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DOI:

[10.1016/j.neubiorev.2022.104586](https://doi.org/10.1016/j.neubiorev.2022.104586)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Pawley, A., Mostert, J. C., Bilbow, A., Reif, A., Vasquez, A. A., Kuntsi, J., & Franke, B. (2022). Sharing knowledge about ADHD comorbidity: lessons learned: lessons learned. *Neuroscience and Biobehavioral Reviews*, 135, [104586]. <https://doi.org/10.1016/j.neubiorev.2022.104586>

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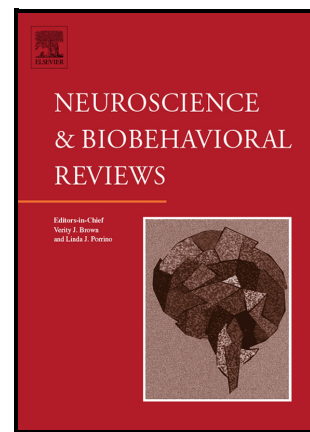
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Journal Pre-proof

NBR Special Issue: Life-span comorbidity of ADHD and related phenotypes – from biology to epidemiology and back

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PII: S0149-7634(22)00075-6

DOI: <https://doi.org/10.1016/j.neubiorev.2022.104586>

Reference: NBR104586

To appear in: *Neuroscience and Biobehavioral Reviews*

Revised date: 14 February 2022

Accepted date: 14

Please cite this article as: Adam Pawley, Jeanette C. Mostert, Andrea Bilbow, Andreas Reif, Alejandro Arias Vasquez, Jonna Kuntsi and Barbara Franke, NBR Special Issue: Life-span comorbidity of ADHD and related phenotypes – from biology to epidemiology and back, *Neuroscience and Biobehavioral Reviews*, (2021) doi:<https://doi.org/10.1016/j.neubiorev.2022.104586>

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NBR Special Issue: Life-span comorbidity of ADHD and related phenotypes – from biology to epidemiology and back

Article Type: Commentary

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Sharing knowledge about ADHD comorbidity: lessons learned

Comorbidity of ADHD across the lifespan is not only a clinical, but also a societal issue. As such, knowledge generated from research should be disseminated to health care professionals, policy makers, patients and their advocates, and the general public. Many of the articles in this special issue originate from the Horizon2020-funded project Comorbid Conditions of ADHD (CoCA, No 667302) that, in addition to performing scientific research, has put a lot of emphasis on dissemination of results and training of early career researchers (ECRs). Despite general awareness of the importance of dissemination, communication and training, clear-cut protocols for dissemination and training activities, and the evaluation of the success of these efforts, are currently still lacking. We therefore aim to provide insights and lessons learned from our actions, in order to assist other research groups, institutions, and consortia in sharing their medical research with societal stakeholders, and effectively train a next generation of scientists.

Lesson 1: Know your stakeholders

According to the Cambridge Dictionary, dissemination is defined as activities “to spread or give out something, especially news, information, ideas, etc., to a lot of people”. As such, dissemination of research entails publishing, presenting at conferences, sharing press releases, writing blog posts, organising open days, giving workshops and courses, creating clinical guidelines, and much more. The choice of dissemination activity depends on the stakeholder that is targeted. For research on ADHD comorbidity, the most relevant stakeholders are other researchers in the field or adjacent fields, health care professionals, patients and patient organizations, policy makers, and industry (i.e. insurance companies, pharmaceutical companies). It should be stressed that dissemination is never an end in itself. It is a tool to start a dialogue with a stakeholder, who in turn determines the relevance and usability of the information (Green et al. 2009).

Lesson 2: Involve stakeholders at an early stage of the research process

To make most use of this dialogue, it is important to start early. As an example, we started the dialogue with the patient organization ADHD Europe (<https://adhdeurope.eu/>) at the

stage of proposal writing for CoCA. ADHD Europe represents individuals with ADHD and their relatives in 21 countries. The voice of individuals with lived experiences is crucial when designing studies that aim to benefit them, such as the use of e-diaries together with mobile apps (see i.e., Koch et al. 2021) that can allow for non-pharmacological lifestyle interventions (Mayer et al, 2018).

Lesson 3: Collaborate closely with patient organizations

Findings on ADHD comorbidities are of significant interest to patients and self-help organizations, in order to raise awareness for such comorbidities and also to empower patients to engage in preventative measures. Patient representatives can help to translate scientific information to patients and their relatives, for instance by organising outreach events and webinars. Vice versa, inviting patient representatives to research meetings and giving them the opportunity to present their work can increase mutual understanding and dialogue. As an additional example from ADHD-related research, ECRs of the Training Network program “Mastering skills in the training Network for attention deficit hyperactivity and autism spectrum Disorders” (MiND) and CoCA researchers collaborated with ADHD Europe to create the short film “Shine a light - understanding ADHD” (<https://youtu.be/XmS7jUhb74A>). This is a key example of effective co-creation between patients and researchers.

Lesson 4: Translate findings into clinical guidelines and clinical education

Another important group of stakeholders is health care professionals. The most efficient step to shape the clinical care landscape is to translate findings into national and international guidelines, targeting both clinicians and policy makers. For instance, research findings on psychiatric and somatic comorbidities, as well as the proneness to accidents observed in people with ADHD, is relevant for guidelines regarding screening and management (see in this NBR special issue i.e., Mayer et al. (2021), Kittel-Schneider et al. (2021), Brunkhorst-Kanaan et al. (2021), Luderer et al. 2021, Homaei et al. 2021). In addition, workshops, courses, webinars, and e-learning can aid in professional education of clinicians, especially in countries where there is little awareness about adult ADHD, even amongst health care professionals. Such activities should also cover studies that investigate the biology underlying the comorbidity, e.g. genetics and studies of the brain substrates of ADHD (Grimm et al. 2021).

Lesson 5: Partner with professional societies for dissemination and training

Professional societies can have an important role in the dissemination of findings to professionals. As a project funded by the European commission, CoCA researchers decided to partner with *ECNP – neuroscience applied*, and founded the ECNP Thematic Working Group on ADHD across the Lifespan (<https://www.ecnp.eu/research-innovation/ECNP-networks/List-ECNP-Networks/ADHD-across-lifespan-network>). This proved instrumental in communicating our work to the scientific community, for example via the website or the Twitter feed. Such networks of scientists also aid in the creation of new projects, to ensure continuation of the research and collaboration between experts. Liaising with professional societies also allows for training beyond project-internal activities, such as providing input to conferences and workshops. The ECNP Network on ADHD across the lifespan ensures a sustainable strategy platform for both research and training.

Lesson 6: Educate ECRs about science dissemination

As argued above, the message that ADHD is a condition prevalent in both children and adults, and that it is often accompanied (or even over-shadowed) by comorbid conditions, is important to share with a broad range of stakeholders from patients to health care professionals and the general public. Dissemination outside academic settings is, however, not yet widely adopted by researchers due to lack of time, incentives, and/or training (Ross-Hellauer et al. 2018). A good way to achieve change in this situation is to educate the next

generation of researchers to do better. In CoCA, for example, we have provided masterclasses on open science, patient-inclusive language, neurodiversity, and inclusive research practices. In addition, ECRs were actively involved in creating “myth-buster” videos for ADHD Awareness Month, in collaboration with ADHD Europe.

Lesson 7: Let the ECRs be in charge of their training program

Given the range of expertise within collaborative international projects, there is a wealth of potential training opportunities for ECRs, and it is pivotal that this knowledge is shared in an effective way. For coordinators of such collaborative consortia, there are significant challenges to choosing topics for training which should be informative and useful for all, given the wide range of backgrounds of ECRs in many of the interdisciplinary collaborative consortia. However, we recommend that the training program should be considered as fluid, flexible and reactive, driven by ECR feedback. Asking ECRs to nominate topics and speakers for webinars and masterclasses was a well-received aspect of the CoCA project. Organising placements or short-term visits to consortium partner institutes can also provide an excellent, and relatively easy to organise, learning experience.

Lesson 8: Training can occur both online and offline

Some forms of training are best done in person. A key training and development opportunity is delivering interactive masterclasses. As described above, in CoCA, the topics for such masterclasses were selected by ECRs themselves. These ranged from academic topics to broader translational skills, such as those related to dissemination. Other examples of effective training opportunities are informal poster presentation sessions. This recognises the importance of effectively communicating your scientific research to others and being open to discussion and disagreement. While these training opportunities are best applied offline, the SARS-CoV-2 pandemic has taught us the benefits of e-learning approaches, enabling ongoing interactions outside face to face meetings; such training approaches can include webinars given by experts. Environmental reasons also call for ecologically responsible training activities. Personal meetings can be complemented by virtual ones, with, in our experience, limited loss of impact.

Lesson 9: Give every ECR the possibility to choose a mentor

An important form of learning within consortia is the opportunity to discuss professional development questions with a senior academic colleague. In CoCA, ECRs were offered mentorship by a senior member of the consortium, to co-develop training plans for achieving personal goals and living a healthy work/private life balance. Ideally, mentors are professionals from a similar or different field, who are not directly involved in the ECR's work. This can for instance be an academic at another institute, or in another research group.

To conclude, large, international and interdisciplinary consortia provide unique opportunities for sharing knowledge, from which not only a wide range of stakeholders, but also ECRs from the consortium itself can benefit. Large-scale, publicly funded projects have a responsibility to effectively communicate scientific findings to a range of stakeholders in a bespoke and meaningful way, and to provide ECRs within these consortia with opportunities to acquire the dissemination and communication skills that modern day society requests from them.

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Acknowledgement of funding sources

All authors have been supported by funding from the Horizon2020-funded project Comorbid Conditions of ADHD (CoCA, No 667302).