Implementation of Survivorship Care Plans in Patients With Glioblastoma

CASEY B. BROWN,1 DNP, RN, AGPCNP-BC, DEBORAH ALLEN,1 PhD, RN, CNS, FNP-BC, AOCNP®, CHRISTINA CONE,1 DNP, APRN, ANP-BC, AOCNP®, and SUSAN M. SCHNEIDER,2 PhD, RN, AOCN®, ACNS-BC, FAAN

From 1Duke Cancer Institute, Durham, North Carolina; 2Duke University School of Nursing, Durham, North Carolina

Authors’ disclosures of conflicts of interest are found at the end of this article.

Correspondence to: Casey B. Brown, DNP, RN, AGPCNP-BC, Duke Cancer Institute, 047 Baker House, Trent Drive, Durham, NC 27710
E-mail: casey.brown@duke.edu

Abstract

Background: The outcomes and survival of patients diagnosed with glioblastoma are improving due to advancements in therapy and better symptom management. Focusing on survivorship is an important initiative for these patients. A quality improvement project performed by an advanced practitioner in adults with glioblastoma evaluated the efficacy and utility of survivorship care plans (SCP). Providing patients and their families with SCPs gives them important information about their cancer, treatment, and follow-up management and care. Methods: Survivors of a glioblastoma who were receiving an oral alkylating agent and/or bevacizumab, as well as those who had completed these therapies within the past year were included. Patients had received surgery and radiation. The National Comprehensive Cancer Network (NCCN) Distress Thermometer and a pre- and postintervention survey evaluated knowledge, distress, and rate of follow-up care. Results: Over 2 months, 18 eligible participants received the SCP with a long-term care coaching appointment with an advanced practitioner. Knowledge pertaining to long-term effects of therapy and chemotherapy regimen improved. Ratings of overall distress and patient-reported primary care follow-up remained the same. Conclusion: Providing patients with glioblastoma with an SCP and an educational visit can improve knowledge pertaining to their chemotherapy regimens and long-term effects of therapy. This can result in more effective long-term management and care.

Glioblastoma is often defined as a terminal diagnosis. Although this is sometimes inevitable, patients are living longer due to advances in therapy and symptom management (National Cancer Institute [NCI], 2013). Patients often go back to work and return to normal activities. Many report that they do not see a primary care provider (PCP). This can result in avoidance of screening for other cancers and chronic health conditions, as patients feel that the cancer and its potential recurrence are more serious (Ganz, Casillas, & Hahn, 2008). Patients often live with untreated...
symptoms. It is important for advanced practitioners (APs) to implement procedures where patients are educated on how to best live as a survivor of brain cancer. The purpose of this project was to implement survivorship care plans (SCPs) in patients with a glioblastoma.

BACKGROUND
Earlier diagnosis and advanced therapy options are allowing patients with cancer to live longer lives (NCI, 2013). Survivorship is frequently used in oncology and refers to living through and with cancer. In 2015, the median overall survival for a glioblastoma was 21 months (Stupp et al., 2015). Focusing on survivorship is a vital part of the patient’s treatment plan. For this project, a survivor is defined as one who has “transitioned to maintenance or prophylactic therapy” (American Society of Clinical Oncology [ASCO], 2016). This includes those who are off therapy and monitored with clinical exams and surveillance brain imaging.

Treatment for a glioblastoma includes surgery, radiation, and chemotherapy. The goals of these therapies are to preserve quality of life and keep patients functional. These treatments have long-term effects such as cognitive impairment and losses in functional status (Lovely et al., 2013). Patients may also experience weight changes, risk for nutritional imbalances, and loss of appetite (Johnson et al., 2015). Some of these changes can lead to an increase in anxiety and depression.

There are reports of fear, anxiety, depression, and survivor’s guilt in cancer survivors (Runowicz et al., 2016). Survivorship care plans can decrease cancer worry and levels of anxiety, resulting in improved well-being (Curcio, Lambe, Schneider, & Khan, 2012; Oancea & Cheruvu, 2016). This evidence supports the need for psychological assessment and emotional support beyond initial cancer treatment. In 2006, the Institute of Medicine (IOM) issued a report that recommended that all cancer survivors receive an SCP (Hewitt, Greenfield, & Stovall, 2006). The Commission on Cancer (2018) mandated that 50% of cancer survivors who are receiving therapy with curative intent are provided with an SCP.

An SCP is a concise document provided by a health-care provider with information about the patient’s cancer, cancer treatment, and recommended follow-up care (ASCO, 2016). They are becoming a common tool in the field of oncology, with their purpose being to enhance communication and improve care coordination (ASCO, 2016). There are multiple versions of SCPs available for use in the general oncology population. A summary of the recommended SCP components from the IOM is in Table 1.

The timing of SCP implementation is important so that its use is beneficial to both patients and providers. Optimal SCP review occurs between 3 and 6 months after the completion of therapy (Brant et al., 2016; Dulko et al., 2013). However, cancer survivors at a later phase of survivorship may still benefit from the information, as continued emotional and physical effects of therapy can often last throughout a patient’s life (Playdon et al., 2016; Runowicz et al., 2016).

For patients to get the most out of an SCP, routine health maintenance and disease prevention should be addressed (Runowicz et al., 2016). Long-term effects of therapy and complications experienced while undergoing therapy should be outlined (Ganz et al., 2008). It is also important to include screening for secondary cancers (Runowicz et al., 2016).

Cancer-related resources, information about employment, financial concerns, and the impact of the physiological burden on the patient and their family is important (Playdon et al., 2016). Promotion of a healthy lifestyle via education on physical activity, smoking cessation, and nutrition should be reviewed (Runowicz et al., 2016). By discussing these elements of survivorship with patients, and providing the information in a written document, they can have a better understanding of their necessary follow-up care.

Overall, patients do not report significant barriers to SCPs. Providers noted barriers that could affect implementation, including lack of survivorship guidelines, lack of time, and billing (Dulko et al., 2013; Faul et al., 2012; Parman, 2013). Survivorship care plans can take up to 75 minutes for providers to complete but the ultimate effect of the SCP can be life-changing for the patient (Curcio et al., 2012).

There are individual outcomes, including identification of symptoms and recognition of health maintenance and disease prevention, that are ben-
efficacy for patients with cancer. However, most studies do not show statistically significant changes in patient, provider, or system outcomes (Tomasone et al., 2016). There is a need for more quality studies among several types of cancer (Mayer et al., 2015). Evaluating the effectiveness of SCPs in patients with gliomas can provide valuable information on SCP utilization for individuals who experience cancer as an incurable chronic condition.

There is evidence in the literature to support the implementation of SCPs (Runowicz et al., 2016). Written SCPs can improve chronic disease management, particularly in patients over age 65, and result in fewer emergency room visits (Kenzik et al., 2016). Patients with advanced cancer report that written information is more beneficial than verbal instruction alone (Mayer et al., 2015). This may be due to the fact that patients with gliomas often have cognitive impairment, and providing written instruction allows them to refer back to the information at a later date.

Implementation of an SCP program in patients with a glioblastoma can improve quality of life and may decrease overall distress as measured by the National Comprehensive Cancer Network (NCCN) Distress Thermometer. The goals of the project were to increase the knowledge of patients pertaining to signs and symptoms of recurrence as well as long-term effects of therapy, decrease distress in patients, evaluate the satisfaction of patients regarding the SCP program, and increase the percentage of patients who establish follow-up care with their PCP.

**METHODS**

An SCP is recommended in neuro-oncology based on evidence with the general oncology population. They are not used routinely in neuro-oncology, and it was anticipated that the use of this tool would affect the way patients are followed at our institution. The implementation of an SCP allowed for systematic education of patients so that they could receive more consistent care, both for their long-term effects of therapy and future disease prevention.

This innovation occurred at the Preston Robert Tisch Brain Tumor Center (PRTBTC) at Duke, a hospital-based oncology clinic within a comprehensive cancer center at a large academic medical center in Durham, North Carolina. The staff of the PRTBTC includes six attending physicians, eleven advanced practitioners, and six clinic nurses. This team works closely with medical oncology teams throughout the country.

This project used a convenience sample. Identification of prescheduled patients occurred through the electronic medical record. Patient participation was voluntary. Inclusion criteria consisted of any patient who had a pathological diagnosis of a glioblastoma who had completed surgery and radiation. They could have also received, or were receiving, chemotherapy with an oral alkylating agent and/or bevacizumab, as these patients have a greater than 6-month life expectancy. Exclusion criteria included inability to speak and disease progression on the day of SCP implementation. This project met the Duke University School of Nursing and Duke University Health System Institutional Review Board criteria for a declaration of exemption from review, as it did not meet the current descriptions for human subject research. Therefore, informed consent was not required for this quality improvement project.

**Outcome Variables**

Participants completed an advanced practitioner-created pre- and postsurvey and the NCCN Distress Thermometer (NCCN, 2018). Patients indicated their distress on a scale of 0 to 10, with 0 being no distress and 10 significant distress. Knowledge pertaining to diagnosis, chemotherapy regimen, indicators of recurrence, and long-term effects of therapy was assessed via pre- and postsurvey. Additionally, the survey evaluated patient satisfaction with their survivorship care and follow-up with their PCP.

The survey asked patients to indicate their specific type of brain cancer and chemotherapy regimen. Patients were also asked to list late ef-
fects of therapy and symptoms that may be an indicator of disease recurrence, as well as their recommended follow-up care. To assess PCP follow-up, patients indicated if they currently had an appointment with their PCP. A Likert scale determined patients’ level of satisfaction with their brain tumor survivorship instruction and care.

The seven-question pre- and postintervention survey took patients less than 10 minutes to complete at each visit. Face validity of the survey was assessed by the neuro-oncologists and advanced practitioners at the PRTBTC and pilot tested with five patients prior to use for evaluation of project outcomes. Descriptive statistics were used to analyze the data.

This quality improvement project utilized a pre- and postdesign. Eighteen patients were identified for potential eligibility per standard clinic practice. All patients completed the NCCN Distress Thermometer per routine clinical care. After the routine clinic visit occurred, the advanced practitioner reviewed the project with the patient and provided the baseline knowledge presurvey.

The SCP document was adapted from the template from ASCO. The document was modified to meet the needs of patients with gliomas. Input was also obtained from physicians, advanced practitioners, and nurses at the PRTBTC. Permission was not required to use the modified document.

Individual SCPs were prepared by the advanced practitioner prior to routine clinic visits and edited to include the patient’s specific diagnosis and treatments. Additional information included specific signs and symptoms for which to monitor based on presenting symptoms and long-term medications. This preparation took approximately 30 minutes. The entire document is available in the Appendix. Table 2 provides a summary of the details of the SCP.

The single-arm quality improvement cohort received the standard of care visit and a copy of the SCP. The document was reviewed by the advanced practitioner with the patient and their family at the time of the visit. This added 20 minutes to each clinic visit. At the next return visit, 2 to 3 months later, patients completed postsurveys, which consisted of the same questions on the presurvey and the NCCN Distress Thermometer. These were completed prior to their visit with the physician.

The information collected from this innovation allowed for assessment of distress and knowledge pertaining to SCPs in patients in neuro-oncology clinics. This process identified knowledge gaps and provided avenues for better education and communication with the patients’ healthcare team.

Statistical Analysis
Demographics and ratings for the study were summarized using the Statistical Package for the Social Sciences (SPSS) to produce descriptive statistics and analyzed before and after the intervention. Distress, late effects of therapy, indicators of disease recurrence, and satisfaction with brain tumor survivorship care were analyzed using a Wilcoxon signed-rank test. Knowledge pertaining to diagnosis and chemotherapy regimen as well as whether the patient had PCP follow-up were analyzed using McNemar’s test. We accepted a significance level of 0.05 for all implementation questions.

RESULTS
Over a 2-month period, 18 patients received an SCP. Initially, 40 patients were identified to receive the intervention. However, 22 did not receive the document based on exclusion criteria, primarily disease progression. A 100% response rate was obtained from the eligible patients (N = 18). The demographic and clinical characteristics of the patients are shown in Table 3. The sample is representative of the clinic’s distribution of gender, age, and chemotherapy regimen.

Knowledge
Survivors answered five questions pre- and postintervention. Fifteen patients were able to indicate their specific type of brain cancer preintervention and two had improved knowledge postintervention. Participants indicated their chemotherapy regimen(s) on the pre-and postintervention survey. Fifteen patients were aware of their general chemotherapy regimen prior to SCP intervention. Seven patients (46%) reported more detail to their chemotherapy regimen and/or correct regimens as compared to their baseline.

Prior to SCP intervention, patients were able to state a median of 2 long-term effects of their therapy. Postintervention, this increased to a me-
A significant improvement between the intervention and knowledge pertaining to long-term effects of therapy was demonstrated with the Wilcoxon signed-rank test ($p = .017$), indicating that patients gained knowledge with SCPs about the long-term effects of their therapy.

Three patients were found to have improved knowledge pertaining to symptoms of disease recurrence. Interestingly, eight patients reported fewer symptoms postintervention (44%). Table 4 shows results of the assessment of patient knowledge pertaining to their diagnosis, chemotherapy regimen, long-term effects of therapy, and indicators of disease recurrence. A statistical analysis was not performed on brain tumor follow-up, as 100% of patients knew their recommended follow-up appointment schedule before the SCP intervention.

**Distress**
Patients indicated their distress on the NCCN Distress Thermometer prior to the visit of SCP intervention and at their routine visit 2 to 3 months later. A Wilcoxon signed-rank test was used to determine changes in distress. The mean distress for pre- and postintervention was 1.8. Distress in four patients (22.2%) increased after the intervention, while distress in two (11.1%) decreased. All others remained the same.

**Follow-Up and Satisfaction**
Patients indicated their level of satisfaction pre- and postintervention on a scale of 0 to 7, with 0 indicating completely dissatisfied and 7 being completely satisfied. A Wilcoxon signed-rank test indicated that ten patients remained completely satisfied, three had an improvement in satisfaction, and five had a reduction in satisfaction.

Primary care follow-up was assessed pre- and postintervention. There was no significant difference in PCP follow-up. Two patients indicated that they now had PCP follow-up as compared to previous reports.

**INTERPRETATION OF FINDINGS**

The results of this quality improvement initiative are similar with findings on the use of SCPs in...
other disease groups. Consistent with findings in colorectal cancer (Faul et al., 2012), knowledge of chemotherapy regimens and long-term effects of therapy improved. These findings provide further support for the use of these documents.

Although 15 patients were able to state their chemotherapy regimen before the intervention, six were able to report more details on the regimen, indicating that written SCPs may be useful in providing patients with details about their chemotherapy regimens. While patients are educated throughout their treatment regimen, they may not recall specific details of their chemotherapy. Using the SCP document, advanced practitioners can consistently reinforce information at clinic visits.

Patients were able to state additional long-term effects of therapy after the SCP intervention. This is helpful for patients and families, as the knowledge can be reassuring. Empowering patients to seek medical attention for nonspecific symptoms, such as generalized fatigue, may allow them to seek provider support sooner, which can in turn improve their quality of life.

Patients reported fewer indicators of disease recurrence after the SCP intervention. It is possible that answers to this question were related to the patient’s current symptoms compared with potential symptoms that could occur. This may be due to symptoms being better managed and subsequently improving due to SCP intervention.

The analysis of the NCCN Distress Thermometer scores showed no significant change in patient distress. Four patients had an increase in distress. All patients reported a low baseline distress score of 3 or less (scale of 0 to 10) at their preintervention survey. This is very similar to what has been reported in the literature, as the mean distress in the oncology setting was found to be 2.8 (Hammelef, Friese, Breslin, Riba, & Schneider, 2014).

Only patients with stable disease received the assessment. Perhaps their distress was initially low secondary to them presenting to clinic without new or progressive neurologic symptoms or concerns. An increase in distress could be related to patients experiencing more fear or anxiety around the time of their follow-up visit due to concern about radiographic disease progression.

Primary care follow-up did not change with this patient population. This is consistent with the literature in that follow up with PCPs is variable (Johnson et al., 2015). Many patients reported being completely satisfied with their survivorship care before the SCP intervention. However, five scores decreased postintervention. This finding needs further exploration. It is possible that making individuals aware that resources they were not using could have influenced their satisfaction.

Based on the results of this project, there is evidence that SCPs provided by advanced practitioners can provide patients with knowledge about their diagnosis. Further exploration can help to determine when it is best to initiate an SCP. Providing patients with the information immediately after completion of temozolomide and radiation may provide knowledge and empowerment earlier in their treatment trajectory.

Limitations
One limitation to this project is the possibility that surveys were not completed by patients alone, as family members were often in the room.

### Table 4. Patient Knowledge Scores

| Diagnosis (number of patients correct) | Pretest | Posttest | Improved posttest | Decreased posttest |
|----------------------------------------|---------|----------|------------------|-------------------|
|                                        | 15      | 16       | 2                | 1                 |
| Chemotherapy regimen (number of patients correct) | Pretest | 15       | Posttest         | More detail       |
|                                        | 16      |          | 6                |                   |
| Long-term effects of therapy (median)   | Pretest | 2        | Posttest         | 2.5               |
|                                        |         |          |                  |                   |
| Indicators of disease recurrence (median) | Pretest | 2        | Posttest         | 1                 |
|                                        |         |          |                  |                   |
| Brain tumor follow-up (number of patients correct) | Pretest | 18       | Posttest         | 18                |
with them for their routine clinic visit. We accept this limitation, as SCPs are also important for family members, who are integrally involved in the care of the cancer survivor. Another limitation is the potential for misunderstanding of questions. While the survey was validated by advanced practitioners and physicians, and reviewed by five patients for clarity, it appears that the question pertaining to current symptoms was not interpreted as expected.

Only 18 of the 40 identified patients received this innovation, primarily due to disease progression noted on the day that they would have received the SCP. While less than half of the patients identified received the document, these 18 patients show that a substantial group of survivors need a summary of their care.

**Future Directions**

For patients receiving care at the PRTBTC, care coordination between local oncology and primary care teams is essential. Survivorship care plans helped to facilitate this coordination. Our experience demonstrated that patients appreciated the documents. This experience may differ based on clinical settings. Given the high recurrence rate of glioblastoma, survivorship care plans may better serve patients with other glioma diagnoses. Further research is warranted regarding the use of these documents for specific patient populations and timing of their implementation. Patient outcomes need to be documented in order to warrant the time expended by clinicians on SCPs.

**CONCLUSION**

Based on the findings from this quality improvement initiative, SCPs, which are provided by an advanced practitioner, can help improve patient knowledge but may not necessarily be helpful in reducing distress or improving PCP follow-up. They are helpful in providing patients with information about the next phase of their cancer care and empowering patients to better understand their symptom burden and follow-up plan. With multiple versions of SCPs available, advanced practitioners throughout the country have the ability to provide patients with treatment summaries that can lead to enhanced follow-up management and care.

**Disclosure**

The authors have no conflicts of interest to disclose.

**References**

American Academy of Ophthalmology. (2015). Frequency of ocular examinations. Retrieved from https://www.aao.org/clinical-statement/frequency-of-ocular-examinations

American Cancer Society. (2018). American Cancer Society Guidelines for the Early Detection of Cancer. Retrieved from https://www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html

American Dental Association. (2017). Clinical Practice Guidelines. Retrieved from https://www.ada.org/en/evidence/guidelines

American Society of Clinical Oncology. (2016). Survivorship care planning tools. Retrieved from https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship-compendium/cancer

American Society of Clinical Oncology. (2017). Alcohol linked to cancer according to major oncology organization: ASCO cites evidence and calls for reduced alcohol consumption. Retrieved from https://www.asco.org/about-asco/press-center/news-releases/statement-alcohol-linked-to-cancer-november-2017

Brant, J. M., Blaseg, K., Aders, K., Oliver, D., Gray, E., & Dudley, W. N. (2016). Navigating the transition from cancer care to primary care: Assistance of a survivorship care plan. Oncology Nursing Forum, 43(6), 710–719. https://doi.org/10.1188/16.ONF.710-719

Centers for Disease Control and Prevention. (2018). Recommended immunization schedules for adults. Retrieved from https://www.cdc.gov/vaccines/schedules/hcp/adult.html

Commission on Cancer. (2018). The CoC clarifies the survivorship care plan standard: What you need to know. Retrieved from https://www.asco.org/about-asco/press-center/news-releases/statement-alcohol-linked-to-cancer-november-2017

Curcio, K. R., Lambe, C., Schneider, S., & Khan, K. (2012). Evaluation of a cancer survivorship protocol: Transitioning patients to survivors. *Clinical Journal of Oncology Nursing, 16*(4), 400–406. https://doi.org/10.1188/12.CJON.400-406

Dulko, D., Pace, C., Dittus, K. L., Sprague, B. L., Pollak, L. A., & Hawkins, N. A. (2013). Barriers and facilitators to implementing cancer survivorship care plans. *Oncology Nursing Forum, 40*(6), 575–580. https://doi.org/10.1188/13.ONF.575-580

Faul, L. A., Rivers, B., Shibata, D., Townsend, I., Cabrera, P., Quinn, G. F., & Jacobsen, P. B. (2012). Survivorship care planning in colorectal cancer: Feedback from survivors & providers. *Journal of Psychosocial Oncology, 30*(2), 198–216. https://doi.org/10.1080/07347332.2011.601261

Ganz, P. A., Casillas, J., & Hahn, E. E. (2008). Ensuring quality care for cancer survivors: Implementing the survivorship care plan. *Seminars in Oncology Nursing, 24*(3), 208–217. https://doi.org/10.1016/j.soncn.2008.05.009

Hammelef, K. J., Friese, C. R., Breslin, T. M., Riba, M., & Schneider, S. M. (2014). Implementing distress manage-
ment guidelines in ambulatory oncology: A quality improvement project. *Clinical Journal of Oncology Nursing, 18*(1), 31–36. https://doi.org/10.1188/14.CJON.S1.31-36

Hewitt, M., Greenfield, S., & Stovall, E. (2006). *From cancer patient to cancer survivor: Lost in transition*. Retrieved from [http://www.nap.edu/catalog/11468/from-cancer-patient-to-cancer-survivor-lost-in-transition](http://www.nap.edu/catalog/11468/from-cancer-patient-to-cancer-survivor-lost-in-transition)

Johnson, C. E., Saunders, C. M., Phillips, M., Emery, J. D., Nowak, A. K., Overheu, K., & Joske, D. J. L. (2015). Randomized controlled trial of shared care for patients with cancer involving general practitioners and cancer specialists. *Journal of Oncology Practice, 11*(5), 349–355. https://doi.org/10.1200/JOP.2014.001569

Kenzik, K. M., Kvale, E. A., Rocque, G. B., Demark-Wahnefried, W., Martin, M. Y., Jackson, B. E., & Pisu, M. (2016). Treatment summaries and follow-up care instructions for cancer survivors: Improving survivor self-efficacy and health care utilization. *Oncologist, 21*(7), 817–824. https://doi.org/10.1634/theoncologist.2015-0517

Lovely, M. P., Stewart-Amidei, C., Page, M., Mogensen, K., Arzbaecher, J., Lupica, K., & Maher, M. E. (2013). A new reality: Long-term survivorship with a malignant brain tumor. *Oncology Nursing Forum, 40*(3), 267–274. https://doi.org/10.1188/13.ONF.267-274

Mayer, D. K., Green, M., Check, D. K., Gerstel, A., Chen, R. C., Asher, G., & Rosenstein, D. L. (2015). Is there a role for survivorship care plans in advanced cancer? *Supportive Care in Cancer, 23*(8), 2225–2230. https://doi.org/10.1007/s00520-014-2586-4

National Cancer Institute. (2013). Surveillance, Epidemiology, and End Results (SEER) Program: Cancer stat facts: Brain and other nervous system cancer. Retrieved from [https://seer.cancer.gov/statfacts/html/brain.html](https://seer.cancer.gov/statfacts/html/brain.html)

National Comprehensive Cancer Network. (2018). NCCN Distress Thermometer and Problem List for Patients. Retrieved from [https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf](https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf)

Oancea, S. C., & Cheruvu, V. K. (2016). Psychological distress among adult cancer survivors: Importance of survivorship care plan. *Supportive Care in Cancer, 24*(11), 4523–4531. https://doi.org/10.1007/s00520-016-3291-2

Parman, C. (2015). Billing challenges for survivorship services. *Oncology Issues, 28*(3), 8–12. https://doi.org/10.1080/10463356.2013.11883843

Playdon, M., Ferrucci, L. M., McCorkle, R., Stein, K. D., Canady, R., Sanft, T., & Cartmel, B. (2016). Health information needs and preferences in relation to survivorship care plans of long-term cancer survivors in the American Cancer Society’s Study of Cancer Survivors-I. *Journal of Cancer Survivorship, 10*(4), 674–685. https://doi.org/10.1007/s11764-015-0513-4

Runowicz, C. D., Leach, C. R., Henry, N. L., Henry, K. S., Mackey, H. T., Cowens-Alvarado, R. L., & Ganz, P. A. (2016). American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline. CA: *A Cancer Journal for Clinicians, 66*(1), 43–73. https://doi.org/10.3322/caac.21319

Stupp, R., Taillibert, S., Kanner, A. A., Kesari, S., Steinberg, D. M., Toms, S. A., & Ram, Z. (2015). Maintenance therapy with tumor-treating fields plus temozolomide vs temozolomide alone for glioblastoma: A randomized clinical trial. *Journal of the American Medical Association, 314*(23), 2535–2543. https://doi.org/10.1001/jama.2015.16669

Tomasone, J. R., Brouwers, M. C., Yukimori, M., Grunfeld, E., O’Brien, M. A., Urquhart, R., & Fitch, M. (2016). Interventions to improve care coordination between primary healthcare and oncology care providers: A systematic review. *ESMO Open, 1*(5), e000077. https://doi.org/10.1136/esmoopen-2016-000077

Appendix on following page
## Appendix. Survivorship Care Plan of the Preston Robert Tisch Brain Tumor Center

### General Information

| Patient name: | Patient DOB: |

### Health-Care Providers

- Duke University Neuro-Oncologist:
- Duke Neuro-Oncology Advanced Practitioner:
- Duke Neuro-Oncology Nurse Clinician:
- Medical Oncologist:
- Radiation Oncologist:
- Neurosurgeon:

### Treatment Summary: Diagnosis

| Location and type of tumor: | Diagnosis date: |

### Biomarker

| Biomarker | Result |
|-----------|--------|
| MGMT      |        |
| Ki-67     |        |
| EGFR vIII |        |
| EGFR amplification | |
| IDH1      |        |
| IDH2      |        |
| TERT      |        |

### Treatment Summary: Presenting Symptoms

(Note: These can also be signs of disease recurrence.)

### Treatment Summary: Treatment Details

#### Surgery

| Initial surgery | Second surgery |
|-----------------|----------------|
| Surgery date:   | Surgery date:  |
| Type of surgery:| Type of surgery:|

#### Radiation

- Dates of radiation:
- Location of radiation:
- Dose of radiation:
  (Temozolomide 75 mg/m² by mouth daily administered during radiation.)

**Note.** This Survivorship Care Plan is a cancer treatment summary and follow-up plan provided to you to keep with your health care records and to share with your primary care provider. This summary is a brief record of major aspects of your cancer treatment. You can share your copy with any of your providers. However, this is not a detailed or comprehensive record of your care. HPV = human papillomavirus; PCP = primary care provider; DEXA = dual-energy x-ray absorptiometry. Information from American Academy of Ophthalmology (2015); American Cancer Society (2018); American Dental Association (2017); American Society of Clinical Oncology (2017); Centers for Disease Control and Prevention (2018).

*Continued on following page*
**Appendix. Survivorship Care Plan of the Preston Robert Tisch Brain Tumor Center (cont.)**

**Adjuvant therapy**

| Therapy                                      | Date                  |
|----------------------------------------------|-----------------------|
| **Temozolomide (Temodar) 150–200 mg/m² po daily, on for 5 days and off for 23 in 28-day cycles** | Start date:          |
| Total number of cycles: __________           | Stop date:            |
| **Temozolomide (Temodar) 50 mg/m² po daily**  | Start date:           |
| Total number of cycles: __________           | Stop date:            |
| **Lomustine (CCNU) ______ mg/m² po once every 6 weeks** | Start date:           |
| Total number of cycles: __________           | Stop date:            |
| **Irinotecan (CPT-11) ______ mg/m² IV every 2 weeks** | Start date:           |
| Total number of cycles: __________           | Stop date:            |
| **Carboplatin AUC ______ IV every ______ weeks** | Start date:           |
| Total number of cycles: __________           | Stop date:            |
| **Bevacizumab (Avastin) _____mg/kg IV every _________ weeks** | Start date:           |
| | Stop date:                                |
| Other:                                       | Start date:          |
|                                             | Stop date:            |

**Clinical Trial Information (Name of Trial and Dates)**

**Possible Symptoms of Disease Recurrence**

Headache, seizures, vision changes, personality changes, significant fatigue, trouble walking, balance issues, dizziness, severe nausea/vomiting, weakness on one side of the body, inability to speak, confusion, difficulty understanding others, decreased sensation on one side of the body

**Possible Late and Long-Term Effects That Someone With This Type Of Cancer and Treatment May Experience**

- Neurologic: Trouble concentrating, memory problems, numbness, tingling
- Emotional health: Depression, anxiety, stress, survivor’s guilt
- Hair, skin, nails: Discoloration or darkening of skin and nails, hair thinning
- Eye: Vision changes
- Digestion: Weight alterations, taste changes
- Other: Sexual dysfunction
- Pulmonary: Shortness of breath
  - Consider CT PE protocol
  - If the patient has been on lomustine and experiences shortness of breath, please check pulmonary function tests.
- Fatigue
  - Although fatigue may be related to brain injury and treatment, there are other causes. Please discuss the following with your primary care provider if fatigue persists or worsens:
    - CBC, CMP, thyroid profile, B₁₂, vitamin D, testosterone (men), or cortisol
    - If fatigue persists, consider head CT or brain MRI

**Note.** This Survivorship Care Plan is a cancer treatment summary and follow-up plan provided to you to keep with your health care records and to share with your primary care provider. This summary is a brief record of major aspects of your cancer treatment. You can share your copy with any of your providers. However, this is not a detailed or comprehensive record of your care. HPV = human papillomavirus; PCP = primary care provider; DEXA = dual-energy x-ray absorptiometry. Information from American Academy of Ophthalmology (2015); American Cancer Society (2018); American Dental Association (2017); American Society of Clinical Oncology (2017); Centers for Disease Control and Prevention (2018).
**Appendix. Survivorship Care Plan of the Preston Robert Tisch Brain Tumor Center (cont.)**

### Long-Term Oral Medications for Brain Tumor (Dose and Frequency)
(Note: Some of these medications may require monitoring with labs.)

- **Anti-seizure medications:**
- **Energy and concentration medications:**
- **Mood medications:**
- **Anticoagulants:**
- **Other:**

### Follow-Up Care
(Note: These will vary individually. Please further discuss with your primary care provider.)

| Visit/exam                        | When/how often                                      |
|-----------------------------------|-----------------------------------------------------|
| Duke Brain Tumor Center           | At least every 2 months for the first year off therapy. |
| Visit with primary care provider  | At least annually. Blood work to be discussed at this visit. |
| Eye exam                          | Baseline at age 40 followed by every 1 to 2 years |
| Mammogram                         | Discussion with your doctor beginning at age 40 |
| Colonoscopy                       | Every 10 years starting at age 50 or earlier pending family history |
| Pap test                          | Women age 21-29: Every 3 years                      |
|                                  | Women age 30–65: Pap with HPV every 5 years         |
|                                  | After age 65: Discuss with your PCP                 |
| Prostate-specific antigen/prostate exam | Discussion with your doctor between the ages of 40-50 |
| DEXA scan                         | Discussion with your doctor. This will vary depending on age, gender, and previous steroid use. |
| Dental exam                       | Every six months                                    |

(Note: Please continue to receive the following vaccines)

| Vaccine      | Indication                                      |
|--------------|-------------------------------------------------|
| Flu          | Annual                                          |
| Pneumonia    | Should receive at age 65                        |
| Tdap         | Every 10 years                                  |
| Shingles     | Should receive at age 60. Discuss new guidelines for age 50 and older with your healthcare professional. |

### Symptom Reporting
Please continue to see your primary care provider for all general health care recommended for your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:

1. Anything that represents a brand-new symptom
2. Anything that represents a persistent symptom
3. Anything you are worried about that might be related to the cancer coming back.

*Note. This Survivorship Care Plan is a cancer treatment summary and follow-up plan provided to you to keep with your health care records and to share with your primary care provider. This summary is a brief record of major aspects of your cancer treatment. You can share your copy with any of your providers. However, this is not a detailed or comprehensive record of your care. HPV = human papillomavirus; PCP = primary care provider; DEXA = dual-energy x-ray absorptiometry. Information from American Academy of Ophthalmology (2015); American Cancer Society (2018); American Dental Association (2017); American Society of Clinical Oncology (2017); Centers for Disease Control and Prevention (2018).*

Continued on following page
### Appendix. Survivorship Care Plan of the Preston Robert Tisch Brain Tumor Center (cont.)

#### Lifestyle
Many lifestyle/behaviors can affect ongoing health, including the risk for the cancer coming back or developing another cancer.

- **Weight**: It is important to maintain a healthy weight.
- **Diet/Nutrition**: Eat a variety of foods including fruits and vegetables. Meat is ok. We have a dietician available to further discuss this with you.
- **Tobacco use/cessation**: Avoid tobacco and second-hand smoke.
- **Alcohol**: The American Society of Clinical Oncology states that alcohol consumption can lead to cancer of the breast, colon, esophagus, and head and neck.
- **Sun**: Limit sun and UV exposure. Use sunscreen with SP of 30 or greater. Avoid tanning beds. Wear sunglasses.
- **Exercise**: Try to be as active as possible and set an exercise plan that works for you.
- **Sleep**: Get enough sleep as this is important to mental and physical health.

#### Common Issues
Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

- Emotional and mental health
- Weight changes
- Stopping smoking
- Physical functioning/fatigue
- Insurance
- School/work
- Financial advice or assistance
- Memory or concentration loss
- Parenting
- Fertility/sexual functioning

**Note.** This Survivorship Care Plan is a cancer treatment summary and follow-up plan provided to you to keep with your health care records and to share with your primary care provider. This summary is a brief record of major aspects of your cancer treatment. You can share your copy with any of your providers. However, this is not a detailed or comprehensive record of your care. HPV = human papillomavirus; PCP = primary care provider; DEXA = dual-energy x-ray absorptiometry. Information from American Academy of Ophthalmology (2015); American Cancer Society (2018); American Dental Association (2017); American Society of Clinical Oncology (2017); Centers for Disease Control and Prevention (2018).