# Crossing the divide: a longitudinal study of effective treatments for people with autism and attention deficit hyperactivity disorder across the lifespan

Declan Murphy, 1\* Karen Glaser, 2 Hannah Hayward, 1 Hanna Eklund, 1 Tim Cadman, 1 James Findon, 1 Emma Woodhouse, 3 Karen Ashwood, 3 Jennifer Beecham, 4 Patrick Bolton, 5 Fiona McEwen, 3,5 Ellie Wilson, 1 Christine Ecker, 1 Ian Wong, 6 Emily Simonoff, 5 Ailsa Russell, 7 Jane McCarthy, 8 Eddie Chaplin, 1 Susan Young 1 and Philip Asherson 3

<sup>1</sup>Sackler Institute for Translational Neurodevelopment and Department of Forensic and Neurodevelopmental Sciences, Institute of Psychiatry, King's College London, London, UK

<sup>2</sup>Institute of Gerontology, King's College London, London, UK

<sup>3</sup>Medical Research Council Social, Genetic and Developmental Psychiatry Centre, Institute of Psychiatry, King's College London, London, UK

<sup>4</sup>London School of Economics and Political Science, London, UK

<sup>5</sup>Department of Child and Adolescent Psychiatry, Institute of Psychiatry, King's College London, London, UK

<sup>6</sup>Department of Pharmacology and Pharmacy, University of Hong Kong, PokFuLam, Hong Kong

<sup>7</sup>Department of Psychology, University of Bath, Bath, UK

8St Andrew's Healthcare, Northampton, UK

**Declared competing interests of authors:** Declan Murphy has received research funding from Shire (Basingstoke, UK) and leads the European Union (EU) Innovative Medicines Inititative consortium EU Autism Interventions – a Multicentre Study for Developing New Medications that receives funding from both the EU and the European Federation of Pharmaceutical Industries and Associations. Ian Wong received a research grant from the European Commission, Hong Kong Research Grant Council and Janssen-Cilag Ltd (High Wycombe, UK) on research to investigate the safety of antipsychotic drugs and attention deficit hyperactivity disorder treatments. In addition, Ailsa Russell has a patent Authors Copyright – Treatment Manual Cognitive–Behavioural Therapy for Obsessive–Compulsive Disorder in Autism Spectrum Disorder pending. Susan Young has received honoraria for consultancy, travel, educational talks and/or research from the Cognitive Centre of Canada, Janssen Pharmaceutical (Raritan, NJ, USA), Eli Lilly (Indianapolis, IN, USA), Novartis (Frimley, UK), HB Pharma (Sorø, Denmark), Flynn Pharma (Stevenage, UK) and Shire. Philip Asherson has received honoraria for consultancy, travel, educational talks and/or research from Janssen Pharmaceutical, Eli Lilly, Novartis, HB Pharma, Flynn Pharma and Shire.

<sup>\*</sup>Corresponding author declan.murphy@kcl.ac.uk

Published June 2018 DOI: 10.3310/pgfar06020

# **Plain English summary**

### Crossing the divide

Programme Grants for Applied Research 2018; Vol. 6: No. 2

DOI: 10.3310/pgfar06020

NIHR Journals Library www.journalslibrary.nihr.ac.uk

## **Plain English summary**

Our aim was to determine if clinical services meet the needs of people with attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) who are 'at transition' from childhood to adulthood and those of their carers; and to identify how improvements could be made. We asked four research questions:

- 1. What are the needs of affected individuals and their carers?
- 2. Are people with ADHD and ASD recognised and treated?
- 3. Can we improve the identification of ADHD and ASD?
- 4. Can we improve the treatment of ADHD and ASD?

We found the following answers.

People with ASD and ADHD have significant needs as they move through adolescence and young adulthood. A major contributor to these is the presence of associated mental health symptoms (e.g. depression and anxiety), which are mostly undiagnosed (and untreated). As affected individuals age, there are less likely to be seen by services. Carer burden may be approximately the same as looking after somebody with a traumatic brain injury or dementia. New changes to the ways people are diagnosed suggest that many individuals will be excluded from services.

Clinical services have a high prevalence of people with ASD and ADHD. However, only a minority of affected individuals are recognised, or treated, by the services they are in touch with. This may reflect a lack of both techniques to identify people with these conditions and staff knowledge.

Our research identified new tools to diagnose the core disorders associated with ADHD and ASD and their associated symptoms and suggests that simple psychological interventions to treat obsessional symptoms may be beneficial. We also found that treatment trials could potentially be run in prisons and that web-based training interventions are useful to clinicians.

## **Programme Grants for Applied Research**

ISSN 2050-4322 (Print)

ISSN 2050-4330 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full PGfAR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/pgfar. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

#### Criteria for inclusion in the Programme Grants for Applied Research journal

Reports are published in *Programme Grants for Applied Research* (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

#### **Programme Grants for Applied Research programme**

The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health Research (NIHR), was set up in 2006 to produce independent research findings that will have practical application for the benefit of patients and the NHS in the relatively near future. The Programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director.

The programme is a national response mode funding scheme that aims to provide evidence to improve health outcomes in England through promotion of health, prevention of ill health, and optimal disease management (including safety and quality), with particular emphasis on conditions causing significant disease burden.

For more information about the PGfAR programme please visit the website: http://www.nihr.ac.uk/funding/programme-grants-for-applied-research.htm

#### This report

The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0606-1045. The contractual start date was in August 2007. The final report began editorial review in August 2013 and was accepted for publication in July 2017. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, NETSCC, PGFAR or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PGFAR programme or the Department of Health and Social Care.

© Queen's Printer and Controller of HMSO 2018. This work was produced by Murphy et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

#### **NIHR Journals Library Editor-in-Chief**

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

#### **NIHR Journals Library Editors**

**Professor Ken Stein** Chair of HTA and EME Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andrée Le May Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

**Professor Matthias Beck** Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Senior Scientific Advisor, Wessex Institute, UK

Dr Peter Davidson Director of the NIHR Dissemination Centre, University of Southampton, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

**Dr Catriona McDaid** Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

**Professor Geoffrey Meads** Professor of Wellbeing Research, University of Winchester, UK

Professor John Norrie Chair in Medical Statistics, University of Edinburgh, UK

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

**Professor James Raftery** Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professor of Child Health Research, UCL Great Ormond Street Institute of Child Health, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

**Professor Helen Snooks** Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

**Professor Jim Thornton** Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

**Professor Martin Underwood** Director, Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk