Enhancing Patient Navigation with Technology to Improve Equity in Cancer Care

2024 Report to the President

Dr. Elizabeth Jaffee, Chair

NCAB December 3, 2024

President's Cancer Panel Overview

Three-member panel established by the National Cancer Act of 1971.

"Shall monitor the development and execution of the activities of the National Cancer Program and shall report directly to the President."

Identifies high-priority topics for which actionable recommendations can be made.

Dr. Elizabeth M. Jaffee, Chair
Sidney Kimmel Cancer Center
Johns Hopkins University
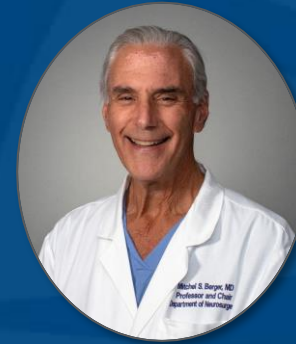
Dr. Mitchel S. Berger
University of California, San Francisco

Dr. Carol L. Brown
Memorial Sloan Kettering Cancer Center

Patient Navigation in Cancer Care

WHAT IS NAVIGATION?

Navigation is a **person-centered healthcare service delivery model** that aims to overcome individual and systemic barriers to accessing timely and quality cancer care.

WHO CAN PERFORM NAVIGATION?

- Patient navigators
- Community health workers
- Social workers
- Physicians
- Nurses
- Other members of the healthcare team

EXAMPLES OF NAVIGATION ACTIVITIES

- Coordinating care
  - > Connecting patients with providers
  - > Providing appointment reminders
  - > Matching patients with clinical trials
- Providing or connecting with resources to address:
  - > Social needs
  - > Psychosocial care
  - > Financial support
- Providing health education

Addressing Challenges in Patient Navigation to Reduce Disparities in Cancer Care

- Many advances in cancer treatment in recent years but not everyone benefits equally
- Many cancer patients face significant barriers in accessing cancer treatment due to:
  - ❖ Individual barriers such as transportation issues to chemotherapy appointments
  - ❖ systemic barriers like navigating our complex medical system
- Certain populations are more likely to experience these barriers, including:
  - ❖ minorities
  - ❖ those living in rural or remote areas
  - ❖ those with limited educational attainment or economic resources
  - ❖ those with disabilities
  - ❖ LGBTQ communities
- Patient navigation REDUCES disparities by addressing barriers and facilitating access to timely, high-quality cancer care
- Patient navigation now has a Medicare reimbursable cost
  - ❖ implementation is ongoing across the country but is limited in services

Current State

- Not all people have access to comprehensive patient navigation services

- Healthcare organizations do not have enough resources or navigators to provide navigation services to all patients

- Many patients experience delays in cancer treatment and are left without support at a time when they need it most

- Technology, when responsibly developed and used, has the potential to extend the reach of patient navigation and expand access to timely, quality cancer care

2023 Meeting Series Stakeholders

Goal: To assess navigation needs and identify opportunities to leverage technology to support patient navigation

- Academic institutions
- Government agencies
- Healthcare systems
- Patient advocates
- Patient navigators
- Private-sector industry
- Technology innovators
- Societies/associations
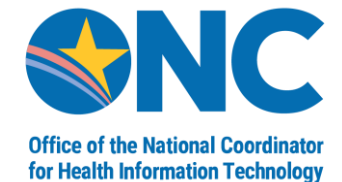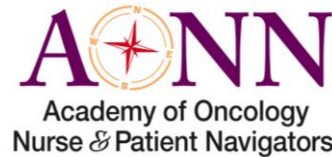
Main Concepts Raised and Addressed

- Many challenges related to patient navigation are amenable to technological solutions

- Introductions of new tools must maintain and build trust between patients, communities, and health systems

- Technology should address the needs of users. End users should be involved throughout the development process

- There are concerns that current policies and regulations do not provide adequate protections for patient information

Report Priorities

USE TECHNOLOGY TO SUPPORT NAVIGATION AND ACHIEVE EQUITY
- Facilitate patient-centered care coordination.
- Link navigators and patients to resources.
- Inform and empower patients.

ENSURE EQUITABLE ACCESS TO TECHNOLOGY
- Fund federal programs for broadband access.
- Increase telehealth access in community places.

PROMOTE RESPONSIBLE DEVELOPMENT AND USE OF TECHNOLOGY
- Adhere to core principles.
- Support research to confirm goals are met.
- Ensure navigators have technology knowledge and skills.

MAINTAIN PRIVACY AND SECURITY WHILE PROMOTING DATA SHARING
- Improve and incentivize interoperability.
- Identify opportunities for a national legal framework.

Foundational Principles

- Technology should be seen as a **supplement**, not a replacement, for people and personalized care

- Technology should be **responsibly developed** and used

- Access to technology should **not be a requirement** for accessing high-quality cancer care and patient navigation

- Technology should help **achieve equity** and close gaps in cancer outcomes

Priority 1: Use Technology to Support Navigation and Achieve Equity

Develop and implement tools that facilitate efficient, patient-centered coordination of cancer care

- Automated tools embedded within EHRs to identify those who will benefit from navigation

- Reduce systemic and individual barriers to timely and high quality care

- Automated prompts when screening and test results require follow up

Develop and implement technologies to help navigators connect cancer patients with organizational and local resources

- Navigator resource dashboards within EHRs

- Reduce administrative burdens, streamline referrals so navigators have more time with patients

Develop and implement tools that provide vetted, personalized cancer-related information for patients and caregivers

- Patient portals, decision support tools, and mobile health apps

- Access to health information can improve conversations between patients, navigators and providers
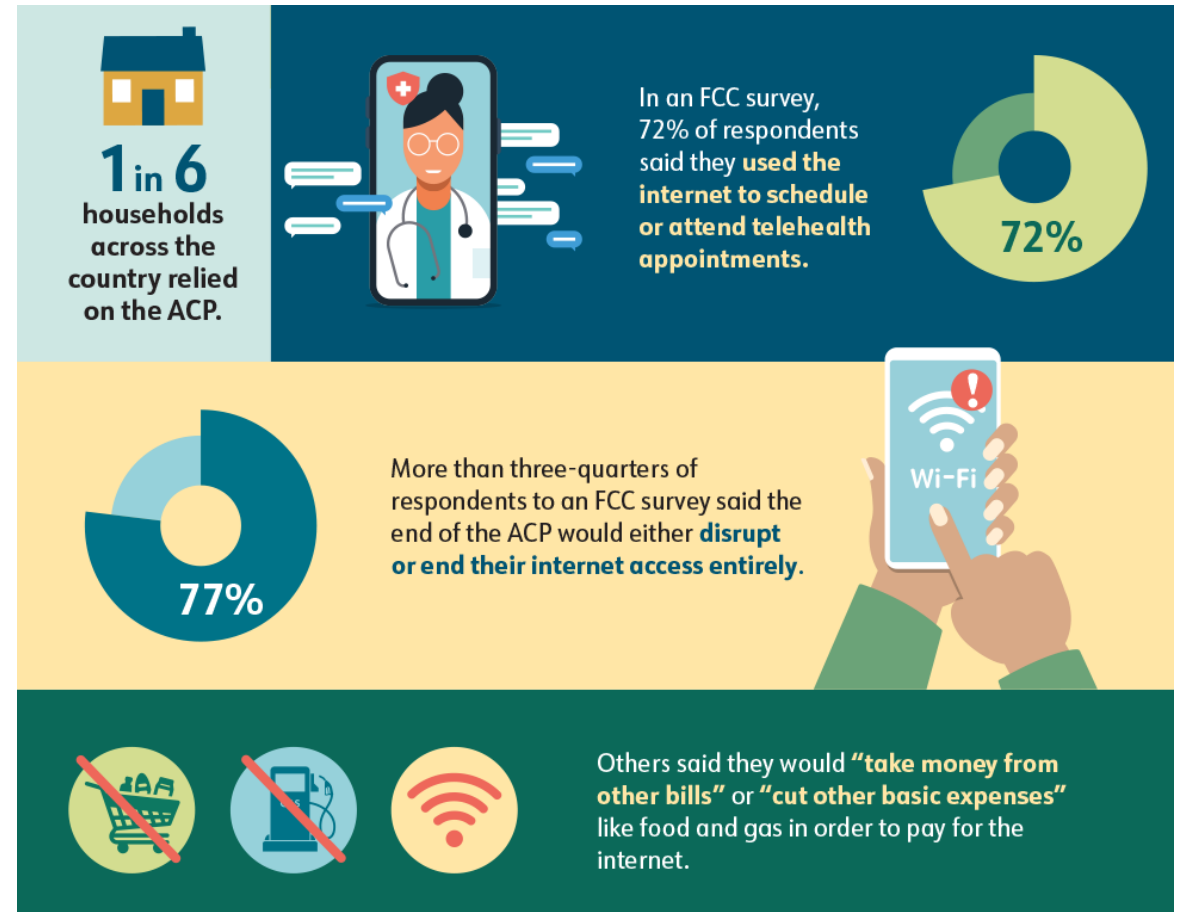
Priority 2: Ensure Equitable Access to Technology

Provide funding for federal programs that facilitate access to broadband internet

- Affordable Connectivity Program – ended May 2024

- Continue through the Universal Service Fund – created before digital age and needs modernization

Increase patient access to devices and private space through community sites to facilitate access to telehealth appointments

- Telehealth spaces (e.g., public libraries, housing shelters, schools, pharmacies)

1 in 6 households across the country relied on the ACP.

In an FCC survey, 72% of respondents said they **used the internet to schedule or attend telehealth appointments.**

72%

77%

More than three-quarters of respondents to an FCC survey said the end of the ACP would either **disrupt or end their internet access entirely.**

Wi-Fi

Others said they would **"take money from other bills"** or **"cut other basic expenses"** like food and gas in order to pay for the internet.

Priority 3: Promote Responsible Development and Use of Technology

Adhere to core principles for responsible development and use of technologies that support cancer patient navigation

- *People-first approach*

- *Equity*

- *User-centered design*

- Effectiveness and validity

- Use of high-quality source data

- Transparency

- Privacy

- Interoperability

- *Ongoing assessment and improvement*

Priority 3: Promote Responsible Development and Use of Technology

- Technology doesn't automatically lead to increased efficiency or improved outcomes

- If not thoughtfully designed and implemented, technology can cause frustration, diminish trust, exacerbate health disparities, and could even result in serious harm through medical errors

- *Ongoing assessment/improvement:* To ensure tools do what they are supposed to do, implementation must include an evaluation plan to monitor for unintended consequences and allow for iterative improvements

Priority 3: Promote Responsible Development and Use of Technology

Support research to ensure that technology support navigation achieves its goals

- Offer incentives for developing and testing technologies that address health disparities

Incorporate technology knowledge and skills into patient navigator training and core competencies

Priority 4: Maintain Privacy and Security While Enabling Data Sharing

Improve and incentivize interoperability to enable portability of patient data across health IT platforms and systems

Evaluate existing privacy and security regulations and laws and identify opportunities for a national legal framework to facilitate data sharing while protecting patient data
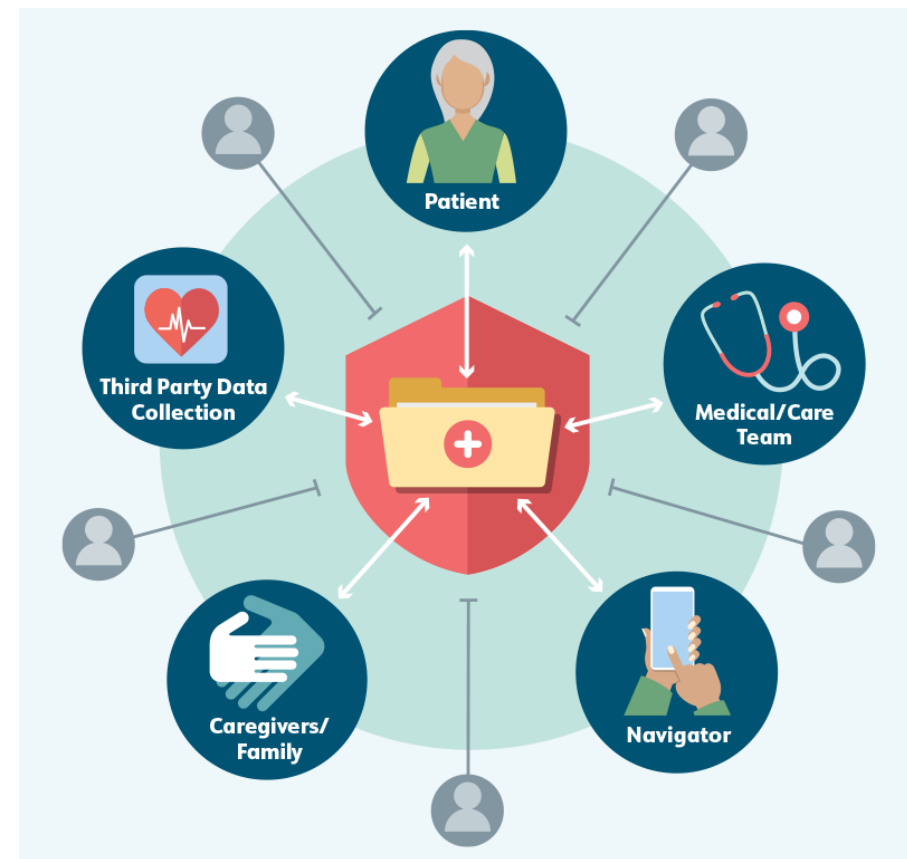
Priority 4: Recommendations to Maintain Privacy and Security While Enabling Data Sharing

- Effective cancer care delivery depends on timely exchange of patient health data

- The federal government has made significant progress towards increasing interoperability in health information technology through ASTP/ONC

- We need continued progress at the federal, industry, and health system levels to enable portability and integration of patient data across health IT platforms and systems

- The main federal law related to health information is the Health Insurance Portability and Accountability Act, or HIPAA
  - ❖ The technological landscape has changed significantly since it was enacted in 1996

- Health data is often generated and stored outside of traditional healthcare settings (apps and wearable health trackers) and are outside the purview of HIPAA

- Congress or HHS should commission the National Academies to evaluate the current regulations and provide regulatory and policy guidance to facilitate data sharing while protecting patient data

Next Steps – National Cancer Plan

- Initial Assessment of the National Cancer Plan released in February 2024
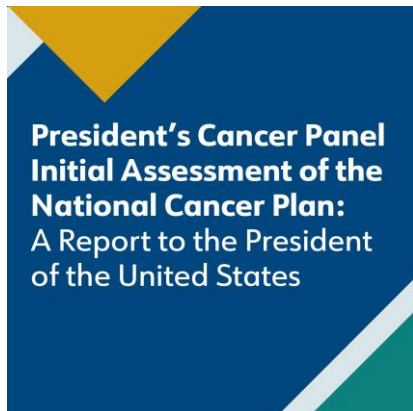
  (5 Recommendations)

  o Increase investment in biomedical research
  o Ensure access to high quality insurance coverage for all
  o **Build a sustainable, robust, and diverse workforce**
  o Promote dynamic and sustainable community engagement
  o Prioritize data sharing and integration to accelerate research

- Developing our next report to the President to be **released in 2025**

  o Based on the September 2024 meeting: *Developing and Retaining a Robust and Diverse Cancer Workforce: Challenges and Opportunities Across the National Cancer Program*

President's Cancer Panel
Initial Assessment of the National Cancer Plan:
A Report to the President of the United States