Outreach and innovation: Communication strategies for the ABCD Study

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ABSTRACT

The Adolescent Brain Cognitive Development (ABCD) Study, a large, longitudinal study of brain development and child health, relies on the engagement of communities, educators, and families to ensure its success. To that end, community and partner relationships, development of targeted messages and materials for specific audiences (educators, families, youth, scientists), and continued and consistent outreach must be an integral part of the Consortium activities. The ABCD Consortium has made these efforts a priority and developed a framework to raise awareness about the study and promote sustained broad-base support from diverse stakeholders.

1. Introduction and guiding framework: principles of communication

The ABCD Study is a collaborative scientific endeavor designed to answer fundamental questions about adolescent development that have the potential to inform a wide array of policies and practices to improve adolescent health and wellbeing. The success of this endeavor hinges on partnerships with participants (approximately 10,000 youth aged 9–10 at recruitment) and their families, as well as educators, scientists, and interested organizations, all of whom are integral to and supportive of the research process (Balls-Berry & Acosta-Pérez, 2017). We use a cross-cutting theoretical framework to design and implement outreach and dissemination objectives for the study (Fig. 1) that draws on principles from multiple domains and is informed by social cognitive theory (Bandura, 1986): health communication (National Cancer Institute [NCI], 2004), social marketing (Kotler & Lee, 2008; McKenzie-Mohr, 2011), and community engagement. Community engaged research involves working collaboratively with segments of the population that have a special interest in the subject matter at the heart of a research program, which can in turn facilitate the adoption of research results to improve the health of a community (Balls-Berry & Acosta-Pérez, 2017; National Institutes of Health [NIH], Centers for Disease Control and Prevention [CDC], 2011). The following principles of the ABCD Study outreach framework guided the early and continued awareness efforts for the study: (1) identification and segmentation of target audiences; (2) gaining support from community leaders and stakeholder organizations who see value in the success of the study and without whose support the study would not exist; (3) development and refinement of outreach materials for specific audiences disseminated through diverse platforms; and (4) feedback and evaluation of ABCD Study messaging and branding. These principles emphasize that communication must involve partners equitably and actively throughout the study engagement process (NIH, CDC, 2011), including scientists (ABCD Study investigators, research assistants, sponsors, as well as external scientists), educators and other local groups, study participants and their families, and partner organizations (e.g., health, mental health, and education professional organizations). Through an iterative process with ongoing feedback from target audiences, the framework underscores the importance of communicating information about the study in language that is clear, accessible and respectful; of listening to interests and concerns of stakeholders; and of translating and disseminating relevant findings in a timely manner (Sofaer et al. 2013; Wilson et al., 2010; McDavitt et al., 2016). Collectively, these efforts engage potential participants and other stakeholders from multiple paths – through schools via flyers, posters, and conversations with teachers and principals; organizations via emails and newsletters; and media through news articles and radio and television stories. Leveraging a multi-platform communication approach, all target audiences become familiar with the study in a relatively brief period and key stakeholders recognize the value of their contributions to the study. This familiarity can enhance ABCD Study awareness, bolster participant recruitment, and ultimately lead to sustained engagement, retention and study success (Cruz et al., 2016; Berry et al., 2014).

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2. Engagement and awareness: building partnerships

An undertaking of this magnitude requires early buy-in from communities that are critical to its success, including scientists, educators, participating families and the media (NIH, CDC, 2011). For the ABCD Study, this community engagement began before the study was initiated. In 2014, the NIH engaged the extramural scientific community to better understand gaps in the scientific literature on adolescent neurodevelopment and to solicit input on the critical research questions and the best methodology and research design to address these gaps. From that point forward and upon initiation of the ABCD Study, the ABCD Consortium has continued to engage various constituencies who can impact and who will benefit from the study findings.

2.1. Partnership with the scientific community

During the early stages of planning for the ABCD Study in May of 2014, several NIH Institutes (the National Institute on Drug Abuse, the National Institute on Alcohol Abuse and Alcoholism, the National Cancer Institute, the Eunice Kennedy Shriver National Institute on Child Health and Human Development, and the National Institute of Mental Health) convened an expert panel workshop to obtain recommendations for general project design parameters for large-scale studies, as well as measures and domains for assessing developmental effects of substance exposure. This was followed by a formal Request for Information (RFI) and a satellite symposium at the annual meeting of the Society for Neuroscience where the extramural research community and other stakeholders provided additional input. These efforts informed the structural framework for the study, leading to the development of open solicitations that resulted in the current consortium. These early efforts also gave rise to the development and refinement of initial ABCD communications and messaging, including finalization of the study name and early discussions toward the need for a ‘look and feel’ for study materials (e.g., branding the study and designing the logo).

2.2. Partnership with educators

The ABCD Study will address the foundational aspects of adolescence that shape a person’s future, and could have profound impact on education policies and practices (Blakemore & Choudhury, 2006), particularly given the established connection between health and academic achievement (Bash, 2010). By partnering with educators, the ABCD Consortium can (1) learn about the issues that are most important to local communities, (2) work with schools to ensure diverse participation in the study, and (3) be a scientific resource for local educators.

The ABCD Consortium reached out to national leaders in the education community to inform them about the goals of the study and to learn what information they would value. Organizations that target school health professionals and school administrators, for example, were excited about the potential for the study to answer questions that could help them enhance academic success.

As described in greater detail in Garavan et al., in press, the ABCD Study is primarily using a school-based recruitment strategy to reach the majority of 9 and 10-year-old children in the study’s catchment areas (the geographic areas surrounding study sites). Therefore, national education organizations have been invaluable in reaching out to constituents highlighting the importance of their participation through letters of support that sites can provide to local schools and webinars, magazine articles, and social media to inform their members about the study. Outreach and dissemination strategies will leverage these partnerships to continue to learn about local educational needs and expand the awareness of the study as a resource for educators.

2.3. Partnership with health organizations

Another community that stands to benefit from the ABCD Study is medical practitioners, particularly in their role as public health leaders. The role of pediatricians, for example, has changed significantly over the past six decades (see Kuo et al., 2012). They are not just responsible for ensuring that children remain disease-free; they are also essential voices for parents in promoting wellness and health behaviors. Parents seek advice from them on how to establish healthy habits for their children (e.g., sleep, nutrition, physical activity, screen time limits). However, these medical practitioners need validated information that can only come from detailed longitudinal studies that evaluate child development from a multidimensional perspective. As such, they are key partners in helping to inform study development, raising awareness of the study among communities, and can help to sustain participant engagement.

The ABCD Consortium leadership reached out to national associations with a focus on child health such as the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, and the American Psychological Association, who have acknowledged that findings from the ABCD Study have the potential to help them provide enhanced health and mental health care for children and families (http://abcdstudy.org/schools-partners.html). These organizations, and others, also serve scientists who may be interested in analyzing ABCD Study data, and will be instrumental during dissemination...
of study findings to ensure that constituents of these organizations receive information in language that is accessible and meaningful.

2.4. Partnership with families

The ABCD Consortium recognizes that the relationships that each study team builds and maintains with participating families are critical to long-term retention and the study’s success (Adamson & Chojenta, 2007). To this end, it is important that families understand the potential far-reaching implications of this study (e.g., the impact of sports injuries, sleep, or screen time on academic and emotional development), even though they do not receive direct clinical information about their child.

The ABCD Consortium has developed multifaceted engagement strategies to help families understand the potential impact of the study as well as opened dialogues with families to learn about their concerns. In the study design phase, several sites conducted a pilot study with families who would not participate in the main study to collect feedback on assessments, time commitment and other logistics. Results helped inform the methods, protocol design, standard operating procedures and scripts to be used in the main study from the perspective of the participant and family, and ensured that questions and concerns raised by this community were addressed from the beginning. More recent engagement strategies include providing opportunities for children to participate in neuroscience activities and demonstrations, and responding to queries and comments from families and others attending outreach sessions hosted during parent/guardian open house nights, parent-teacher association meetings and school outreach programs. Feedback from these events informs study design moving forward, and helps to refine messaging about how the study’s findings may have universal benefits for adolescent health.

2.5. Media outreach

Working with media outlets to expand general awareness of the study helps amplify messages provided through more targeted communications. When recruitment was initiated in Fall 2016, a coordinated press launch involving NIH collaborators and many ABCD Study research sites promoted awareness about the study at both national and local levels.

Continued collaboration with a wide range of media outlets will help bring research findings and their potential impact to the public via mainstream communication channels while reinforcing the information received through recruitment channels. These efforts help participants understand their value in being part of the study, and may help boost study engagement and long-term participant retention. For example, ABCD Study investigators at the University of Vermont participated in a call-in radio show about the study with Vermont Public Radio. The show generated local interest and contributed to early recruitment success. At the national level, recent coverage of the study on the Today Show resulted in an up-tick in general interest from communities across the country.

3. Framing ABCD Study messaging and materials for target audiences: educators, families, students, & scientists

The ABCD Study and the potential outcomes from the research are of interest to multiple stakeholders with diverse interests. Therefore, framing the study for specific target audiences is a critical aspect of our communication strategy (NCI, 2004; Schmid et al. 2008). For example, study materials for educators may focus on questions that could guide and shape education policy whereas materials intended for parents/guardians may highlight the potential influences of childhood experiences on health and behavior. Similarly, the ABCD Study website has sections tailored for specific stakeholders (educators, families, students and scientists), including FAQs, videos and testimonials detailing the study’s objectives, procedures, and significance in language that is relatable and informative to each audience. The website is flexible and dynamic by design such that ongoing feedback from all constituent groups informs and continually refines ABCD Study messaging.

Audience-specific materials (including Spanish versions) have been developed for outreach, participant recruitment, and promotion of the study. To ensure consistency of branding and messaging, all materials are designed centrally, reviewed by the ABCD Outreach & Dissemination Workgroup, and approved by the centralized IRB before being made available to the study sites via a centralized web-based portal located at the ABCD Coordinating Center.

3.1. Educators

Educators are primary influencers in adolescent development. From early childhood through early adulthood, educators help to shape cognitive, emotional and behavioral development. Therefore, educators are not only a critical target audience because they provide a gateway for introducing families to the study; they are also important end-users of the research results. Materials for educators highlight research questions that the ABCD Study is poised to answer which may help educators address achievement gaps, academic infrastructure and curricula.

These materials also address concerns educators may have (e.g., burden to the school for participation) and provide resources that could be valuable to educators (e.g., neuroscience lesson plans). Letters of support from leaders of professional organizations provide additional context and validation of the ABCD Study and underscore the relevance of the study to organizations that educators value.

3.2. Families

For families, the overall goal of material development and messaging is to present the ABCD Study in language that is accessible, respectful, and relevant. The Families section of the website, for example, includes detailed information about the goals of the study, the enrollment process, and assessment protocols and procedures. This information, coupled with FAQs that will be updated regularly as families move through the study, highlight questions the study may be able to answer that are of interest to parents/guardians as well as address concerns about the study (e.g., safety of MRI). Other materials (e.g., flyers, brochures, point of purchase cards) were designed to introduce families to the study. To address diversity of individual sites and their local constituents, materials have been packaged in multiple formats to provide flexibility for sites to choose which are most useful to their outreach needs (e.g., electronic vs. printed flyers).

3.3. Students

The Students’ section of the ABCD Study website provides information and FAQs that are updated as students mature. In addition, the consortium offers neuroscience learning opportunities (e.g., online brain games, virtual and live neuroscience demonstrations, videos, articles about the brain) via the website and events at local schools.

ABCD Study flyers (print and electronic) provide basic facts about brain development and introduce students and their families to the study. The flyers also provide local contact information for families to begin the study enrollment process. Once enrolled, students receive an ABCD t-shirt that they wear during the MRI portion of the study to ensure that there are no metallic components that could interfere with the magnet. The shirts also facilitate conversations among students about the study and brain development. The combination of innovative materials and messaging helps the ABCD Study teams provide consistent information in a manner that is both developmentally appropriate and educational.
3.4. Scientists

The scientists’ section of the website includes descriptions of the study design as well as detailed, downloadable summaries of the assessment protocols, workgroup rosters to further opportunities to liaise with study investigators and collaborators, and information about procedures for accessing study data. These materials provide full transparency for the scientific community, including information and resources for protocol harmonization and data sharing that are accessible to interested investigators worldwide.

4. Ongoing and future engagement efforts

4.1. Refinement of materials and outreach strategies

The ABCD Consortium is made up of 21 research sites from diverse areas throughout the country. Some regions have large, urban populations; others include more rural communities. Some consist of a single, large school district; others have many small districts; all have unique district policies and practices. In addition, population demographics can vary widely from one region or community to another. Therefore, it is critical that sites have access to a menu of outreach strategies and materials from which to select the best fit for their local culture and practice. Once general materials that could be used by the entire Consortium were developed and disseminated, site-specific needs (e.g., recruitment of twins) could be addressed. This “boutique” approach has been beneficial since outreach and communication materials that work for some sites may not be as effective for others (e.g., significant non-English speaking populations in some catchment areas necessitated additional language translations of parent flyers).

In addition to language translation and site-specific tailoring of materials, we have also adjusted general content to address nuances in interpretation such as duration of study visits and the target age range of potential participants. Some sites reported that families with 8-year-old children had discarded study flyers because the age range specified 9–10 years of age. Since many of these children would meet eligibility requirements, turning 9, before the recruitment period ended, we adjusted flyers specifying 8–10 as the age range and sites communicated to these families that they would move forward with the enrollment process just prior to their child’s 9th birthday. Continuously refining and adjusting communication materials based on feedback from the sites and participants enhances the effectiveness of outreach efforts to bolster recruitment and retention.

4.2. Cyclic and dynamic communication

Given the long duration of the study, ensuring participant retention will be vital to the study’s success (see Feldstein Ewing et al., 2017). Toward this aim, we are developing materials to engage participants throughout the intervening year before their next appointment. Regular and dynamic contact between visits helps maintain awareness and interest. Retention materials include birthday, thank you, seasonal, and holiday cards, as well as appointment reminders and an ABCD Study newsletter.

The ABCD Study newsletter is an electronic publication that is emailed to participating families and subscribing stakeholders each month. Each issue showcases one of the ABCD Study sites, includes news stories about the study, fun facts about local culture, and contributions from student participants such as drawings and quotes about their visit. The newsletter gives families the opportunity to get to know other sites in the Consortium and to appreciate the study’s scale and scope. Students particularly enjoy communicating their impressions about the study and seeing their artwork and comments published each month. Looking ahead, the newsletter will include a summary of data findings so that families can be kept up-to-date on study results. These cyclic communications with targeted messaging and design help develop and build rapport with all study stakeholders and partners.

4.3. Community Liaison Boards

As discussed in previous sections, community engagement is a critical component of the ABCD theoretical framework for outreach and dissemination. To maintain efficient and effective bidirectional communication with the study’s various constituencies, the Consortium will establish community liaison boards (local leaders, educators, families) to foster community support, feedback and transparency at the local level. The boards will serve as a forum to disseminate information about study progress, as well as keep the Consortium abreast of stakeholder priorities and concerns and bring attention to issues of national policy importance.

4.4. Scientific outreach

As the study progresses, engagement with the scientific community will focus on leveraging the unprecedented scale and scope of the research design, highlighting ways in which the ABCD Study is a valuable resource for protocol harmonization and data analysis among investigators worldwide. Toward this aim, the Consortium disseminates information about the ABCD protocol design and individual measures via scientific meetings and publications as well as making this information publicly available on the ABCD Study website. As the study continues, assessment protocols for subsequent data collection time points will also be made available through these venues.

One goal of the ABCD Study is to create a unique data resource for the entire scientific community by embracing an open science model. In partnership with the NIH Data Archive (NDA), the ABCD Study is releasing curated data annually, including all assessment domains, and fast-track data on an ongoing basis that contain unprocessed imaging data from ABCD Study participants to date. All personally identifiable information is removed from the data to ensure participant confidentiality and anonymity. The inaugural curated dataset was released in February 2018 and includes high quality baseline data from the first ~4500 participants, including minimally processed brain image volumes, tabulated MRI data, non-imaging assessment data related to physical & mental health, substance use, culture & environment, neurocognition, and biospecimen analyses, and residential history derived data. These annual versioned releases will be promoted at times of release and in venues where the scientific community convenes. Webinars will be held to assist the scientific community with data access and use.

Continued engagement with the scientific community ensures broad utilization of the study data and resources, offering scientists opportunities to pool resources and thus enriching the value of the study.

4.5. Web-based analytics and metrics to ensure effective outreach

A critical component of any outreach effort is measuring the impact of various dissemination vehicles to adjust as needed (Sullivan et al., 2004). Toward this aim, Google Analytics will be used to ensure that the study is communicating effectively by gathering basic information about how users interface with the ABCD Study website. These metrics will provide insight into messaging, channel performance and information consumption, and can inform future targeted messaging and outreach strategies.

5. Conclusion

The success of a large multi-site, longitudinal investigation relies on effective engagement and sustaining partnerships with study participants and many other stakeholder groups over time (NIH, CDC, 2011). The ABCD Study has taken a multi-faceted outreach approach to provide flexibility in design, development and dissemination of targeted
materials, as well as opening an ongoing dialogue with community members. The consortium is fortunate that many ABCD Study site institutions have Clinical Translational Science Awards (CTSAs) that can provide additional guidance and expertise on audience segmentation and tailored messaging which is of great benefit to the ABCD Study enterprise and its long-term success. As the study progresses, outreach efforts through stakeholder feedback and analytic tools will continue to be monitored to ensure that the interests and concerns of study participants and their families, scientists, educators, and partner organizations are being addressed and incorporated into existing materials to foster stronger relationships with stakeholders and leverage study resources to the benefit of all.

Conflict of Interest

None.

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