

## Cancer Survivorship 2



# Improved models of care for cancer survivors

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The number of survivors of cancer is increasing substantially. Current models of care are unsustainable and fail to address the many unmet needs of survivors of cancer. Numerous trials have investigated alternate models of care, including models led by primary-care providers, care shared between oncology specialists and primary-care providers, and care led by oncology nurses. These alternate models appear to be at least as effective as specialist-led care and are applicable to many survivors of cancer. Choosing the most appropriate care model for each patient depends on patient-level factors (such as risk of longer-term effects, late effects, individual desire, and capacity to self-manage), local services, and health-care policy. Wider implementation of alternative models requires appropriate support for non-oncologist care providers and endorsement of these models by cancer teams with their patients. The COVID-19 pandemic has driven some changes in practice that are more patient-centred and should continue. Improved models should shift from a predominant focus on detection of cancer recurrence and seek to improve the quality of life, functional outcomes, experience, and survival of survivors of cancer, reduce the risk of recurrence and new cancers, improve the management of comorbidities, and reduce costs to patients and payers. This Series paper focuses primarily on high-income countries, where most data have been derived. However, future research should consider the applicability of these models in a wider range of health-care settings and for a wider range of cancers.

## Introduction

The number of survivors of cancer is growing substantially.<sup>1</sup> Survivors of cancer commonly experience a range of issues, many of which are poorly identified and addressed within dominant specialist-led models of care.<sup>2</sup> Furthermore, current models of specialist-led care are unsustainable, with large numbers of survivors of cancer in follow-up, and an inadequate health workforce,<sup>3</sup> leading to calls for new approaches to address the needs of patients living after a cancer diagnosis.<sup>2,4</sup>

Policy makers and health-care managers need to determine how to implement more sustainable and effective models of care to support and coordinate greater involvement of non-oncologists in the care of survivors of cancer. Active involvement of a range of end users and stakeholders, such as public health agencies; community groups and agencies; patients and caregivers with lived experience of survivorship care; and multidisciplinary providers from differing care sectors, will be crucial to the design of relevant survivorship services based on the evidence, that address the needs of local constituents, perhaps using best practices in codesign.<sup>5</sup>

The first paper in this Series describes common issues faced by survivors of cancer and practical guidance for clinicians. This paper considers how care could be better planned and delivered for survivors of cancer. The focus of this paper is on high-income countries, as most published data is derived from these settings, but we provide brief consideration of survivorship care in low-income and middle-income countries.

The seminal US Institute of Medicine (IOM) report identified essential components of survivorship care:

(1) prevention of recurrent and new cancers, and late effects from treatments; (2) surveillance for recurrence and new cancers, and for medical and psychosocial effects; (3) management of consequences of treatments, including symptom management and assistance with practical aspects; and (4) coordination between cancer and primary-care providers, to ensure that all needs of the survivor of cancer are met.<sup>2</sup>

This Series paper considers the randomised controlled trial (RCT) evidence for non-specialist-led models of survivorship care, and implementation evidence, specifically focusing on how all the IOM goals might be achieved. This paper considers appropriate models of care for different patient groups, and different settings, and includes considerations for implementation and future research.

## Search strategy and selection criteria

Between Jan 4 and July 2, 2021, we searched MEDLINE, Embase, and Google databases using terms relevant to particular sections of the paper. We focused on reports published in English since 2005, when the pivotal Institute of Medicine report was released. We combined search terms relevant to cancer (eg, "cancer", "neoplasm", "malignancy") with search terms relevant to the post-treatment phase (eg, "follow up", "after care", "post-treatment", "surveillance", "survivorship"). We also used general search terms (eg, "models of care") and specific search terms relevant to specific models of care (eg, "shared care"). We combined these search terms with terms relevant to clinical trials, systematic reviews, and meta-analyses, and we prioritised evidence from systematic reviews and meta-analyses.

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This is the second in a Series of three papers about cancer survivorship

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### Beyond traditional specialist-led follow-up

Follow-up of survivors of cancer has traditionally been led by cancer specialists (ie, medical oncologists, surgical oncologists, radiation oncologists, and haematologists).<sup>2</sup> Specialist-led follow-up care remains the dominant model of survivorship care across most health-care systems in high-income countries.<sup>2,4,6</sup> Follow-up consultations generally focus on detection of cancer recurrence or new cancers even though there is scarce evidence of benefit from routine medical review,<sup>7,8</sup> particularly as the risk of recurrence for many cancers is low. Traditional follow-up frequently leaves survivors of cancer with unmet needs and inadequately responds to the broader IOM goals of addressing the medical and psychosocial consequences of cancer and its treatment, or care coordination between providers.<sup>2,9-11</sup> Additionally, it has been noted that standard models of care cannot continue due to the growing number of survivors who require complex care, inadequate capacity in either the oncology or primary-care environment to provide patients with follow-up care, and the need to control costs with growing emphasis on value-based care.<sup>12</sup>

Three main alternative models of care have emerged over the last 25 years and been investigated in RCTs: general practitioner-led care; care that is shared between the general practitioner and cancer specialist; and oncology nurse-led care. Evidence to support these models is presented below.

### Follow-up led by general practitioners

General practitioner-led follow-up refers to care that is provided predominantly or solely in the primary-care setting. Responsibility of care is transferred from oncology providers to the general practitioner. General practitioners are well placed to provide ongoing follow-up care for survivors of cancer.<sup>13</sup> Patients often have a pre-existing relationship with their general practitioner and already consult them for general care, preventive care, and the management of other chronic health conditions.<sup>13-15</sup> General practitioners might also be more accessible to the patient than cancer specialists, and from a health-care system perspective, general practitioner-led care could be cheaper than specialist-led care.

The first RCT investigating general practitioner-led follow-up of survivors of cancer was conducted in England over 25 years ago.<sup>16-18</sup> This study found that, for women with early-stage breast cancer, general practice can provide a safe, effective, and acceptable alternative to hospital-based survivorship care, showing non-inferiority in clinical outcomes (detection of recurrence and time to diagnose recurrence), and health-related quality of life.<sup>18</sup> Patients receiving general practitioner-led care were more satisfied,<sup>19</sup> and there were reduced costs for both patients and health-care systems compared with patients receiving specialist-led care.

Several RCTs have been conducted since that landmark study and these have been examined in several systematic

reviews.<sup>20-27</sup> Together, these studies show that primary-care-led follow-up is non-inferior to traditional follow-up in terms of detection of cancer recurrence. As discussed in the first paper in this Series, no trial has systematically considered the management of common issues that survivors of cancer might have in the post-treatment phase. Likewise, none of the trials to date has examined management of comorbid illness or modification of health behaviours, which arguably represent some of the potential benefits of closer involvement of the primary-care team.

Notably, these studies have generally been conducted in high-income countries (Australia, Canada, the UK, and Norway),<sup>28</sup> in health-care settings with universal health care, and have considered a restricted number of groups of survivors of cancer (mostly patients with breast cancer, but also colorectal cancer and melanoma). Generally, the studies recruited people at low risk of recurrence and late-effects. None of the studies was designed, or adequately powered, to show a difference in survival rates.<sup>28</sup>

Current evidence suggests that primary-care-led follow-up is likely to be a cost-effective alternative to traditional follow-up for people treated for early-stage breast, colorectal, and prostate cancers, and early-stage melanoma, recognising that these groups represent the most prevalent populations of survivors of cancer. However, adoption of general practitioner-led models has not been widespread, partly because oncologists and survivors can have little confidence in general practitioners,<sup>29,30</sup> and can prefer traditional models of care.<sup>8,29,31</sup>

### Shared care between oncology providers and primary-care providers

Shared care refers to a formalised collaboration between cancer specialists and general practitioners to provide follow-up care. These models seek to combine optimal cancer-specific care with optimal generalist care, including management of comorbid illness and preventive care (panel 1). Shared care might be more palatable than general practitioner-led care to cancer specialists, as they do not have to relinquish follow-up care. Shared care could also be preferred by general practitioners, who might not feel confident to provide all aspects of comprehensive survivorship care; and to survivors of cancer, who remain connected with both specialist oncology-care and generalist-care providers.

A small number of trials of shared care have been reported to date.<sup>27</sup> An Australian RCT investigated the effectiveness of shared care for survivors of low-risk to medium-risk prostate cancer.<sup>32</sup> Results indicated no differences between shared and usual care regarding adherence to prostate-specific antigen testing, patients' quality of life, patients' distress, and patients' unmet needs. Furthermore, patients who had shared care preferred this model.<sup>32</sup> Shared care cost less per patient compared with usual care.<sup>32</sup> Further randomised trials of

### Panel 1: Perspective of a survivor of cancer

I am a long-term survivor of four cancer diagnoses. Over the past 27 years, I have experienced aggressive mantle radiotherapy, high-dose chemotherapy, a stem-cell transplant, surgery, and hormonal therapy. I have been hospitalised and treated for a myriad of related side-effects and late effects, and I continue to require ongoing end-of-treatment follow-up.

I have experienced nurse-led survivorship care and a model of care shared between my general practitioner and a late-effects service.

Nurse-led care was gratefully received in preparation for stem-cell transplant and during follow-up. Some years later, the ministrations of a breast-care nurse were offered during breast cancer treatment.

This model of care offered me information, advice, and support for concerns, along with timely responses to queries and speedy re-entry into the system when required. The interactions with my nurse provided reassurance between specialist visits.

As an experienced survivor of cancer, I had total confidence in the nurses undertaking my care and was appreciative of the intimacy and immediacy of nurse-led follow-up care. I had a sense of less hurried attention, which suggested I was more than just another patient.

Perhaps, had I been new to the system, I might not have had the confidence to seek out the allied and supportive care I required along the way. Similarly, I might, as many survivors do, have been reluctant to let go of the comforting hand of my primary specialist and would have preferred to remain within the hospital environment.

Currently, I am part of a shared care arrangement between the Peter MacCallum Cancer Centre Late Effects Service and my general practitioner. The late-effects clinic monitors me for known and unexpected late effects from my previous treatments, manages the paperwork and coordinates shared care, updates my survivorship care plan annually, and provides

speedy access back into the system, as needed. This arrangement works smoothly and efficiently. Appointments are organised well in advance, and tests and scans are conducted efficiently and at no cost to me within the hospital system.

Shared care with my general practitioner offers attention within a familiar environment, close to home. My general practitioner knows me well, sees me regularly, and has initiated a chronic health-care plan that ameliorates the cost of lengthy annual visits.

Although localised care does remove the need for travel, parking fees, and often lengthy waiting times in a busy hospital situation, there might be a cost differential when tests, scans, or allied health follow-up are conducted within the community rather than in the publicly funded hospital setting.

Many survivors come to their cancer experience suddenly, without warning. Therefore, shared care requires a local general practitioner in whom the survivor has confidence.

There is no single solution to care. What works for me might not work for the next survivor. Each survivor has their own individual needs and capacity and should be offered the chance to find the model of care that works best for them.

#### What might work?

- A start might see clinicians familiarising themselves with the available models of care and which might be most appropriate for each individual patient
- Patients should be supported and educated with information around what to expect from each of those models of care
- Patients should be empowered with the skills required to navigate the system and self-manage, when appropriate
- Patients should be encouraged to establish a regular relationship with a trusted general practitioner
- Clarification of roles and responsibilities is essential (ie, role of the patient, the specialist, the general practitioner, the nurse): who does what?

shared care are underway, including for survivors of colorectal<sup>33</sup> and breast cancer.<sup>34</sup> Key success factors for shared care models include strong communication between providers, clarity of the roles and responsibilities of all members of the care team, care coordination, follow-up guidelines, and information resources (eg, survivorship care plans).<sup>35,36</sup>

Two systematic reviews have examined the evidence for shared care models in cancer care, noting that many studies that were included focused on shared care given while patients were still undergoing cancer treatment, rather than focusing on shared care during the post-treatment survivorship phase.<sup>23,27</sup> Primary studies were conducted in Australia, Denmark, Canada, the USA, the Netherlands, Norway, and Sweden.<sup>28</sup> These reviews did not consider monitoring for cancer recurrence as an

outcome, there were scarce data on symptom monitoring and management of comorbid illness, and there was little attention paid to lifestyle and behavioural risk factors.<sup>28</sup> Shared care is associated with high levels of patient satisfaction, and is cheaper than traditional follow-up.<sup>23,27</sup>

### Oncology nurse-led survivorship care

Nurse-led care might be provided by specialist cancer nurses in a range of settings, and could be delivered in person, by telephone, or online. Cancer nurses have the appropriate training, skills, and expertise to identify and manage symptom issues, support survivors of cancer to self-manage, provide health promotional advice, and refer to appropriate services (panel 1). A number of systematic reviews have examined nurse-led versus traditional

specialist-led follow-up.<sup>21,22,24,37-39</sup> Over 20 RCTs have been conducted, particularly in the UK (over ten RCTs), but also in the USA, the Netherlands, Sweden, and Turkey.<sup>28</sup> Several trials included survivors of breast cancer, but other trials recruited survivors of gynaecological cancers, colorectal cancers, urological cancers, oesophagogastric cancers, head and neck cancers, and lung cancers.<sup>28</sup> Together, these trials showed no differences between nurse-led and traditional models in recommended follow-up or detection of cancer recurrence.<sup>21,22,24,37-39</sup> These studies generally did not consider the management of broader common survivorship issues and concerns or of comorbid illness, and did not have a specific focus on health-related behaviours.<sup>28</sup> Nurse-led models seem to be less costly than traditional models of care.<sup>40</sup>

As is the case for oncology nurse-led models of care, in the USA at least, increasing emphasis has been placed on leveraging the skills of advanced practice providers (nurse practitioners and physician assistants) to provide post-treatment survivorship follow-up care.<sup>41</sup> A retrospective review of the records of 622 survivors of cancer (210 survivors of breast cancer, 208 survivors of prostate cancer, and 204 survivors of colorectal cancer) in a large comprehensive cancer programme showed that nurse practitioners can provide concordant surveillance monitoring and can address the symptom management and health promotion needs of survivors of cancer.<sup>42</sup> However, only a small number of countries have widespread availability of highly trained advanced practice providers.

### Long-term follow-up clinics

Long-term follow-up services (panel 1) have been developed to manage survivors of cancer who have more complex needs or who are at substantial risk of late-effects.<sup>41</sup> Multiple medical specialties, allied health professionals, and expert nurses might be involved, according to the clinical needs of the specific survivor group. These services could be recommended for adult survivors of childhood and adolescent cancer, as discussed in the first and third paper in this Series, and for survivors of complex treatments, such as allogeneic bone marrow transplantation. Survivors of cancer attending these services might also participate in a shared care model with a primary-care provider (panel 1), be supported to self-manage aspects of their survivorship care, and be linked with rehabilitation services.

Advantages of long-term follow-up services are that they can consider the breadth of issues that some survivors of cancer could experience, particularly for less common cancers and treatments. Long-term follow-up services can act as a one-stop shop, but these services often need to be centralised to ensure appropriate multidisciplinary expertise, and could be expensive to run. Data regarding the comparative effectiveness of late-effects services compared with traditional oncology follow-up are scarce.

### Supported self-management

Promoting the survivor's capacity to self-manage their health and the emotional, psychosocial, physical, and functional sequelae of cancer and its treatment is integral to optimising health, quality of life, and survival,<sup>43</sup> and is desired by survivors of cancer.<sup>44</sup> Self-management might be combined with other models, including shared care, general practitioner-led care or nurse-led care. In the UK, for example, this combination of care forms the mainstay of the model of follow-up for some low-risk survivors of cancer (panel 2).<sup>4,45-57</sup> However, effective self-management requires support with evidence-based, structured programmes, and coaching by health-care clinicians or trained peers to support the proactive follow-up, adoption of healthy behaviours, and self-management skills of survivors of cancer (eg, problem-solving and goal setting).<sup>58</sup>

Systematic reviews and meta-analyses of RCTs across various modes of delivery (ie, digital, group, or individual) show that supported self-management of survivors can improve their quality of life, fatigue, anxiety, coping skills, insomnia, emotional distress, lymphoedema, overall health, and self-efficacy albeit with heterogeneous effects across studies.<sup>59-63</sup> Interventions targeting self-management strategies for specific problems (eg, pain) combined with motivational interviewing are necessary to improve effectiveness.<sup>43,64</sup> Supported self-management programmes targeting lifestyle behaviours (eg, physical activity, weight management, and nutrition) also show positive effects on function, weight loss, cardiorespiratory fitness, and biomarkers associated with disease progression and survival.<sup>57,65</sup>

Supporting self-management is not routine in cancer care. Rather, survivors of cancer are commonly encouraged to rely on cancer providers, rather than self-managing. Successful implementation of supported self-management requires clinician training and the use of well established change management and quality improvement methods (eg, champions and implementation teams). Self-management support does not yet reach large numbers of survivors of cancer regardless of geographical location and should be tailored to the needs of diverse populations.

### Comprehensive multidisciplinary rehabilitation

Rehabilitation is defined as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment".<sup>66</sup> Comprehensive multidisciplinary cancer rehabilitation is a necessary component of survivorship care to address the multi-dimensional sequelae of cancer and treatment, and to optimise physical, psychological, vocational, and social functioning.<sup>67</sup>

There is widespread variation in the availability of rehabilitation and integration with cancer care, internationally.<sup>68</sup> As with supported self-management, rehabilitation should ideally be combined with other

models of care, and could contribute to more holistic models of shared care.

Rehabilitation interventions should be tailored using a stepped care approach according to need, differing levels of comorbidities, and impairment.<sup>69</sup> A Cochrane review (13 RCTs, 1669 participants)<sup>70</sup> and a review (six RCTs, 682 participants)<sup>71</sup> of multidimensional outpatient rehabilitation programmes showed positive effects on quality of life, physical and emotional functioning, and return to work. Exercise interventions can lead to improvement in physical capacity and cardiorespiratory fitness, can improve fatigue and depression,<sup>72</sup> and could improve survival.<sup>73</sup> Attention has now shifted to prehabilitation before treatment<sup>74</sup> and prospective surveillance models of rehabilitation (ie, early identification, treatment, and support of physical impairments) integrated with disease treatment to prevent or mitigate acute and long-term cancer morbidity.<sup>69</sup> Further long-term effectiveness, health economic research, and implementation research are needed to inform integration of rehabilitation into routine models of care.

### Evaluating models of survivorship care

The principal goal of redesigned care should be to improve outcomes for cancer survivors in a sustainable, affordable, and equitable manner, without having negative effects on caregivers or health professionals. Measures to evaluate new models of survivorship care include improved survival, reduced risk of recurrence, reduced risk of new cancers, improved quality of life, improved functional outcomes, improved patient experience, minimised health-care utilisation, and lower costs to survivors of cancer and payers.<sup>75,76</sup>

A key recommendation from the IOM report was that all survivors should receive a survivorship care plan (panel 1), which should include a summary of the individual's diagnosis and treatment, details of recommended follow-up, strategies to remain well, and a list of support and resources.<sup>2</sup> Provision of such a plan was previously considered a key indicator of quality survivorship care, particularly in the USA.<sup>77</sup> Accumulating evidence suggests that survivorship care plans do not have the anticipated effect on patient outcomes,<sup>78</sup> although they might still be a useful communication tool and could support care coordination. The USA has shifted focus from survivorship care plan completion, as a marker of quality care, to the availability of a multidisciplinary survivorship programme.<sup>77</sup>

Many RCTs that have explored different models of care, some of which were conducted even before the release of the IOM report, have not considered the full extent of survivorship care, and most have not measured the full breadth of outcomes.<sup>28</sup> Many early studies were designed to provide evidence for absence of harm, with outcome measures focused on adherence to recommended surveillance tests and detection of cancer recurrence. Some studies also included patient preferences,

### Panel 2: Reforming post-treatment survivorship care in the UK

The UK has seen a major national shift in the model of post-treatment care. Other countries, including Australia and the USA, have developed recommendations that are aligned with this experience.<sup>4,45,46</sup>

#### How were services redesigned?

From 2008 to 2014, National Health Service organisations in the UK tested personalised stratified follow-up care pathways for survivors of breast, prostate, and colorectal cancer. Patients were triaged into pathways that focused on self-management with little routine follow-up, or to usual care.<sup>47-50</sup> A small group of survivors of cancer, with complex needs, required multidisciplinary management, potentially through a long-term follow-up service.

All patients continued to see their general practitioner for non-cancer care, including management of comorbidities.<sup>51</sup> Patients received personalised care planning based on a brief needs-assessment tool.<sup>47-49,52</sup> In addition, patients were provided information and support to maintain wellbeing, an end-of-treatment summary, and a primary care review. Together, these were described as the recovery package.<sup>45,53</sup>

#### What worked?

Approximately 50% of patients with colorectal cancer, 80% of patients with breast cancer, and 50% of patients with prostate cancer treated with curative intent could safely self-manage and have their needs met.<sup>47-49,54,55</sup> Personalised stratified follow-up care pathways led to more efficient use of oncology time, reduced hospital visits, and reduction in overall costs.<sup>4,53,48</sup>

Key factors to successful implementation include:

- Systems to support remote monitoring
- Routine holistic assessment of needs
- Access to services meeting the needs of survivors of cancer
- Adequate support for general practitioners

#### What required modification?

Triage was initially based solely on risks of recurrence, risk of new cancers, and ongoing treatment-related effects. Triage was subsequently adapted to account for functional ability, comorbidity, psychosocial issues, health literacy, and confidence to self-manage.<sup>47,50,54,55,56</sup>

#### Current status of survivorship care in the UK

Personalised stratified follow-up pathways have resulted in estimated savings of £90 million over 5 years in the UK,<sup>4</sup> leading to improvements in the quality of life, psychological wellbeing, and satisfaction of patients.<sup>54</sup> Such pathways for breast cancer, colorectal cancer, and prostate cancer have now become part of national cancer strategies across the UK. By 2019, 85% of English trusts had adopted personalised stratified follow-up pathways for breast cancer.<sup>53</sup> In Northern Ireland, over 60% of patients with breast cancer had entered supported self-management pathways after treatment.<sup>48</sup>

#### What uncertainties remain?

Are personalised stratified follow-up pathways applicable to survivors of cancers other than breast cancer, prostate cancer, and colorectal cancer? Are there particular populations for whom self-management is not suitable? Will personalised stratified follow-up pathways lead to greater inequities in survivorship outcomes?

measures of quality of life, and the cost to deliver the model of care.<sup>28</sup>

Despite these limitations, overall the trial evidence shows that several different models of care appear to be safe, cost-effective, and applicable to large numbers of survivors of cancer. Trials have generally considered



survivors of breast cancer, colorectal cancer, prostate cancer, or melanoma, and these models might not apply to survivors of other cancers.

In parallel with the conduct of these trials, and informed by some earlier trials, major service reform has been undertaken in the UK to redesign survivorship care (panel 2). Personalised stratified follow-up has been widely implemented, with survivors of cancer receiving different levels of follow-up intensity, as well as support to self-manage. Personalised follow-up has resulted in patient benefits, reduced demand on the health-care system, and cost savings. It is notable that the UK approach was not directly derived from the available trial evidence but was built upon strong principles around survivorship care (panel 2). Also notable is that the resulting data have not been published in the peer-reviewed literature,<sup>47,48</sup> bringing into question whether additional evidence generation about new models of care should focus on further RCTs, or implementation-effectiveness designs, which might more readily enable local adaptation.

### Selecting models of care

The most appropriate model of care for an individual survivor will depend on several factors (panel 2), including patient-level factors such as the presence and type of ongoing concerns and the risk of longer-term effects and late effects.<sup>4</sup> These decisions must be placed in the context of the local health-care setting and relevant health policy governing care.

#### Patient-level factors

As described in the first paper in this Series, patients treated with specific therapies are at risk of developing a range of long-term effects and late effects requiring strategies to reduce risk, screen for, and manage these treatment consequences. In this circumstance, a shared care model might be suitable, potentially involving a late-effects clinic for particular groups of survivors of cancer. For instance patients treated with intensive treatments, such as chemoradiation to treat an oropharyngeal cancer, could benefit from multidisciplinary rehabilitation to deal with possible issues with nutrition, speech, pain management, and others, and could require ongoing specialist-led care. An individual's desire and capability to self-manage might also affect decisions about the required level of ongoing medical care. Some survivors of cancer might feel that, with support, they can manage many aspects of their survivorship care, together with guideline-recommended surveillance testing supported by automated reminder systems (so-called remote monitoring). For many, the amount of time since the end of treatment will reduce the need for contact with the specialist health-care team. Furthermore, if there are no substantial long-term effects, general practitioner-led care might be a safe, and more convenient, option. Where the survivor lives and works, in relation to

specialist health-care teams, could be an important factor in recommending an alternative model of care. For example, an individual who has a good relationship with their local general practitioner might prefer general practitioner-led care or a shared care arrangement, whereas someone living in a remote area might prefer a model of care with more use of telehealth, potentially supported by oncology nurse-led care. Patient preference must be considered, recognising that patients are far more likely to support a model of care that they have already experienced.<sup>4,31</sup> In the US context, some patients might not be able to access or be able to afford the full breadth of survivorship care due to variable health plan coverage. Issues of funding and potential financial toxicity from ongoing care need to be part of discussions about preferred models of care.

#### Health-care system-level factors

Cancer services should be able to define pathways for most survivors of cancer, on the basis of local services and patient factors described, and discuss with survivors of cancer, early on in their care, which model of care is likely to suit them. The UK model might not readily transfer to other settings. For example, experts convened to discuss implementation of the UK survivorship model in the USA voiced concerns about the diversity of health-care delivery systems and health plans.<sup>4</sup> Care provided by advanced practice providers could be a better alternative model in the USA. Shared electronic health records between providers, frequent in the USA, are an important enabler of integrated models of survivorship care.

#### Policy-level factors

Most evidence on the effectiveness of new models of survivorship care has been generated in countries with well established, integrated primary health-care systems, such as Australia, Canada, the UK, and the Netherlands, where the general practitioner is the first contact for the majority of care.<sup>13</sup> General practice has a substantial role in chronic disease management and disease prevention, and stratified models of cancer survivorship care map closely onto existing models of chronic disease care for other conditions.<sup>79</sup> This model of care is further enabled in countries where patients are registered with a general practice, and where most survivors of cancer have an established long-term relationship with a general practitioner.

Payment models are an additional contextual element that can create incentives or barriers to adopting new models of survivorship care. Countries with single payer systems, such as the UK and the Netherlands, tend to have greater levels of integration between hospital and primary-care services than countries with multiple payers, and might have common financial drivers to adopt stratified models of cancer survivorship care. Additionally, the predominant capitation-based funding of UK general practice further incentivises the adoption of

self-management as a core component of survivorship care. In Australia, the mix of public and private hospital services creates greater complexities and different sets of drivers between systems. Pressures on workloads in public hospitals and the need to meet targets for newly diagnosed patients with cancer could act as enablers of new models of survivorship care, taking pressure off outpatient services. Private hospital systems, which might be less concerned by workload and depend on fee-for-service models of care, could potentially be more reluctant to transition to new models of survivorship care that reduce activity. In the USA, changes in payment models might be needed to incentivise new patient visits over follow-up appointments and reimburse core components of survivorship care including self-management interventions and care planning.<sup>4</sup>

Top-down policy leadership is also required to drive the implementation of new models of survivorship care as illustrated by the reform work in the UK (panel 2).<sup>80</sup> Many countries do not have a specific focus on the post-treatment phase, and models of survivorship care are not explicitly considered within national cancer control plans.<sup>81</sup> In health systems in which individual hospitals and practitioners have substantial autonomy, top-down policies to implement new models of survivorship across the health-care system could face greater challenges.

### The effect of COVID-19 on post-treatment survivorship care

The COVID-19 pandemic has affected cancer care worldwide. Many countries reduced face-to-face consultations, to minimise the risk of nosocomial infection, and redirected care to people with COVID-19. An international study of oncology professionals in mid-2020 found clinicians saw a median of ten fewer outpatients per week (face to face or remotely) compared with before the pandemic, with an eight-fold increase in telehealth-based reviews.<sup>82</sup>

Although telehealth-based follow-up presents potential benefits, several reports note problems related to this form of follow-up. A quarter of surveyed professionals were worried that survival could be impacted as a result of telehealth-based care.<sup>82</sup> This concern is because telehealth-based care might be less effective in detecting cancer recurrence or assessing the adverse effects of treatments. Guidance on how to deliver telehealth effectively is emerging.<sup>83</sup> The shift to telehealth could exacerbate disparities in care and outcomes. Not all patients with cancer and survivors of cancer have sufficient digital health literacy, access to the necessary equipment, or internet connectivity to ensure equal access to telehealth as an option for follow up. During the COVID-19 pandemic, survivors of cancer could be required to take on greater self-management, while also dealing with social isolation, financial hardship, loneliness, and uncertainty.<sup>84</sup> Jones and colleagues propose steps to promote effective survivorship care during the COVID-19 pandemic.<sup>85</sup> Steps

proposed for effective care include: anticipating and assessing COVID-19 burden in real time; providing close to guideline-based care; not delaying needed in-person visits; cautious use of telemedicine; optimising workflows between primary care and oncology care; and addressing financial effects of the COVID-19 pandemic.<sup>85</sup> It will be important to monitor the effect of the COVID-19 pandemic on the survival and quality of life of survivors of cancer, including potential worsening of inequities.

Despite these concerns, the COVID-19 pandemic could lead to permanent, substantially advantageous changes to models of care delivery. Telehealth, if delivered well, can result in care at home, work, or wherever is convenient for the survivor of cancer.<sup>83</sup> Surveillance testing closer to home, and the use of remotely collected patient-reported outcomes, could guide care and improve the survivorship experience. Changed reimbursement for telehealth-based care could enable greater flexibility in models of care, supporting shared care coordinated by primary care and community-based providers and greater use of allied health professionals in survivorship care.

### The future of survivorship care

Evidence from clinical trials, UK implementation of personalised stratified follow-up, and other international pilot programmes identifies some key principles to improve survivorship care.<sup>4,86</sup> Methods to better identify patient needs in routine care are needed, potentially through electronic patient-reported outcome collection systems. Triage to different models of survivorship care should be influenced by more than the risk of cancer recurrence or late effects,<sup>4,52</sup> and should take into account the holistic health-care needs and personal preferences of individuals. New models should include options for remote monitoring,<sup>54,56</sup> reducing face-to-face visits and supporting patients to self-manage.<sup>71</sup> Better tools are needed for information exchange between oncology-care providers, primary-care providers, and patients. Care plans and treatment summaries are useful communication tools but are not sufficient to bridge this gap.<sup>87</sup> Next generation models of care should integrate rehabilitation services, to meet the functional and work-related needs of survivors of cancer. Furthermore, it is important not to underestimate the culture change required to implement new models of follow-up, especially among cancer specialists. For new models of care to become routine, all stakeholders need to be engaged, securing buy-in, and using change management and continuous improvement principles.

England and Northern Ireland's efforts to build a successful follow-up care model showed the importance of engaging all stakeholders in the design of care transformation. This model included both top-down (ministerial approval) and bottom-up efforts to engage patients, families, and front-line clinicians, and ensure that new workflows were feasible and responsive to patients' needs (panel 2).<sup>48</sup> Additionally, survivorship

programmes should engage with programmes and services outside of clinical care—eg, by leveraging cancer control programmes, coalitions, and community or organisational partners in a coordinated public health approach to meet the needs of survivors of cancer.<sup>88</sup>

Immediate and medium-term steps for the implementation of new models of survivorship care have been defined.<sup>4</sup> Commonly cited challenges include insufficient knowledge and confidence in primary-care providers,<sup>4,8,29–31</sup> which could be addressed by routinely providing patient-specific guidance for primary-care providers during and after the treatment phase, to better meet patients' information needs. Survivors of cancer are known to be more accepting of a model of care if they are prepared early, and after they have experienced the model of care, so cancer teams should endorse these new models of care with their patients.<sup>4,31</sup>

### Survivorship care in low-income and middle-income countries

Over half of the global cancer incidence is from low-income and middle-income countries.<sup>1</sup> In many resource-poor settings, numbers of survivors of cancer are growing, as are the challenges to delivering quality survivorship care.<sup>68</sup> Most published survivorship research is from high-income countries, and most of the countries with a focus on post-treatment survivorship care within national cancer control plans are high-income countries.<sup>81</sup> Recommendations for advancing survivorship care more equitably worldwide have been suggested.<sup>89</sup> First, more data are required regarding current survivorship care, globally. Second, more countries should include a focus on survivorship care within national cancer control plans. Third, resource-stratified guidelines for survivorship care should be developed and disseminated. Finally, regional partnerships should be formed, with a focus on improved palliative care access and delivery.<sup>89</sup>

### Future research

We believe there is a strong evidence base to justify the widespread implementation of new models of care described in this Series paper, especially for common cancers. We recognise that none of the trials testing these new models of care has been powered to detect differences in survival. But given the low-risk populations in which these models of care have been tested, trials to detect improved survival might simply be too large to conduct, or too large to be considered worthy of funding. Although there are international calls for research to explore new models of care for survivors of cancer, the same trials in similar settings should not simply be repeated.<sup>28,90–91</sup> Models need to be tested in cancers other than breast cancer, colorectal cancer, prostate cancer, and melanoma. Furthermore, research into models of care should adapt what is known to meet the needs of survivors of less common cancers. Focus should then be on strategies to

successfully implement and disseminate evidence-based models.

Ideally, future trials and implementation studies will consider endpoints other than detection of cancer recurrence, quality of life, and satisfaction. Other endpoints might include functional gain (including return to work or study), optimal management of comorbid illness, improvement in patient activation and health-related behaviours, costs to patients, and costs to payers. A stronger evidence base for optimal follow-up and surveillance schedules also needs to be developed. Recommended schedules are largely consensus-based and there are scarce data to justify the frequency of recommended testing or clinical reviews. Guidelines should be based on data showing that interventions benefit patients and are cost-effective.

### Contributors

MJ and JE provided oversight of the paper. MJ, DH, QL, KL, JM, CMA, and JE contributed to the identification and selection of relevant literature and evidence. MR provided the consumer perspective, drafting the specific section and contributing to the overall focus of the paper. All authors contributed to the planning, drafting, and approval of the final version of the manuscript.

### Declaration of interests

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