RECRUITING PARTICIPANTS FOR CLINICAL STUDIES USING SOCIAL MEDIA: STAKEHOLDER ENGAGEMENT, CASE STUDIES, AND LESSONS LEARNED

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#### **Committee:**

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- Dianne Farb, J.D., CHRC, Assistant Director of Research and IRB-01 (Medical) Vice Chair
- Ira Fischler, PhD, Chair, UF IRB-02 (Social/Behavioral)
- Cheryl Granto, Information Security Manager, Information Security, UF IT
- Peter lafrate, PharmD, Chair, UF IRB-01 (Medical)
- Michael Mahoney, Director, Research Operations and Services, Office of the Vice President, UF Office of Research
- David Wilkens, Director of Privacy, UF Health Shands Privacy Office

#### Workgroup:

- Claire Baralt, Director of Strategy and Planning, UF CTSI
- Elizabeth Flood-Grady, PhD, Postdoc Associate, UF CTSI Recruitment Center and STEM Translational Communication Center, UF College of Journalism & Communications
- Deaven Hough, Communications Specialist, UF CTSI
- Janice L. Krieger, PhD, Co-Director, CTSI Recruitment Center and Director, STEM Translational Communication Center, UF College of Journalism & Communications
- Tamara Lowrey, Communication Specialist, HealthStreet, UF CTSI
- Meghan Meyer, Associate Director of Communications, UF CTSI
- Holly Morris, Director of Research Services, UF CTSI
- Tiffany Pineda, Research Navigator, UF CTSI
- Lauren Solberg, JD, MTS, UF CTSI Regulatory Knowledge and Support; Asst Professor and Director, Program in Bioethics, Law and Medical Professionalism, UF College of Medicine
- **Jeff Stevens**, Assistant Director for Web Services, UF Health Communications
- Lauren Light, Recruitment Specialist, UF CTSI Recruitment Center

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## **Presentation overview**

- Development of institutional guidelines
- Creation of UF Studies Facebook Page
- Evaluating social media recruitment: Pilot phase
- Lessons learned and opportunities to collaborate





# Background

- Increased interest in using social media for recruitment among investigators at the university
- Limited guidance at the federal level
- Uncertainty regarding social media protocols





## University-wide initiative

In November 2016, CTSI organized institutional stakeholders and subject-matter experts to:

- 1. Develop institutional guidelines for using social media in research recruitment (most common use case encountered by IRB)
- 2. Develop a coordinated approach to assess risks, discuss modifications and facilitate decisions on IRB protocols involving complex social media use cases





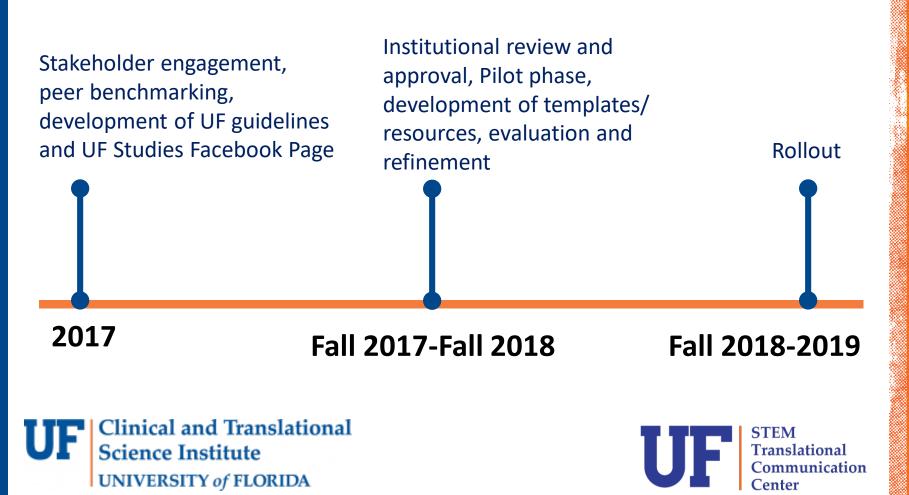
## Committee and workgroup expertise

- Institutional stakeholders represented on committee:
  - IRB (medical and social/behavioral), general counsel, information security, privacy and research offices
- Subject-matter experts included on workgroup:
  - Communication professionals and researchers, recruitment coordinator, community-engagement specialists, regulatory navigator, bioethics and legal expert





# Timeline



# Thematic content identified through benchmarking peer guidelines

- Compliance with platform terms of use
- Social media as a tool for participant recruitment
- Participant privacy, confidentiality and data security
- Social media as a venue for research





# **UF** guidelines

Scope:

• Guidelines for research teams using social media to recruit participants

#### Sections:

- Compliance with Social Media Terms of Use
- Participant Privacy, Confidentiality and Data Security
- Procedures and Considerations for Using Social Media to Recruit Participants, including elements of social media management plans





## **UF guidelines:**

Elements of social media management plans submitted to IRB \*Elements submitted if UF Studies Facebook page is used (streamlined option)

<ul> <li>*Sites to be used</li> <li>Official UF or UF Health social media accounts (approval of account manager required)</li> <li>If applicable: Public or private groups</li> </ul>	<ul> <li>*Mockup of materials</li> <li>Images</li> <li>Text</li> <li>Description of placement</li> <li>Website materials will link to</li> <li>If applicable: targeting criteria for paid ad campaigns</li> </ul>
<ul> <li>Personnel &amp; Page Management:</li> <li>Statement describing adherence to site terms and policies</li> <li>Who will monitor, post and respond to comments and inquiries</li> <li>Process and language for responding to comments or messages</li> </ul>	<ul> <li>If applicable:</li> <li>Plan for collection, storage and use of any identifiable data to be collected during recruitment</li> <li>Privacy, data security, and identity verification for private messaging</li> </ul>
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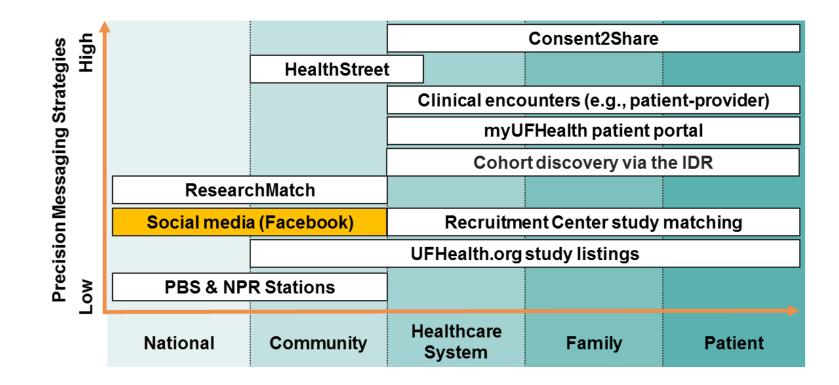
# **UF STUDIES FACEBOOK PAGE**

- Established in 2016
- Co-directed by Dr. Janice
   Krieger & Dr. Linda Cottler
- CTSI Recruitment Center Aims:
  - Optimize recruitment and retention of study participants
  - Contribute to the science of recruitment and retention of research participants

## CTSI RECRUITMENT CENTER

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# Multi-level communication strategy to support participant recruitment and retention







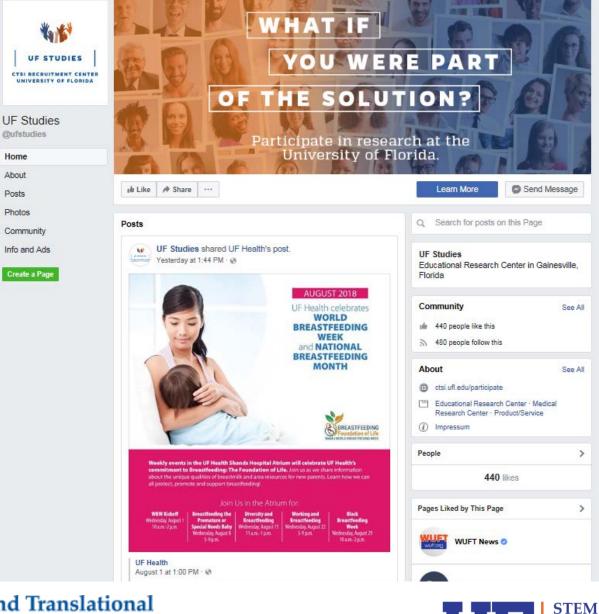
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- Pre-vetted and approved for use by the IRB, key offices at UF
- Approved by UF and UF Health as an official social media channel
- Managed by CTSI Recruitment Center
  - Offers consults, templates, services
  - Evaluates social media recruitment strategies
- Content Strategy
  - IRB-approved study advertisements
  - Informational posts about research, including dissemination of findings and ways to participate (e.g., ResearchMatch)
  - Shared posts from UF, UF Health, CTSA hubs, NIH and other researchrelated pages



*Goal:* increase participation in clinical research and assess effectiveness of Facebook as a recruitment channel

### **Page View**



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## **UF Studies Facebook Page: Sample Content**



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#### UF Studies

UFL QUALTRICS.COM

Survey for Mothers

The purpose of this study

Written by @ Lauren Light (?) - March 22 - @

Study for mothers of toddlers interested in sharing their experiences about motherhood. Moms will receive a free webinar on emotion regulation.



UF Studies shared a post. Published by @ Lauren Light [?] - June 8 - 3

University of Florida College of Pharmacy May 29 . 0

Researchers in the UF College of Pharmacy are teaming with Brigham and Women's Hospital to study medication safety during pregnancy.

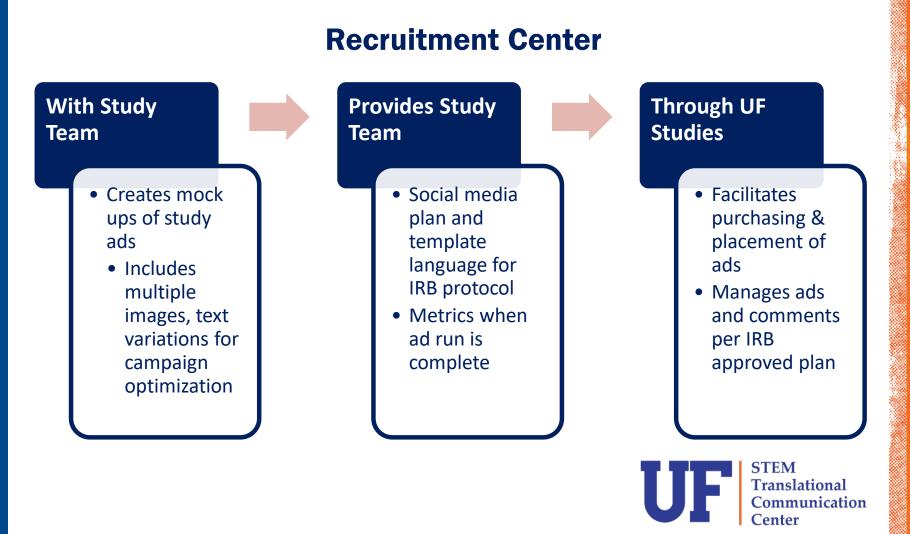


PHARMACY.UFL.EDU UF and Harvard researchers secure FDA grant to assess medication safety during pregnancy



### **Process for Recruiting through UF Studies**

After an initial consultation with study team:



### **Process for Recruiting through UF Studies**

After an initial consultation with Recruitment Center:

#### **Study Team**

Submits or revises existing protocol to IRB for approval and includes UF Studies as a recruitment channel

Submits payment for advertisements to CTSI recruitment Center

Provides data on study recruitment and enrollment to **CTSI** Recruitment Center

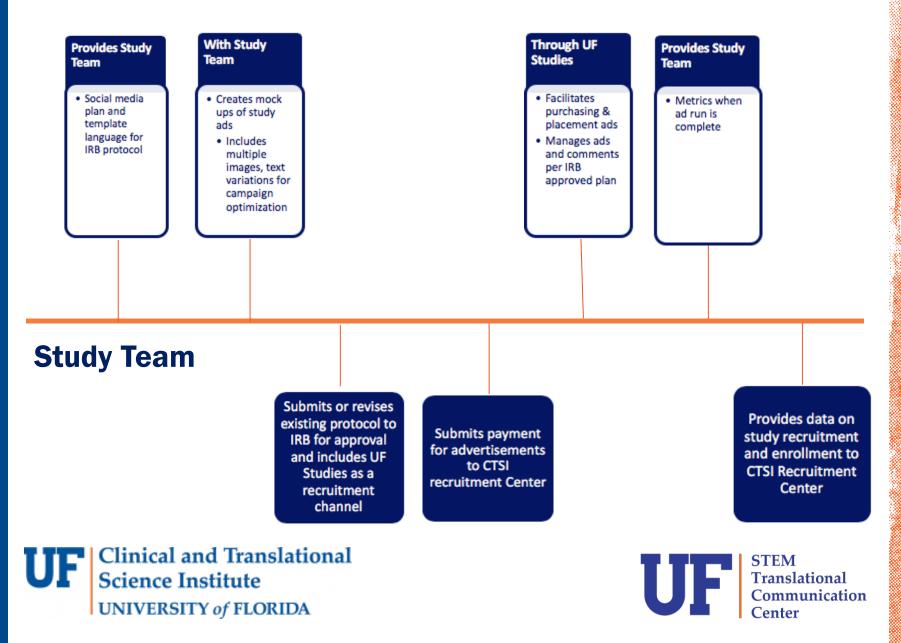
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Communication

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#### **Recruitment Center**



## EVALUATING SOCIAL MEDIA RECRUITMENT: PILOT PHASE

## Measuring success

#### Engagement

- **UF Studies Facebook Page:** followers, likes, shares, comments
- **Posts**: likes, shares, comments associated with posted content, video views

#### Account utilization

Number and satisfaction of researchers at UF who use the UF Studies Facebook page as a channel for recruiting participants

#### Paid campaign tracking using Facebook advertising metrics (per study)

- Reach, clicks, impressions, cost (per ad, click, etc.)
- Google Analytics goal tracking on UFHealth.org & UF study pages to determine page views & unique visitors generated from the UF Studies Facebook page

#### **Science of Recruitment**

- Message effectiveness (language, photos, etc.)
- **Recruitment & enrollment results**





## Pilot phase evaluation & case studies

- UF Studies Facebook page: audience engagement metrics, staff time/cost required to manage page
- Pilot campaigns (approved by IRB): advertising and recruitment metrics for 7 study-specific paid ad campaigns, staff time/cost required to manage campaigns

#### Types of studies recruiting

- Interventional (n = 3)
- Observational (n = 1)
- Survey/interview (*n* = 3)

# Range of target participant demographics

- Parents of toddlers, preschoolers, preteens, teens
- Healthy adult volunteers
- Pregnant women
- Older adults (>65)





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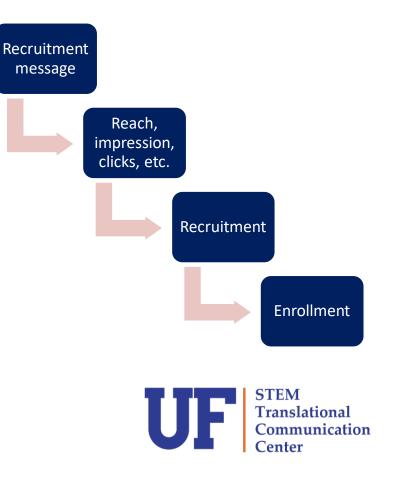
## Pilot phase evaluation & case studies

#### **Science of Recruitment:**

Identify effective message strategies to increase recruitment and enrollment in clinical research

- Recruitment message development
  - Content and visual strategies in study advertisements
    - Linguistic strategies
    - Emotional appeals
- Recruitment message evaluation
  - User engagement
  - Recruitment results
  - Enrollment results







# LESSONS LEARNED & OPPORTUNITIES FOR COLLABORATION



# Institutional guidelines for social media recruitment

- 1. Benefits to engaging multiple stakeholders
- 2. Start with targeted focus on social media recruitment
- 3. Benefits to establishing a central channel for hosting study recruitment and templates for research teams
- 4. Social media recruitment "process" is ongoing





## **Opportunities to Collaborate**







#### STEM TRANSLATIONAL COMMUNICATION CENTER

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