

# Recruiting Underrepresented Populations in ME/CFS Research

Many research studies have included primarily white women with access to ME/CFS medical specialists, increasing the risk for sampling bias. BIPOC patients, the severely ill, and men often go undiagnosed, and thus are often underrepresented in studies. Sedentary controls are recommended in order to rule out deconditioning as a potential confounding factor.

(1) Title of your study

(2) What are advantages of increasing recruitment in the populations on which you've chosen to focus? Why is this important (internal/external validity)?

## Strategies for engagement

You have \_\_\_\_\_ points to 'spend' on outreach. Each point represents an investment of time, money, and energy into the outreach process. What strategy or effective combination of strategies will you use? Consider mixed methods.

<p><b>General Strategies</b></p> <ul style="list-style-type: none"> <li>• <b>Contact</b> advocacy organizations, e.g. <a href="#">#MEAction</a>, <a href="#">Solve ME</a> for study promotion (1)</li> <li>• <b>Post</b> on <a href="#">ME/CFSnet website</a> (1)</li> <li>• <b>Utilize</b> <a href="#">Clinical and Translational Science Awards (CTSAs) hubs</a>(1)</li> <li>• <b>Partner</b> with the <a href="#">Community Advisory Committee</a> (2)</li> <li>• Post on <a href="#">Clinical Trials.gov</a> (note: non-interventional studies are allowed) (2)</li> <li>• Use <b>site-specific recruitment services</b> (eg Columbia University <a href="#">Recruit Me</a>) (2)</li> <li>• Use <b>paid recruitment services</b> such as <a href="#">researchmatch.org</a> (3)</li> <li>• <b>Partner with ME/CFS clinical sites</b> in the region, Bateman-Horne, Simmaron Research, Stanford ME/CFS, etc. (3)</li> </ul>	<p><b>Severely ill patients</b></p> <ul style="list-style-type: none"> <li>• Contact social media groups for <a href="#">severely ill patients</a> and <a href="#">caregivers</a> (1)</li> <li>• <b>Partner</b> with multiple ME clinics and/or clinicians in order to reach recruitment goals for severe patients (4)</li> <li>• Use <b>mobile phlebotomy</b> services to increase participation from home (4)</li> </ul>	<p><b>BIPOC patients</b></p> <p><b>Reach out to:</b></p> <ul style="list-style-type: none"> <li>• Clinical settings such as Federally Qualified Health Centers (FQHCs) (4)</li> <li>• <a href="#">Organizations for medical providers and public health organizations</a> that serve BIPOC communities (3)</li> <li>• Local <a href="#">ESL</a> learning centers and translate recruitment flyers into multiple languages (3)</li> <li>• Organizations such as <a href="#">WEGO Health</a> to identify patient leaders in your target population(2)</li> <li>• <a href="#">BIPOC fraternities and sororities</a> and/or <a href="#">National Pan-Hellenic Council (The "Divine Nine")</a> (4)</li> <li>• Religious, spiritual and community centers (4)</li> <li>• Veterans Administration Clinics (4)</li> </ul> <p><b>Advertise</b> in outlets that focus on your target population, including:</p> <ul style="list-style-type: none"> <li>• Advertisements in magazines/journals (2)</li> <li>• Podcasts (5)</li> <li>• Social media (1)</li> </ul> <p>Consider use of the <b>DePaul Symptom Questionnaire (DSQ)</b> before assessment by an expert to expand the potential subject pool.</p>
	<p><b>Sedentary Controls</b></p> <ul style="list-style-type: none"> <li>• <b>College campuses</b> for young, sedentary controls from university health centers (2)</li> <li>• <b>Physical therapy practices</b> with access to subjects who are healthy yet sedentary (3)</li> <li>• <b>Clinical entities</b>, such as the <a href="#">Bateman-Horne Center</a>, with a connection to a university hospital system, or large-scale care providers such as <b>Kaiser</b> or <b>One Medical</b> (3)</li> </ul>	
	<p><b>Men</b></p> <ul style="list-style-type: none"> <li>• Place online flyers within <b>groups designated for men</b> with ME/CFS, such as the <a href="#">#MEAction Men's Facebook Group</a> (1)</li> <li>• <b>Advertise</b> in outlets that focus on men and men's issues, especially in healthcare (2)</li> </ul>	

No matter how many 'points' you have to spend, too many different methods will overwhelm your study coordinator. Choose no more than six strategies for your study and list them below.

	POPULATION	METHOD	TIME/ENERGY (POINTS)
(1)			
(2)			
(3)			
(4)			
(5)			
(6)			
		TOTAL:	