

## UTOPIAN Primary Care Trials Group – Session 13 *Minutes*

Wednesday, March 31<sup>st</sup>, 2021 from 4:00 p.m. to 5:00 p.m., Zoom teleconference

Item	Topic	Minutes	Action	Responsible
1	Introductions (Andrew Pinto)	<ul style="list-style-type: none"> <li>Andrew Pinto introduced those present via Zoom and on the phone</li> </ul>		
2	Review and approval of Feb 25, 2021 draft meeting minutes (All)	<ul style="list-style-type: none"> <li>Minutes of the previous meeting were approved by those present</li> </ul>	Approved	All
3	Presentation: Consent for Contact (C4C): Engaging Patients in Research to Improve Care (Andrew Pinto)	<p><b>Preauthorization to be contacted for research studies (C4C):</b></p> <ul style="list-style-type: none"> <li>Ethical principles – including autonomy, justice beneficence and non-maleficence – guide our research</li> <li>Free and informed consent is crucial, as well as not harming patients (bothering them, release of private information, etc)</li> <li>Recruitment can happen currently: <ol style="list-style-type: none"> <li>Self-identify: potential participant sees an advertisement (poster, flyer, social media or via a friend/family member) and contacts the study team</li> <li>From within the circle of care, but with caution around ensuring no impact on care or undue pressure <ul style="list-style-type: none"> <li>Can be direct from provider – notify study team that patient is agreeable</li> <li>Can be on behalf of provider via letter</li> </ul> </li> </ol> </li> <li>Limits to current approach: <ul style="list-style-type: none"> <li>Failure to recruit</li> <li>Massive amounts of (public) resources spent on recruitment: ads, flyers, etc.</li> <li>Bias in recruitment! <ul style="list-style-type: none"> <li><i>Orkin AM, Nicoll G*, Persaud N, Pinto AD. Reporting of socio-demographic variables in randomized trials, 2014-2020. JAMA Network Open (in press).</i></li> </ul> </li> <li>Patients do not hear about research or participate. Reinforce idea that primary care is a “research free zone” or we do not do research.</li> <li>For-profit survey companies or CROs (which recruit and maintain vast lists or potential participants without much concern for privacy,</li> </ul> </li> </ul>		

		<p>etc) have an advantage over public funded, academic researchers.</p> <ul style="list-style-type: none"> <li>• Consent for Contact (C4C): <ul style="list-style-type: none"> <li>○ “We have done this sort of research ....”</li> <li>○ “But to continue this work, we need your help.”</li> <li>○ “Have you considered participating in research?”</li> <li>○ “Let your clinician know or contact us directly”</li> <li>○ Will be noted in your EMR, our researchers can then look at your record and contact you about research. You can decide then if you would like to take part</li> <li>○ NEVER have to participate</li> <li>○ NEVER affect your care</li> <li>○ “it just lets our researchers know you are interested in participating”</li> </ul> </li> <li>• Robotham, D., Riches, S., Perdue, I. et al. Consenting for contact? Linking electronic health records to a research register within psychosis services, a mixed method study. <i>BMC Health Serv Res.</i> 15, 199 (2015).  <a href="https://doi.org/10.1186/s12913-015-0858-4">https://doi.org/10.1186/s12913-015-0858-4</a> <ul style="list-style-type: none"> <li>○ “Service users appeared much more likely to join the register if they felt control over what they signed up to, this necessitated understanding that they could decide when, how often, and by whom they were contacted, that joining the register did not automatically enlist them to future studies, and that they could change their mind in the future.”</li> </ul> </li> </ul>		
Meeting adjourned at 5:00 p.m.				
Next meeting: May 27, 2021; 4:00 p.m.-5:00 p.m. (virtual)				