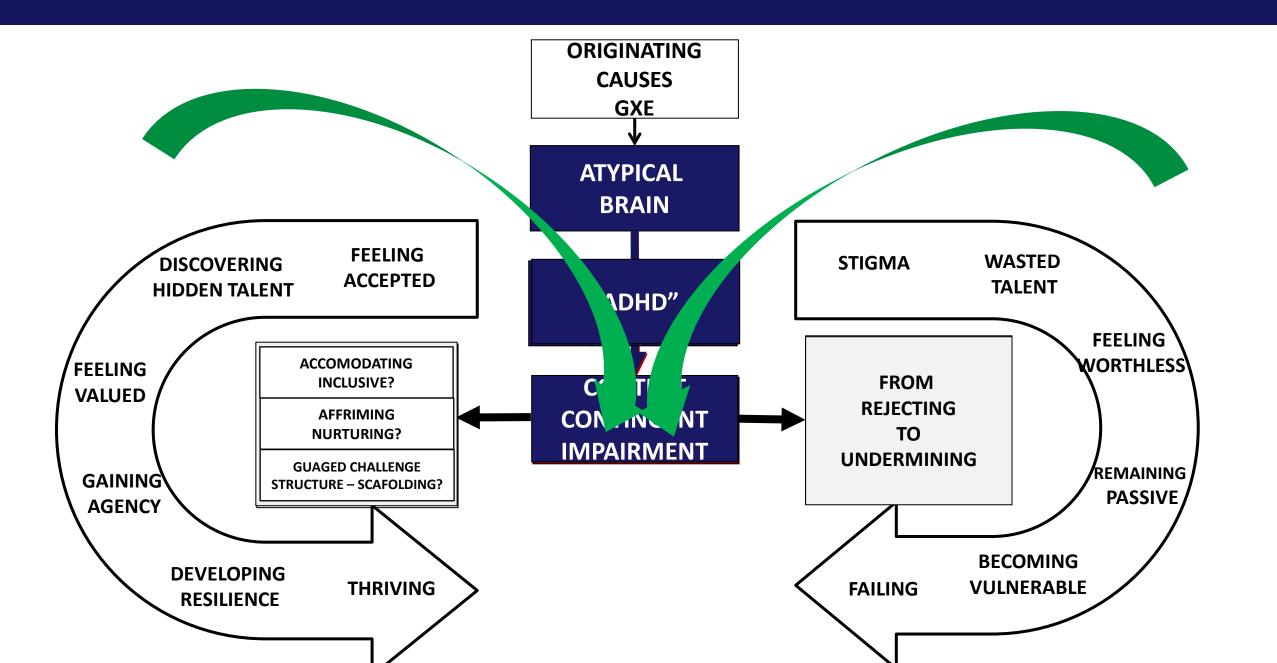
### Neurodiversity paradigm changes what's studied

Reframes "ADHD" as divergent attention/activity caused by natural brain variations.

Breaks the link impairment and disorder – presents it as contingent, situated & socially constructed.

Focuses research on how cultural norms impose environmental constraints to impair, stigmatize & stifle potential.

### Key science question: What defines "ADHD" positive environments?



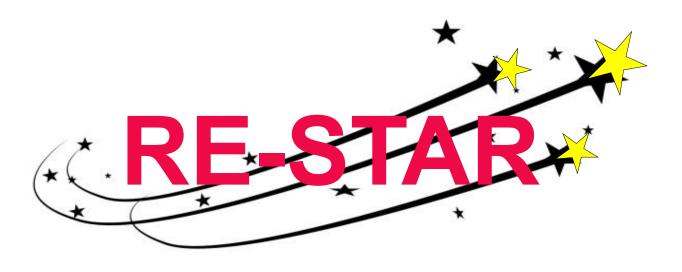
### Neurodiversity paradigm changes what's studied and how!

Reframes "ADHD" as divergent attention/activity caused by natural brain variations.

Redefines impairment as contingent, situated & socially constructed.

Places the personal experience of neuro-divergent people at the heart of these attempts.

Focuses research on how cultural norms impose environmental constraints to impair, stigmatize & stifle potential.



## Regulating Emotion – Strengthening Adolescent Resilience

An experiment in co-intentional translational science

Part of UKRI's Adolescent Mental Health & the Developing Mind initiative.

# Integrated care to improve 21<sup>st</sup> Century child and adolescent health

#### Mina Fazel

Professor of Adolescent Psychiatry, University of Oxford Consultant in Child & Adolescent Psychiatry, Children's Psychological Medicine, Oxford University Hospitals

# The Changing Face of Medicine

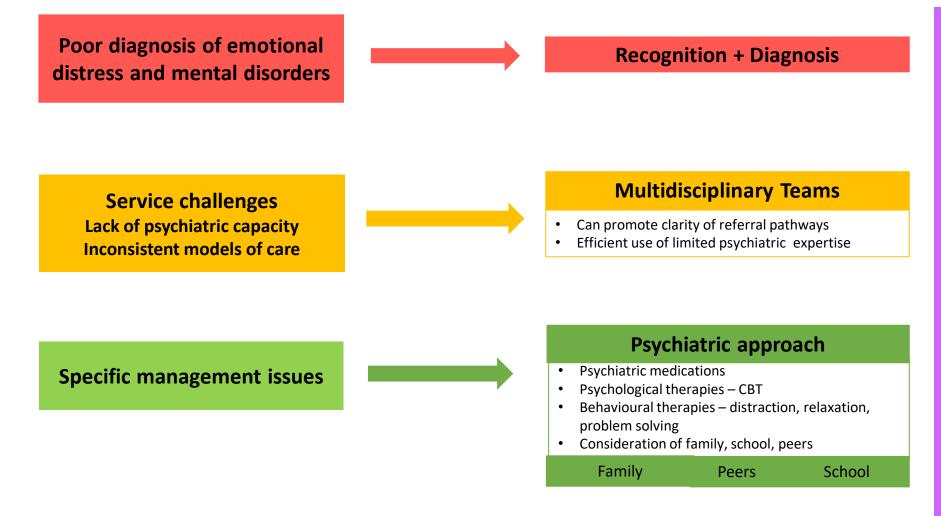
- Infancy, childhood and adolescence
  - Physical growth
  - Cognitive capacities
  - Social relationships
  - Communication
- Children with chronic and increasingly complex health problems
  - Medical and technical advances
  - Improved survival
  - Heavy burden of health care
- Legacy of separation

# Models of care: how and by whom

- Complex needs mainly treated in tertiary hospitals
- Previous model: single specialist
- Contemporary paediatrics
  - Specialisation
  - Sophistication of technical tools
  - Multidisciplinary teams
- Can be easy to neglect non-biological aspects of care

### Mental health

- Increasing awareness of mental health difficulties
- Especially for those children with chronic health difficulties
- Affects treatment adherence, health outcomes, quality of life
- Social and environmental determinants of health



# Areas of need for psychiatry services in children's hospitals

### Main areas

- Life limiting illnesses
  - High burden of care
- Disorders involving the brain
  - Epilepsy; TBI
- Common chronic conditions
  - Diabetes, Asthma
- Psychiatric emergencies
- Disorders where psych and paeds intertwined
  - Gender dysphoria
  - Severe eating disorders

### Coordinated Care needs communication

Minimal collaboration

Basic collaboration at a distance (e.g telepsychiatry)

### Co-located Care needs physical proximity

Basic collaboration on Site

Close collaboration with some system integration

### Integrated Care needs practice change

Close collaboration approaching an integrated practice

Full collaboration in a transformed/merged practice

### Young Person's account

Disorders involving the brain

When I first came to the hospital I thought my problems were physical. When I was told I didn't have epilepsy I had a mixed bunch of emotions. Initially I was very confused because I had been taking antiepileptic medication for 5 years....

Now I really understand what epilepsy is, and that I don't have it, but I needed help to understand it. If at that point I had been told I needed to go somewhere else to get mental health support, I would have felt that they were brushing me off. I would have been angry and annoyed towards the health care system. I probably would have become depressed.

I don't think I would have been able to trust medical professionals again."

[15 year old presenting with seizure].

#### Parent account

A defining moment that still brings tears to my eyes is when I recall the meeting that we had with our neurologist and psychiatrist. This was the meeting where as a team, the neurologist and psychiatrist told us that they were 95% sure that our son did not have epilepsy. That was a very scary (and also a very hopeful) time for us. Before we left the meeting the doctor locked eyes with our son and said 'on behalf of the medical profession, I apologise'.

That statement was a turning point for our whole family. It took courage to say it and it helped us move on to the next step of getting care. We felt that we could do that because the psychiatrist was part of that process and that conversation. We were turned over to their care, quite literally, on that day with the neurologist in the room.

### Models of integration

- Bring biological, psychodynamic, pharmacological, developmental, family, and systems perspectives into the consultation
- 1930 John Hopkins: first example of collaborative care paediatric psychology unit
- In North America
  - Triple Board training
  - Paediatric portal training

### Conclusions

#### Increasing numbers

#### Psych comorbidity affects

• Treatment adherence, health outcomes, quality of life

### Current configuration erode opportunities to better integrate

- Inertia of institutions to change
- Need to incorporate adolescent voice to shape services

#### LMICs

- Focus on acute care
- Low mental health literacy
- Mental illness highly stigmatised

### Dissemination - instagram



**View Insights** 

**Not Approved** 







oxchildpsych



Liked by josiemcpherson and 78 others

oxchildpsych Our team recently researched whether there was a need for integrative care for children and adolescents. This post contains a little more... more

redgle02 Yes we do! Is the simple answer, from day one. It should be a health system and not a sickness system. Active healthcare instead of



Our researchers recently published a paper on how new types of hospital 'integrated care' teams are needed for young people with the most complex health problems- with paediatricians, psychiatrists and surgeons all working together in larger teams with families, schools and allied health professionals





Paediatricians don't understand mental health and sometimes say things that are inappropriate, and make you feel worse about yourself. Mental health people are not confident with physical stuff and often panic and send you to hospital. Maybe if physical and mental health were more together they could learn from each other and provide what is best for the patient.

-14 year old female with an eating disorder



It has been invaluable to have mental health as part of my treatment in the hospital. I am anxious and I know anxiety makes my symptoms worse. I was referred to Mental Health services in the community, but they didn't understand IBD [inflammatory bowel disease], and they didn't work out the connection. They thought that I had an eating disorder because I was under- weight. I need somebody that understands both and the impact on each other.

-13 year old with IBD

Definitely having mental health support is very important for children with cancer. It is a massive thing and it affects you in every way, physically, emotionally and socially. You need someone there and then, you can't wait.





Mina Fazel @minafazelox... · 26/10/2021 · · · Our newly published clinical review on integrated care. The art of medicine needs to adapt to the explosion & sophistication science has brought to 21st century child health @profmsharpe @OxPsychiatry @arc\_oxtv @TheJCPPadvances @OUHospitals @susansawyer01 acamh.onlinelibrary.wiley.com/doi/10.1002/jc...









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### Thanks

M Fazel, A Townsend, H Stewart, M Pao, I Paz, J Walker, SM Sawyer, M Sharpe. Integrated care to address child and adolescent health in the 21st century: a clinical review. *JCPP Advances* 2021;e12045

Professor Michael Sharpe
Oxford University Hospitals

Young people who shared their experiences

Josie- insta and tiktok assistance

### How small is a small effect size? Reflections on the pandemic

Argyris Stringaris
Professor of Child & Adolescent Psychiatry
University College London
04/06/2022

### Research findings in plain English.

Scientists are asked to communicate in plain English in order to explain their findings to non-specialists, including politicians and journalists.

This became an urgent need during the pandemic when scientists found themselves at the epicentre of public debates.

For the sake of communication scientists often resort to translations of numerical findings into plain language.

How well does this translation work?

### Research findings in plain English.

For example, some scientists have reassuringly told us that the negative effects of the pandemic on young people are "small".

How reassured should we be? Haven't CAMHS presentations increased (<sup>1</sup>) since the pandemic?

I will take this "small" as my point of departure and try to simulate the problem.

Ford TJ, John A, Gunnell D (2021) Mental health of children and young people during pandemic BMJ 2021;372,

### Standard take on effect sizes.

The most common interpretation of effect sizes comes from **Jacob Cohen**. He declared (and apparently later regretted having done so), that for an effect size *d*, defined thus:

d = difference in the average between two conditions / standard deviation of these two conditions pooled together

the following holds:

- · A value of 0.2 represents a small effect size.
- A value of 0.5 represents a medium effect size.
- A value of 0.8 represents a large effect size.

### A good study to estimate effect size.

Assume you have done the ultimate study:

- Is longitudinal with two periods (pre- and during)
- · Accounts for regression to the mean
- Does careful statistical inference

and have arrived at an effect size about the difference in depression scores in children before and during the pandemic.

You find and effect size of d = 0.14.

I will try to put this **small effect** in context

Mansfield R (2022) The impact of the COVID-19pandemic on adolescentmental health: a natural experiment, R Soc Open Sci, doi:

### Simulating the pandemic: data.

Consider the Mood and Feelings Questionnaire, a common depression measurement tool, as your outcome.

Let the mean pre-pandemic<sup>1</sup> in adolescents be:

MFQ\_mean\_pre = 4.90 with an SD of MFQ\_sd\_pre = 4.49

For an effect size close to d = 0.14 as per Mansfield<sup>2</sup>, the mean post-pandemic would have to be:

**MFQ\_mean\_post** = 5.53 (let's keep the standard deviation the same)

and let the **threshold** for caseness be the standard **MFQ threshold = 12** 

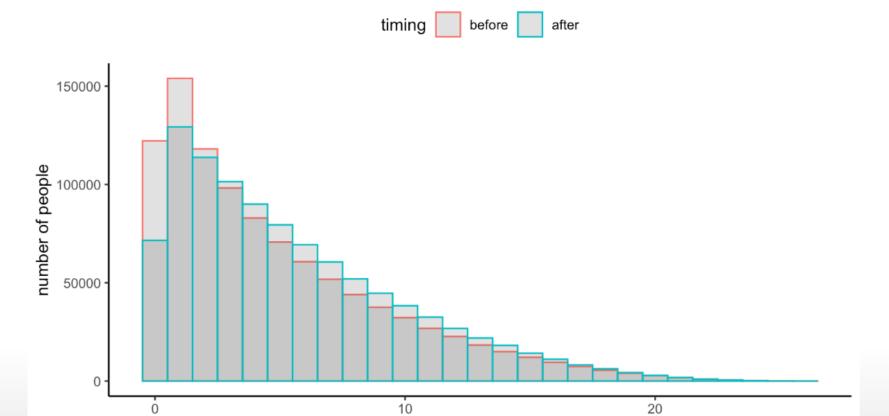
1.Kwong A (2019) Examining the longitudinal nature of depressive symptoms in the Avon Longitudinal Study of Parents and Children (ALSPAC), Wellcome Open Res, https://doi.org/10.12688/wellcomeopenres.15395.2.

# Simulating the pandemic: two distributions.

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I used a scaled beta distribution to simulate the data.

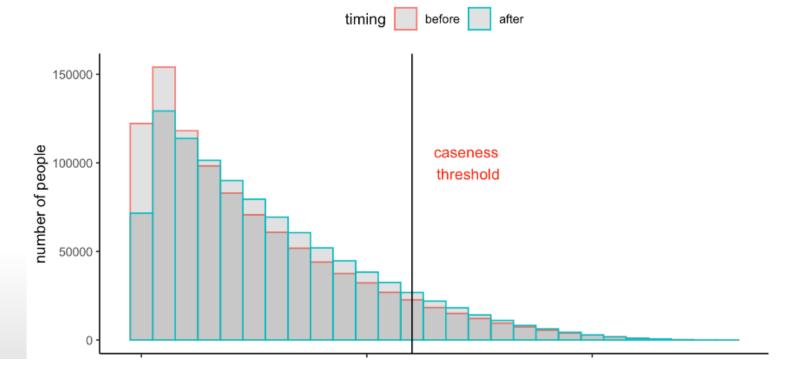
Shifts in depression \*\*means\*\* during a pandemic affecting 1M YP at Cohen's d ~ 0.14



### Simulating the pandemic: two distributions.

Here you see the two distributions with the threshold. It looks fairly innocuous.

Shifts in depression \*\*means\*\* during a pandemic affecting 1M YP at Cohen's d ~ 0.14



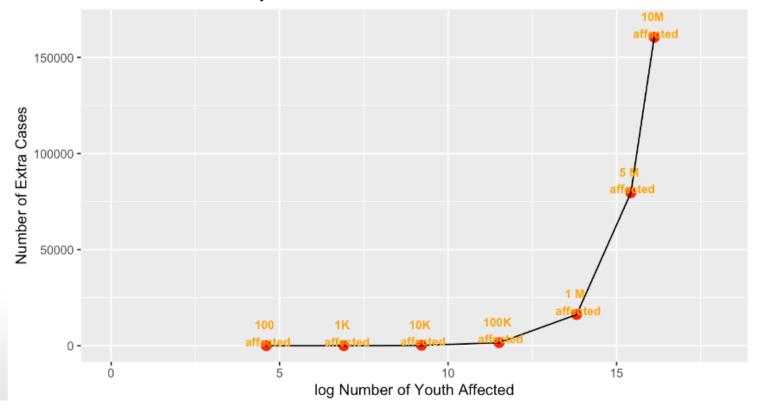
# Simulating the pandemic: what happens to the cases.

But is it that innocuous?

## Simulating the pandemic: excess cases due to the pandemic.

Here you see what the shift in mean values does to the tails.

Increase in Depression \*\*cases\*\* during a Pandemic at Cohen's d ~ 0.14 by Number of Youth Affected



### Simulating the pandemic: a reality check.

According to Mansfield et al<sup>1</sup>, the empirical **excess prevalence**, is about 1.6%.

This number corresponds to our simulation results:

e.g. for **1M** people, we get about **16K** excess cases of depression.

1.Mansfield R et al (2022) The impact of the COVID-19pandemic on adolescentmental health: a natural experiment, R Soc Open Sci, doi: 10.1098/rsos.211114.

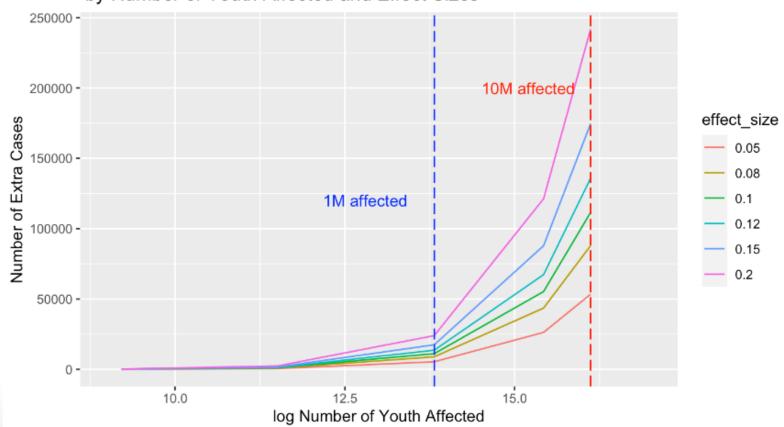
### Simulating the pandemic: small effects

## Warning: Removed 12 row(s) containing missing values (geom\_path).

### Simulating the pandemic: small effects

I have now varied the small effects to give you an idea of the range.

Increase in Depression \*\*cases\*\* during a Pandemic by Number of Youth Affected and Effect Sizes



### Small effects at large scales

Small effects are irrelevant (mostly) in a clinic.

That's why the label makes sense in clinical medicine.

Small effects are **very relevant** when they scale.

· That's why the label makes no sense in public health.

Other factors, such as *effects for what* are important too.

The approach presented here emphasises the value of simulation.

Useful Readings:

Matthay EC (2019) Powering population health research: Considerations for plausible and actionable effect sizes. SSM Population

Health, 19, 100789

Funder DC, Ozer DJ (2019) Evaluating Effect Size in Psychological Research: Sense and Nonsense,

### Small effects and reality

The findings here have implications about how we perceive reality and how we communicate about it.

Conventions (e.g. **small effects**) and summary statitstics (e.g. **Cohen's d**) are useful and necessary.

But they can also be highly misleading.

We propose that presentations of raw data, absolute numbers and simulations become the norm in scientific abstracts.

Last but not least: think how important small effects may be for interventions.

Greenberg MT, Abenavoli R (2017) Powering population health research: Considerations for plausible and actionable effect sizes.



# Pre-registering child mental health research using existing data: Challenges and potential solutions

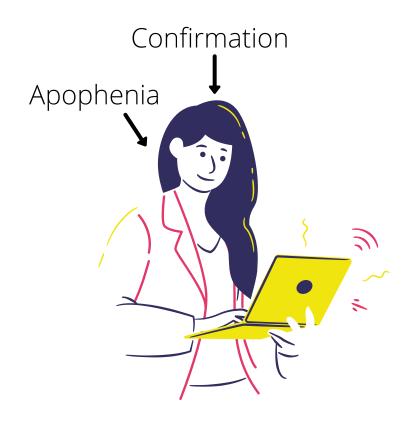
Jessie Baldwin

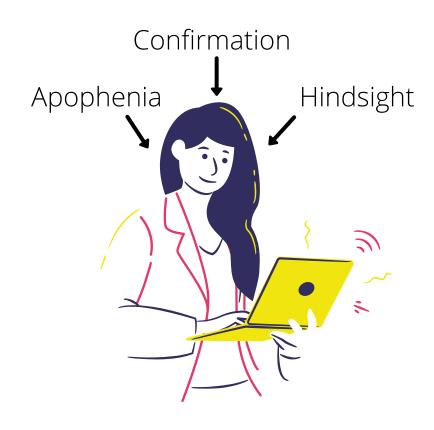
Sir Henry Wellcome Postdoctoral Fellow

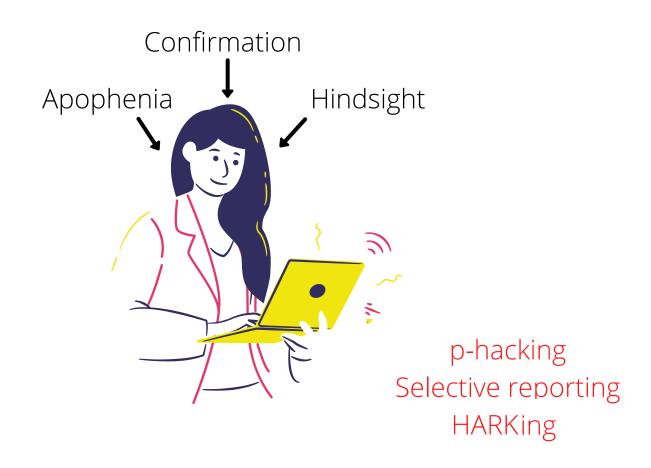










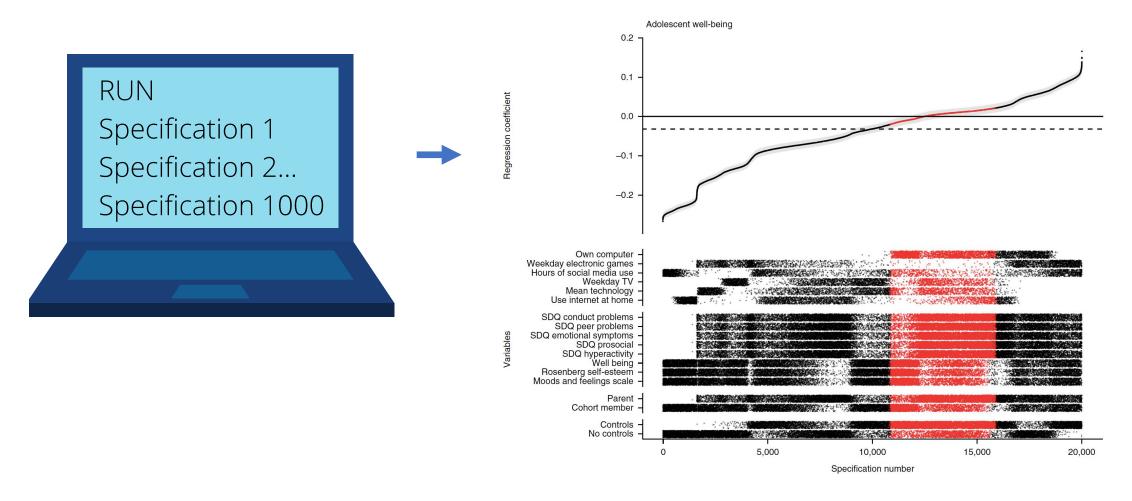




**Challenge 1: Prior access to data** 







### Challenge 2: Pre-registered analyses not appropriate for the data

Var 1	Var 2	Var 3
5	6	1
3	8	NA
NA	3	4

Var 1	Var 2	Var 3	
5	6	1	
3	8	NA	
NA	3	4	

Var 1	Var 2	Var 3	Var 1	Var 2	Var 3
5	6	1	3	3	NA
3	8	NA	NA	6	4
NA	3	4	5	8	1

Var 1	Var 2	Var 3	Var 1	Var 2	Var 3
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Var 1	Var 2	Var 3	Var 1	Var 2	Var 3
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3	8	NA	NA	6	4
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Data distribution = same

Var 1	Var 2	Var 3	Var 1	Var 2	Var 3
5	6	1	3	3	NA
3	8	NA	NA	6	4
NA	3	4	5	8	1

Data distribution = same Missingness = same

Var 1	Var 2	Var 3	Var 1	Var 2	Var 3
5	6	1	3	3	NA
3	8	NA	NA	6	4
NA	3	4	5	8	1

Data distribution = same

Missingness = same

Associations = different

Exposure 1	Exposure 2	Covariate 1	Covariate 2	Outcome
5	7	6	1	NA
3	2	8	2	NA
2	1	3	4	NA

Exposure 1	Exposure 2	Covariate 1	Covariate 2	Outcome
5	7	6	1	NA
3	2	8	2	NA
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Multivariable distributional characteristics

Exposure 1	Exposure 2	Covariate 1	Covariate 2	Outcome
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Multivariable distributional characteristics <a>Collinearity <

Exposure 1	Exposure 2	Covariate 1	Covariate 2	Outcome
5	7	6	1	NA
3	2	8	2	NA
2	1	3	4	NA

Multivariable distributional characteristics

Collinearity <

Predictors of missing data <

Challenge 3: Research may not be hypothesis-driven

Research question: Is X causally related to Y?		
Results	Interpretation	
$\beta_{\text{adjusted}} = \beta_{\text{unadjusted}}$	Causal	
$\beta_{ m adjusted} < \beta_{ m unadjusted}$ $\beta_{ m adjusted} > 0$	Partly confounded; partly causal	
$\beta_{\text{adjusted}} = 0$	Non-causal	

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• Effect size thresholds for interpretation

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- Effect size thresholds for interpretation
- Smallest effect size of interest

 Pre-registration poses challenges for child mental health research based on existing data

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- Data managers have a role to play in adopting approaches
  - E.g., providing blinded datasets, encouraging pre-registration
- Initiatives to increase ease of adoption = wider uptake

### Acknowledgments

European Journal of Epidemiology https://doi.org/10.1007/s10654-021-00839-0

ESSAY



Jean-Baptiste Pingault

Tabea Schoeler

Hannah Sallis

Marcus Munafò

Protecting against researcher bias in secondary data analysis: challenges and potential solutions

Jessie R. Baldwin<sup>1,2</sup> • Jean-Baptiste Pingault<sup>1,2</sup> • Tabea Schoeler<sup>1</sup> • Hannah M. Sallis<sup>3,4,5</sup> • Marcus R. Munafò<sup>3,4,6</sup>





@jessiebaldwin









## The extent and drivers of the gender-gap in adolescent mental health

**Praveetha Patalay** 

**June 2022** 

CENTRE FOR LONGITUDINAL STUDIES

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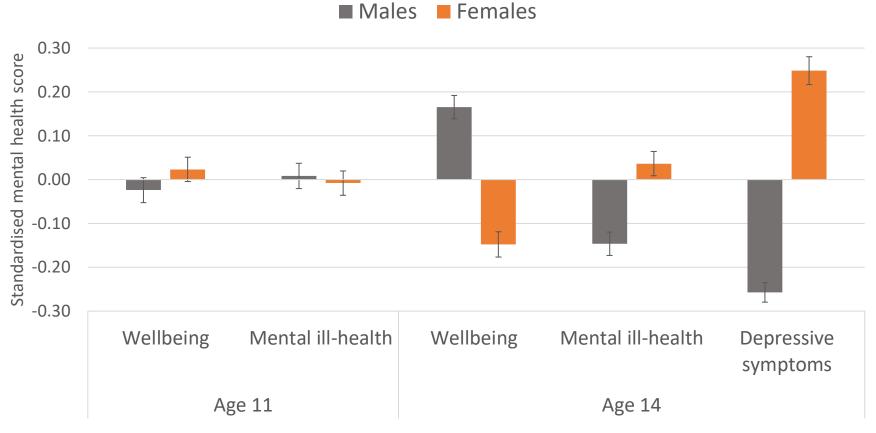


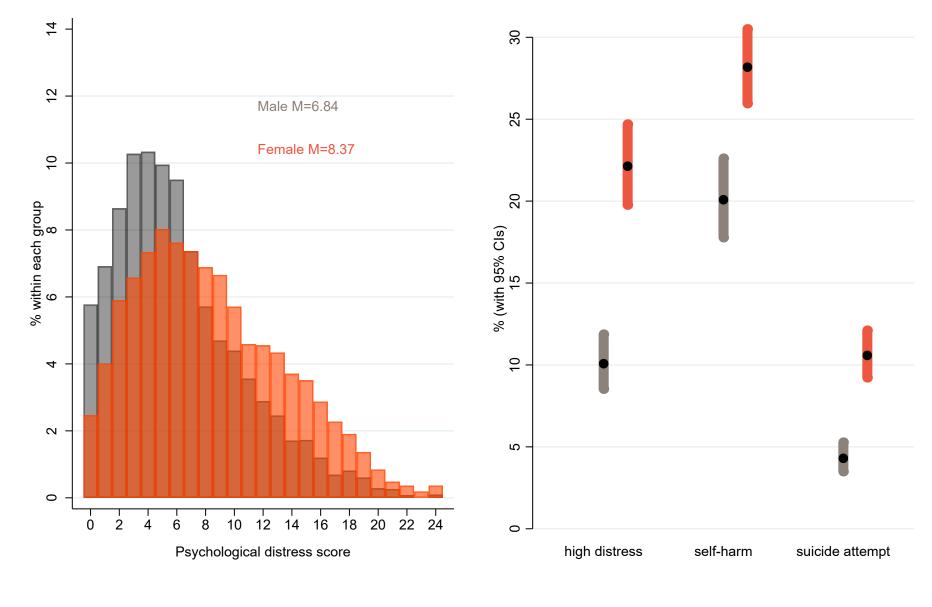
@pravpatalay

Estimate double the prevalence of internalising difficulties/disorders in females

This gap seems to appear in adolescence, and persist across the lifecourse

Also seen in other key mental health outcomes such as life satisfaction and wellbeing





### Why is there a gender gap?

 Some literature investigating this question, no consensus and evidence base is weak

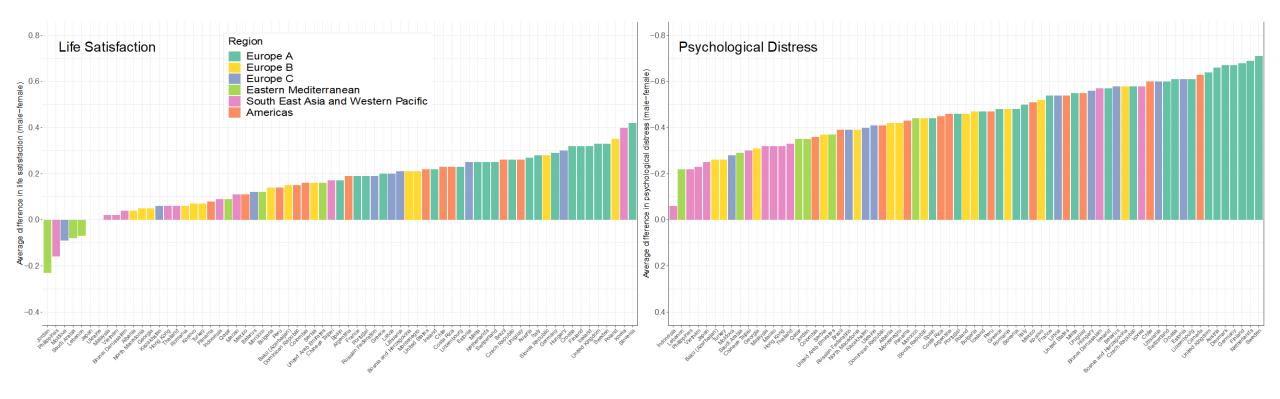
It is widely assumed that the gender-gap is universally consistent

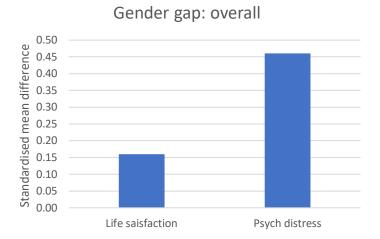
Is it though?!?!?!?!

COPING SETTICS

- Social support
- Hormones
- Neurotransmitter systems

Note the lack of good quality and longitudinal evidence for possible causes for emergence of gender differences

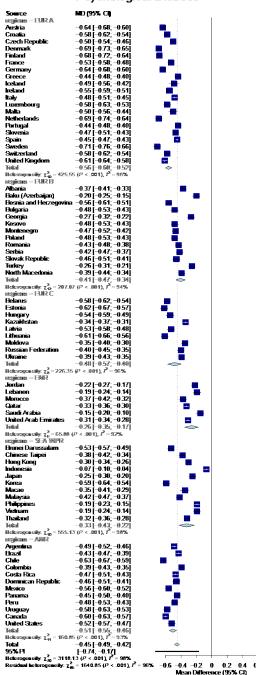




Over 500,000 adolescents from over 70 countries (data: PISA 2018)



#### Psychological Distress



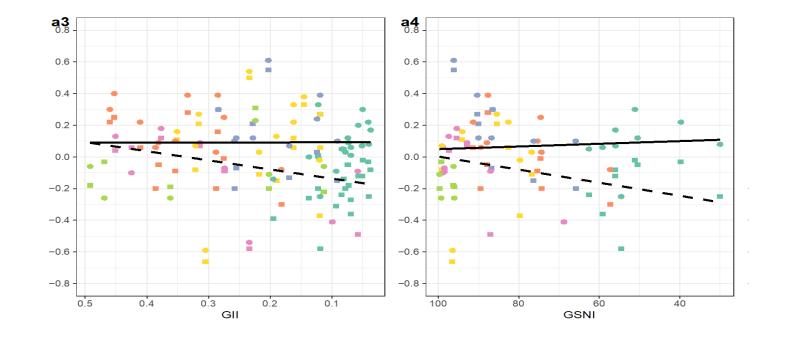
I<sup>2</sup> is the percentage of variation across nations due to heterogeneity rather than chance.

High  $I^2 > 95\%$  indicates that there is considerable and non-random variation

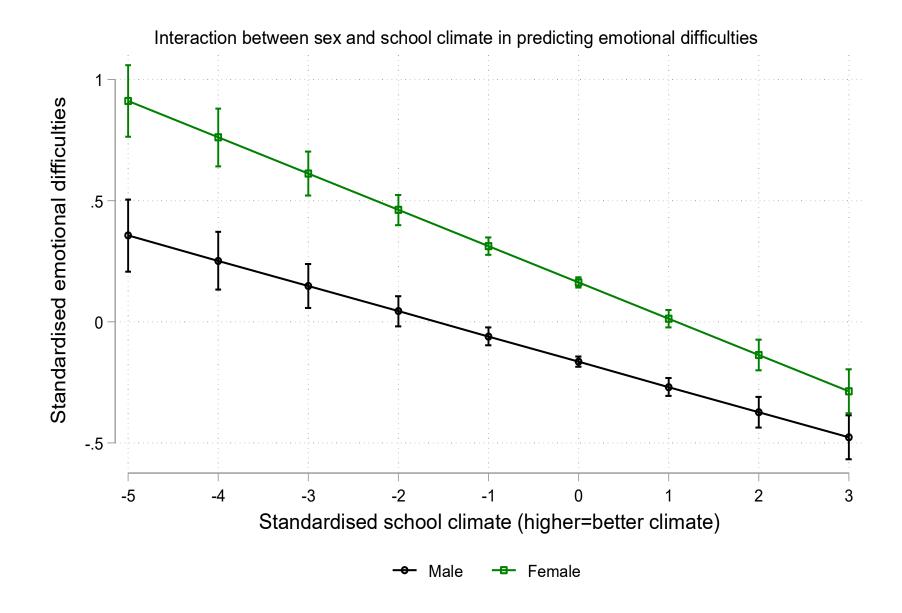
Why are we not interested in the reasons for the excess common mental health difficulties experienced by females ???

# Country level gender equality: Complex associations

- Suggested by other studies too (inc for depression diagnosis)
- Hypothesized explanations inc expectation-reality gap; comparison group and multiple role pressures...
- Some studies suggest 'U' shape associations...no countries with perfect gender equality

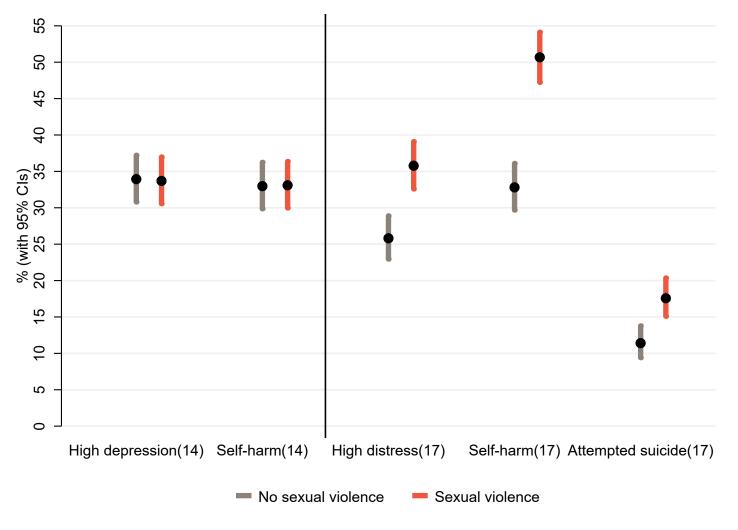


Environments (e.g school): differential impacts?



# Gendered risk factors: e.g. sexual violence

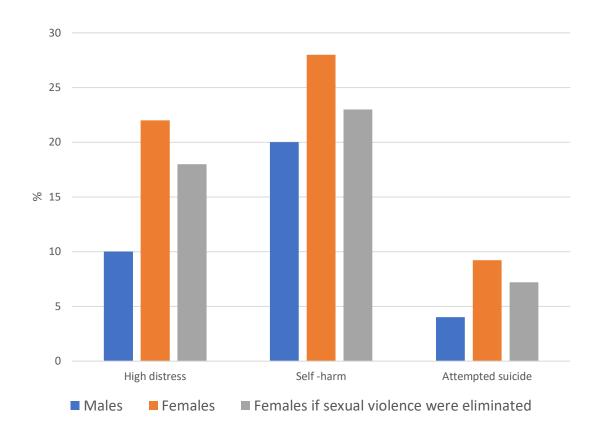
#### Prevalence of mental health outcomes at ages 14 and 17 in girls





### Assuming this effect is causal...

- We estimated Population Attributable Fractions that could be attributed to sexual violence
  - 16-21% of mental health difficulties in females at this age may not occur in hypothetical scenario where mid-adolescent sexual violence does not occur

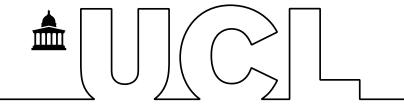


## • Large sex/gender inequalities in internalising mental health that appear in adolescence (and then the gap persists through life)

 The gender gap in mental ill-health and wellbeing might not be inevitable

 Understanding why it varies and identifying context dependent factors that reduce it is important for reducing this disparity (prevention)





### Thank you

CENTRE FOR LONGITUDINAL STUDIES

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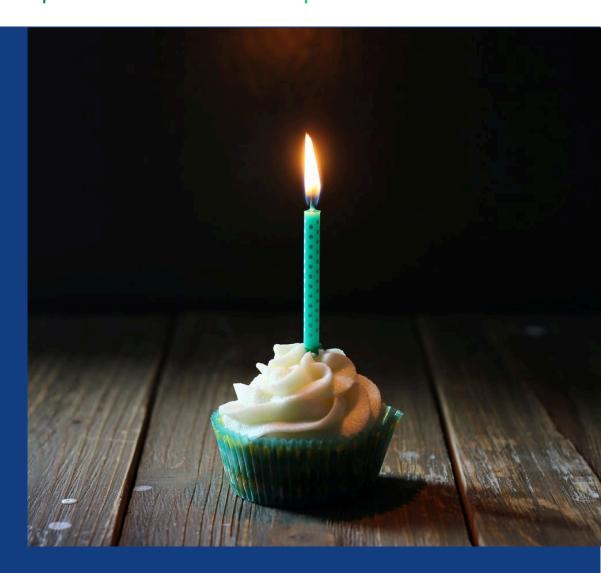


@pravpatalay



## JCPP Advances from conception to our first birthday

**Sarah Oates Senior Editorial Director, Wiley** 





2022

20 years working in partnership

WILEY





# The Journal of Child Psychology and Psychiatry

- **The leader:** the leading international journal in child and adolescent psychology and psychiatry
- World class editorial team
- **Highly cited:** Impact factor growth from 2 to nearly 9
- Internationally read: 5 years ago, 1 million downloads a year. 2021 approaching 2 million

# 2019-2021: Funders and universities demand change...



PROFESSIONAL IOBS EVENTS RANKINGS STUDENT

European Commission Announces Official Launch of Open Research Europe, New Platform Powered by F1000 Research

Filed by Gary Price on March 24, 2021

From the European Commission:

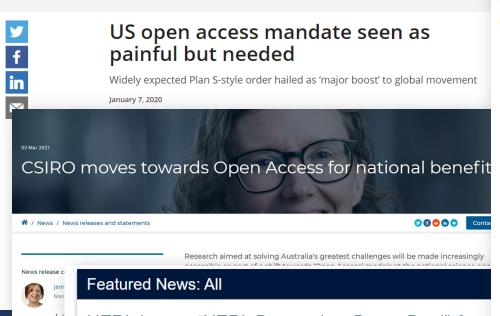
Today, the European Commission launched Open Research Europe, a publishing platform for scientific papers that will be accessible to everyone. The platform will present the results of research funded by Horizon Europe, the EU research and innovation programme for 2021-2027 and its predecessor. Horizon 2020.

Open Research Europe will give everyone, researchers and citizens alike, free-of-charge access to the latest scientific discoveries. It directly addresses major difficulties often associated with publishing scientific results, including delays and barriers to the re-use of results and high costs. The platform is an optional service for Horizon Europe and Horizon 2020 beneficiaries so that they can comply with their funding requirements for immediate open access, at no cost to them





Science journals end open-access trial v



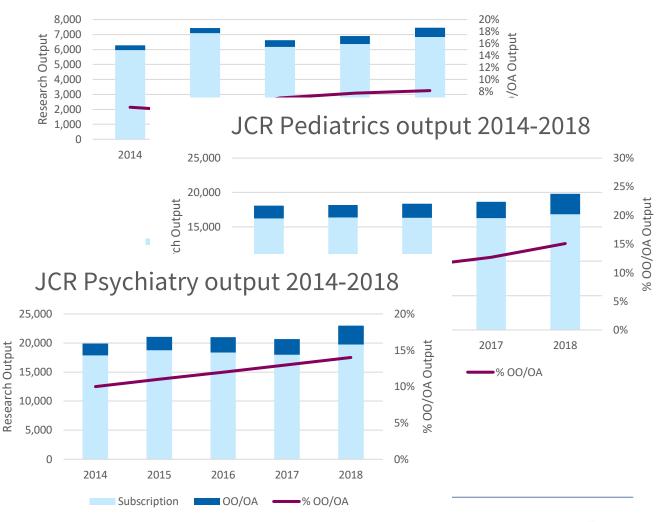


NERL Issues "NERL Demands a Better Deal" State Guide Negotiations with Publishers

https://www.crl.edu/The NERL Consortium issued a statement, "NERL Demands a Better Deal," articulating the values NERL will adopt in negotiating agreements with publishers.



### JCR Psychology, Developmental output 2014-2018









#### Our mission for *JCPP* Advances is to:

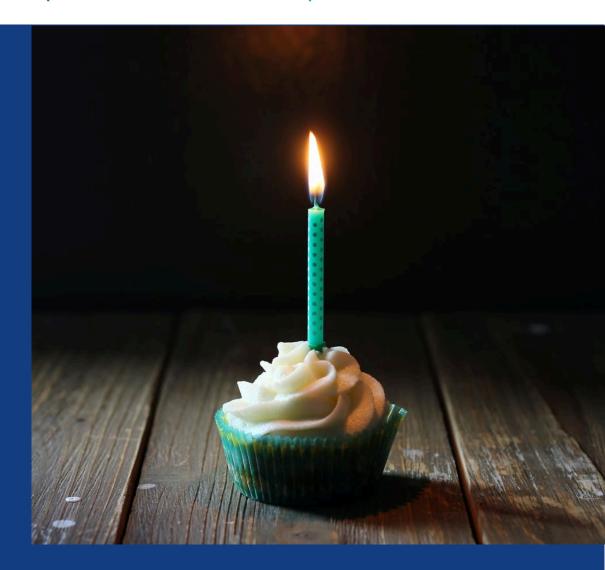
- Advance open science
- Value robust methodological standards & adhere to strong reporting standards (CONSORT, trial registration and PRISMA)
- Create a welcoming platform for innovative methods to be published side by side with large scale, international studies
- Offer a fast and easy publishing experience for our authors







### So what have we achieved to date?



# What does JCPP Advances bring to the field?

### Ease of publishing

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# What does JCPP Advances bring to the field?

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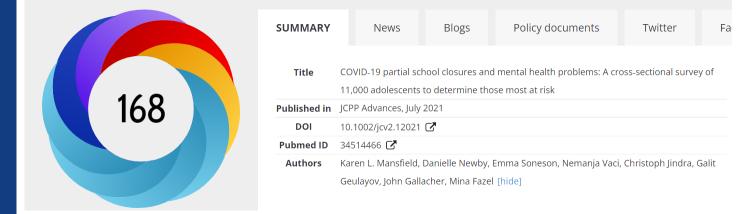


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# What does JCPP Advances bring to the field?

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Ultimately, we hope that the work published in *JCPP* and *JCPP Advances* will lead to a better understanding of, and better outcomes for, children, teenagers, and young adults in our society.

