

Patient Engagement: What Matters Most

April 13, 2021



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Sites NOW @ Work!

Sites NOW: September 2020 Recap



COLLABORATE FORWARD

SCRS Welcomed 80 clinical research executives to the first Sites NOW program.



COLLABORATE FORWARD

Thank you to the SCRS Sites NOW Supporters & Featured Speaker:

Michael Jay

Director, Special Project, Society for Clinical Research Sites

Budgets & Contracts



Sites NOW Highlights Issues Impacting Site Operations in September Launch

"Our main goal here is collaboration towards information." With these impactful words, the first-ever SCRS Sites NOW session was launched. In a dynamic session that attracted more than 80 clinical executives, unreleased data and industry perspectives were shared freely in a virtual environment that emulated the face-to-face energy of past Site Solutions Summits.

Sites NOW is a virtual discussion and content project created in response to the COVID-19 pandemic and focused on the changing landscape clinical research sites and industry partners face in 2020.

Over the next 12 months, Sites NOW will provide a forum for content-sharing, open discussion, and networking among industry stakeholders, to include sites, sponsors, CROs, and solution providers. At each session, subject matter experts provide a 30-minute presentation focused on providing meaningful metrics and invaluable insight into one central theme impacting research today. Following the presentation, attendees participate in team breakout sessions to discuss industry standards, best practices, and pressing questions related to the presentation with the overall objective of providing information for site success.

While advancing site sustainability is the underlying mission of SCRS, Sites NOW delivers a platform to meet, share, and explore solutions that advance thoughts, best practices, and – most importantly – relationships.



WHO OWNS A STUDY?

The initial session tracked different industry perspectives on one central theme: why sites matter. Industry leader David Vulcano, vice president of clinical research at HCA Healthcare, kicked off the meeting by presenting new data from a recent SCRS Site Survey to convey the rich and varied perspectives on why sites matter in 2020. Mr. Vulcano provided a comprehensive overview of the evolution of the site and how its function has changed congruently with clinical trial format.

SCRS SITES NOW



SCRS **SITES** **NOW** 

For Today

- Data and intelligence about patient engagement before and during the pandemic
- What successful patient engagement looks like
- What patients want to know about your site and study
- Breakouts: What patient engagement advancement is most important to help clinical research over the next 12 months?



CHATS NOW ->

Possibility of side effects: 36%

Risks to my overall health: 29%

Stopping treatments that patient is
already taking: 8%

Receiving Placebo: 8%

Patient Engagement: What Matters Most



Ken Getz
CISCRP
and
Tufts University



Casey Orvin
StudyKIK

What Matters Most – Digging into the Research

Convenience

Connection

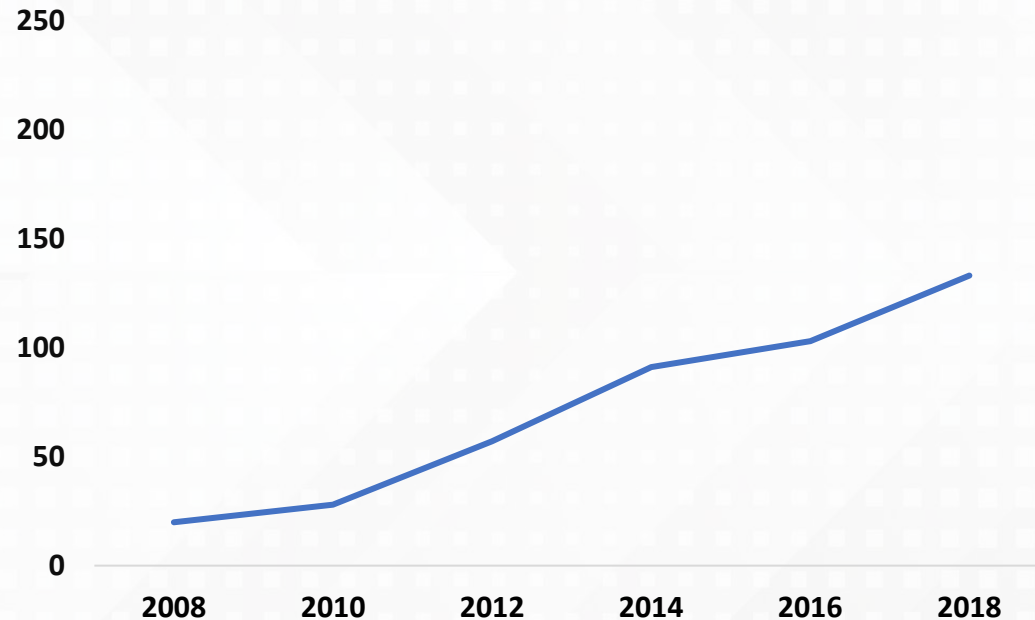
Trustworthiness

Truthfulness



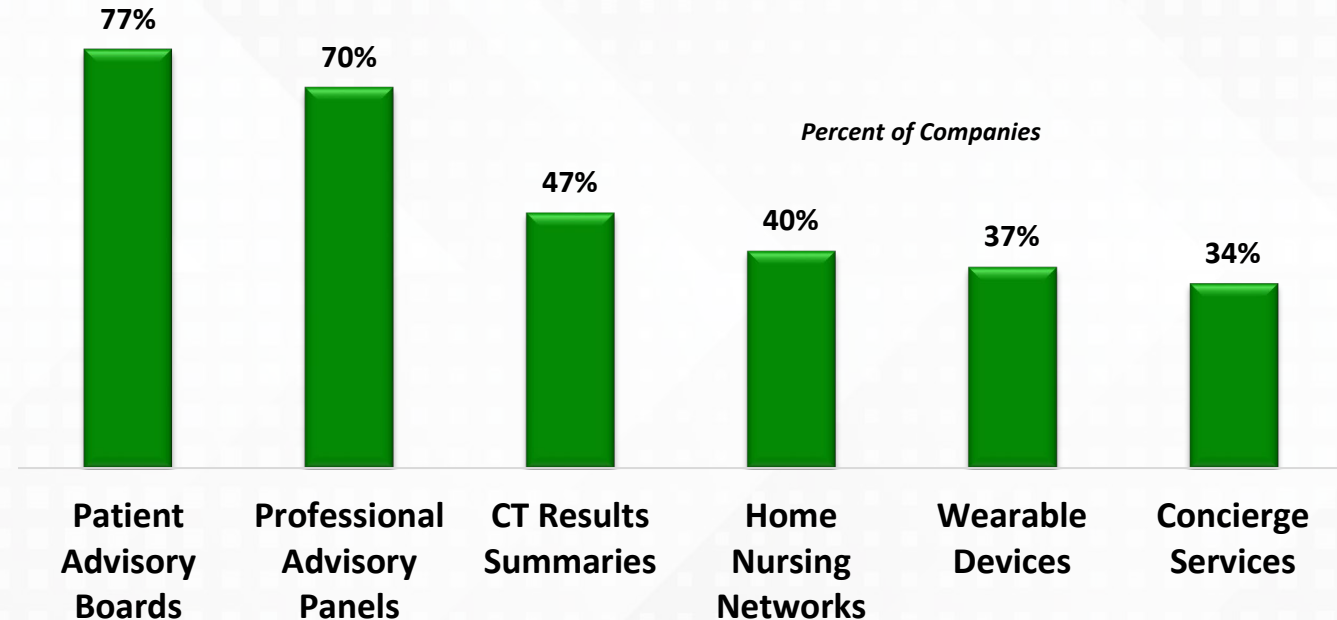
Patient Engagement Pre-Pandemic

Number of Clinical Trials in PubMed Citing Patient-Centric Characteristics



Source: Economist Intelligence Unit 2019

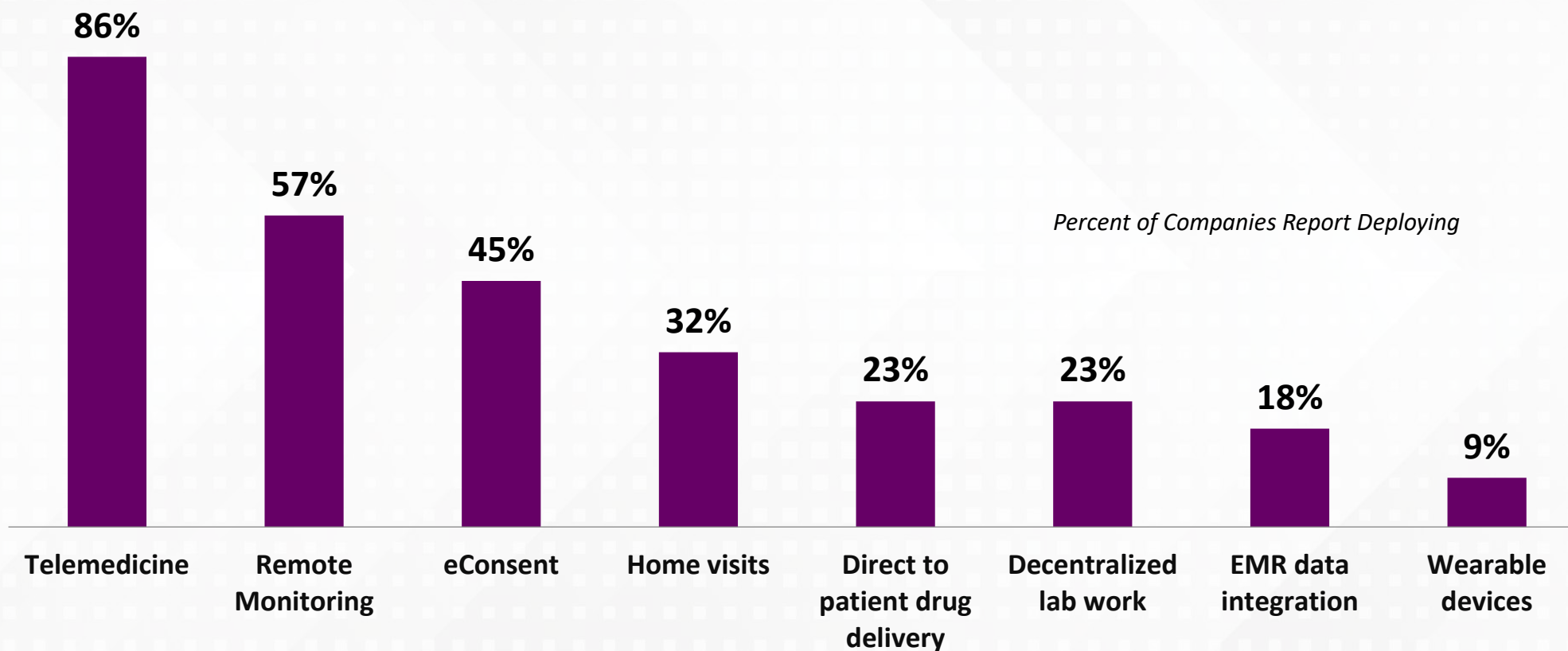
Top Patient Centric Activities Being Implemented and Piloted



Source: Tufts CSDD, 2018 (N=38 sponsor and CRO companies)



Patient Engagement During the Pandemic



Source: Tufts CSDD; N = 39 of the Top 50 Largest Sponsor Companies, September 2020



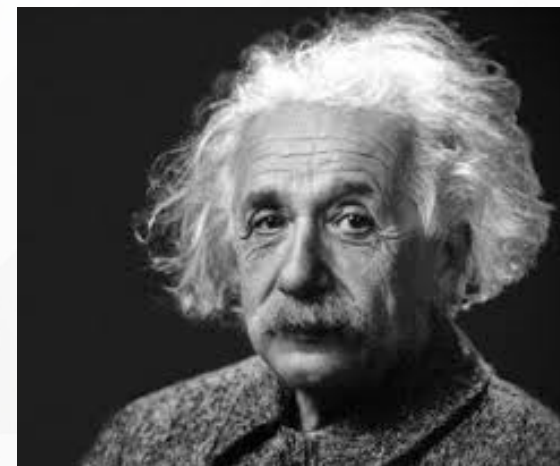
Strengthening Patient Engagement

Communities	What Matters Most
Public	<ul style="list-style-type: none">• Increase Clinical Research Literacy• Create Trust and Relevance
Patients	<ul style="list-style-type: none">• Establish health journey continuity• Engage HCPs• Improve access



An 'Unfamiliar' Enterprise

- 86% of the public reports that they understand the term clinical research 'very well' and 'somewhat well'
- 59% do not know where clinical research is conducted
 - Most assume it is integrated/coordinated with their clinical care*
- 66% can't name an agency that oversees research safety
- 40% believe that it takes less than 5 years to develop a new medical therapy
- 77% can't name a living scientist conducting health or medical research



*Source: CISCRP, 2017 Perceptions & Insights Study; N= 10,233 people who have never participated; * BRIDGING Clinical Trials 2018*

Diversity and Participant Perceptions

	Black	Hispanic	White
Disparity Percentage of Pivotal Trials for Approved NDAs/BLAs	-65%	-12%	+14%
Comfort level providing PHI (Very/Somewhat)	89%	86%	93%
Receptivity to virtual clinical trial participation (Very/Somewhat)	76%	79%	75%
Receptivity to home visit supported clinical trials (Very/Somewhat)	84%	75%	80%

Source: Tufts CSDD 2021; CISCRP, 2020



Recruitment and ‘Last Mile’ Challenges

	Pre-Pandemic		During Pandemic	
<i>Percent or total</i>	White Communities	Minority Communities	White Communities	Minority Communities
CLINICAL TRIALS*				
Perceived as Unsafe	7%	9%	30%	37%
Not Willing to Participate	14%	15%	53%	57%

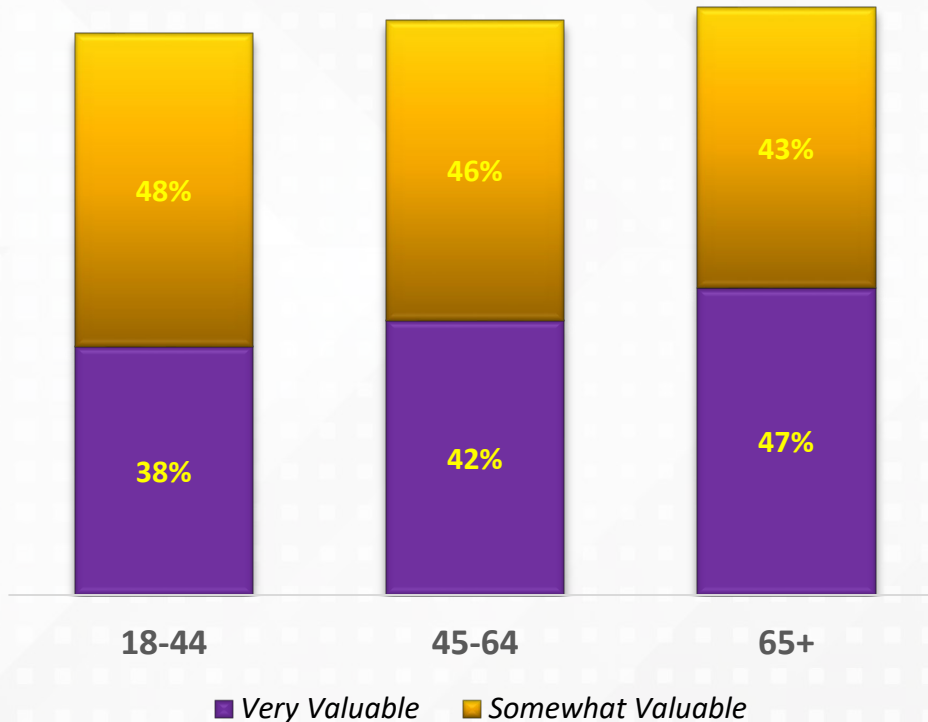
COVID VACCINES#				
Concerned about Development Process	N/A	N/A	44%	46%
Unlikely to be Vaccinated	N/A	N/A	18%	31%

Source: * CISCRP 2020 N=10,010 Americans; # McKinsey N=2,467 Americans



Preference for HCPs as Engagement Enablers

Percent of patients feel it would be 'Very' and 'Somewhat Valuable' for clinical research options to be presented during regular office visits



- 68% of patients rate their HCP as the top preferred source for information about clinical research
- 71% of patients say that they would speak with their physician or nurse prior to deciding to participate
- 83% of patients consider their physician's recommendation a top factor influencing their decision to participate
- 91% of patients agree that having clinical study procedures conducted during regular doctor visits would be more convenient
- 4 Factors Associated with higher HCP Referral Rates:
 - Past participation experience;
 - Proximity to research activity;
 - Familiarity with the research team;
 - Ready access to information about the clinical trial

Source: CISCRP 2019



Strengthening Patient Engagement

Communities	What Matters Most
Active Volunteers	<ul style="list-style-type: none">• Reduce Participation demands and burden• Improve continuous feedback
Post-Study	<ul style="list-style-type: none">• Convey appreciation and value• Establish ongoing connection and support• Offer greater transparency and disclosure



Measures of Participation Burden

After Reviewing the Informed Consent From, what led you to decide NOT to participate	Percent of Total
Expected burden of participation	54%
Scientific/study risks	25%
Lack of sufficient information	14%
Concerns about privacy and confidentiality	7%

Source: CISCRP, 2019

What did you least like about your participation experience? (Top 5 mentions)	Percent of Total
Not knowing whether I was getting the investigational treatment	30%
Location of the research center	22%
Study visits were too time consuming	19%
Compensation was not enough given study demands	16%
Study procedures were too cumbersome	15%



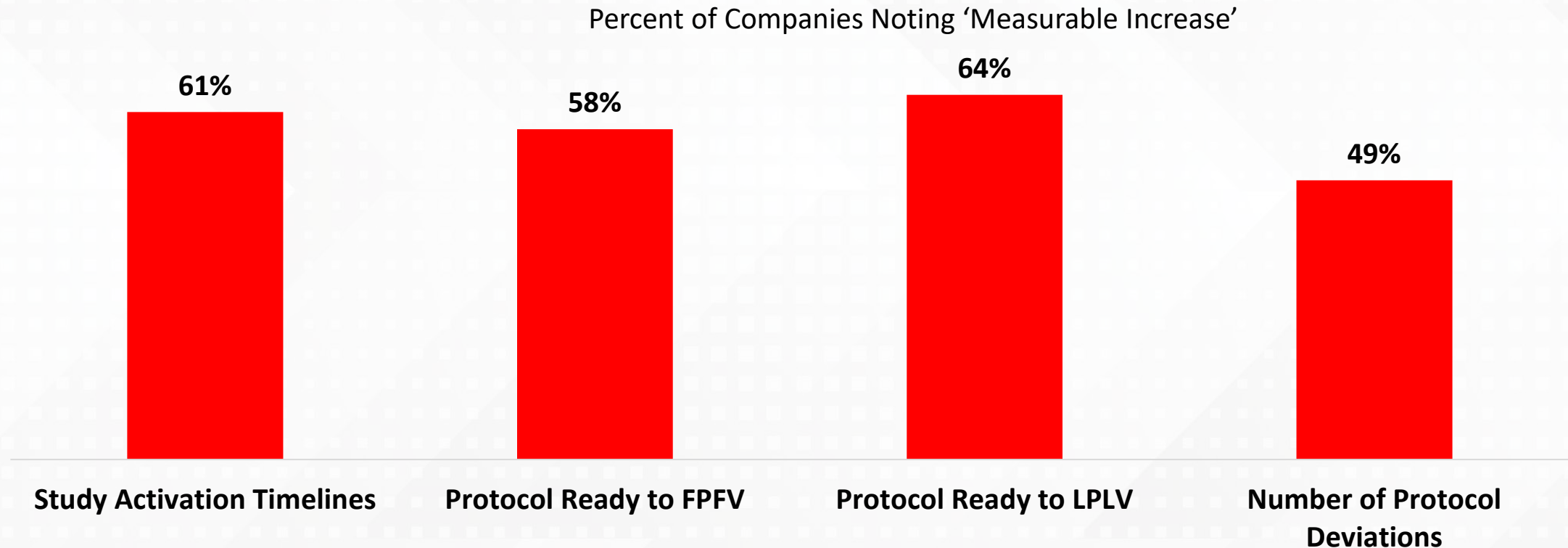
Impact of Clinical Trial Complexity on Performance

Phase III Pivotal Trials	10-year Change	Significance
Study Initiation Duration (approval to FPFV)	27.2%	<.05
Study Conduct Duration (FPFV – LPLV)	36.9%	<.001
Study Closeout Duration (LPLV to DBL)	16.3%	<.05
Total Number of Substantial Amendments	113.3%	<.001
Drop-Out Rate	105.1%	<.001

Source: Tufts CSDD, 2020



Early Feedback: Perceived Pandemic Impact of Clinical Trial Performance (Non-COVID Studies)



Source: Tufts CSDD, 2021. n= 301 Companies



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HOW HAS COVID-19 AFFECTED SOCIAL MEDIA & DIGITAL COMMUNICATIONS?

- DURING COVID-19 SOCIAL MEDIA USAGE HAS **SURGED OVER 60%** OF NORMAL USAGE RATES!
- MESSAGING ACROSS FACEBOOK, INSTAGRAM, AND WHATSAPP IS **UP 50%** IN MOST COUNTRIES THAT HAVE BEEN HIT HARD FROM THE VIRUS.
- TWITTER'S DAILY ACTIVE USERS IS **UP 23%** OVER LAST YEAR.



Engagement on Social Media

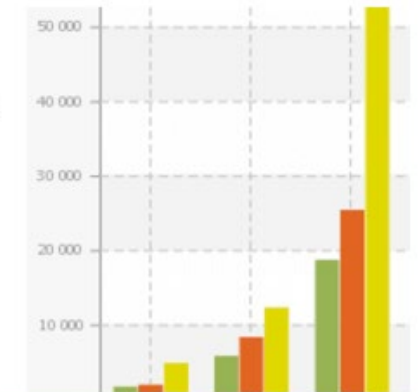
DOES YOUR SITE HAVE AN ONLINE COMMUNITY GROUP?

- ABILITY TO HAVE VERY TARGETED GROUPS (MODERATED)
- CONTENT IS RANKED HIGHER THAN BASIC PAGE CONTENT
- ABILITY TO IN-DEPTH POLLING AND INFORMATION

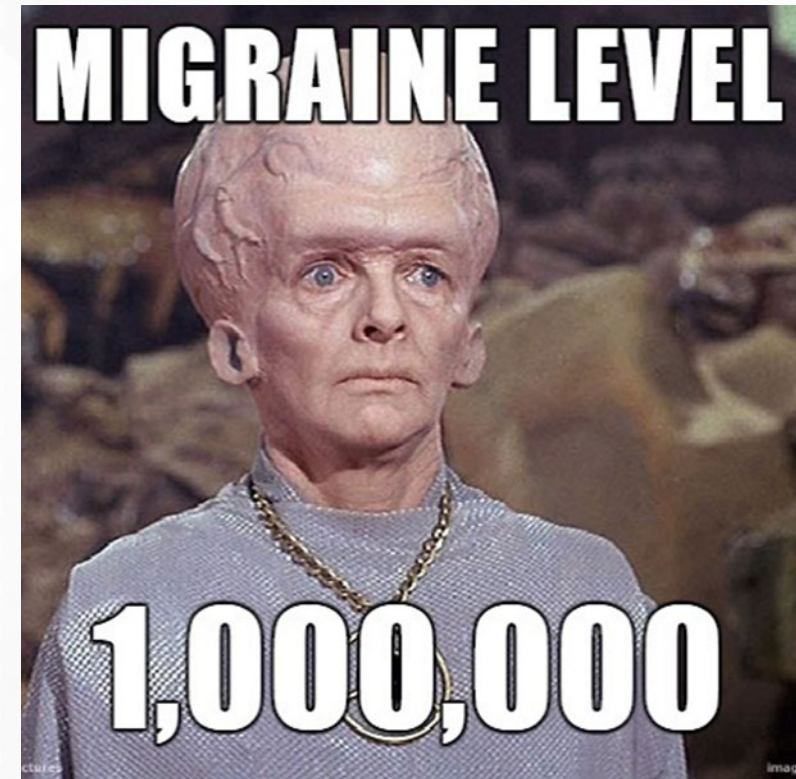
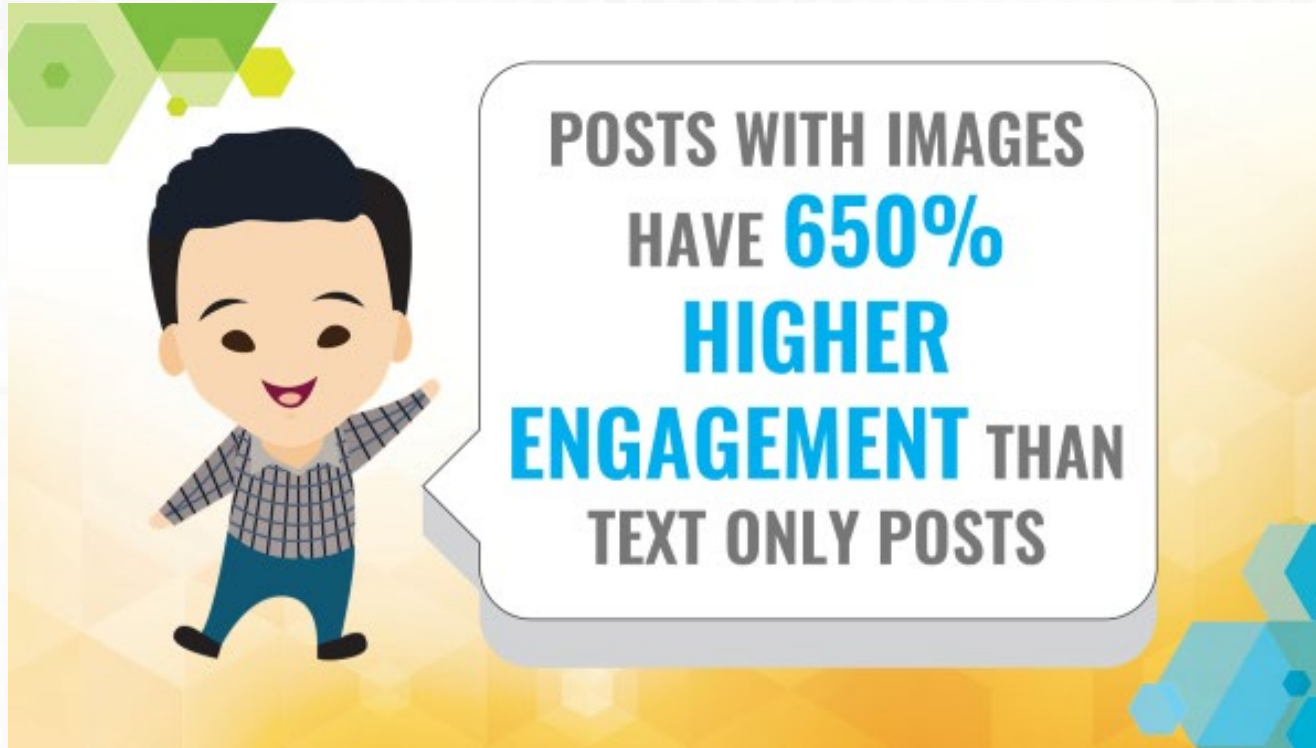
****ENGAGED GROUPS FOR ENROLLMENT!!!**

THE GROWTH IS STAGGERING!

ONLINE GROUPS
ARE GROWING AT A
**300%
MONTHLY
RATE....**



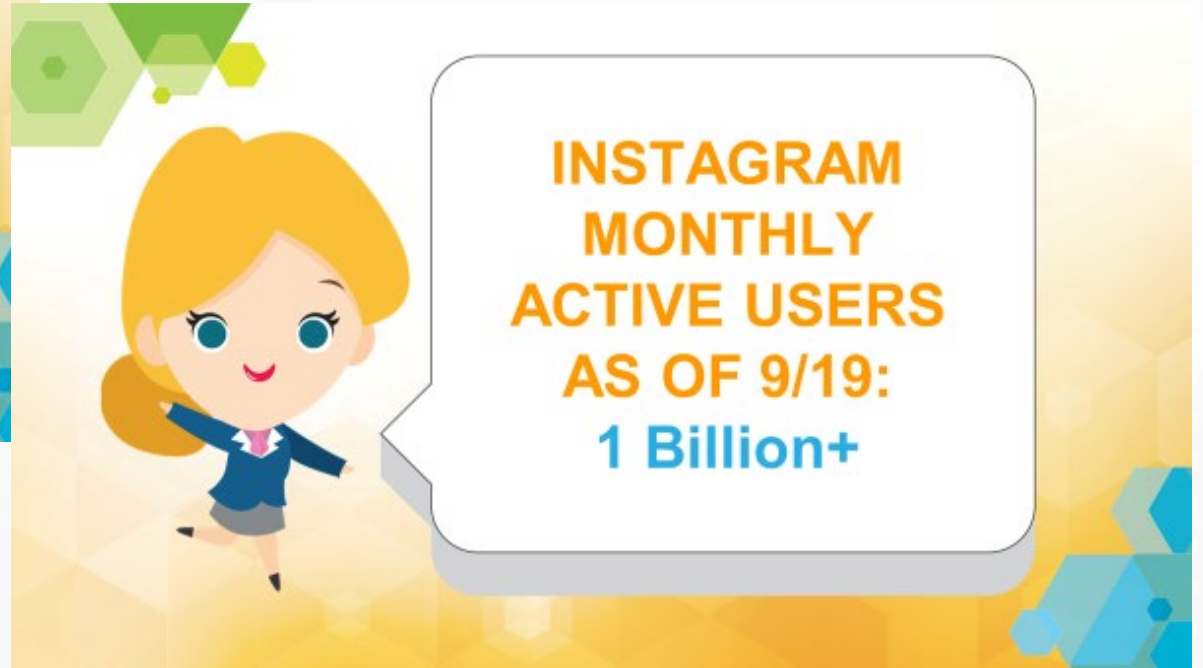
Engagement on Social Media



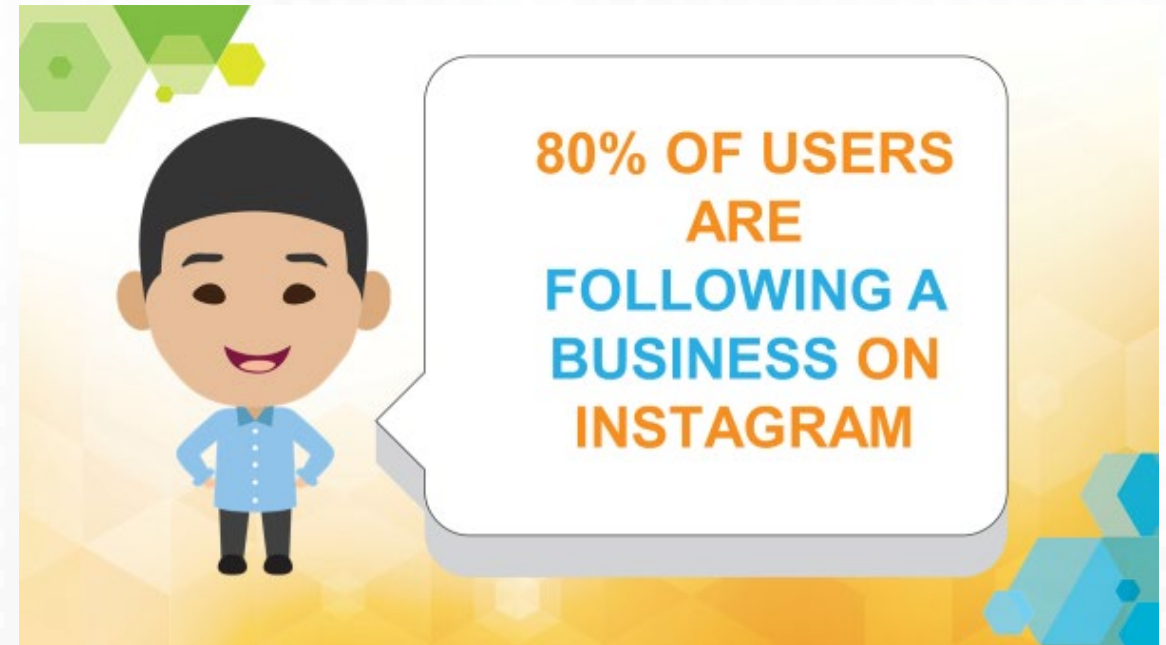
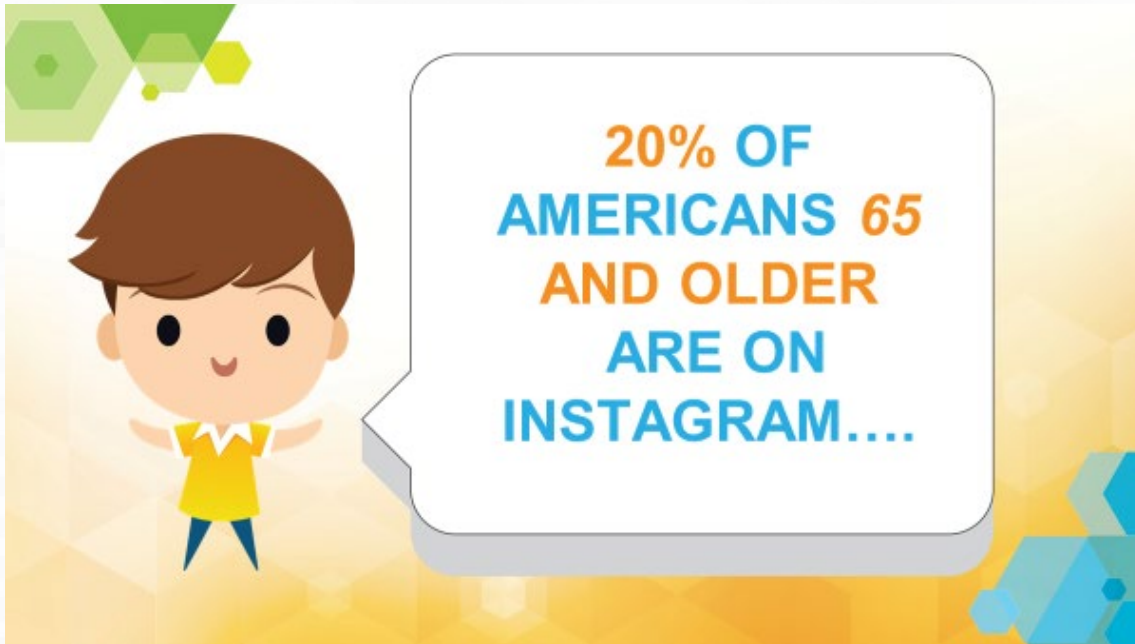
Patient Engagement is more than posting and discussing trials....



The Power of Social Media



Finding and Engaging Patients



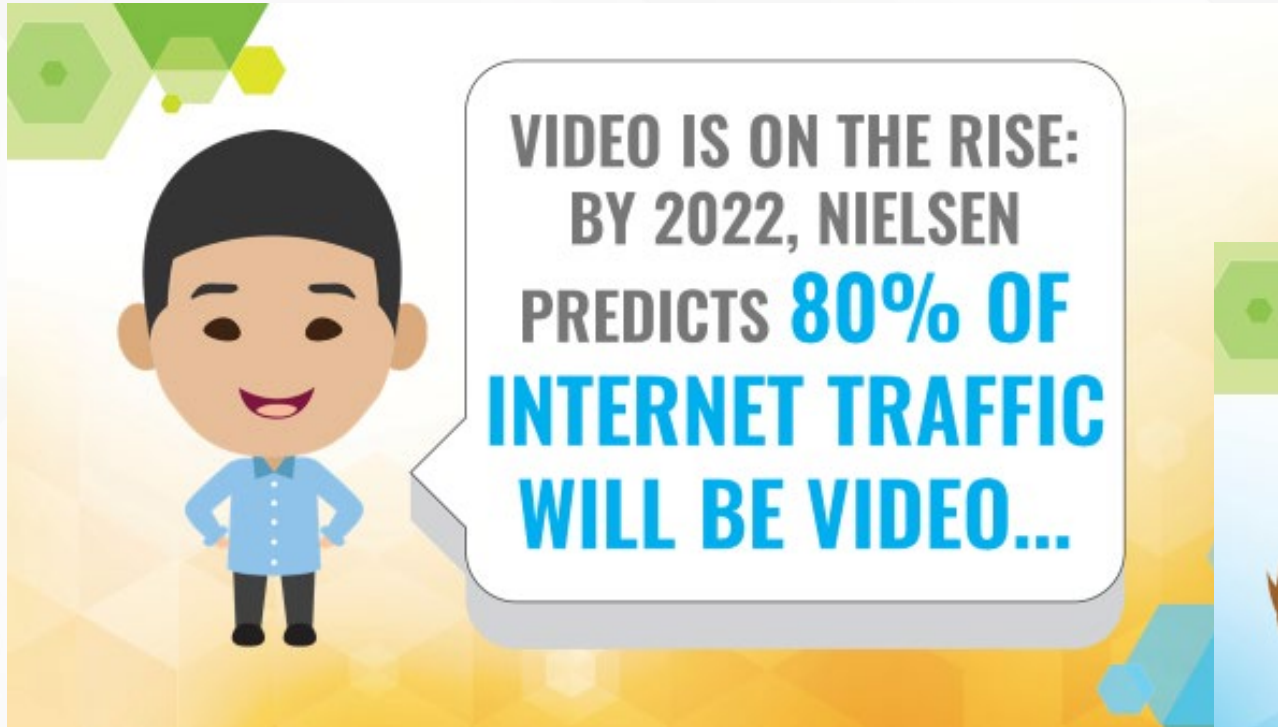
- FROM MARCH 1ST - APRIL 1ST, **TEXT MESSAGE USAGE BETWEEN PATIENTS AND CLINICIANS HAS GROWN**
- THAT RATE IS **37X MORE** THAN THE TEXT MESSAGES SENT TO PATIENTS BETWEEN JANUARY 1ST TO FEBRUARY 1ST.



WHY FOCUS ON PATIENT ENGAGEMENT

**YOU ARE COMPETING WITH
A MINIMUM OF 1500
POSTS AT ANY GIVEN TIME!!!**

Trends in Social Media Impacting Patient Journey



Building Relationships of Trust

► “Building TRUST is a process.

Trust results from **consistent** and **predictable** interaction over time”

Barbara White



#1 Becoming Acquainted



#2 Build on Common Ground

4? or

6?



#3 Listen

“You cannot establish **TRUST** if you cannot **LISTEN**. A conversation is a relationship. Both speaker and listener play a part, each influencing the other. The listener has **as much** to do in shaping the conversation as the speaker?”

-Bruce Wilson



#4 Share

- **Look for opportunities to share**
- **Share first and then ask questions**



#5 Connect

“We **TRUST** people we can count on.
We count on people who do what
they say they will do.....when they
say they will do it”

~Tim Wright



QUICK Review of BRT

So....why the TENNIS BALLS?



- 1. Become Acquainted**
- 2. Build on Common Ground**
- 3. Listen**
- 4. Share**
- 5. Connect**

Example of BRT'ing



Patient Engagement:

Importance of Soft Skills and Building Relationships of Trust



Ice breaker: The last book you read was?

Breakouts: What patient engagement advancement is most important to clinical research over the next 12 months?