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Apr 3rd, 2:47 PM - 2:59 PM

# Improving Access to Rare Disease Clinical Trials Through Telemedicine

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Haynes, Dylan; Topham, Christina; and Greiling, Teri, "Improving Access to Rare Disease Clinical Trials Through Telemedicine" (2019). *OHSU-PSU School of Public Health Annual Conference*. 10.  
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**Title:** Improving Access to Rare Disease Clinical Trials Through Telemedicine

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**Keywords:** Rare disease; randomized clinical trial; access; telemedicine

## **Abstract**

**Introduction:** Rare diseases affect nearly 400 million individuals worldwide. The geographic density of any single disease, however, can prohibit access to care and research efforts. Telemedicine has improved access barriers in the clinical setting, though its application in rare disease trials has not been evaluated.

**Objective:** To assess the impact on access to care of videoconferencing in a rare disease clinical trial.

**Materials and Methods:** Preliminary analysis was performed on the first five participants to complete our ongoing trial (NCT03485976) evaluating the efficacy of ixekizumab for the treatment of pityriasis rubra pilaris. Participants were required to travel to Oregon Health & Science University (OHSU) for their enrollment and 24-week endpoint visits. All remaining visits were completed by remote videoconferencing. Questionnaires were administered to patients and providers following study visits and graded on true/false or 5-point Likert scales.

**Results:** Mean flight distance between participant hometown and OHSU was 1787 miles (range 207-2436). All participants (5/5) reported having the necessary equipment to complete videoconferencing visits prior to learning about the study. All participants (5/5) were strongly satisfied with the quality, safety, and privacy of their remote visits at the 24-week exit survey. Providers reported being unable to perform an accurate full-body skin exam during 4/15 visits, though did not report any instances of compromised patient safety (0/15). One participant reported they would not have enrolled had all visits required travel to OHSU.

**Conclusions:** Inclusion of remote videoconferencing in clinical trials may improve recruitment and access to care for individuals with rare disease.

## Analysis (ignore)

tele\_q\_prov\_4 Provider satisfied (strong dis to strong agr)

```
. tabulate tele_q_prov_4
```

Overall, I was satisfied with the remote visit	Freq.	Percent	Cum.
Strongly Disagree	1	6.67	6.67
Disagree	4	26.67	33.33
Neutral	1	6.67	40.00
Agree	7	46.67	86.67
Strongly Agree	2	13.33	100.00
Total	15	100.00	

tele\_q\_prov\_5 Preferred performing in person (strong dis to strong agr)

I would have preferred performing this visit in person	Freq.	Percent	Cum.
Neutral	8	53.33	53.33
Agree	7	46.67	100.00
Total	15	100.00	

tele\_q\_prov\_6 Able to accurately assess (strong dis to strong agr)

I was able to accurately assess the patient over the videoconferencing software	Freq.	Percent	Cum.
Disagree	4	26.67	26.67
Neutral	7	46.67	73.33
Agree	4	26.67	100.00
Total	15	100.00	

tele\_q\_prov\_7 Able to express concern (strong dis to strong agr) 14 strong agr, 1 agr

tele\_q\_prov\_8 Felt safety was compromised (strong dis to strong agr) 14 strong dis, 1 dis

tele\_questions\_obs\_1 Would enroll even if all travel to OHSU (y/n) y,n,y,y,y

tele\_questions\_obs\_6 Used video for healthcare before (y/n) all no

tele\_questions\_obs\_10 patient satisfied (strong dis to strong agr) all strong agree

tele\_questions\_obs\_11 Able to express concern (strong dis to strong agr) all strong agree

tele\_questions\_obs\_12 Knew who to contact if emergency (strong to strong) all strong agree

tele\_questions\_obs\_13 Felt comfortable inj (strong to strong) all strong agree

tele\_questions\_obs\_15 comf using new tech (strong to strong) agree, neut, agree, strong ag, strong ag

upload\_pt

vid\_quality very bad, poor, fair, good, excellent

accuracy t/f

Variable	Obs	Mean	Std. Dev.	Min	Max
tele_q_pro~4	15	3.333333	1.234427	1	5
tele_q_pro~5	15	3.466667	.5163978	3	4
tele_q_pro~6	15	3	.7559289	2	4
tele_q_pro~7	15	4.933333	.2581989	4	5
tele_q_pro~8	15	1.066667	.2581989	1	2
tele_ques~_1	5	.8	.4472136	0	1
tele_ques~_2	5	1	0	1	1
tele_ques~_6	5	0	0	0	0
tele_ques~_7	5	1	0	1	1
tele_quest~9	0				
tele_ques~10	5	5	0	5	5
tele_ques~11	5	5	0	5	5
tele_ques~12	5	5	0	5	5
tele_ques~13	5	5	0	5	5
tele_ques~15	5	4.2	.836666	3	5