Opening up mental health research

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Open science provides a compelling framework for accelerating global collaborations and enabling discoveries to understand and treat mental health disorders. Herein, we discuss the advantages and obstacles to adopting open science in mental health research, considering the particularities of sensitive and diverse data types, the potential of co-designing projects with research participants and the opportunity of amplifying open science by integration with mental health care. We present a practical example of how this landscape may be navigated to adopt open science across an entire research centre, in 5 steps, namely leadership committing to open science; finding models, resources and allies; identifying needs; defining open science principles; and putting principles into practice. We derive lessons learned that can be built upon by researchers and research organizations joining the open science movement in mental health.

Introduction

Mental health disorders present an incredibly complex set of unsolved issues, both in terms of understanding their underlying causes and in developing the appropriate interventions to benefit each health care user. There is an urgent need to accelerate discovery and develop novel treatments, given that the burden of mental health conditions — currently amounting to more than 14% of years lost to disability globally — translates to immense economic costs and personal suffering.[1,2] Furthermore, conventional approaches to innovation, which restrict knowledge access and reuse, have had low yields in most instances.[3]

The emerging notion of open science provides a compelling framework to enable the global collaboration and discoveries required to understand and treat mental health disorders. As recently delineated by the United Nations Educational, Scientific and Cultural Organization (UNESCO), open science "combines various movements and practices aiming to make multilingual scientific knowledge openly available, accessible and reusable for everyone, to increase scientific collaborations and sharing of information for the benefits of science and society, and to open the processes of scientific knowledge creation, evaluation and communication to societal actors beyond the traditional scientific community."[4] Indeed, the COVID-19 pandemic has shown that accelerated discovery happens when research groups openly share data, samples and expertise.[5,6] We foresee a rapid shift to open approaches in the science of mental health over the next decade, taking data-driven learning in mental health to a new era.

Herein, we discuss the advantages and obstacles to the adoption of open science in mental health research. We focus on areas that are simultaneously challenging and potentially transformative, including maximizing openness while safeguarding sensitive data and codesigning open science with research participants and health care service users. We also guide the readers to many references that allow a deeper understanding of the discussed topics. We present a case study of our own journey of open science, reflecting on how the Douglas Research Centre (hereafter, Douglas) became the first Canadian research organization entirely dedicated to mental health research to adopt open science principles at an institutional level. We provide a template for instituting specific organizational changes that can be used by research-focused mental health institutions to accelerate their move toward open science.

Open science in mental health research

Open science entails a commitment to make research outputs findable, accessible, interoperable and reusable (FAIR). Research outputs extend beyond the data generated and the knowledge gained from research activities to also encompass publications and tools such as methods, codes and biological

samples. However, open science practices are not limited to the data collection, analysis and publication stages of the research lifecycle. Community engagement and codesign of research projects with stakeholders such as research participants may be involved in research project ideation while, at later stages, knowledge mobilization practices are used to communicate results to users, including health care providers.[7] Together, these activities increase the value, broaden the utility, and improve the verifiability and integrity of research.[8]

Open data sharing is a particularly rewarding and challenging area for mental health research, but different types of data face distinct challenges. For data from animal models, most complexities associated with open data sharing are of a technical nature and revolve around identifying or developing appropriate (meta) data standards and open data sharing platforms (e.g., MouseBytes for rodent cognition data).[9] In contrast, when collecting and processing highly sensitive data from vulnerable populations, several issues need to be addressed not only from technical but also ethical and legal standpoints.

With regard to policy, mandates for transparency over research data management (e.g., from the Tri-Agency in Canada) or open data sharing (e.g., from the National Institutes of Health in the United States) are becoming the norm.[10,11] Despite the evolving policy landscape, and although the open science movement has gained traction over the last few years, data sets are still frequently kept closed.[12] Concerns for data safety are laudable and necessary, but numerous strategies may be combined to maximize access to data while preserving the confidentiality of research participants within local legal obligations (e.g., Quebec's Law 25).[13] An entire spectrum of data access can be explored, from closed data sets to completely open data sets that are available to the general public.[14] For example, the data set from the Presymptomatic Evaluation of Experimental or Novel Treatments for Alzheimer's Disease (PREVENT-AD) cohort makes raw basic demographic and neuroimaging data openly available, but more sensitive data are only accessible by registered researchers.[15] At the level of data hosting, cybersecurity measures — such as coded storage, data encryption and the use of data enclaves with systems to verify and authenticate — are critical.[16] At the level of the data, there are well-defined protocols for anonymization and deidentification of data sets as diverse as magnetic resonance imaging (MRI) scans and speech data.[17,18] The strategies of sharing data in the form of synthetic data sets and allowing processing through trusted research environments preserve confidentiality while enabling analysis of sensitive data, such as from electronic health records.[19,20]

Even if all technical steps are taken to protect highly sensitive data, the concept of open science still raises several questions of consent, ethics and law. Open science is generally met with enthusiasm by research participants. A recent publication by the PREVENT-AD program reported that, upon recontacting a cohort of cognitively unimpaired older individuals with a family history of Alzheimer disease, 90% of research participants retrospectively agreed to openly share data including imaging, biochemical, cognitive and medical information.[15] Although certain conditions (e.g., schizophrenia[21]) may lower a participant's capacity to consent, the motives to consent and the validity of consent provided by an informed person are considered to hold the same value, irrespective of their health status.[22,23] The legal frameworks for handling data do not discriminate against mental illnesses and are often identical to that of other clinical populations across many jurisdictions (e.g., Australia, Canada, China, India, US, European Union). Nevertheless, personal concerns from patients and families with lived experience of a mental illness may be distinct from those with experience of physical or neurologic conditions (e.g., aphasia, brain injury). Recent work with people with lived experience of psychiatric symptoms reported that, although most were open to recordings of speech, their most important concern revolved around privacy.[24]

We advocate for a codesigning approach toward open data sharing and open science. Codesigning projects with health care service users and research participants is critical to tackle concerns regarding data use and privacy. In particular, codesigning with under-represented groups and Indigenous partners is essential to specify the acceptable data donors and users for various projects. Codesigning can also identify the best technical means for data acquisition and optimal levels of data deidentification or anonymization, and define how data use will be monitored and reported. This is essential to meet the needs of vulnerable and underrepresented groups.[25] Service users could codesign resources (e.g., leaflets) for informed consent; fully informing participants who consent to sharing their data is key to successful open science — in the absence of this, reapproaching participants for consent or applying for waivers is essential.

Beyond sharing data at the level of the research project, open science holds a transformative potential when implemented at the interface between research and clinic. Making data or any other research outputs generated available worldwide for reuse has the potential to accelerate clinically relevant discoveries.[6] Among many prerequisites for enabling secondary use of clinical and administrative data, we highlight fostering FAIR principles, a challenging task that has showed promising advances during the COVID-19 pandemic.[26] In addition to ensuring wider access to data, which is being achieved by initiatives such as the Banque Signature,[27] open science can also drive open innovation through public–private partnerships and citizen science, thus accelerating population-based data gathering exponentially.[28,29]

In what follows, we describe how these challenges are being addressed at the Douglas and present the issues arising from this process. Using this example, we can draw inferences that would be applicable to other mental health research institutions.

Leading open science at the Douglas Research Centre

The Douglas is the second largest mental health research institution in Canada, with integrated research and clinical activities that span neurodevelopment, youth mental health, aging, stress, anxiety disorders, mood disorders, sleep disorders, aging and Alzheimer disease. Our 70 principal investigators

lead research programs from the molecular to the societal level, resulting in diverse types of research outputs (e.g., biological samples or codes) and types of data (e.g., animal behavioural data, human MRI scans). The Douglas is affiliated with 2 organizations, McGill University and Quebec's Ministry of Health and Social Services, under the local authority of the Montréal West Island Integrated University Health and Social Services Centre.

In 2019, the Douglas began a transformation to adopt open science at the institutional level, with the goals of encouraging transparency, improving collaboration and becoming an organization where open science practices are part of each research project and all institute-wide initiatives. We describe our Open Science journey (Figure 1), focusing on the several phases critical to defining our strategy (Table 1) and ensuring the initiative's sustainability.

Leadership committing to open science

Our journey toward institute-wide adoption of open science began with the recognition by the Douglas leadership that doing so would have substantial advantages, not least of which was the potential to develop treatments for mental health disorders for which few options currently exist. Most importantly, we identified a clear appetite for open science at the Douglas, with many research programs having open science practices at their core, including sharing large data sets (e.g., the longitudinal cohort of PREVENT-AD[15]), sharing brain tissue through the Douglas-Bell Canada Brain Bank[30] and supporting a strong program for knowledge mobilization.[31,32]

Yet, the complexity of committing to institute-wide open science was also evident, demanding not only cultural changes but also new processes, policies and technical solutions. From an organizational standpoint, we foresaw challenges arising from our intertwined research and clinical environments, with commitments to both our affiliated university and local public health network. For example, public hospitals must follow regulations regarding infrastructure, data management policies and informatics frameworks. Simultaneously, many of the

challenges of implementing open science in the context of mental health research were experienced firsthand by Douglas researchers — in particular, the long tradition of keeping data from service users and research participants highly restricted from broader research use.

Two key actions allowed us to successfully commit to our open science program and create a solid open science strategy. First, we secured funding from the Tanenbaum Open Science Institute (TOSI) to generate our institutional open science strategy.[33] Second, we assigned 2-full time employees to our open science team, which enabled us to efficiently map our landscape and identify available resources, partners and needs.

Finding open science models, resources and allies

Addressing both context-specific and general challenges to the adoption of open science can be daunting if done in isolation; however, a flourishing open science community is eager to share knowledge and experience, and to develop joint initiatives. In the spirit of open science, we have relied on, reused and adapted foundational work done by individuals and organizations both locally and internationally. Collective initiatives that have curated open science resources, such as the UNESCO conference,[4] greatly facilitate following and recommending best practices over a multitude of open science activities.

We found our key model from the Montreal Neurological Institute and Hospital (known as The Neuro),[34] given their commitment to institute-wide open science and our similarities, including our affiliation with McGill University and our local funding and policy landscapes. We were supported by TOSI, who shared lessons learned as a result of The Neuro's open science journey and who, together with the Douglas Foundation,[35] provided funding crucial for the sustainability of our open science commitment and team.

Within our affiliated institutions, we identified existing support services and available training, and established collaborations with specialists in research data management, open access publishing, secondary use of clinical and administrative
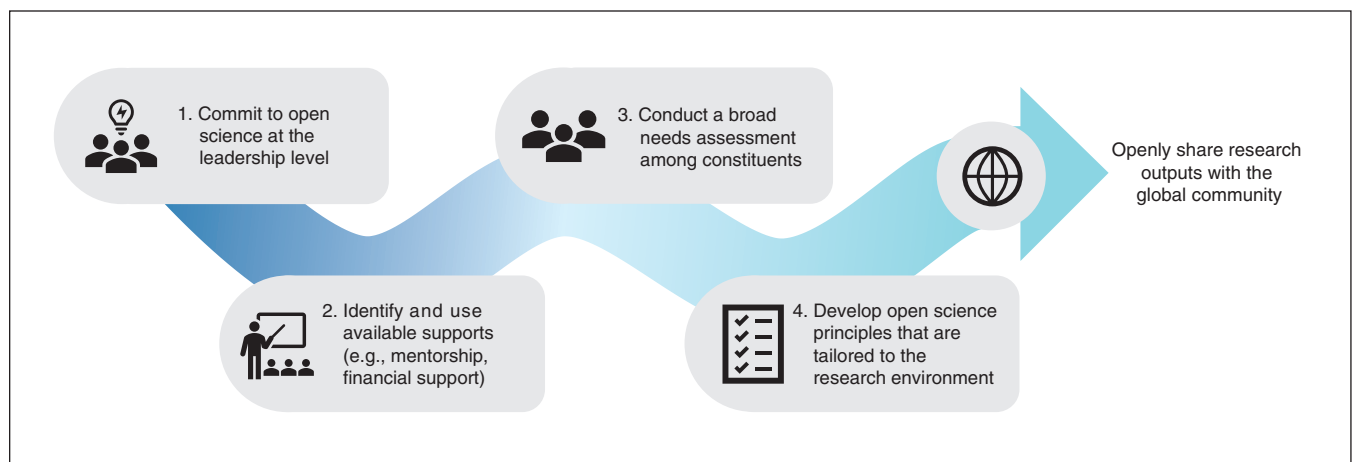
Figure 1: The open science journey that carries research institutions through critical steps to promote open sharing of research outputs with local and global communities.

data and knowledge mobilization. These partnerships were crucial not only as collaborations but also to quickly increase the service offering to our community. Finally, Douglas researchers who were already involved in open science helped to catalyze change. Identifying these internal allies and understanding their open science journeys strongly motivated our needs assessment.

Identifying open science needs

Adopting institute-wide open science requires broad stakeholder support and defining a strategy that speaks to the actual needs of researchers on the ground. We designed a questionnaire and conducted interviews to identify open science needs, experiences with open sharing of research outputs and factors contributing to, or preventing from, embracing

open science (Appendix 1, available at www.jpn.ca/lookup/doi/10.1503/jpn.220199/tab-related-content). We engaged internal stakeholders (i.e., researchers, students and research staff), including representatives of key substructures within the centre, such as research divisions, theme-based groups, clinical research initiatives and core facilities like our microscopy platform and brain bank.

Our interviews found overall positive attitudes toward open science and different levels of familiarity and involvement with open science practices. In agreement with previous observations by The Neuro,[34] our interviewees felt that dedicated support and compatible infrastructure and services were prerequisites for the implementation of a successful open science program. Our interviewees reported that an environment conducive to open science would encompass funding and financial sustainability of projects with open

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Table 1: Douglas Research Centre's guiding principles of open science

Principle	Items
Publicly release research outputs* following FAIR principles	• Openly share new research outputs following FAIR principles • Support access to sustainable open science by enabling platforms, developing in-house digital infrastructure and facilitating the use of external open science tools • Integrate the Douglas' research platforms into the open science initiative • Offer support, through dedicated personnel, for sharing research outputs and identifying open science practices that best fit individual research projects (e.g., those involving animals v. those involving humans) • Develop institutional policies and best practices that facilitate and guide sharing research outputs • Develop tools to monitor progress on sharing research outputs
Facilitate the use of shared research outputs for educational, health and societal impact	• Reduce barriers to access and use of research outputs by actively promoting them in appropriate forums and sharing them in ways that enable their modification, remixing, adaptation and adoption • Curate, translate and adapt research outputs and knowledge for greater accessibility and use by clinicians, teachers, research participants, service users, policy-makers, the general public and other potential users • Collaborate with other institutions — including educational, nonprofit, industrial, philanthropic and governmental organizations — to promote public education and knowledge mobilization • Make processes and results available to the provincial Ministry of Health and Social Services to inform measurement-based care initiatives
Prioritize the well-being and privacy of research participants and service users	• Guarantee that service users have the right to decline to participate in open science research, with no repercussions on the quality of the clinical care they receive at the Douglas • Ensure that research participants and service users have the necessary information to understand the Douglas' open science practices and the mechanisms regulating future usage of open data and other research outputs • Adapt consent processes and research ethics frameworks to allow for open science practices while ensuring the privacy, dignity and confidentiality of research participants and service users • Develop a data management policy with the provincial Ministry of Health and Social Services, to define conditions and processes for sharing service user data • Encourage and support the engagement of research participants and service users in the design of research activities and the implementation of open science at the Douglas
Respect researcher autonomy while recognizing open science activities	• Support the autonomy of internal stakeholders, including but not limited to researchers, staff and trainees, by recognizing their right to decline to participate in open science activities • Create awards and incentives to reward, encourage and enable open science activities • Develop and adapt researcher evaluation criteria to incentivize open science practices while accounting for the variety of researcher profiles and research programs • Establish a community of practice and train a new generation of scientists who are well versed in open science • Document and publicize all steps of the Douglas' open science journey, to actively support culture change at the Douglas and serve as role-models for collaborating institutions
Minimize the use of restrictive intellectual property protection on research outputs	• Apply appropriate open licenses to research outputs as often as possible, including licenses that require proper attribution • Provide full institutional support for researchers wishing to pursue research, collaboration, innovation, translation and valorization strategies that explicitly forgo restrictive intellectual property • Diligently consider in a transparent manner when restrictive intellectual property protection may be appropriate to maximize the impact of discoveries and innovations on the prevention and treatment of mental health disorders • Incorporate open science practices into partnerships and research contracts with commercial, governmental, nonprofit and philanthropic partners.

FAIR = findable, accessible, interoperable and reusable
*Research outputs include but are not limited to raw data, articles, code, software, methods, research tools, reagents, materials and biological samples.

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science components; access to information, infrastructure and specialized support services that enabled open science practices; synergy between ethics frameworks and open science goals, safeguarding the confidentiality and security of research participant data; and rewards for participating in open science activities (Figure 2). Although some needs were shared by all categories of internal stakeholders, others were reported only by particular groups; students emphasized the need for training, while staff highlighted the importance of infrastructure and support services.

Despite reporting both their own enthusiasm and also that of research participants toward open science projects, all stakeholder groups expressed the need to safeguard the privacy, dignity and confidentiality of research participants and service users, and reported that current ethics processes and consent language frequently do not include open data sharing. This observation was consistent with our general expectation for mental health research, and constituted the main perceived barrier to engaging in open science practices at the Douglas.

Finally, our needs assessment showed that needs and the interest for open science practices differed not only by stakeholder group but also by project type (e.g., those involving humans v. those involving animals) and volume of data. For example, some interviewees were avid data sharers, and others were experienced users of open data or experts in knowledge mobilization. The same diversity emerged within our core platforms; some used open-source software or hardware, while others created conditions to broadly share images or biological materials.

Our environment showed a plurality of needs and stakeholder profiles, which set the tone of our open science strategy, calling for an inclusive approach that focused on the uniqueness of each stakeholder and project while drawing on the versatility of open science practices.

Defining open science principles

We used our needs assessment to formulate 5 guiding principles for open science at the Douglas (Table 1). These principles were formally adopted in December 2021, making the Douglas the first research organization in Canada entirely dedicated to mental health research to adopt an institute-wide open science strategy.[33]

Creating a set of principles — refined over the course of 10 months through a combination of mentoring provided by TOSI, small-group discussions and presentations to faculty members — was essential to building a common understanding for internal stakeholders and reinforced the desire for an opt-in approach to open science. The Neuro's guiding principles provided a starting point for our initial discussions, but our needs assessment validated the necessity of reframing these principles to fit not only the Douglas' reality but also that of other mental health research organizations looking to join us.[34] The final principles collectively sought to address all needs summarized in Figure 2.

There was a need to support the Douglas' stakeholder and project diversity, as well as the resulting variety of research outputs and data types. Addressing the need for infrastructure,
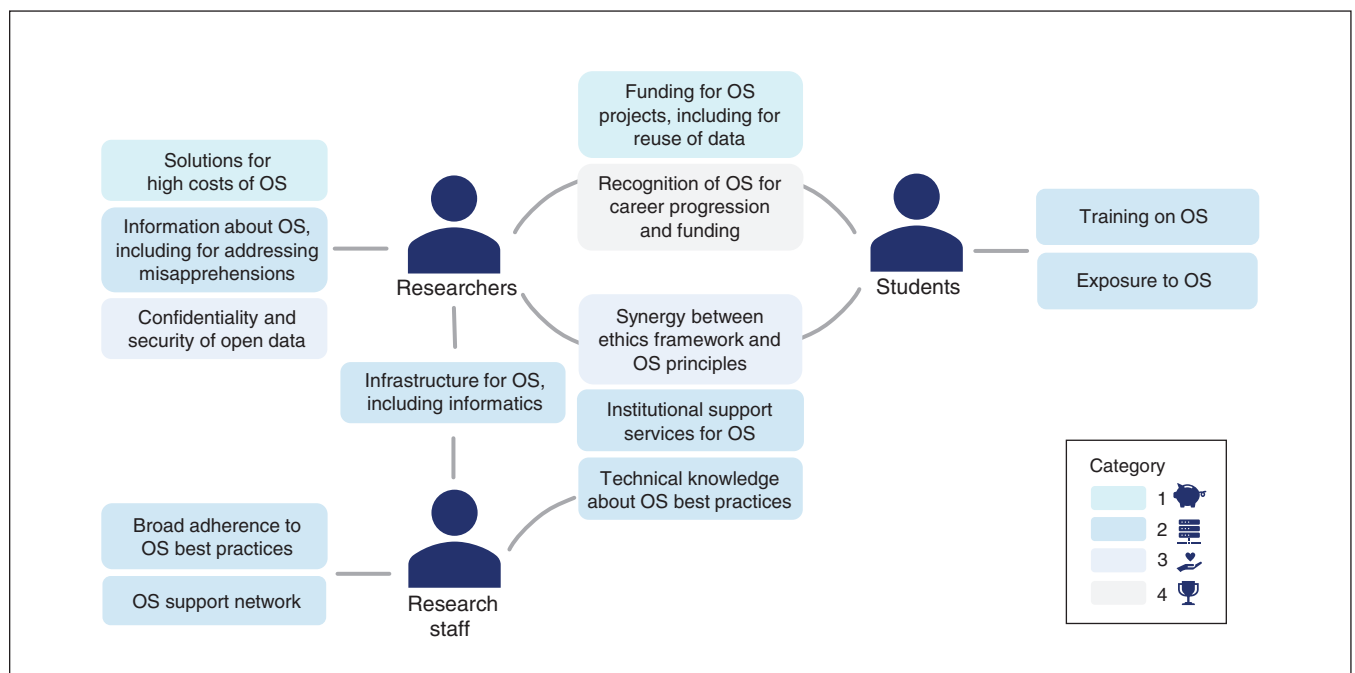
Figure 2: Main needs identified through the open science (OS) needs assessment. Data were collected in 2020 and 2021 through conversational interviews with researchers, research staff and students. We grouped the needs voiced by each category of stakeholders into 4 categories: (1) the funding and financial sustainability of open science projects; (2) access to information, infrastructure and specialized support services that enable open science practices; (3) synergy between ethics frameworks and open science goals that safeguards the confidentiality and security of research participant data; and (4) rewards for participating in open science activities.

training and services to support diverse open science practices and skill levels is at the core of our first principle, which encourages sharing research outputs (e.g., data, methods, code) throughout the lifecycle of scientific projects, from ideation through data collection, analysis and publication.[7]

There was an opportunity to draw on the Douglas' strong clinical activities and knowledge mobilization program to broaden the audience reached by our discoveries and enable their use for informed decision-making beyond our walls.[7,31,32] We pursued this goal through our second principle by invoking varied strategies, such as sharing our clinical and research expertise in mental health and developing digital mental health and measurement-based care initiatives with our local health authority. The latter component expresses our belief that the benefits of open science extend beyond the academic setting; by fostering the acquisition of digital, FAIR data in mental health care, we expand the reach of open science projects, enable rapid application of our discoveries and fuel new research questions.[26,27]

Mental illnesses create unique emotional, social and cognitive vulnerabilities. Our third principle recognizes research participants and service users as active members of the Douglas' community and commits to empowering them to make informed decisions about open data sharing and engage in continuous codesign of our developments. It is essential for our approach to open science to respect the privacy, dignity and confidentiality of research participants, without compromising the quality of care. In parallel, we commit to synergizing open science goals with research data management and ethics processes, and to building on our strong collaborations with our public health authority and provincial initiatives to define conditions for secondary use of clinical and administrative data. This principle states our goal of developing frameworks that are translatable to other mental health research organizations and fields in which data are particularly sensitive.

We envisioned an opt-in approach to open science, where open science practices are regarded as advantageous. Rather than enforcing open science using a top-down approach, we believed much was to be gained by supporting change through education, resourcing, facilitation and removal of perceived barriers.[36–38] We sought to reward engagement in open science practices, through internal incentives (e.g., local award competitions) and collaboration with our academic partners to acknowledge open science activities in research assessment.[39] Through our fourth principle, we respect the right of internal stakeholders to decline participation in open science activities, to engage in open science activities at their own pace and to select the open science practices that best fit their context — unless mandated by funders (e.g., open access publishing), in which case we commit to providing the best conditions to fulfill external obligations.[40]

Finally, our fifth principle ensures that research outputs from the Douglas avoid restrictive intellectual protection (e.g., patents and unrestricted copyright) as much as is practicable, throughout the research cycle. We reinforce our opt-in philosophy by supporting researchers in exploring alternative avenues regarding intellectual property and

commercialization (e.g., using open-source research software, engaging in open science partnerships, applying open licenses to papers, through which openness is not only possible but is a core asset).[28] This principle promotes openness, facilitates the goals of our other principles and ensures that our research outputs are readily applicable to public mental health care without the delays and high costs often associated with restrictive intellectual property protection.[41]

Putting our open science principles into practice

Our open science transformation has already yielded noticeable results and valuable lessons. One of our first and most important realizations was that there are many prerequisites for adopting institute-wide open science. Through our needs assessment, we identified infrastructure and frameworks for high-quality research data management as crucial for current and future open science activities. In particular, it was necessary to support the requirements of varied data types and the ethics, cybersecurity and protection needs of particularly sensitive data. We have used several approaches to address this challenge, including strategy and policy development with our affiliated institutions, neuroinformatics infrastructure for secure data storage and internal collaboration and revision of projects as case studies to appropriately integrate open science and ethics workflows.[42] Of particular relevance to mental health research is refining consent language, processes (e.g., for previously acquired data requiring reconsent) and conditions (e.g., fully open v. registered access data sets) for sharing a wide variety of participant data.[14] Although valuable guidance and templates have been shared by organizations worldwide, institutions must adapt these resources to rapidly evolving local legislation and changing landscapes.[43,44] Lastly, fostering digital and FAIR data formats within clinical activities opens the door for secondary use of data in a much broader context.

Many of the prerequisites and direct goals of our open science program were complex projects on their own, involving diverse interested parties within and beyond our research centre. These projects required implementing the changes we could within our sphere of influence while advocating effectively for the changes needed outside of it, for example within our affiliated institutions. We experienced firsthand the power of partnering with other organizations to achieve long-term open science goals. For example, instituting incentives for open science practices was a multifaceted challenge that required local actions but also major cultural shifts in research assessment and funding. At the institute level, we took our first step by launching an award program supporting a new generation of scientists well versed in open science.[39] With our local partners, we signed the Declaration on Research Assessment and are proposing changes at the departmental level. We are collaborating with external research groups to further understand how to monitor and reward open science practices.[45]

Such long-term projects also required us to design strategies to foster culture change and engagement in short time frames. As it requires little technical knowledge and is

mandated by funders, we embraced open access publishing as a way to develop capacity through low-cost, high-reward engagement.[6,47] By offering individualized services and by developing an open access policy with contextualized guidance (e.g., to use McGill University's institutional repository for self-archiving and discounts on article processing charges), we increased the proportion of openly accessible Douglas publications.[40] Most importantly, we saw members of our community engage with our open science team for support.

Mobilizing our community also called for constant development of technical expertise and combining leadership and community-led initiatives. Douglas researchers and research groups are highly autonomous and diverse, and research centre–wide transformations must meet them where they are, providing tailored incentives and support. Rather than mandating a universal uptake of every proposed open science practice, we are encouraging diverse approaches to openness; for example, our newly created awards have recognized projects ranging from knowledge mobilization to the development of open data sharing tools. In parallel, our core facilities are engaging our community in open science practices from the moment of project conceptualization and data acquisition. For example, the Molecular and Cellular Microscopy Platform, was, in 2016, the second research platform in Canada to adopt OMERO — open-source software that enables open sharing of raw images and linkage with publications.[48] Other examples are our Cerebral Imaging Centre's open database for neuroimaging research,[49] the McGill-Mouse-Miniscope Platform use of open-source hardware to collect neuronal activation data[50] and the Douglas-Bell Canada Brain Bank, which shares brain tissue, synchronizing its database with the Clinical Biospecimen Imaging and Genetic Repository.[30,33] We now also host the Discourse in Psychosis consortium, an international effort to create a Speech Bank for psychosis, with de-identified samples of speech digitally archived for linguistic studies in psychosis.[51] Finally, the Douglas Neuroinformatics Platform is already providing our community with data storage solutions, following best practices in research data management while running on open-source software.[42]

Looking forward to open mental health research

We believe open science can and should become the standard in mental health research. Reseachers owe it to service users and to everyone with a mental health disorder to take every opportunity to make the discoveries and breakthroughs needed to increase their well-being. The adoption of open science can begin at different levels, including projects, research groups, departments, research centres and scientific organizations. The path followed by the Douglas provides a framework for adopting open science in mental health and outlines key actions to guide initial steps, namely to commit to open science at a leadership level; find role models, resources and allies; assess needs; define guiding principles; and gradually bring them into practice. Taken together, these steps identify and address many prerequisites for adopting open science.

Most importantly, open science initiatives may take many shapes and forms, adapting to the nature and stage of research projects, data and outputs. That open science can range from sharing of large data sets to citizen science and knowledge mobilization is a strength that will greatly benefit mental health research.

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