Implementing Personalized Pathways for Cancer Follow-Up Care in the United States: Proceedings from an American Cancer Society–American Society of Clinical Oncology Summit

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Abstract

A new approach to cancer follow-up care is necessary to meet the needs of cancer survivors while dealing with increasing volume and provider shortages, knowledge gaps, and costs to both health care systems and patients. An approach that triages patients to personalized follow-up care pathways, depending on the type(s) and level(s) of resources needed for patients' long-term care, is in use in the United Kingdom and other countries and has been shown to meet patients' needs, more efficiently use the health care system, and reduce costs. Recognizing that testing and implementing a similar personalized approach to cancer follow-up care in the United States will require a multipronged strategy, the American Cancer Society and the American Society of Clinical Oncology convened a summit in January 2018 to identify the needed steps to move this work from concept to implementation. The summit identified 4 key strategies going forward: 1) developing a candidate model (or models) of care delivery; 2) building the case for implementation by conducting studies modeling the effects of personalized pathways of follow-up care on patient outcomes, workforce and health care resources, and utilization and costs; 3)

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creating consensus-based guidelines to guide the delivery of personalized care pathways; and 4) identifying and filling research gaps to develop and implement needed care changes. While these national strategies are pursued, oncology and primary care providers can lay the groundwork for implementation by assessing their patients' risk of recurrence and the chronic and late effects of cancer as well as other health care needs and resources available for care and by considering triaging patients accordingly, referring patients to appropriate specialized survivorship clinics as these are developed, helping to support patients who are capable of self-managing their health, setting expectations with patients from diagnosis onward for the need for follow-up in primary care and/or a survivorship clinic, and improving coordination of care between oncology and primary care.

Keywords

cancer survivors; disease management; evidence-based practice; policy; risk assessment; survivorship

The Need for Personalized Pathways for Cancer Follow-Up Care

The number of cancer survivors in the United States is rising, from 15.5 million currently[1] to an estimated 20 million by 2026.[2,3] Survivors need appropriate follow-up care to manage chronic and late effects of cancer and comorbid conditions; screen for and treat recurrence and subsequent cancers; address psychosocial, economic, and family concerns; and improve lifestyle behaviors.[4–7] Moreover, focused efforts must be made such that adherence rates to long-term treatment and follow-up care guidelines are increased in the care of these patients.

Current follow-up care models are inadequate. Survivors report numerous unmet physical, functional, psychosocial, and financial needs and problems with subsequent cancers, fatigue, pain, lymphedema, neuropathies, balance problems, mobility issues, bladder and bowel problems, dysphonia and other communication difficulties, dysphagia, cardiopulmonary and other end-organ function declines, sexual dysfunction, depression and anxiety, and cognitive problems, among others.[8–14] These problems can lead to reduced work productivity,[15] quality of life,[16,17] and survival.[18–22] A confluence of several factors is limiting the resources of both health care systems and patients to offer and participate in needed follow-up care services. These factors include: the growing number of survivors, especially those older than 65 years, who require the management of multiple comorbid conditions in addition to their cancer-specific concerns[2]; health care provider shortages in oncology, primary care, and nursing[23–26]; scarce provider education or training in how to provide cancer follow-up care, especially for the primary care workforce[27]; and the increasing costs of cancer care[28] and posttreatment survivorship care.[29] The growing number of oncology patients is increasing wait times for cancer treatment in the United States for all cancers.[30] As such, a one-size-fits-all approach attempting to see most follow-up patients in oncology clinics will exacerbate problems with the timely scheduling of patients with newly diagnosed cancer. This problem will only worsen if a different model(s) of follow-up is not developed, tested, and implemented.[31]

An innovative approach to follow-up care is needed to meet the needs of cancer survivors while dealing with provider shortages, gaps in knowledge of primary care providers (PCPs), and costs to both health care systems and patients. One possibility is the personalized follow-up care pathway approach that has been tested in England and Northern Ireland and is being adapted for other countries.[32,33] Patients are triaged to 1 of 3 different follow-up care pathways based on the severity of ongoing treatment sequelae; risk of recurrence, subsequent cancers, and late effects; functional ability; psychological health; social issues; and the resulting needs for the types of providers and intensity of care.[34] All patients continue to see their PCP for noncancer-related care. In addition, the stratified cancer follow-up care pathways include: 1) a predominate focus on supporting patients in self-managing their postcancer needs outside of surveillance tests; 2) shared care, in which patients continue to see a limited number of clinicians for cancer-related needs but otherwise self-manage their follow-up; or 3) complex care management, in which patients with high needs (eg, high risk of recurrence or subsequent cancers, significant cancer-related morbidity and psychosocial distress) are treated by a multidisciplinary team of providers. Patients are monitored on their pathway and can switch between care pathways as needed. This care was originally called "risk-stratified care." However, because the complexity of health care needs and the types of providers required are determined by more than a risk of recurrence or late effects,[34] this language is evolving. Perspective reports have been published calling for the United States to adopt a personalized pathway-based approach of this type[35–38]; however, efforts are needed to define, test, and implement personalized follow-up care pathway models that work in diverse types of US health care systems.

Recognizing that testing and implementing personalized cancer follow-up care pathways in the United States along the lines of the models tested in England and Northern Ireland will require a multipronged strategy, the American Cancer Society (ACS) and the American Society of Clinical Oncology (ASCO) convened a summit in January 2018 to identify the needed steps to move this work from concept to implementation. Participants represented oncology, oncology nursing, primary care, academic research, health care delivery systems, government, research funders, cancer and advocacy organizations, and accreditation bodies as well as UK Survivorship Initiative leaders, who presented lessons learned and outcomes from the England and Northern Ireland testing and implementation of their stratified follow-up care models. Summit sessions focused on reviewing the evidence articulating the need to shift follow-up care from current practice, current data available to develop personalized care pathways, as well as next steps in needed research, clinical care, and policy to shape this care change. Each session featured brief presentations to summarize the current status of data, care, or policy followed by robust group discussion outlining the next steps for each strategy. This article summarizes the findings generated from the summit, consensus about the next steps in moving forward from concept to practical implementation of personalized follow-up care pathways in the United States, and the steps outlined by summit participants that oncology clinicians and PCPs can pursue now to facilitate this shift in care. The authors drafted this report based on presentations and discussions from the summit, and all summit participants had the opportunity to provide input to the report to assure that it accurately captured the discussions and recommended strategies for action.

Making Personalized Follow-Up Care Pathways Work: Lessons Learned from England and Northern Ireland

In England, the National Cancer Survivorship Initiative (NCSI) launched in September 2008 as a partnership between the English Department of Health, the cancer charity Macmillan Cancer Support, and National Health Service (NHS) Improvement, the NHS agency responsible for driving practice change. NCSI work created a posttreatment "Recovery Package," which was used to test stratified follow-up care delivery. The 4 elements of the Recovery Package are seen as keys to making personalized care pathways work, including:

1. Responses from a 10-minute, electronic, holistic needs assessment are used to inform patient-provider communication and care plan development. These data drive needs-based use of health care services. In early testing, most cases involved simply discussing patient concerns, sign-posting them to relevant services (84%), and providing written information (83%), whereas fewer required a further appointment (30%), prescribed medication (26%), or referral for further services (18%) for more complex needs.[39] These percentages may evolve as new patients present with sequelae of novel therapies (eg, immunotherapy); however, the process will remain the same. Although this report deals with care in the postoncology care time period, it is worth mentioning that, in the NCSI model, assessment and care planning are triggered as several care points, including at diagnosis, after treatment, when positive or negative significant events occur (triggered by patients or clinicians), and on the transition to end of life care.

2. A treatment summary shared with both the patient and their PCP includes information on long-term treatment consequences of treatment to look out for[40] and promotes critical continuity of care between a hospital and primary care.

3. The treatment summary informs a cancer care review discussion between the patient with cancer and their PCP or primary care nurse. Templates and links are embedded in the 3 commonly used primary care electronic patient record systems, and guidance is provided on the Royal College of General Practitioners website.[41]

4. Community-based health and well-being events are organized locally to provide an opportunity for people to find out more about coping with the ways cancer affects their lives, including information and local referrals for symptoms, financial support, and lifestyle advice.

In parallel, the NCSI developed and tested a stratified approach to follow-up care for cancer. They began this work using both available data on cancer incidence, survival, prevalence, and mortality and clinical assumptions about patient needs and outcomes to segment the population of people living with cancer into needs-based phases that would suggest where to target clinical care reform and redistribute resources.[42] They used this information to develop clinical consensus on how to create stratified pathways that differentiated people who require close, clinical-led follow-up from the majority who can self-manage issues they experience, requiring only limited clinical follow-up in addition to planned tests. The NCSI

then pilot tested the use of these stratified pathways in England in 14 sites among patients with colorectal, breast, and prostate cancer.[43] The NCSI pilot data demonstrated that 50% of patients with colorectal cancer, 80% of those with breast cancer, and 50% of those with prostate cancer who were treated with curative intent were able to self-manage posttreatment.[43,44] Implementing stratified pathways freed up specialist time and enhanced the quality and productivity of the health care system. It is projected that this approach will save England £90 million over 5 years.[45] As a result, England has been implementing the Recovery Package and stratified follow-up pathways since 2015.[29,46] National reporting on the implementation of these care delivery changes in 2017 indicated that just under 50% of NHS trusts had criteria and protocols for implementing stratified follow-up care for patients with breast cancer, 33% of trusts had these in place for those with colorectal cancer, and 31% had them in place for those with prostate cancer.[47] In that report, over one-half of patients on stratified protocols were being triaged to supported self-management, including 67% of patients with breast cancer, 53% of those with prostate cancer, and 47% of those with colorectal cancer.[47] The expectation is that full implementation of stratified pathways in England will occur by 2020. At that time, the effects of this care delivery change will be fully evaluated on several outcomes, including: survival; symptoms and quality of life; patient experience; management of comorbidities; demand for cancer team, urgent/ emergency, and/or PCP care; reduction in cancer waiting times; and system efficiencies.

The English pilot tests spurred Northern Ireland's similar redesign of follow-up care, starting with breast cancer. Processes that facilitated the changes in care delivery in England were used and evaluated in Northern Ireland. Specifically, an external evaluation of the Northern Ireland initiative indicated that assuring buy-in from leaders, clinicians, and patients was critical for success.[48] Ministerial approval was obtained for the project and then leveraged to engage the support of senior stakeholders. At the same time, patients, families, and health care professionals were engaged to assure that workflow was feasibly implemented. For example, workgroups of clinicians were brought together to solve problems that emerged with implementation. Evaluation of the 2-year Northern Ireland program indicated that 58% of all new patients with breast cancer were allocated onto a self-management pathway, and the reduced need for follow-up appointments freed clinic visits in surgery and oncology, allowing clinicians to spend more time with patients who had complex needs.[48] Two-thirds (67%) of patients reported that they felt supported in managing the emotional impact of cancer (vs 44% preprogram), and 75% felt able to manage the physical consequence of their cancer (vs 59% preprogram).[48] In addition, the number of review (surveillance) mammograms performed as scheduled increased 20% because of improved compliance from patients with their aftercare plans.[48] The proportion of patients who were aware of the importance of lifestyle changes to their ongoing health also increased, from 45% to 79%.[48] Evaluation results also indicated that redesigning follow-up care involved using outcome data from the pilots to spur cultural change among clinicians: Whereas clinicians initially were nervous about moving to a method of follow-up in which they saw some patients less than others, presenting clinicians with evidence demonstrating the success of stratified follow-up care allayed these concerns[48].

Although significant differences exist between the single-payer health care system in England and Northern Ireland and the diverse health care delivery systems that operate in the

United States, the success of these pilots presents intriguing data for the United States to consider in implementing a similar model of care delivery. First, the pilots demonstrated that personalized survivorship care pathways are both conceptually sound and technically achievable in a real-world setting. Second, they demonstrated that the cost-effectiveness of a stratified model depends on reducing face-to-face medical visits, which can be achieved by reducing visits for asymptomatic patients and helping as many patients as possible to self-manage their ongoing symptoms. Third, they demonstrated that the capacities of patients and clinicians to recognize and report symptoms and needs and to access test results were more important than the patient's actual risk of recurrence or side effects in determining the most appropriate care pathway.

Developing a Blueprint for Implementation in the United States

The outcome data from the experience in England and Northern Ireland of shifting to a personalized follow-up care pathway delivery model improved patient outcomes, with more efficient use of oncology time, reductions in visits for many survivors, and reduced overall costs, make a compelling case for considering the adoption of similar care in the United States. However, simply adopting the process used in the United Kingdom is not likely to be successful in the United States. Several differences in how care is delivered and reimbursed in the United Kingdom versus the United States complicate the adoption and implementation of this model for US care delivery settings. Most notably, these include the UK's single-payer, coordinated system versus numerous and diverse fragmented US health care delivery systems; limited information flow or coordination of care between oncology and primary care in the United States; and care reimbursement models in the United States that, despite recent shifts, still predominately focus on fee-for-service rather than outcome/value as in the United Kingdom. The summit participants discussed the application of a personalized care pathway approach for follow-up care in the United States and identified 4 key strategies to move this approach forward (for specifics, see Table 1). They also discussed the critical role oncology clinicians and PCPs now play in helping to shift care delivery practices (Table 2).[25,49–54]

Strategy 1: Develop a Candidate Model (or Models) of Care Delivery That Can Be Tested in Varied Health Care Delivery Sites

Evidence has been shaping the development of personalized or stratified models of care in the United States over time. In 2006, Oeffinger and McCabe articulated that diverse models of follow-up care were needed with varied care frequency and intensity.[55] Later publications underscored the role of the PCPs in follow-up care.[35,56] In more recent reports, authors have begun to characterize survivors into 3 categories indicating a low, medium, and high risk of recurrence, subsequent cancers, and chronic and late effects, and have described different care pathways (by care setting, type of clinicians involved, etc) for these groups.[35–37] The concept of stratification also has become more nuanced, where triage into care pathways is influenced by these issues of risk and also by individual needs for health care, which can be governed by comorbid conditions, psychological health, social and economic issues, geography, the capacity of health care systems to deliver care, and other factors.[34]

Key findings

- *Expert consensus and modeling are needed to determine how to classify the personalized care needs of patients.* Integrating across available models from the literature[35–37] and the UK modeling of patient categorization[57] yields a starting point for developing a candidate stratified care model that *categorizes the types of patients and appropriate pathways of follow-up care based on the type(s) and level(s) of resources needed for their long-term care (see* Table 1).

- To improve patient outcomes and downstream health care utilization, *US models for follow-up care may follow the UK process and focus on chronic disease management,*[49–52] *where the basis of care across care pathways is supporting patients in self-managing their symptoms and follow-up care needs* while identifying those patients who need more medical intervention.

- Communication between oncology, primary care, and specialty care providers and communication with patients are essential for delivering personalized follow-up care pathways.[25,53,54]

Strategy 1 tactics

- Use clinical databases to develop and validate a candidate framework for personalized follow-up care pathways for given types of patients.

- Identify best-practice methods for supporting cancer survivors in self-managing their health after cancer and for incorporating self-management as the basis of follow-up care.

- Develop tools to facilitate communication between oncology, primary, and specialty care providers and with patients to enable care coordination and patient-self-management.

Strategy 2: To Build the Case for Implementation, Model the Effects of Personalized Follow-Up Care Pathways on Patient Outcomes, Workforce, and Health Care Resources and on Utilization and Cost Outcomes

An ASCO-commissioned Association of American Medical Colleges workforce report modeled the anticipated effects of several potential care changes as solutions for the shortage of oncologists relative to projected patient needs. The report concluded that increasing fellowship slots or delaying oncologist retirements, using electronic health records to improve clinic efficiency, and increased use of advanced practice nurses or physician assistants or PCPs to see cancer survivors would narrow the gap but would not be sufficient to meet patient needs.[31] To build the case for implementation of a shift to personalized care pathways, similar modeling studies are needed to anticipate the effects of implementing this care delivery change. Once the candidate personalized follow-up care pathway framework has been identified, studies can model the effects of applying this framework to anticipate the health care resources (numbers and types of providers and other resources such as clinic space) needed to implement this care as well as anticipated outcomes of delivering this care. Alternatives to face-to-face encounters, such as e-consults, virtual visits, and/or shared medical appointments,[58] will need to be developed and tested to meet the needs of survivors

while delivering quality care. A report[59] addressing capacity in the US health care system for handling the potential caseload when a disease-modifying therapy for Alzheimer disease becomes available and strategies for reducing capacity limitations and avoiding delays in access to care could be a model for projecting needed changes in cancer follow-up care.

Key findings

- *The personalized follow-up care pathway framework from Strategy 1 can be used to guide population modeling studies that estimate the numbers of patients in the United States who could be triaged to each care stratum* and the number and types of providers and other resources needed for care delivery.

- The personalized follow-up care pathway framework from Strategy 1 can be used to guide simulation studies that anticipate the effects of the implementation of personalized follow-up care pathways on patient function and other outcomes, health care utilization and health care costs.

Strategy 2 tactics

- Use large clinical databases, SEER-based US cancer prevalence figures, and the candidate personalized follow-up care pathway framework from Strategy 1 to generate the numbers of patients the framework would triage to the individual care pathways, and use these patient numbers to model the workforce and resources needed to deliver personalized care pathways according to the framework.

- Use large clinical databases and simulation modeling to anticipate the effects of implementing the personalized follow-up care pathways framework from Strategy 1 on outcomes, including patient functioning (physical and psychosocial), health care utilization, and costs.

Strategy 3: Create Consensus-Based Guidelines to Guide the Delivery of Personalized Follow-Up Care Pathways

Expert consensus-based guidelines for implementing personalized follow-up care pathways can be developed by leveraging existing data and then refined as new data demonstrate best practices in care delivery. Producing personalized follow-up care pathway guidelines by cancer type/disease site could take into account pre-exposure factors and ongoing health needs of the individual patient and may be easiest to use in clinical practice. Producing comprehensive personalized follow-up care pathway guidelines by disease type should incorporate the harmonization of existing guidelines that describe components of follow-up care (eg, symptom reduction). In addition, there must be greater attention placed on dissemination and implementation as a part of the guidelines-generation process—simply having guidelines does not translate into implementation at the point of care.

Key findings

- Personalized follow-up care pathway guidelines should be produced by a multistakeholder group.

- *Existing guidelines are not sufficiently disseminated and implemented.* Strategies to implement guidelines must accompany their creation including point-of-care *decision support tools programmed into the electronic health record* and point-of-need, *patient-facing decision aids.*[25,53,54]

Strategy 3 tactics

- Once there is clarity on the models of personalized follow-up care pathways resulting from the work of Strategies 1 and 2, a multiorganizational group should develop consensus-based guidelines to guide the use of personalized follow-up care pathways.

- Once personalized follow-up care pathway guidelines have been created, the multiorganization group should drive implementation and dissemination efforts, including the development of digital tools, to assist clinicians in providing guideline-consistent care and engage patients in their care.

Strategy 4: Identify Research Gaps to Develop and Implement Personalized Follow-Up Care Pathways

Filling major gaps in the science that currently exist will allow for the development and implementation of better personalized follow-up care pathways in the future. Data are specifically needed in 3 main areas.[34,35] First, data are needed to better understand and predict the risk of morbidity and mortality and ongoing health care needs. For example, the biology driving late effects and the long-term implications of novel therapies (eg, immunotherapy) are unknown. Existing risk-prediction models for late effects should be refined to facilitate the identification of follow-up care needs.[60] Disease-prediction models in high-risk populations could help identify and intervene in patients at higher risk of future events. For example, the Childhood Cancer Survivor Study developed and validated risk-prediction models for heart failure,[61] ischemic heart disease and stroke,[62] and subsequent cancers,[63] providing a framework for applying therapy-based risk stratification.[62] Such models can be extended to account for both the direct adverse effects of cancer treatment on major organs systems[61,62] and secondary lifestyle factors (eg, physical inactivity, weight gain)[64–66] that drive late effects among cancer patients, and factors like comorbidity and patient resources that affect health care needs. Approaches should integrate a multitude of medical, physiological, and behavioral characteristics rather than single variables to identify individuals at high risk of late sequelae[67,68] and the types of providers and care that individuals need. The integration of multidimensional data necessitates new analytic and bioinformatics methods, such as machine learning, which has resulted in novel risk stratification in patients with heart failure,[69,70] as well as within the survivorship setting. As an initial step, Dood et al[71] applied hierarchical clustering analyses to overall survival data from a total of 2317,185 patients (median age, 63 years; 49.8% female) with 66 primary tumor types and identified 6 risk cluster groups that significantly differed in medial survival and mortality gap compared with the general population (eg, a "low-risk" cluster had a median survival of 16.2 years and a 1.4% mortality gap; a "high-risk" cluster had a median survival of 1.6 years and a 6.1% mortality gap). Importantly, their study defined survivorship clusters based on patient-level factors, such as stage and histologic subtype, rather than

tumor location (eg, breast, prostate) and distinguished clusters that would benefit from oncology-lead care or early PCP-led care within the first 5 years after treatment cessation. To continue this work, research should leverage Dood et al's modeling and integrate other factors that determine personalized care pathways, including comorbidity management needs; psychosocial factors; functional status; patient geography, resources, preferences for care, and capacity for self-management; and health care system capacity to provide care. In addition, models created with today's science will need to be modified over time with new data. For example, because the benefit of follow-up is only seen where interventions exist to manage the problems that emerge (eg, documented cost effectiveness of intensive follow-up for colorectal cancer recurrence),[72] models articulating personalized care pathways will need to be refined over time as research identifies more of these risk-reducing interventions and documents the benefits of follow-up.

Second, in concert with the prediction of risk and health care needs, the design of targeted or personalized interventions is needed to optimize patient outcomes.[68] As more types of clinical and patient-generated data become available, efforts will be needed to integrate these to better understand how to personalize interventions in terms of type, intensity, and dose of intervention needed; mode of care delivery (eg, in-person vs community-based vs remote/technology-delivered), and other factors. Efforts to leverage multiple types of data to personalize the prescription of exercise and diet interventions are illustrative. For example, the National Aeronautics and Space Administration (NASA) has examined the applicability of deep phenotyping to prescribe tailored doses and types of exercise interventions[73] to mitigate the cardiovascular empact of long space travel. In addition, Zeevi et al have used clinical deep phenotyping with multidimensional data in conjunction with machine-based learning to personalize the specific components of diet interventions.[74] Such models could be used to help guide personalized interventions for maximum efficacy in patients with cancer.

Third, data are needed on how best to implement personalized care pathways in both academic centers and community cancer and primary care settings and by survivors. Implementation science approaches in particular are needed to understand how to collect and integrate data to assess risk and health care needs; how to create practical, reliable, and valid tools for pathway personalization in the clinic; how to effectively shape clinician and patient expectations for follow-up care and overcome barriers to delivering personalized pathway-based care; how to deliver personalized care pathways ideally in diverse types of settings; how to coordinate cancer-related care with other care an individual patient might need for comorbidities or general health; and how to evaluate the effects of new models of care delivery using reliable outcome measures at the patient, clinic, and health care system levels that are sufficiently sensitive to detect meaningful differences.[34,35] Because current evidence on the efficacy of follow-up care approaches is limited and rapid improvements in care delivery are needed, future research efforts need to use hybrid approaches that simultaneously test efficacy outcomes and implementation. Research also can identify how to best support patients in self-managing aspects of their follow-up care on a population level and test methods of monitoring patients throughout follow-up to assess ongoing care needs and outcomes of care and to trigger referrals back to oncology or other providers when needed.

Key findings

- Data are needed to better understand and predict the risk of morbidity and mortality and health care needs to guide the development of personalized follow-up care pathways; better personalize the care included in the pathways; and facilitate the implementation of this shift to personalized care pathways.

- New methods, for example artificial intelligence/machine learning-based algorithms, to analyze multisource, big data may better predict the risk of morbidity/mortality and care needs and guide personalized follow-up care interventions at the point-of-care and the point-of-need.

Strategy 4 tactics

- A prioritized research agenda should be developed through critical literature review and expert consensus to help direct funding resources and drive research initiatives. This research agenda should identify key research questions, current data sources and methods, and new data sources or methods needed to accomplish this work. Because some research questions may be answered best by using data sets from other countries, this research agenda should also indicate where international collaborations might be beneficial.

Conclusions and Immediate Next Steps

Developing, testing, and implementing personalized follow-up care pathways in the United States will require a multipronged strategy. This summit identified the first steps as developing and validating candidate personalized follow-up care pathway models and using them to anticipate the health care resources needed for, and the anticipated outcomes of, implementing this care. Orienting providers and patients toward supporting patients in self-managing their health must occur in parallel with these efforts and should involve developing digital tools that support point-of-need self-management outside of clinic visits. With the candidate personalized care pathway models identified, follow-up care guidelines can be developed to educate clinicians about best practices for providing this care.

Alongside these efforts, researchers can contribute to improved care in the future by improving prediction models that guide the choice of personalized care pathways, understanding the components of care that should be offered in the pathways, and testing how to implement new personalized care pathway models in diverse settings. The ACS convened researchers in the fall of 2018 to review available research on and databases available to build personalized follow-up care and is using a Delphi process to garner consensus on a prioritized research agenda to accelerate progress in implementation. The group will publish this agenda so that scientists and funders can pursue research grants in these key areas.

The summit identified 2 other critical strategies. First, regulatory policy strategies likely will be needed to ensure coverage of services and overcome the lack of financial incentives that could serve as a barrier to changes in care delivery. Currently, there are few incentives for US oncology teams to triage follow-up of any posttreatment patients (eg, incentivizing the

number of new patients seen). To spur this change in care, personalized pathway follow-up approaches need to be incentivized and also reported as essential parts of quality follow-up care. Quality metrics (eg, ASCO's Quality Oncology Practice Initiative, Oncology Nursing Society clinical quality measures, Commission on Cancer accreditation standards) should be developed to drive and measure care changes. To speed this progress, the National Cancer Institute held a multistakeholder meeting in December 2018 to review a framework for measuring the quality of cancer follow-up care and outline the next steps in implementing the quality framework in clinical care, research, and policy.

Second, as new science and guidelines become available to guide these care changes, multiple stakeholders from advocacy and clinical professional groups must educate providers and patients about the benefits of personalized follow-up care pathways and self-management and engage them to facilitate these changes. Currently, many patients prefer to get their cancer follow-up care from their oncology team.[75] For oncology clinicians, seeing follow-up patients in their caseload who are doing well may lessen the stress of constantly providing bad news to patients that contributes to burnout.[76,77] New approaches to follow-up care that shift some aspects of care to patient self-management and shift low-risk/low-need patients out from the rosters of the oncology team will need to be developed in ways that facilitate patients' and providers' comfort and assure that this care meets patients' needs. In addition, strategies will need to be developed to help oncology teams improve their job satisfaction to prevent burnout.

While these national strategies are pursued, the summit participants discussed how both oncology and PCPs have important roles to play in laying the groundwork for the implementation of personalized follow-up care pathways (Table 2). Oncology clinicians and cancer program administrators should examine their own patient rosters, clinic utilization patterns, and new patient visit slots and consider how shifting care of low-risk/low-need survivors (eg, those who are 5 years or more from treatment with a low risk of recurrence or late effects and minimal problems with cancer-related symptoms) to primary care or to disease-based advanced practice practitioner(s) practices would affect these factors. As more specialized follow-up clinics are developed, oncology clinicians can begin to triage their patients who need more intensive, comprehensive follow-up to these clinics. Oncology clinicians should clearly discuss expectations with patients from the time of diagnosis, emphasizing the role that their PCP will play during treatment and for the management of nononcology issues and indicating that the goal is to ultimately transition back to predominantly primary care or a survivorship follow-up clinic after treatments ends. Oncologists can then reinforce these expectations through continued conversations throughout cancer treatment with patients and with the PCP to help the provider understand the ongoing needs of an individual survivor, and can review this information during survivorship care plan delivery.[78]

PCPs should ask patients about their cancer history, request oncology treatment records (including a survivorship care plan, if available), and document the treatments and other details of their cancer and care needs in the electronic health record.[79] PCPs can avail themselves of formal (eg, survivorship continuing medical education offered through ASCO, ACS/The George Washington Cancer Institute, and others) and informal training to increase

their understanding of cancer-related chronic and late effects. With this knowledge, they can learn how to co-manage patients during active treatment and increase their comfort in providing follow-up care for patients who are triaged to them after oncology care. As more specialized follow-up clinics are developed, PCPs can refer patients who may have had extensive cancer treatment and/or those who are experiencing chronic and late effects of cancer for consultation and comanagement, as needed. Oncology and PCPs can both work on methods to support patients who are doing well in self-managing their health outside of clinic visits (during treatment) or follow-up surveillance visits. In addition, each should be working to build bridges with the other in their health care settings to better coordinate care and facilitate referrals back to oncology if the need arises.[80] US cancer care delivery systems need to adapt to the changes in the number and types of cancer survivors and changes in health care workforce availability to ensure that quality cancer care is available to all in need.

Acknowledgements:

References

1. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2018. CA Cancer J Clin. 2018; 68:7–30. [PubMed: 29313949]

2. Bluethmann SM, Mariotto AB, Rowland JH. Anticipating the "Silver Tsunami": prevalence trajectories and comorbidity burden among older cancer survivors in the United States. Cancer Epidemiol Biomarkers Prev. 2016;25:1029–1036. [PubMed: 27371756]

3. American Cancer Society. Cancer Treatment and Survivorship Facts & Figures 2016–2017. Atlanta, GA: American Cancer Society; 2016.

4. Runowicz CD, Leach CR, Henry NL, et al. American Cancer Society/American Society of Clinical Oncology breast cancer survivorship care guideline. J Clin Oncol. 2016;34:611–635. [PubMed: 26644543]

5. Cohen EE, LaMonte SJ, Erb NL, et al. American Cancer Society head and neck cancer survivorship care guideline. CA Cancer J Clin. 2016;66:203–239. [PubMed: 27002678]

6. El-Shami K, Oeffinger KC, Erb NL, et al. American Cancer Society colorectal cancer survivorship care guidelines. CA Cancer J Clin. 2015;65:428–455. [PubMed: 26348643]

7. Skolarus TA, Wolf AM, Erb NL, et al. American Cancer Society prostate cancer survivorship care guidelines. CA Cancer J Clin. 2014;64:225–249. [PubMed: 24916760]

8. National Research Council of the National Academies, Institute of Medicine; Hewitt M, Greenfield S, Stovall E, eds. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: The National Academies Press; 2005.

9. National Research Council of the National Academies, Institute of Medicine; Hewitt M, Weiner SL, Simone JV, eds. Childhood Cancer Survivorship: Improving Care and Quality of Life. Washington, DC: The National Academies Press; 2003.

10. National Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/ Families in a Community Setting; Adler N, Page A eds. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: The National Academies Press; 2008.

11. Centers for Disease Control and Prevention, Lance Armstrong Foundation. A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. Atlanta, GA: Centers for Disease Control and Prevention; 2004.

12. President's Cancer Panel. Living Beyond Cancer: Finding a New Balance. Bethesda, MD: National Cancer Institute; 2004.

13. O'Dell MW, Stubblefield M, eds. Cancer Rehabilitation: Principles and Practice. New York: Demos Medical Publishing; 2009.

14. Silver JK, Baima J, Mayer RS. Impairment-driven cancer rehabilitation: an essential component of quality care and survivorship. CA Cancer J Clin. 2013;63:295–317. [PubMed: 23856764]

15. Alfano CM, Kent EE, Padgett LS, Grimes M, de Moor JS. Making cancer rehabilitation services work for cancer patients: recommendations for research and practice to improve employment outcomes. PM R. 2017;9(9 suppl 2):S398–S406. [PubMed: 28942911]

16. Penttinen H, Saarto T, Kellokumpu-Lehtinen P, et al. Quality of life and physical performance and activity of breast cancer patients after adjuvant treatments. Psychooncology. 2011;20:1211–1220. [PubMed: 20878646]

17. Pergolotti M, Deal AM, Williams GR, et al. Activities, function, and health-related quality of life (HRQOL) of older adults with cancer. J Geriatr Oncol. 2017; 8:249–254. [PubMed: 28285980]

18. Braithwaite D, Satariano WA, Sternfeld B, et al. Long-term prognostic role of functional limitations among women with breast cancer. J Natl Cancer Inst. 2010;102:1468–1477. [PubMed: 20861456]

19. van Deudekom FJ, Klop HG, Hartgrink HH, et al. Functional and cognitive impairment, social functioning, frailty and adverse health outcomes in older patients with esophageal cancer, a systematic review. J Geriatr Oncol. 2018;9:560–568. [PubMed: 29680585]

20. van Deudekom FJ, Schimberg AS, Slingerland M, van der Velden LA, Mooijaart SP. Functional and cognitive impairment, social environment, frailty and adverse health outcomes in older patients with head and neck cancer, a systematic review. Oral Oncol. 2017;64:27–36. [PubMed: 28024721]

21. Pinquart M, Duberstein PR. Depression and cancer mortality: a meta-analysis. Psychol Med. 2010;40:1797–1810. [PubMed: 20085667]

22. Satin JR, Linden W, Phillips MJ. Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. Cancer. 2009;115:5349–5361. [PubMed: 19753617]

23. Hortobagyi GN. A shortage of oncologists? The American Society of Clinical Oncology Workforce Study. J Clin Oncol. 2007;25:1468–1469. [PubMed: 17360965]

24. Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future supply and demand for oncologists: challenges to assuring access to oncology services. J Oncol Pract. 2007;3:79–86. [PubMed: 20859376]

25. American Society of Clinical Oncology. The state of cancer care in America, 2014: a report by the American Society of Clinical Oncology. J Oncol Pract. 2014; 10:119–142. [PubMed: 24618075]

26. Association of American Medical Colleges. 2018 Update. The Complexities of Physician Supply and Demand: Projections from 2016 to 2030: Final Report. Washington, DC: Association of American Medical Colleges; 2018 aamc-black.global.ssl.fastly.net/production/media/ filer_public/bc/a9/bca9725e-3507-4e35-87e3-d71a68717d06/ aamc_2018_workforce_projections_update_april_11_2018.pdf. Accessed February 5, 2019.

27. Potosky AL, Han PK, Rowland J, et al. Differences between primary care physicians' and oncologists' knowledge, attitudes and practices regarding the care of cancer survivors. J Gen Intern Med. 2011;26:1403–1410. [PubMed: 21785923]

28. Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010–2020. J Natl Cancer Inst. 2011;103:117–128. [PubMed: 21228314]

29. Zheng Z, Yabroff KR, Guy GP Jr, et al. Annual medical expenditure and productivity loss among colorectal, female breast, and prostate cancer survivors in the United States [serial online]. J Natl Cancer Inst. 2016;108:djv382.

30. Bilimoria KY, Ko CY, Tomlinson JS, et al. Wait times for cancer surgery in the United States: trends and predictors of delays. Ann Surg. 2011;253:779–785. [PubMed: 21475020]

31. Association of American Medical Colleges (AAMC) Center for Workforce Studies. Forecasting the Supply of and Demand for Oncologists: A Report to the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies. Washington, DC: Association of American Medical Colleges; 2007 dl4a.org/uploads/pdf/Oncology%20Workforce%20Report%20FINAL.pdf. Accessed February 5, 2019.

32. Richards M, Corner J, Maher J. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. Br J Cancer. 2011;105(suppl 1):S1–S4.

33. Jefford M, Roland J, Grunfeld E, Richards M, Maher J, Glaser A. Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA. Br J Cancer. 2013;108:14–20. [PubMed: 23257892]

34. Watson EK, Rose PW, Neal RD, et al. Personalised cancer follow-up: risk stratification, needs assessment or both? Br J Cancer. 2012;106:1–5. [PubMed: 22215103]

35. McCabe MS, Partridge AH, Grunfeld E, Hudson MM. Risk-based health care, the cancer survivor, the oncologist, and the primary care physician. Semin Oncol. 2013; 40:804–812. [PubMed: 24331199]

36. Jacobs LA, Shulman LN. Follow-up care of cancer survivors: challenges and solutions [serial online]. Lancet Oncol. 2017;18:e19–e29. [PubMed: 28049574]

37. Nekhlyudov L, O'Malley DM, Hudson SV. Integrating primary care providers in the care of cancer survivors: gaps in evidence and future opportunities [serial online]. Lancet Oncol. 2017;18:e30–e38. [PubMed: 28049575]

38. McCabe MS, Bhatia S, Oeffinger KC, et al. American Society of Clinical Oncology statement: achieving high-quality cancer survivorship care. J Clin Oncol. 2013; 31:631–640. [PubMed: 23295805]

39. Ipsos MORI. Evaluation of the Electronic Holistic Needs Assessment (eHNA) Final Evaluation Report. London, UK: Ipsos MORI; 2015 macmillan.org.uk/documents/aboutus/health_professionals/recoverypackage/macmillanehnafinalevaluationreport.pdf. Accessed February 5, 2019.

40. Macmillan Cancer Support. Treatment Summary How-To Guide. London, UK: Macmillan Cancer Support; 2013; be.macmillan.org.uk/Downloads/CancerInformation/ResourcesForHSCP/MAC16788Treatment-SummaryGuideWEB.pdf. Accessed February 5, 2019.

41. Royal College of General Practicioners. Recovery Package. London, UK: Royal College of General Practicioners; 2019 rcgp.org.uk/clinical-and-research/resources/toolkits/consequences-of-cancer-toolkit/recovery-package.aspx. Accessed February 5, 2019.

42. Maher J, McConnell H. New pathways of care for cancer survivors: adding the numbers. Br J Cancer. 2011;105(suppl 1): S5–S10. [PubMed: 22048033]

43. National Health Service. Stratified Pathways of Care—From Concept to Innovation. London, UK: National Health Service; 2012 england.nhs.uk/improvement-hub/publication/stratified-pathways-of-care-from-concept-to-innovation/. Accessed February 5, 2019.

44. Maher J, Petchey L, Greenfield D, Levitt G, Fraser M. Implementation of nation-wide cancer survivorship plans: experience from the UK. J Cancer Policy. 2018;15:76–81.

45. National Health Service (NHS) Improving Quality. Stratified Cancer Pathways: Redesigning Services for Those Living With or Beyond Cancer. London, UK: NHS Improving Quality; 2013 arms.evidence.nhs.uk/resources/qipp/1029456/attachment. Accessed February 5, 2019.

46. National Health Service (NHS) England. Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020. Report of the Independent Cancer Taskforce. London, UK: NHS England; 2015cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf. Accessed February 5, 2019.

47. National Health Service (NHS) England. Living With and Beyond Cancer—Baseline Activity January-March 2017. London, UK: National Cancer Programme, NHS England; 2018 england.nhs.uk/wp-content/uploads/2018/07/national-living-with-and-beyond-cancer-baseline-activity.pdf. Accessed February 5, 2019.

48. Macmillan Cancer Support. Evaluation of the Transforming Cancer Follow-up Programme in Northern Ireland. Final Report. London, UK: Pricewaterhouse-Coopers LLP; 2015 macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/ourresearchpartners/tcfufinalreportfeb2015.pdf. Accessed February 5, 2019.

49. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns. 2002; 48:177–187. [PubMed: 12401421]

50. Corbin JM, Strauss AL. Unending Work and Care: Managing Chronic Illness At Home 1st ed Jossey-Bass Health Series; Jossey-Bass Social and Behavioral Science Series. San Francisco: Jossey-Bass Publishers; 1988.

51. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med. 2003; 26:1–7. [PubMed: 12867348]

52. Brady TJ, Murphy L, O'Colmain BJ, et al. A meta-analysis of health status, health behaviors, and healthcare utilization outcomes of the Chronic Disease Self-Management Program [serial online]. Prev Chronic Dis. 2013;10:120112. [PubMed: 23327828]

53. Miller RH, Sim I. Physicians' use of electronic medical records: barriers and solutions. Health Aff (Millwood). 2004;23:116–126. [PubMed: 15046136]

54. Clauser SB, Wagner EH, Aiello Bowles EJ, Tuzzio L, Greene SM. Improving modern cancer care through information technology. Am J Prev Med. 2011;40(5 suppl 2): S198–S207. [PubMed: 21521595]

55. Oeffinger KC, McCabe MS. Models for delivering survivorship care. J Clin Oncol. 2006;24:5117–5124. [PubMed: 17093273]

56. Cohen HJ. A model for the shared care of elderly patients with cancer. J Am Geriatr Soc. 2009;57(suppl 2):S300–S302. [PubMed: 20122034]

57. McConnell H, White R, Maher J. Categorising cancers to enable tailored care planning through a secondary analysis of cancer registration data in the UK [serial online]. BMJ Open. 2017;711: e016797.

58. Reed SC, Partridge AH, Nekhlyudov L. Shared medical appointments in cancer survivorship care: a review of the literature. J Oncol Pract. 2015;11:6–11. [PubMed: 25424650]

59. Liu JL, Hlávka JP, Hillestad R, Soeren M. Assessing the Preparedness of the US Health Care System Infrastructure for an Alzheimer's Treatment. Santa Monica, CA: Rand Corporation; 2017 rand.org/pubs/research_reports/RR2272.html. Accessed February 5, 2019.

60. Salz T, Baxi SS, Raghunathan N, et al. Are we ready to predict late effects? A systematic review of clinically useful prediction models. Eur J Cancer. 2015;51: 758–766. [PubMed: 25736818]

61. Chow EJ, Chen Y, Kremer LC, et al. Individual prediction of heart failure among childhood cancer survivors. J Clin Oncol. 2015;33:394–402. [PubMed: 25287823]

62. Chow EJ, Chen Y, Hudson MM, et al. Prediction of ischemic heart disease and stroke in survivors of childhood cancer. J Clin Oncol. 2018;36:44–52. [PubMed: 29095680]

63. Kovalchik SA, Ronckers CM, Veiga LH, et al. Absolute risk prediction of second primary thyroid cancer among 5-year survivors of childhood cancer. J Clin Oncol. 2013;31:119–127. [PubMed: 23169509]

64. Garmey EG, Liu Q, Sklar CA, et al. Longitudinal changes in obesity and body mass index among adult survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. J Clin Oncol. 2008;26:4639–4645. [PubMed: 18824710]

65. Hoffman MC, Mulrooney DA, Steinberger J, Lee J, Baker KS, Ness KK. Deficits in physical function among young childhood cancer survivors. J Clin Oncol. 2013;31:2799–2805. [PubMed: 23796992]

66. Adams MJ, Lipsitz SR, Colan SD, et al. Cardiovascular status in long-term survivors of Hodgkin's disease treated with chest radiotherapy. J Clin Oncol. 2004;22:3139–3148. [PubMed: 15284266]

67. Hayward RA, Kent DM, Vijan S, Hofer TP. Multivariable risk prediction can greatly enhance the statistical power of clinical trial subgroup analysis [serial online]. BMC Med Res Methodol. 2006;6:18. [PubMed: 16613605]

68. Scott JM, Nilsen TS, Gupta D, Jones LW. Exercise therapy and cardiovascular toxicity in cancer. Circulation. 2018; 137:1176–1191. [PubMed: 29530893]

69. Katz DH, Deo RC, Aguilar FG, et al. Phenomapping for the identification of hypertensive patients with the myocardial substrate for heart failure with preserved ejection fraction. J Cardiovasc Transl Res. 2017;10:275–284. [PubMed: 28258421]

70. Shah SJ, Kitzman DW, Borlaug BA, et al. Phenotype-specific treatment of heart failure with preserved ejection fraction: a multiorgan roadmap. Circulation. 2016;134:73–90. [PubMed: 27358439]

71. Dood RL, Zhao Y, Armbruster SD, et al. Defining survivorship trajectories across patients with solid tumors: an evidence-based approach. JAMA Oncol. 2018;4:1519–1526. [PubMed: 29860375]

72. Renehan AG, O'Dwyer ST, Whynes DK. Cost effectiveness analysis of intensive versus conventional follow up after curative resection for colorectal cancer [serial online]. BMJ. 2004;328:81. [PubMed: 14715603]

73. Scott JM, Martin D, Ploutz-Snyder R, et al. Efficacy of exercise and testosterone to mitigate atrophic cardiovascular remodeling. Med Sci Sports Exerc. 2018;50:1940–1949. [PubMed: 29570536]

74. Zeevi D, Korem T, Zmora N, et al. Personalized nutrition by prediction of glycemic responses. Cell. 2015;163:1079–1094. [PubMed: 26590418]

75. Hudson SV, Miller SM, Hemler J, et al. Adult cancer survivors discuss follow-up in primary care: 'not what I want, but maybe what I need'. Ann Fam Med. 2012;10:418–427. [PubMed: 22966105]

76. Murali K, Banerjee S. Burnout in oncologists is a serious issue: what can we do about it? Cancer Treat Rev. 2018;68:55–61. [PubMed: 29860137]

77. Back AL, Deignan PF, Potter PA. Compassion, compassion fatigue, and burnout: key insights for oncology professionals [serial online]. Am Soc of Clin Oncol Educ Book. 2014;2014:e454–e459.

78. Boyajian RN, Grose A, Grenon N, et al. Desired elements and timing of cancer survivorship care: one approach may not fit all. J Oncol Pract. 2014;10:e293–e298. [PubMed: 24963136]

79. Burton J History of lymphoma [serial online]. JAMA Oncol. 2018;4:292. [PubMed: 29049551]

80. Dossett LA, Hudson JN, Morris AM, et al. The primary care provider (PCP)-cancer specialist relationship: a systematic review and mixed-methods meta-synthesis. CA Cancer J Clin. 2017;67: 156–169. [PubMed: 27727446]

TABLE 1.

Key Findings and Recommendations for Action for Advancing Personalized Cancer Follow-Up Care Pathways in the United States

KEY FINDINGS	RECOMMENDED ACTION
Strategy 1: Develop a candidate model (or models) of care delivery that can be tested in varied health care delivery sites	
Integrating across available models from the literature yields a starting point for categorizing patients based on risk and health care needs and developing a candidate personalized follow-up care pathway model that depends on the type(s) and level(s) of resources needed for patients' long-term care; as a starting point, the risk of recurrence/subsequent cancers/late effects can be determined by the literature: • "Low-risk patients": those with common cancers; with early-stage disease who have completed active therapy and are at low risk for recurrence; who did not receive treatment with alkylating agents, anthracycline, bleomycin, epipodophyllotoxin, or radiation; and have mild or no cancer-related treatment toxicity • "Moderate-risk patients": those with less common or late-stage cancers; with a moderate risk of recurrence; who received multimodal therapies (ie, low/moderate doses of alkylating agents, anthracycline, bleomycin, epipodophyllotoxin, or radiation); or have experienced or are at risk for treatment-related effects and comorbid medical conditions • "High-risk patients": those with rare cancers, who received complicated or high-dose regimens, and have an existing or substantial risk of chronic and late effects of cancer Data on patient risk of recurrence, subsequent cancers, and late effects must be combined with data on ongoing physical, psychosocial, and functional issues; geographic and financial constraints; capacity of health care systems to deliver care; patient capacity for self-management; and other issues to point to the appropriate stratified pathway for a given individual	Use clinical databases to develop and validate a candidate personalized follow-up care pathway framework for identifying subtypes of patients and their respective care pathways: • Develop the model(s) through expert consensus using large clinical databases to model potential risk predictors and health care needs identified from the literature with outcomes of mortality, comorbid disease burden, symptom burden, and patient function • Validate the model(s) using a second clinical database; assign patient records into care pathway groups using the prediction model identified from the regression; investigate care pathway group differences in all-cause and cancer-specific mortality, comorbid disease and symptom burden, and other patient-oriented outcomes as well as health care utilization and costs • The likely starting point for this development and validation process may be a single disease or 2 diseases (eg, breast and prostate cancers), but other stratifying predictor variables (type of treatments, time since treatment, comorbid conditions, functional status) may be specified
US models for follow-up care may adopt the UK process in which the basis of care is supporting patients in self-managing their symptoms and follow-up care needs while identifying those patients who need more medical intervention: • Supporting self-management involves helping patients build strategies they can use to manage the symptoms of cancer and its treatment, make healthy behavior changes,[49] and actively participate in their care[50] • Building patients' core self-management skills, including problem-solving, decision making, resource utilization, partnering with health care providers, and catalyzing action,[51] can improve patients' self-efficacy, symptom management, psychological health, health behaviors, and downstream health care utilization[52] • The England and Northern Ireland pilots identified 3 keys to success with implementing self-management into follow-up care: 1) factoring in a patient's ability to self-manage when triaging patients into care pathways; 2) counseling patients that self-management is part of their continuing care and providing them with a reassuring, easy process to return to oncology care if/when needed; and 3) enabling patients and primary care providers to identify the early signs and symptoms of recurrence or the late effects of treatment by building a robust patient symptom surveillance platform with expeditious referrals to specialty care	Identify best-practice methods for supporting cancer survivors in self-managing their health after cancer and for incorporating self-management as the basis of follow-up care: • Leverage existing educational materials and self-management resources, especially those that can be delivered digitally or otherwise, at the point of need rather than only in point-of-care delivery settings, such as the National Cancer Institute/American Cancer Society mobile health (mHEALTH) self-management resource • Test the effects of electronic patient-reported outcome screening processes and other methods of surveillance of patient needs over time in helping patients and providers feel more comfortable with self-management by providing a link back to the health care system when symptom levels get too high for self-management
Communication between oncology and primary care and specialty care providers is essential in delivering personalized follow-up care pathways: • Regardless of the personalized care pathways, ongoing communication, coordination, and education are needed for all providers who care for patients after cancer • Care coordination across health care settings is critical and can be facilitated by effective communication across providers and with patients	Develop tools to facilitate communication and coordination between oncology, primary, and specialty care providers, and with patients—ideally leveraging technology and optimizing the use of electronic health records for the efficient transfer of information
Strategy 2: Model the effects of personalized follow-up care pathways on patient outcomes, on workforce and health care resources, and on utilization and cost outcomes	

KEY FINDINGS	RECOMMENDED ACTION
To make the case for implementation, the personalized follow-up care pathway framework from Strategy 1 can be used to guide population modeling studies that estimate the numbers of patients in the United States who could be triaged to each care stratum and the number and types of providers and other resources needed for care delivery	Use large clinical databases, Surveillance, Epidemiology, and End Results (SEER)-based US cancer prevalence figures, and the candidate personalized follow-up care pathway framework from Strategy 1 to generate the numbers of patients the framework would triage to different care pathways: • Using these patient numbers and estimates of provider capacity, model the number of providers and types of expertise (oncology, primary care, and specialty care for the management of chronic and late effects) that would be needed to deliver personalized care pathways according to the framework • Use these projections, along with clinical or claims databases, to model the anticipated health care resources (eg, clinic space, number of other providers, rehabilitation programs, etc) that would be needed to deliver this care
The personalized follow-up care pathway framework from Strategy 1 can be used to guide simulation studies that anticipate the effects of the implementation of personalized follow-up care pathways on patient function, health care utilization, and health care costs	Use large clinical databases and simulation modeling to anticipate the effects of implementing the personalized follow-up care pathway framework from Strategy 1 on outcomes at multiple levels, including: • Patient symptom burden, comorbidity burden, and function in work and other roles; • Health care utilization (eg, oncology clinic ability to see new patients, downstream emergency department or hospital utilization); and • Costs, including overall health care costs and patient out-of-pocket costs
Strategy 3: Create consensus-based guidelines for the delivery of personalized follow-up care pathways	
Personalized follow-up care pathway guidelines should be produced by a multistakeholder group: • These may be stand-alone documents or can be integrated into existing disease-based guidelines	Once there is clarity on the models of personalized follow-up care pathways from engaging in the work of the first 2 strategies, a multiorganizational group should use the results of these efforts to develop consensus-based guidelines to guide the delivery of pathway-consistent care: • The group should harmonize existing follow-up care guidelines and include them as a part of personalized care pathway guidelines • Harmonization of guidelines nationally may strengthen the recommendations and reduce clinician confusion about what care to provide • Developing a guideline before there is more clarity on the models of care would be counterproductive, although wording that suggests transition of care and the importance of self-management may be incorporated into existing guidelines
Existing guidelines are not sufficiently disseminated and implemented; strategies to implement guidelines must accompany their creation, including: • Decision-support tools programmed into the electronic health record (EHR) can shape clinician behavior;[25,53,54] supporting oncology and primary care providers to deliver guideline-consistent follow-up care; however, the care pathway personalization variables outlined earlier must be easily coded and accessed, and data standards are needed for the EHR tools so there can be shareable, comparable data generated across vendors and platforms • Patient-facing digital tools can be used to aid understanding about the different types of follow-up care they might receive, solicit patient preferences/needs for care, and engage patients in their care	Once personalized care pathway guidelines have been created, the multiorganization group should drive implementation and dissemination efforts, including the development of digital tools to assist clinicians in providing guideline-consistent care and engage patients in their care
Strategy 4: Identify research gaps to develop and implement personalized follow-up care pathways	
Data are needed to fill critical gaps in science, including: • How to better understand and predict the risk of morbidity and mortality and ongoing health care needs to guide the triage of patients into personalized care pathways • How to better personalize the care included in the individual pathways • What are the best practices for implementing personalized care pathways in diverse settings? • What are methods for supporting large numbers of patients in self-managing aspects of their follow-up care?	A prioritized research agenda should be developed through critical literature review and expert consensus to help direct funding resources and drive research initiatives; this research agenda should: • Identify key research questions needed to develop and implement personalized follow-up care pathways; • Identify current sources of big data and methods that can be used now to develop better risk and health care needs predication models and care pathways in survivors; and • Point to the development of new data sources (or new combinations of existing data sources) and new methods needed to accomplish this work; this may involve collaborations with other

KEY FINDINGS	RECOMMENDED ACTION
• What are ways of monitoring patients throughout follow-up for ongoing care needs, to assess the outcomes of care, and to trigger care pathway changes and referrals back to oncology or other providers? • How can new methods, such as artificial intelligence/machine learning-based algorithms, be used to analyze multisource big data to predict the risk of morbidity/mortality and health care needs better and to personalize follow-up care interventions?	countries that have sources of data for risk prediction or care personalization, data on the comparative effectiveness of varied treatments/pathways of care, or implementation data not available in the United States

TABLE 2.

Summit Recommendations for Immediate Next Steps for Oncology and Primary Care Clinicians to Lay the Groundwork for Delivery of Personalized Follow-Up Care Pathways

ACTIONS ONCOLOGY CLINICIANS CAN PURSUE NOW	ACTIONS PRIMARY CARE PROVIDERS CAN PURSUE NOW
• Examine current patient rosters, clinic utilization patterns, and new patient visit slots and consider how shifting care of low-risk/low-need survivors to primary care or advanced practice practitioners would affect these factors	• Ask patients about their cancer history, request oncology treatment records and survivorship care plans, and document treatments and care needs in the electronic health record
• Begin to triage patients who need specialized follow-up to survivorship clinics as they are developed	• Participate in formal (eg, continuing medical education) and informal training to increase understanding of cancer-related chronic and late effects
• Clearly communicate to patients from the time of diagnosis that they will be expected to continue to be followed by their primary care provider and likely will transition back to predominately primary care or a follow-up clinic after treatments ends	• Learn how to co-manage patients during active treatment and ongoing oncology-based follow-up care (eg, with a focus on providing routine care, treatment of chronic disease and respective risk factors, as well as health promotion)
	• Participate in educational activities to increase comfort and skills in providing follow-up care for patients with cancer who are transitioned from oncology care
• Reinforce expectations about follow-up by ongoing communication throughout cancer treatment	• Refer patients who previously received extensive cancer treatment and/or those experiencing chronic and late effects of cancer for specialized survivorship care
• Work toward supporting patients who are doing well in self-managing their health outside of clinic visits	• Work toward supporting patients who are doing well in self-managing their health outside of surveillance visits
• Build bridges with primary care to better equip primary care providers with information they need to care for their patients who are cancer survivors, coordinate care, and facilitate referrals back to oncology if needs arise	• Build bridges with oncology to understand survivors' risks and ongoing health care needs, better coordinate care, and facilitate referrals back to oncology if needs arise