

Why participate in a PCORnet study?

Alfred Fisher, M.D. Ph.D.
Professor and Chief
Division of Geriatrics, Gerontology and
Palliative Medicine
Department of Internal Medicine
University of Nebraska Medical Center

HOME INSTEAD
CENTER FOR
SUCCESSFUL AGING

What is a PCORnet study?

- Address research questions that may need large patient populations – to find participants or to answer a research question with a well powered study
- Questions are often pragmatic and real life practice focused
- Data collection can be partially automated from EMR
- Often we are one site among many



Studies that I am involved in

- PREVENTABLE: Studies effects of statins in individuals over 75 years of age including effects on dementia and disability (site PI)
- PCOG90: Seeks to identify individuals over 90 years of age without dementia to identify protective factors (project co-I and site PI)
(Scored 3 points from payline)



Pluses to PCORnet studies

- Often working with a team of established investigators
 - Great for less experienced researchers
 - Faculty with more experience in bench, health services, or other research
- Typically single IRB
- Study design is fairly sophisticated and detailed
- Often greater research infrastructure involved
- Funding application easier or already funded



Pluses to PCORnet studies (cont)

- Might use a computable phenotype
 - Inverts typical process (patient relationship -> study to study -> some patient relationship)
 - Allows recruitment from across Neb Medicine
 - Does require chart review to be sure that patient is a good fit
 - Do not require individual clinicians to find and refer patients (I even recruited patients from my clinic that I wasn't thinking about)



How does this benefit individual faculty?

- Way to build a track record in clinical research and be invited for subsequent studies
- Typically single IRB
- Can learn about clinical research in structured environment
- Can build connections with other investigators – particularly for promotion
- Potential for publications



How can this benefit a department or division?

- Great way for getting a foothold into clinical research
- Attractive for generalists or to study common diseases
- Great for specialties without much industry sponsored research
- Offer access to research for patients



Downsides to PCORnet studies

- Need to review budget to be sure that it will cover costs or have help in this regard
- Unlikely to be able to pay for full-time staff like a study coordinator
- Faculty effort can add up
- You have often little relationship with the participants



How are we doing?



Site	Total Enrolled	Total Randomized	Potential Participants Approached	Most Recent Enrollment
All SITES	3810	3604 (95%)		
1703 - Vanderbilt University Medical Center	247	237 (96%)	6489	06/30/2022
1801 - Essentia	247	230 (93%)	7326	06/29/2022
1204 - Marshfield Clinic	216	205 (95%)	13265	06/30/2022
1705 - Wake Forest	170	162 (95%)	19240	06/29/2022
1203 - Medical College of Wisconsin	138	133 (96%)	20026	04/12/2022
1704 - University of North Carolina	137	134 (98%)	4321	06/16/2022
1706 - Duke University	123	118 (96%)	5371	06/21/2022
1103 - University of Chicago	122	120 (98%)	4110	06/28/2022
2025 - Milwaukee VA Medical Center	121	115 (95%)	3338	06/29/2022
1701 - Mayo Clinic	108	106 (98%)	2434	06/27/2022
1102 - Rush	107	102 (95%)	3084	06/30/2022
1504 - University of Pittsburgh	101	93 (92%)	2417	06/23/2022
1210 - Intermountain Healthcare	100	89 (89%)	12756	06/29/2022
2035 - St. Louis VA Medical Center	94	87 (93%)	21863	06/28/2022
1208 - University of Missouri	81	79 (98%)	1038	06/22/2022
1804 - Yale University	80	78 (98%)	18008	06/27/2022
1205 - University of Nebraska Medical Center	78	75 (96%)	2450	06/23/2022
1206 - University of Texas Health Science Center at San Antonio	73	69 (95%)	4770	06/16/2022
2038 - VA Boston Healthcare System	72	64 (89%)	5846	06/30/2022
1707 - Atrium Health	63	59 (94%)	7841	06/30/2022
2009 - Cincinnati VA Medical Center	62	59 (95%)	2698	06/28/2022
1209 - University of Utah	59	53 (90%)	11502	06/27/2022
1207 - University of Texas Southwestern Medical Center	58	53 (91%)	1783	06/30/2022
2030 - Providence VA Medical Center	58	55 (95%)	2171	06/28/2022
2028 - North Chicago VA	57	56 (98%)	3420	06/23/2022
1304 - Weill Cornell Medical College	54	47 (87%)	1469	06/28/2022
1404 - University of Florida - Gainesville	53	47 (89%)	7985	06/23/2022
1201 - University of Kansas Medical Center	52	51 (98%)	4701	06/17/2022
2020 - Kansas City VA Medical Center	52	48 (92%)		06/30/2022
2015 - Durham VA Medical Center	51	50 (98%)	3376	01/10/2022
2027 - VA Tennessee Valley Healthcare System	50	49 (98%)	8932	06/07/2022
1501 - Johns Hopkins University	49	46 (94%)	1130	06/28/2022
1603 - Ochsner Health	43	39 (91%)	9500	04/06/2022
2002 - Atlanta VA Medical Center	43	43 (100%)	2455	05/24/2022
1202 - University of Iowa Healthcare	42	40 (95%)	2014	05/27/2022
2006 - Central Arkansas Veterans Healthcare	35	34 (97%)	6904	06/15/2022
2013 - Dallas VA Medical Center	33	32 (97%)	1015	06/29/2022
1405 - University of Florida - Jacksonville	27	27 (100%)	7985	06/23/2022
1709 - Duke Kannapolis	27	25 (93%)	439	06/28/2022
2050 - VA Salt Lake City HCS	25	25 (100%)	303	05/12/2022
2001 - Asheville VA Medical Center	23	21 (91%)	204	06/14/2022
1502 - Ohio State University	22	20 (91%)	204	02/18/2022
2016 - Fresno VA	22	21 (95%)	252	05/28/2022
2004 - Birmingham VA	19	18 (95%)	1955	06/29/2022
2029 - Omaha VA Medical Center	19	17 (89%)		06/22/2022
1402 - University of Miami	17	15 (88%)	4923	09/22/2021
1710 - Mayo - NW Wisconsin	17	16 (94%)	505	06/30/2022
2034 - San Antonio VA	17	16 (94%)	1550	05/26/2022
2039 - VA Connecticut HCS	17	17 (100%)	1126	06/16/2022
1104 - University of Illinois at Chicago	16	16 (100%)	3655	06/24/2022
2021 - Long Beach VAMC	16	14 (88%)	62	02/11/2022
1711 - Mayo - SW Wisconsin	15	15 (100%)	501	06/16/2022
2012 - Columbia VA Health Care System	15	13 (87%)	191	06/28/2022
2057 - Togus Maine VA	15	12 (80%)	2918	06/28/2022
2022 - Louisville VA Medical Center	13	13 (100%)	480	06/27/2022
1605 - Doctors Hospital at Renaissance	12	11 (92%)	554	06/24/2022
1212 - University of Texas - Houston	11	10 (91%)	950	06/22/2022
2019 - Indianapolis VAMC	11	9 (82%)	601	06/23/2022
2003 - Bay Pines VA Health Care System	10	9 (90%)	1508	06/16/2022
2042 - VA Greater Los Angeles	10	10 (100%)	439	06/13/2022
1802 - University of Mississippi Medical Center	9	9 (100%)	92	05/04/2022
2023 - McGuire VA Medical Center	9	8 (89%)	840	06/27/2022
2007 - Charleston VA	8	8 (100%)	166	05/25/2022
2018 - Hines VA Medical Center	8	7 (88%)	25	02/18/2022
2017 - Gainesville VA	7	7 (100%)		06/14/2022

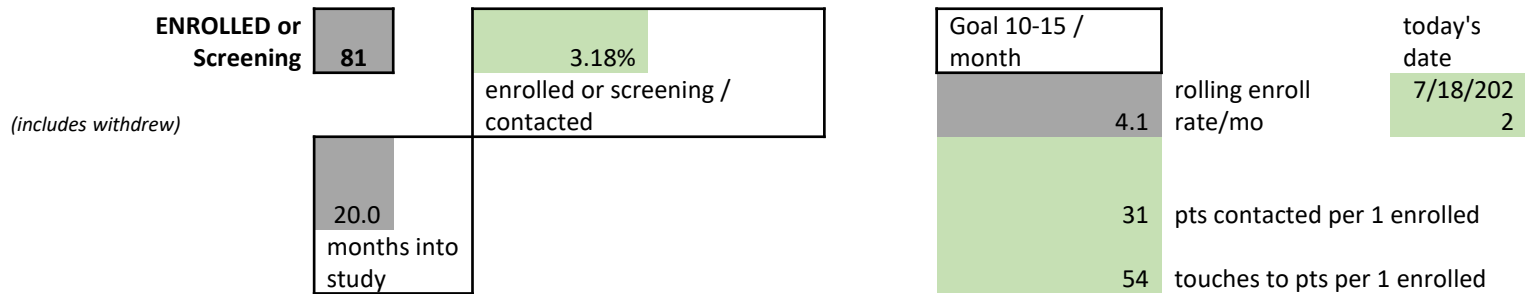


Our Experience with PREVENTABLE

2550 Total reached out to at least 1x		
Declined:	1209	47%
Ineligible:	724	28%
Total # touches to patients to date		
4389 (does not include total attempts)		
note: with early statin filter issues, est 400 marked ineligible		
Total emails sent out on 1st contact	432	17%
phone(to us)	3	
Total mychart sent out on 1st contact	1414	55%
on 1st contact	701	
Total ltrs/postcards sent out		27%



Our Experience with PREVENTABLE



- Good number of patients are ineligible – take statin, have CAD/stroke history, etc.
- Need to contact many folks to enroll a patient – concerns about being in research, concerns about statin, etc.



Lessons Learned

- Want to work with IRB early on
 - Study had single IRB but local policies can be in conflict
 - Needed to get an ethical access waiver to expand beyond Geriatrics clinic
 - Needed to get permission to have physician consent be confirmatory and done via phone



Lessons Learned (cont)

- Be sure the sites know about your project
 - We needed to get explicit consent due to COVID protocols – ended up being very positive
 - Presented to clinic medical directors or even at clinic staff meeting
 - Found that they wanted to participate, and that potential subjects would often contact PCP for advice



Lessons Learned (cont)

- Run queries to find your best sites
 - Initially excluded Bellevue and Grand Island
 - Later found that these were sites with the most patients
- Try to avoid bottlenecks
 - This is typically me – so need to dedicate time and prioritize messages from team



Summary

- Working with PCORnet can be a great way to get involved in research and network with researchers
- PCORnet team is a great resource in the process
- Do need to be mindful of budget before committing to project
- Be sure to engage IRB and clinical sites in the process



Acknowledgements

Thank you to UNMC PCORnet team:

Sarah Kirke RN

Annette Wolfe MBA

Carol Geary PhD

Jim Campbell MD

Jim McClay MD

