National Cancer Institute Research Priorities Within an Evolving Health Communication Landscape

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Health Communication and Informatics Research Branch

NIH NATIONAL CANCER INSTITUTE

UNC Lineberger Comprehensive Cancer Center
Cancer Outcomes Grand Rounds
March 29, 2022

NCI — National Cancer Institute

DCCPS — Division of Cancer Control and Population Sciences

BRP — **Behavioral Research Program**

HCIRB — **Health Communication and Informatics Research Branch**

BRP formed in 1998, HCIRB in 1999

Founding BRP Director: Bob Croyle

Current BRP Director: Bill Klein

1st branch chief: Gary Kreps

2nd branch chief: Brad Hesse

3rd branch chief: Robin Vanderpool

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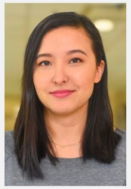

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Research Areas:

- Rural cancer control
- HPV vaccination
- Cancer screening
- Cancer survivorship
- Implementation science
- Patient-provider communication
- Community outreach and engagement

April Oh (IS), Wendy Nelson (BBPSB), Amanda Acevedo (BBPSB), Maria Roditis (TCRB), and Cindy Vinson (IS) have secondary appointments in HCIRB.

HCIRB Mission and Scientific Priorities

Mission

To advance research on the processes and effects of communication and informatics across the cancer control continuum.

Priorities

- **Communication Science**
- **Multilevel health communication**
- **Technology-mediated communication**
- **Behavioral Informatics**
- **Health Disparities and Health Equity**

Cancer Risk Communication

JNCI MONOGRAPHS

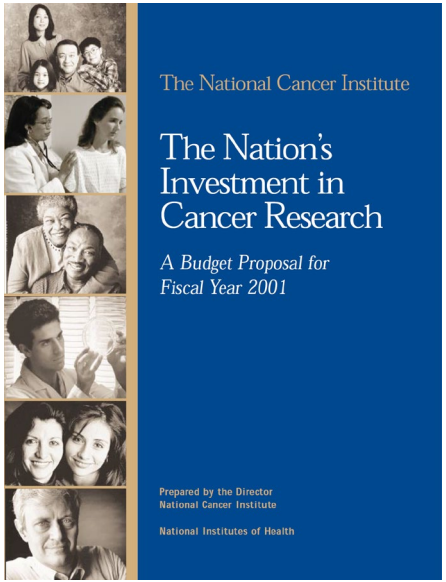
Cancer Risk Communication: What We Know and What We Need To Learn — *1999 Number 25*

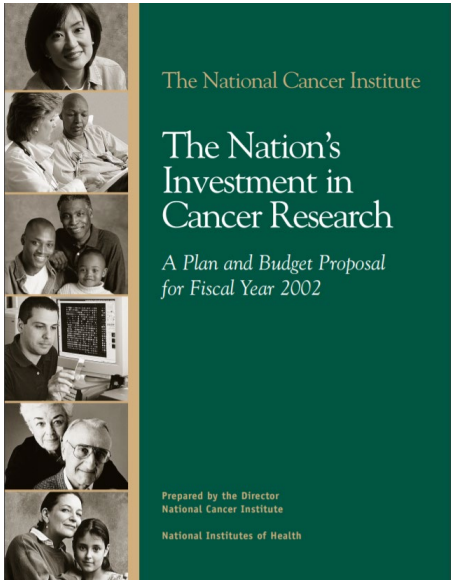
Contents

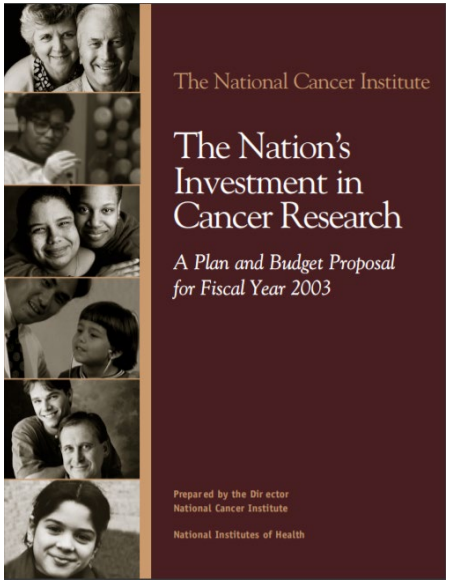
NCI-Sponsored Conference (1998)

Monograph – *Cancer Risk Communication: What We Know and What We Need to Learn* (1999)

Cancer Communication:
An Extraordinary Opportunity (2001-2003)



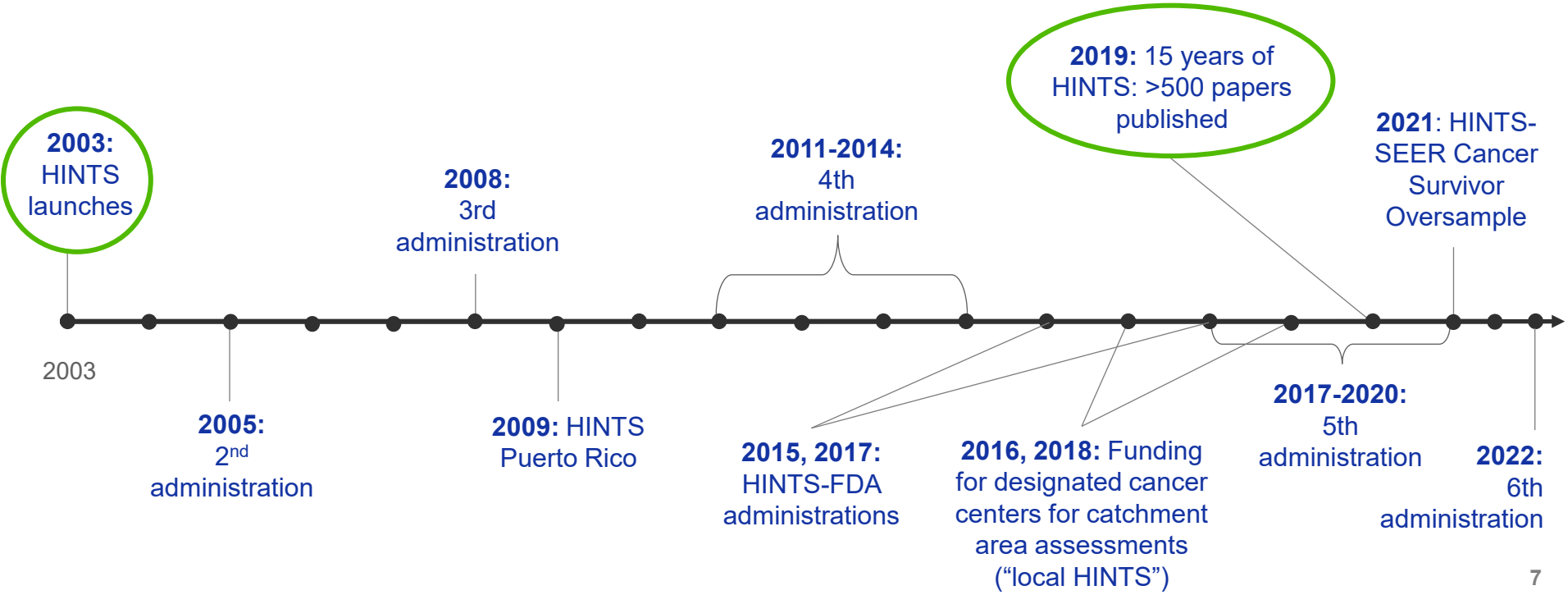




"At this pivotal juncture, there is a need for a public institution such as NCI to provide leadership in the cancer communications arena; the broad and reasoned perspective that NCI brings to patients and healthcare providers alike is essential to successfully implement communication strategies to reduce the cancer burden." *(2001)*

HINTS Overview and Timeline

HINTS: One of NCI's longest running surveys



Decade of P50 Centers Funding (2003-2013)

Centerpiece of NCI's Extraordinary Opportunity in Cancer Communication

University of Michigan (CECCR I & II)

University of Pennsylvania (CECCR I & II)

University of Wisconsin (CECCR I & II)

Washington University in St. Louis (CECCR I & II)

Cancer Research Network (CECCR II)

Past HCIRB Initiatives and Milestones

2001: NCI Digital Divide Pilot Projects

2010: SBIR portfolio transitioned to NCI OD

2011, 2015: Small Grants Program for Behavioral Research in Cancer Control Evaluation

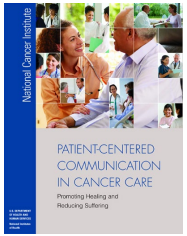
2013-2017: "Using Social Media to Understand and Address Substance Use and Addiction" RFA

2016: NCI SPRINT

2007-2013: "Understanding and Promoting Health Literacy" PARs

2016: HPV Vaccination Uptake Special Interest Project (CDC)

FY 2016, FY 2018: Cancer Centers' Population Health Assessment Supplements



2007: NCI Monograph on Patient-Centered Communication in Cancer Care

2011-2012: Partnering Against Cancer Today (PACT)

2012-2013: JNCI Monographs Supplement

2014: FLASHE study

2015-2016: President's Cancer Panel Report on Connected Health

2018: JAMA Viewpoint *Addressing Health-Related Misinformation on Social Media*

Current Initiatives and Milestones

2018:
R15 and K18 funding for mhealth/digital health

2018-2022:
TCORS 2.0

2016-present:
Cancer Communication in the New Information Ecosystem PAR

2012-present:
Smart and Connected Health (NSF)

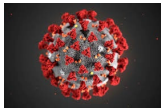
2019-2025:
Cancer Moonshot Initiatives (e.g., ACCSIS, PE-CGS)

2018-2020:
L.A.U.N.C.H.

FY 2020-2024:
Implementation Science Centers in Cancer Control (ISC3)

FY 2020 – 2022:
Community Outreach and Engagement Cancer Center Supplements; Social Media Ethics Supplement

FY 2020-present:
COVID-19 Research



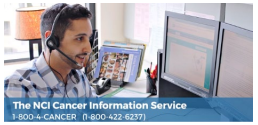
Fall 2020:
Special Issue: Misinformation, Health, Social Media

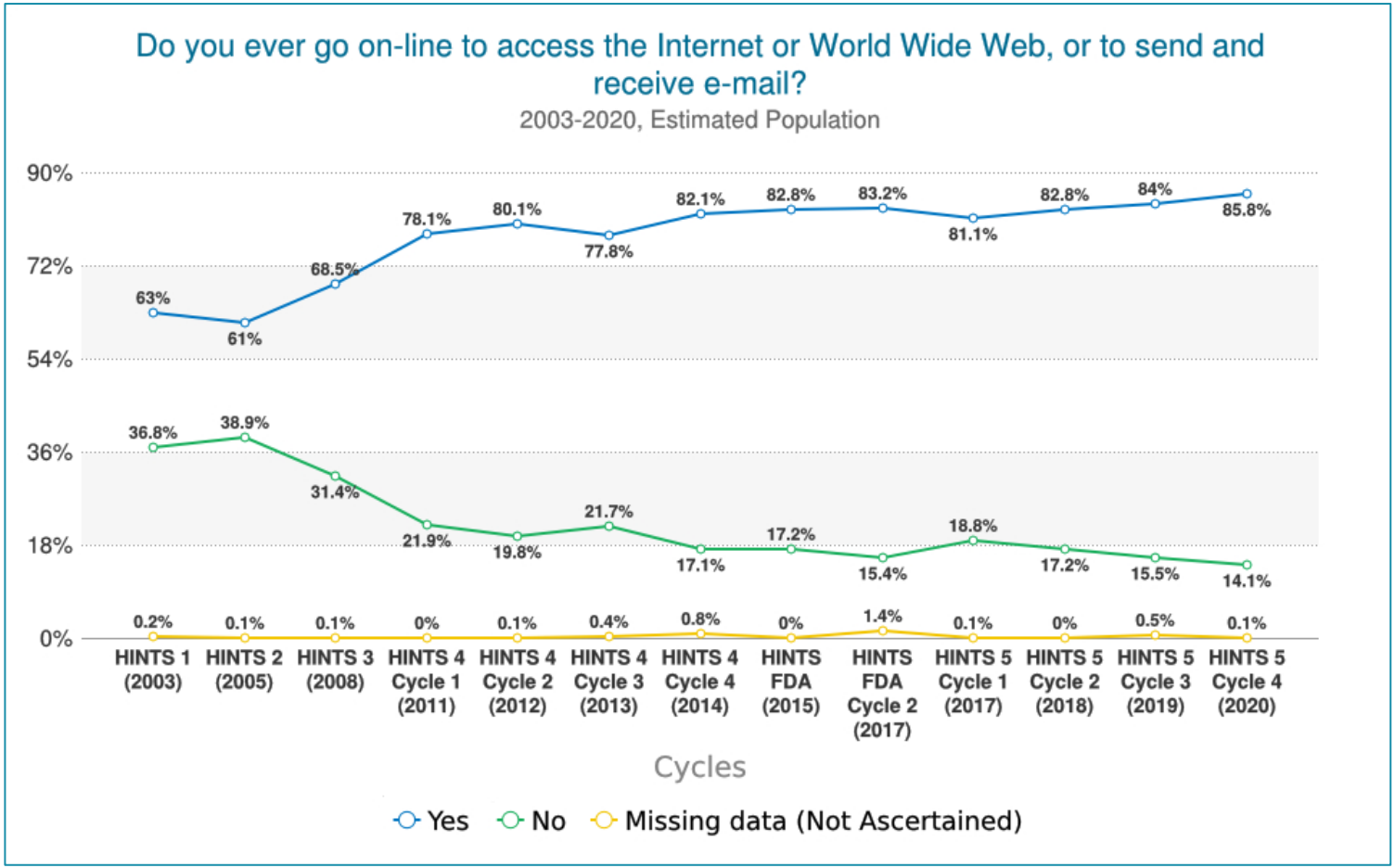
2022:
HINTS 6

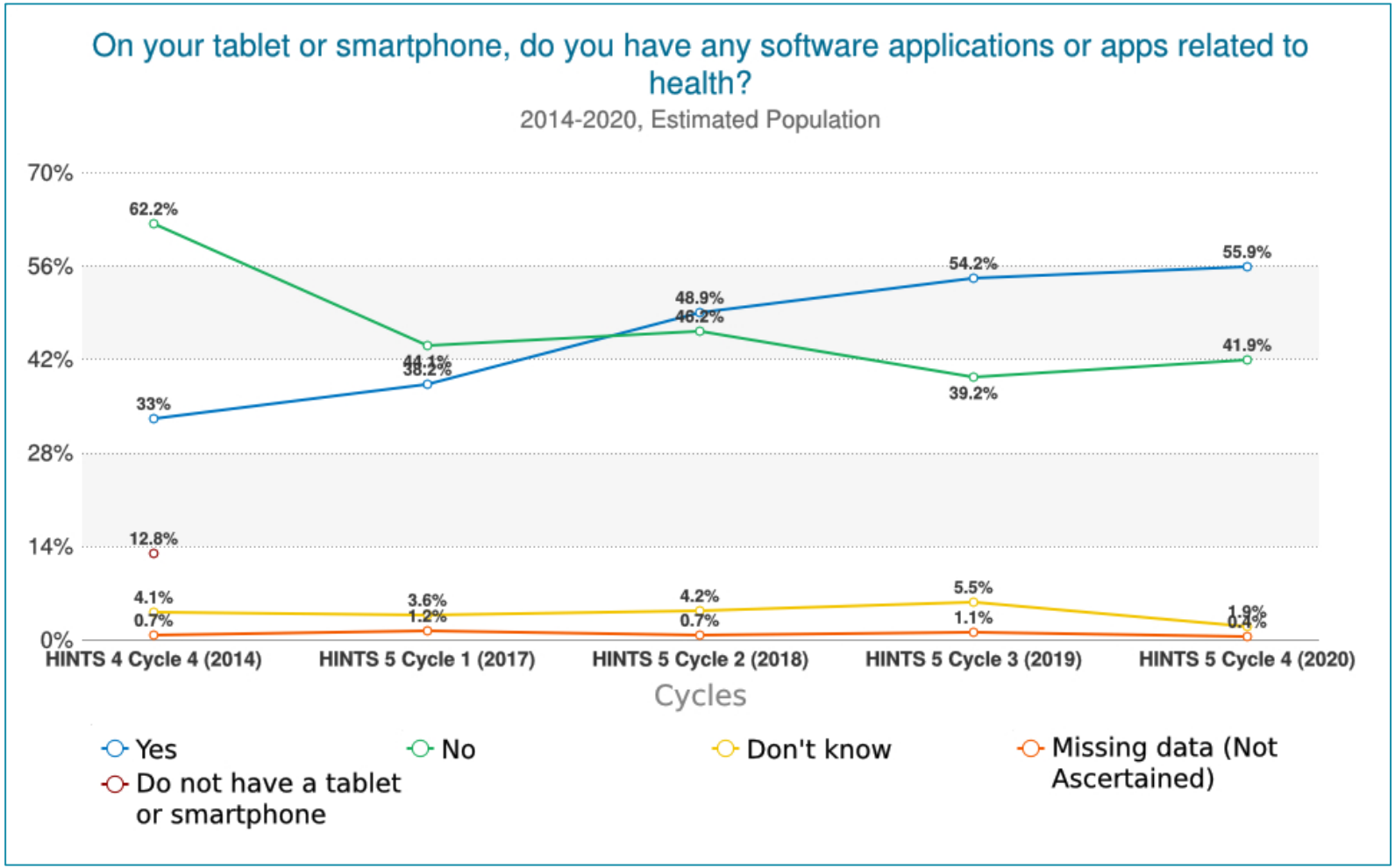
FY 2021:
Rural Prevention PAR

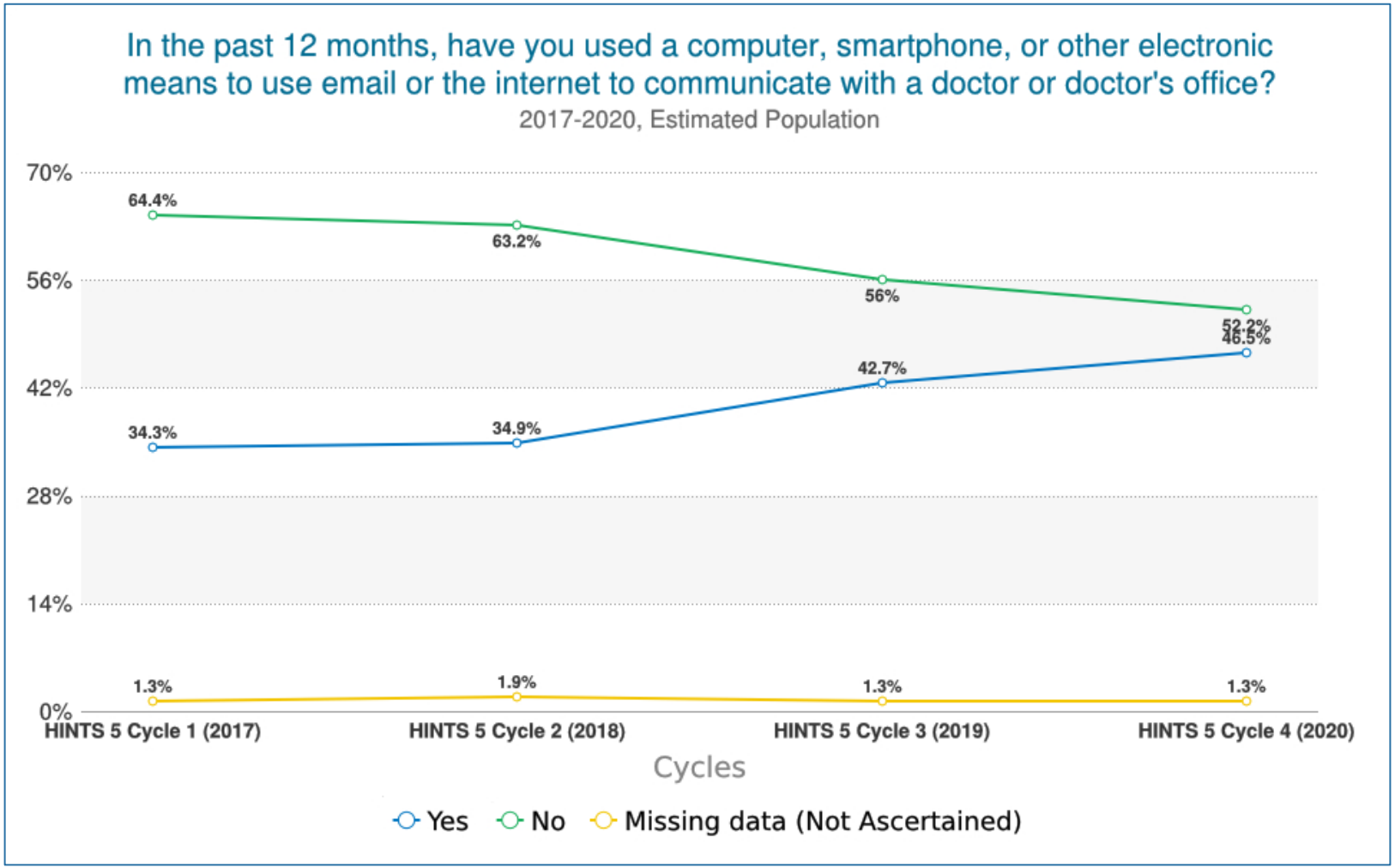
FY 2022:
Telehealth Research

2020-present:
CIS Research Collaboration




Do you ever go on-line to access the Internet or World Wide Web, or to send and receive e-mail?
2003-2020, Estimated Population
90%
72%
54%
36%
18%
0%
63%
61%
68.5%
78.1%
80.1%
77.8%
82.1%
82.8%
83.2%
81.1%
82.8%
84%
85.8%
36.8%
38.9%
31.4%
21.9%
19.8%
21.7%
17.1%
17.2%
15.4%
18.8%
17.2%
15.5%
14.1%
0.2%
0.1%
0.1%
0%
0.1%
0.4%
0.8%
0%
1.4%
0.1%
0%
0.5%
0.1%
HINTS 1 (2003)
HINTS 2 (2005)
HINTS 3 (2008)
HINTS 4 Cycle 1 (2011)
HINTS 4 Cycle 2 (2012)
HINTS 4 Cycle 3 (2013)
HINTS 4 Cycle 4 (2014)
HINTS FDA (2015)
HINTS FDA Cycle 2 (2017)
HINTS 5 Cycle 1 (2017)
HINTS 5 Cycle 2 (2018)
HINTS 5 Cycle 3 (2019)
HINTS 5 Cycle 4 (2020)
Cycles
Yes
No
Missing data (Not Ascertained)


On your tablet or smartphone, do you have any software applications or apps related to health?
2014-2020, Estimated Population
70%
56%
42%
28%
14%
0%
62.2%
44.1%
38.2%
33%
48.9%
46.2%
54.2%
39.2%
55.9%
41.9%
12.8%
4.1%
0.7%
3.6%
1.2%
4.2%
0.7%
5.5%
1.1%
1.9%
HINTS 4 Cycle 4 (2014)
HINTS 5 Cycle 1 (2017)
HINTS 5 Cycle 2 (2018)
HINTS 5 Cycle 3 (2019)
HINTS 5 Cycle 4 (2020)
Cycles
Yes
No
Don't know
Missing data (Not Ascertained)
Do not have a tablet or smartphone


In the past 12 months, have you used a computer, smartphone, or other electronic means to use email or the internet to communicate with a doctor or doctor's office?
2017-2020, Estimated Population
70%
56%
42%
28%
14%
0%
64.4%
63.2%
56%
52.2%
46.5%
42.7%
34.3%
34.9%
1.3%
1.9%
1.3%
1.3%
HINTS 5 Cycle 1 (2017)
HINTS 5 Cycle 2 (2018)
HINTS 5 Cycle 3 (2019)
HINTS 5 Cycle 4 (2020)
Cycles
Yes
No
Missing data (Not Ascertained)

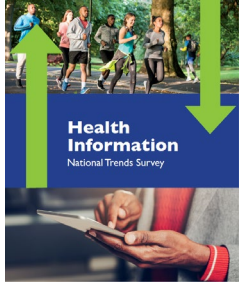
Select HCIRB Activities

- *HINTS-SEER*
- *HINTS 6 + HINTS panel*

HINTS-SEER

- Analytic sample of 1,200 cancer survivors drawn from 3 SEER registries – Greater Bay Area, Iowa, and New Mexico.
- Standard HINTS postal administration procedures were used to field the survey individually with each registry cohort between January - August 2021.
- Most items were taken from the HINTS 5 Cycle 4 (2020) survey, but a few unique items were added (e.g., impact of cancer treatment, social isolation, COVID-19), and some items were modified to make them more salient to cancer survivors.
- Dataset contains metadata from the SEER registries for each respondent (e.g., cancer histology, SEER summary stage)
- Analyze HINTS-SEER data from each of the 3 registries individually or combine across the 3 registries; compare HINTS-SEER results with other cycles of HINTS

HINTS 6 + HINTS Panel



- HINTS 6 is fielding now (March 2022)
  - Dual mode: postal and push-to-web
  - African American, Hispanic, and rural populations oversampled
  - Includes new items about misinformation, telehealth, social determinants of health, etc.

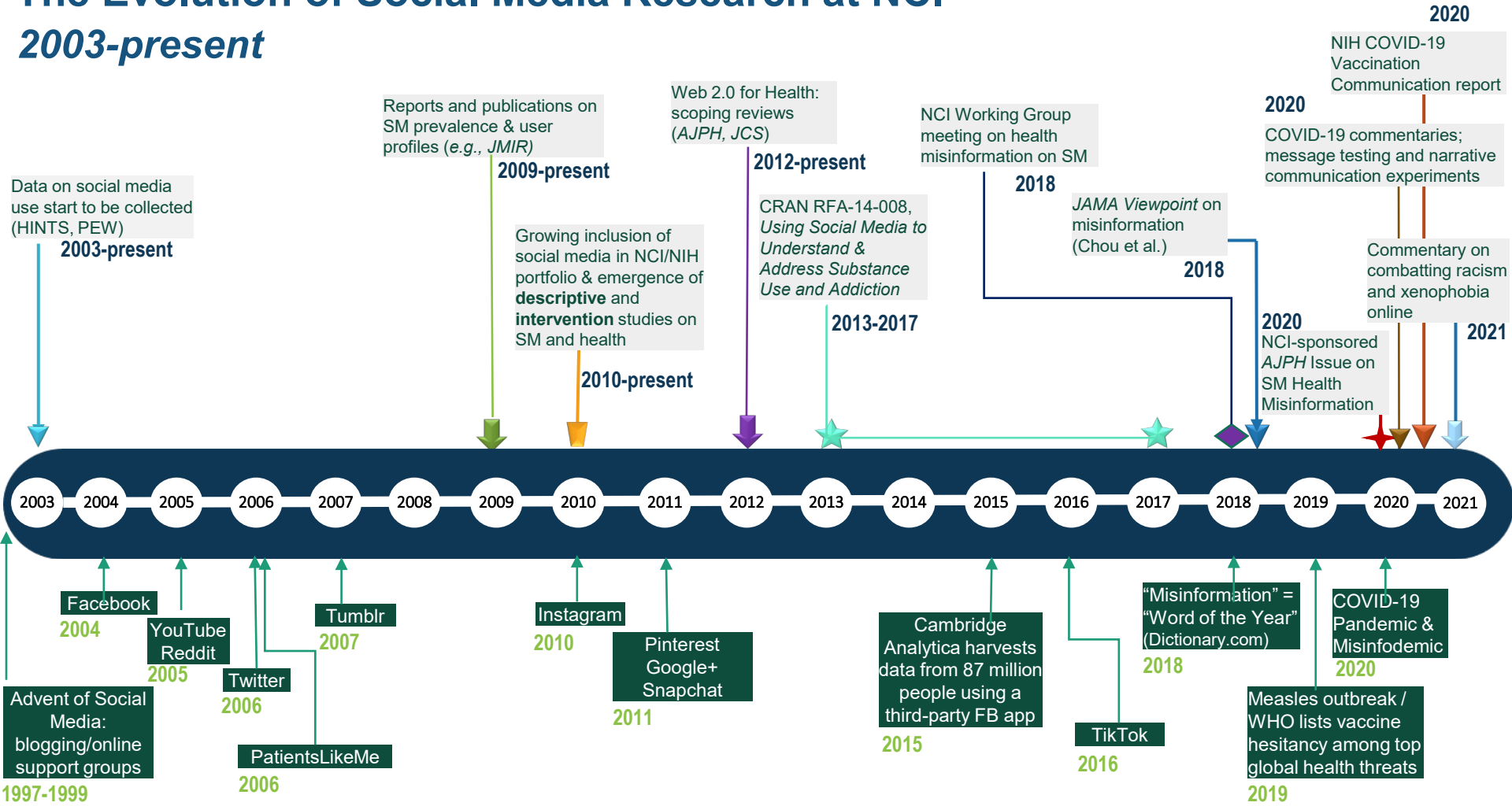
- Established a **HINTS panel** for longitudinal follow up with a subset of HINTS respondents
  - On HINTS 6, respondents were given the option of providing their contact information if they were interested in joining a HINTS Panel to participate in future studies.
  - HINTS Panel members will be asked to complete up to 5 surveys per year after enrolling.
  - Results from these surveys will allow researchers to identify trends over time and to do deeper dives into various topics.
  - Other novel uses include message testing and communication experiments.

Select HCIRB Research Priorities

- *Health Misinformation*
- *Telehealth and Cancer Care Delivery*

The Evolution of Social Media Research at NCI

2003-present



Role of Behavioral Science

"This [science misinformation] has turned out to be a much more severe situation than I would have imagined a year ago. **I wish we had more insights from behavioural social science research into how this has come to pass, and why it could have gotten so completely widespread.** I want to call this out as one of my most major concerns as I stepped down from the NIH, of looking at the situation in our nation."

Francis Collins in *Nature*, 12/3/21

"It does make me, at least, realize, "Boy, there are things about **human behavior** that I don't think we had invested enough into understanding." **We basically have seen the accurate medical information overtaken, all too often, by the inaccurate conspiracies and false information on social media.** It's a whole other world out there. **We used to think that if knowledge was made available from credible sources, it would win the day. That's not happening now.**"

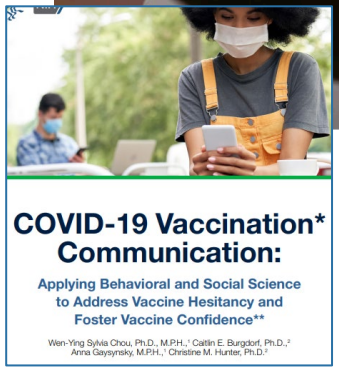
Francis Collins on *NPR*, 12/7/21

"You know, **maybe we underinvested in research on human behavior**. I never imagined a year ago, when those vaccines were just proving to be fantastically safe and effective, that we would still have **60 million people who had not taken advantage of them because of misinformation and disinformation that somehow dominated all of the ways in which people were getting their answers.** And a lot of those answers were, in fact, false. And we have lost so much as a result of that."

Francis Collins on *PBS NewsHour*, 12/20/21

NCI's scientific leadership on social media and health misinformation

- A longstanding portfolio of observational and intervention studies (RFAs, PAs)
- 2018 working group on health misinformation
- Staff-led peer-reviewed publications, including *JAMA Network*
- NCI-sponsored *American Journal of Public Health* 2020 theme issue
- Expert consultation to National Academy of Medicine, ASCO, WHO, Office of Surgeon General, HHS
- Vaccination communication (HPV and COVID-19)
- Trans-NIH initiative on health and science communication



- The spread of misinformation could affect many aspects of cancer control efforts, including:
  - **Prevention, screening, and treatment** (e.g., decision-making, delays in care, use of unproven therapies)
  - **Patient-provider relationship** (e.g., exposure to conspiracy theories might reduce trust in providers/medical system)
  - **Psychological and emotional effects** (e.g., anxiety, confusion)
  - **Potential financial loss** (e.g., “miracle” products sold to vulnerable people)
  - **Exacerbation of cancer health disparities** (e.g., availability of high-quality information and content moderation enforcement in other languages

Telehealth and Cancer Care Delivery

“Necessity is the mother of innovation”

COVID-19 pandemic brings telehealth center stage for oncologists and their patients

Rapid Rollout of Telemedicine Aids Cancer Care During COVID-19 Pandemic

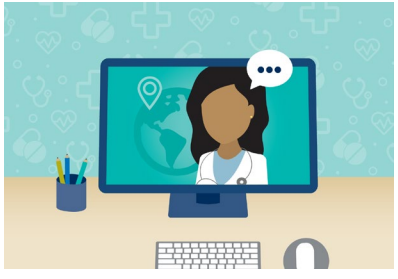
Telehealth helps cancer patients continue treatment

Telemedicine Takes the Lead in Cancer Care Strategy During the COVID-19 Outbreak

Cancer Care Goes Virtual in Response to COVID-19

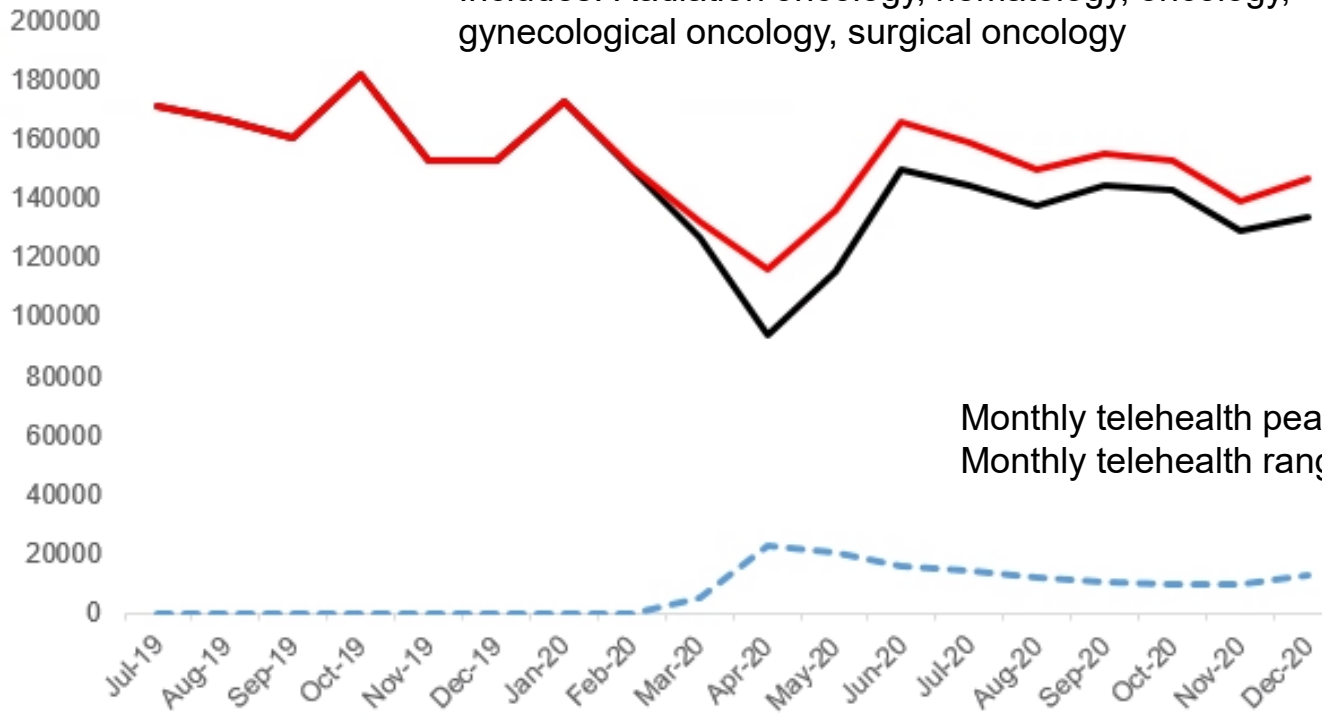
Oncology-Related Uses of Telehealth in COVID-19 Era

- Pre-screen patients for exposure to COVID-19 or symptoms of COVID-19 infection prior to clinic visits
- Discuss treatment plans and management options
- Recruit, manage, and monitor patients on clinical trials
- Monitor patients in active treatment
- Conduct routine follow-up visits with patients who have completed treatment



Monthly telehealth use by Medicare FFS beneficiaries, oncologists only

Includes: Radiation oncology, hematology, oncology, gynecological oncology, surgical oncology



Total

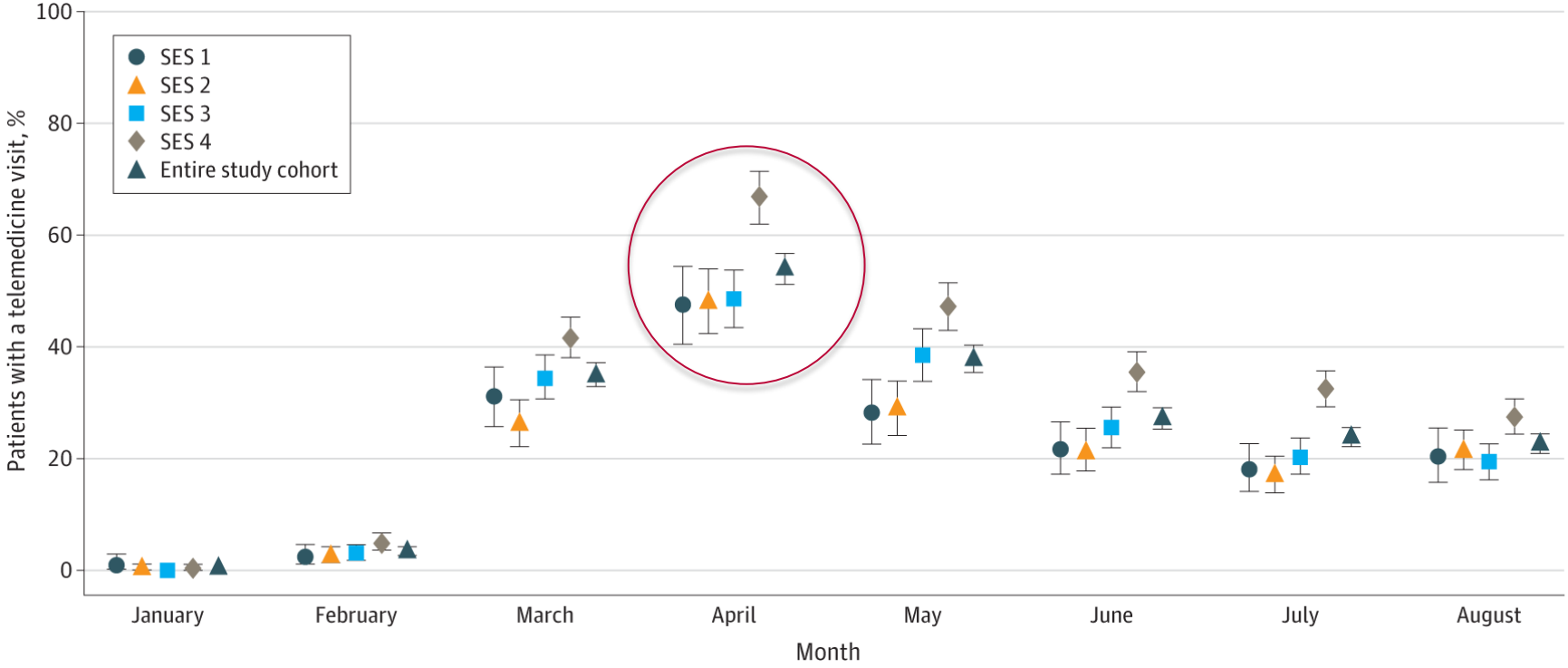
In-person E&M

Telehealth E&M

Monthly telehealth peak: 19%
Monthly telehealth range July-Dec 2020: 6-9%

Source: Ellimoottil et al. analysis of 20% sample of national Medicare fee-for-service claims

Telemedicine Use Among Patients With Newly Diagnosed Cancer by Socioeconomic Status

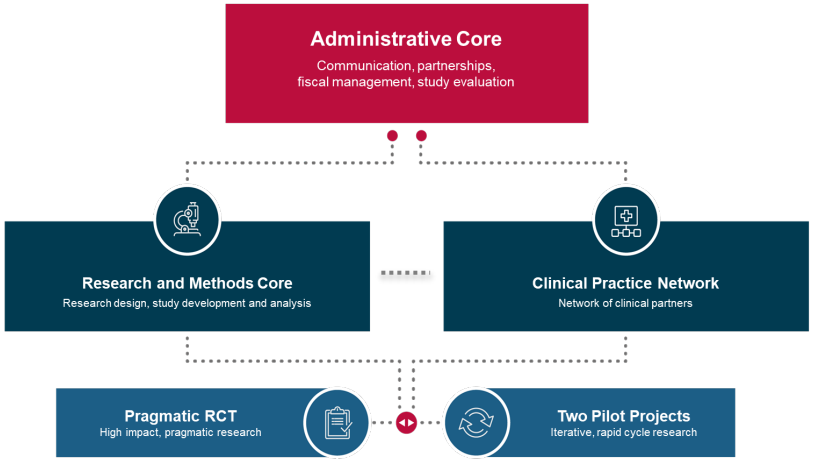


Katz et al, JAMA Oncol. 2022;8(1):161-163

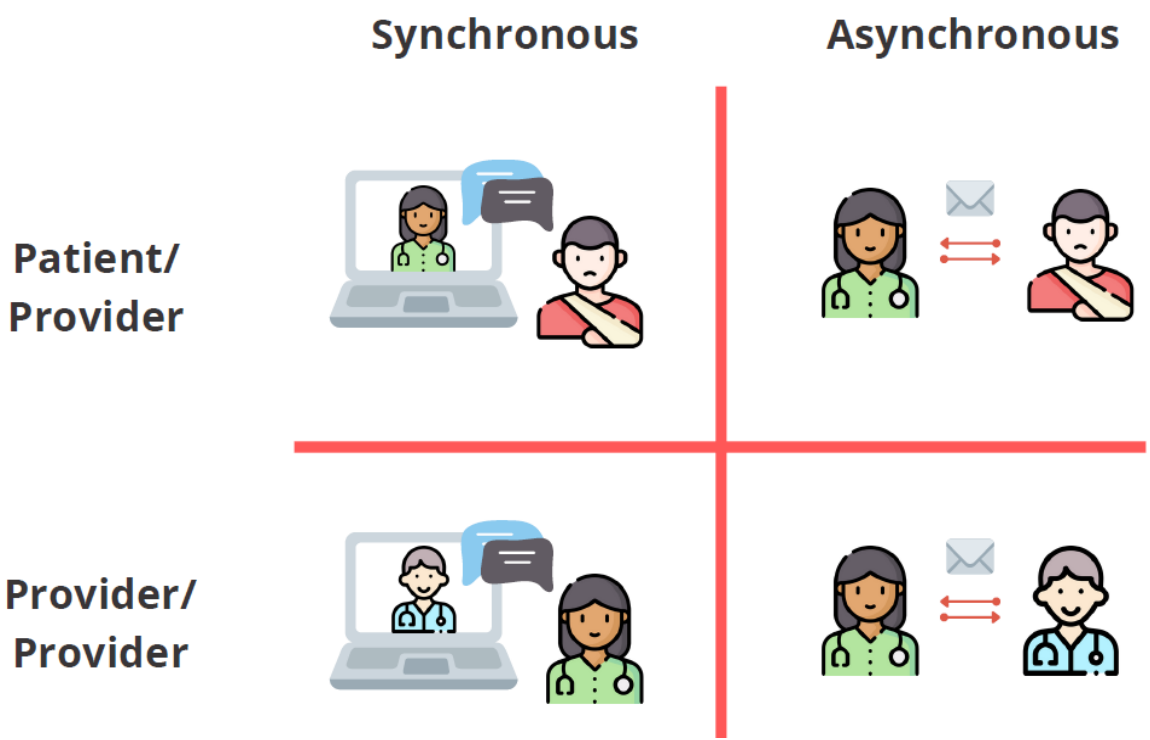
Telehealth and Cancer Care Delivery

- Despite increased use of telehealth, notable research gaps remain regarding the use of telehealth in the context of cancer control. HCIRB is leading several new telehealth-related initiatives that seek to address these gaps:

  - **NCI Telehealth Research Centers of Excellence (TRACE)**
    This initiative will fund 3 research centers with the goal of supporting the development of a telehealth-focused evidence base across the cancer control continuum.



Telehealth: Interaction Type and Communication Format



How can patient-centered communication be supported in telehealth interactions?

- Are **patients and providers** comfortable with using telehealth, even for difficult conversations?
  - How are non-verbal cues interpreted via telehealth?
  - How are sensitive issues related to treatment planning, palliative care, and end-of-life discussions handled via telehealth?
  - Do virtual patient navigators increase patient self-efficacy and comfort with technology?
  - Can telehealth-specific physician training improve communication?
    - "Soft skills" and practicing medicine via telehealth

WEBINAR SERIES

Telehealth and Cancer:
Studying its Role in Cancer Control and Care Delivery

Friday, February 25, 2022
Introduction to Telehealth and Cancer Webinar Series

Monday, March 21, 2022
Patient-Provider Communication and Cancer-Related Telehealth

Tuesday, April 26, 2022
Telehealth Models of Cancer Care Delivery

Thursday, May 19, 2022
Telehealth Research to Address Cancer Health Disparities

Tuesday, June 21, 2022
Overview of NCI's Telehealth Research Centers of Excellence (TRACE)

All webinars: 12:00 PM – 1:00 PM EST

https://cancercontrol.cancer.gov/events

Relevant NCI Funding Opportunities

- Investigator-initiated R03s and R01s to the parent mechanism
- Innovative Approaches to Studying Cancer Communication in the New Information Ecosystem (PAR-19-348 and PAR-19-350) *[reissuance expected in June 2022]*
  - R01: https://grants.nih.gov/grants/guide/pa-files/PAR-19-348.html
  - R21: https://grants.nih.gov/grants/guide/pa-files/par-19-350.html
- Research on Telehealth for Cancer Care NOSI (NOT-CA-21-043)
  - https://grants.nih.gov/grants/guide/notice-files/NOT-CA-21-043.html
- Notice of NCI Participation in RFA-MD-22-008, “Understanding and Addressing Misinformation among Populations that Experience Health Disparities [BRAND NEW!]
  - R01: https://grants.nih.gov/grants/guide/notice-files/NOT-CA-22-066.html

Branch Alignment with DCCPS Research Priorities

- Cancer screening, especially post-COVID-19
- Cancer survivorship
  - Advanced or metastatic disease
  - Health behaviors
- Tobacco prevention and control
- Cancer-related stigma
- Community outreach and engagement
- Catchment area research
- Financial hardship and cancer
- HPV vaccination
- Rural cancer research
- Persistent poverty
- Alcohol use and cancer
- Climate change
- Social determinants of health
- Implementation science
- Pragmatic research

THANK YOU!

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www.cancer.gov

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