Sarcoma (SARC)

<u>Instructions:</u> The Enrollment Form should be completed for each TCGA qualified case, upon qualification notice from the BCR. All information provided on this form should include activity and known history from the date of initial diagnosis to the most recent date of contact with the patient ("Date of Initial Pathologic Diagnosis" and "Date of Last Contact" on this form).

Questions regarding this form should be directed to the Tissue Source Site's primary Clinical Outreach Contact at the BCR.

#### Please note the following definitions for the "Unknown" and "Not Evaluated" answer options on this form.

**Unknown:** This answer option should only be selected if the TSS does not know this information after all efforts to obtain the data have been exhausted. If this answer option is selected for a question that is part of the TCGA required data set, the TSS must complete a discrepancy note providing a reason why the answer is unknown.

**Not Evaluated:** This answer option should only be selected by the TSS if it is known that the information being requested cannot be obtained. This could be because the test in question was never performed on the patient or the TSS knows that the information requested was never disclosed.

Tissue Source Site (TSS):TSS Identifier:			TSS Unique Patient Identifier:			
Comp	oleted By (Interviewer Nam	e in OpenClinica):	Completed Date:			
Gene	General Information					
#	Data Element	Entry Alternatives	Working Instructions			
1	Is this a prospective tissue collection?	□ Yes □ No	Indicate whether the TSS providing tissue is contracted for prospective tissue collection. If the submitted tissue was collected for the specific purpose of TCGA, the tissue has been collected prospectively.  3088492			
2	Is this a retrospective tissue collection?	□ Yes □ No	Indicate whether the TSS providing tissue is contracted for retrospective tissue collection. If the submitted tissue was collected prior to the date the TCGA contract was executed, the tissue has been collected retrospectively.  3088528			
	ient Information					
Dat	e of Birth		Drawide the date the nations was how			
3*	Date of Birth	Month Day Year	Provide the date the patient was born. 2896950 (Month), 2896952 (Day), 2896954 (Year)			
4*	Gender	☐ Female ☐ Male	Provide the patient's gender using the defined categories. 2200604			
5	Race	☐ American Indian or Alaska Native ☐ Asian ☐ White ☐ Black or African American ☐ Native Hawaiian or other Pacific Islander: ☐ Not Evaluated ☐ Unknown	Provide the patient's race using the defined categories.  2192199  American Indian or Alaska Native: A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.  Asian: A person having origins in any of the original peoples of the far East, Southeast Asia, or in the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.  White: A person having origins in any of the original peoples of the far Europe, the Middle East, or North Africa.  Black or African American: A person having origins in any of any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."  Native Hawaiian or other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.  Not Evaluated: Not provided or available.  Unknown: Could not be determined or unsure.			
6	Ethnicity	<ul> <li>□ Not Hispanic or Latino</li> <li>□ Hispanic or Latino</li> <li>□ Not Evaluated</li> <li>□ Unknown</li> </ul>	Provide the patient's ethnicity using the defined categories.  2192217  Not Hispanic or Latino: A person not meeting the definition of Hispanic or Latino.  Hispanic or Latino: A person of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture or origin, regardless of race.  Not Evaluated: Not provided or available.  Unknown: Could not be determined or unsure.			

7	History of Other Malignancy	☐ Yes ☐ No	Indicate whether the patient was, at any time in their life, diagnosed with a malignancy prior or synchonous to the diagnosis of the specimen submitted for TCGA. If the patient has had a prior or synchonous malignancy, an additional form (the "Other Malignancy Form") must be completed for each prior or synchronous malignancy. If the OMF was completed and submitted with the Initial Case Quality Control Form, the OMF does not need to be submitted a second time.  3382736  If this question cannot be answered because the answer is unknown, the case will be excluded from TCGA.  If the patient has a history of multiple diagnoses of basal or squamous cell skin cancer, complete an OMF for the first diagnosis for each of these types.			
8	Neo-adjuvant (Pre- Operative) Therapy for Tumor Submitted for TCGA	☐ Yes ☐ No	Indicate whether the patient received neo-adjuvant treatment (radiation, pharmaceutical, or both) prior to the collection of the tumor that yielded the sample submitted for TCGA.  3382737  Systemic therapy and certain localized therapies (those administered to the same site as the TCGA submitted tissue) given prior to the collection of the sample submitted for TCGA is exclusionary.			
9	Tumor Status (at time of last contact or death)	☐ Tumor free ☐ With tumor ☐ Unknown	Indicate whether the patient was tumor/disease free at the date of last contact or death.  2759550			
10	Vital Status (at date of last contact)	☐ Living ☐ Deceased	Indicate whether the patient was living or deceased at the date of last contact.  5			
11	Date of Last Contact	Month Day Year	If the patient is living, provide the date of last contact with the patient (as reported by the patient, medical provider, family member, or caregiver).  2897020 (Month), 2897022 (Day), 2897024 (Year)			
12	Date of Death	Month Day Year	If the patient is deceased, provide the date of death.  2897026 (Month), 2897028 (Day), 2897030 (Year)			
13	Adjuvant (Post- Operative) Radiation Therapy	☐ Yes ☐ No ☐ Unknown	Indicate whether the patient had adjuvant/ post- operative radiation therapy.  2005312  If the patient did have adjuvant radiation, the Radiation  Supplemental Form should be completed.			
14	Adjuvant (Post- Operative) Pharmaceutical Therapy	☐ Yes ☐ No ☐ Unknown	Indicate whether the patient had adjuvant/ post- operative pharmaceutical therapy.  2785850  If the patient did have adjuvant pharmaceutical therapy, the Pharmaceutical Supplemental Form should be completed.			
Prim	rimary Tumor Pathologic/ Prognostic Information					
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#	Data Element Entry Alternatives W		Working Instructions	
15	Histological Type	□ Dedifferentiated liposarcoma □ Leiomyosarcoma (LMS)* □ Undifferentiated Pleomorphic Sarcoma (UPS), NOS □ Pleomorphic 'MFH' / Undifferentiated pleomorphic sarcoma □ Giant cell 'MFH' / Undifferentiated pleomorphic sarcoma with giant cells □ Inflammatory 'MFH' / Undifferentiated pleomorphic sarcoma with prominent inflammation □ Malignant Peripheral Nerve Sheath Tumors (MPNST) □ Desmoid Tumor □ Myxofibrosarcoma □ Synovial Sarcoma - Monophasic □ Synovial Sarcoma - Poorly differentiated	Using the patient's pathology/laboratory report, select the histology and/or subtype of the tumor submitted for TCGA. 3081934  If the histological type is Leiomyosarcoma, please complete the three additional questions below. For all other histological subtypes these three questions can be skipped.	

# **Enrollment Form** Sarcoma (SARC)

#	Data Element	Entry Alternatives	Working Instructions
16	Leiomyosarcoma: Histological Subtype	<ul> <li>□ Well-differentiated leiomyosarcoma (resembling leiomyoma)</li> <li>□ Conventional leiomyosarcoma</li> <li>□ Poorly differentiated/ pleomorphic/ epithelioid leiomyosarcoma</li> </ul>	If the histological subtype is Leiomyosarcoma, using the patient's pathology/laboratory report, select the histological subtype of the tumor submitted for TCGA.  2831122
17	Leiomyosarcoma: Uterine Involvement	☐ Yes ☐ No ☐ Unknown	If the histological subtype is Leiomyosarcoma, using the patient's pathology/laboratory report, indicate whether there was uterine involvement.  2775554
18	Leiomyosarcoma: Major Vessel Involvement	□ No □ Unknown □ Yes - NOS □ Yes - Jugular/carotid □ Yes - Subclavicular □ Yes - Superior vena cava/chest □ Yes - Inferior vena cava □ Yes - Brachial vein/ axillary vein □ Yes - Renal vein	If the histological subtype is Leiomyosarcoma, using the patient's pathology/ laboratory report, indicate whether there was major vessel involvement. If the patient did have major vessel involvement, indicate where it was located. 3243330
19	Synovial Sarcoma: SS18-SSX Fusion Status	□ Positive - SS18-SSX1 □ Positive - SS18-SSX2 □ Positive - Subtype □ Negative □ Unknown	Using the patient's pathology/cytogenetics/molecular diagnostics laboratory report, indicate whether evidence of an SS18-SSX fusion was reported and the testing method.  3733516
20	Synovial Sarcoma: SS18-SSX Testing Method	□ RT-PCR □ FISH for SS18 split □ Both □ Unknown	Using the patient's pathology/cytogenetics/molecular diagnostics laboratory report, indicate the testing method for SS18-SSX.  3733517
21	MPNST: Does the patient have neurofibrobromatosis?	□ NF1 □ NF2 □ No □ Unknown	Using the patient's medical records, indicate whether the patient had neurofibrobromatosis.  3733521
22	MPNST: If the patient has neurofibrobromatosis, is it familial or sporadic?	☐ Familial ☐ Sporadic ☐ Unknown	If the patient had neurofibromatosis, indicate if it was known to be familial or sporadic.  3733535
23	MPNST: Pre-exisiting plexiform neurofibroma at site of MPNST?	☐ Yes ☐ No ☐ Unknown	Using the patient's medical records, indicate whether the patient had pre-exisiting plexiform neurobibroma at site of MPNST.  3733551
24	MPNST: Was NF1 Genetic Testing Performed?	☐ Yes, mutations identified ☐ Yes, mutations were NOT identified ☐ No ☐ Unknown	Using the patient's medical records, indicate whether NF1 genetic testing was performed.  3733556
25	MPNST: If NF1 genetic testing was performed and mutations were identified, please identify the specific mutations.		If NF1 genetic testing was performed, provide any specific mutations that were identified.  3733558
26	Tumor Depth	□ Superficial □ Deep □ Unknown	Using the patient's pathology/ laboratory report, indicate the depth of the tumor. 3808610
27	Primary Site of Disease	□ Head & Neck       □ Retroperitoneum/         □ Head       Upper abdominal         □ Neck       □ Retroperitoneum         □ Other, specify       □ Intraabdominal         □ Chest       □ Kidney         □ Lung/pleura       □ Liver         □ Mediastinum       □ Colon         □ Chest wall       □ Gastric	Using the patient's pathology/laboratory report, select the anatomic site of disease of the tumor submitted for TCGA. 2735776  If the histological type is Leiomyosarcoma and the primary site of disease is skin, this case is excluded.

### Enrollment Form Sarcoma (SARC)

#	Data Element	Entry Alternatives		Working Instructions	
		☐ Diaphragm	□ Duodenum		
		☐ Breast	☐ Small Intestines		
		☐ Other, specify☐ Superficial Trunk	☐ Pancreas☐ Other, specify		
		Abdominal wall	Lower abdominal/		
		■ Buttock	Pelvic		
		☐ Flank	☐ Pelvic		
		■ Back	■ Bladder		
		☐ Other, specify	■ Prostate		
		☐ Upper Extremity	Rectum		
		☐ Shoulder/axilla	☐ Spermatic Cord		
		☐ Upper arm/elbow☐ Forearm	☐ Scrotum/testis☐ Other, specify		
		☐ Hand/wrist	☐ Gynecological		
		☐ Other, specify	☐ Uterus		
		☐ Lower Extremity	□ Ovary		
		☐ Thigh/knee	☐ Cervix		
		Groin	☐ Fallopian tube		
		☐ Lower leg/calf☐ Foot/ankle	☐ Other, specify		
		Other, specify			
		= other, specify		If the primary site of disease on the pathology/laboratory	
28	Other Primary Site of			report is not available or does not specifically match the	
20	Disease			provided sites above, describe the site(s) of disease. 2584114	
				Provide the date the patient was initially pathologically	
29	Date of Initial			diagnosed with the malignancy submitted for TCGA.	
	Pathologic Diagnosis	Month Day	Year	2896956 (Month), 2896958 (Day), 2896960 (Year)	
		□ Positive (+) ≤ 1mm		Provide the margin status after the patient's first surgical	
30	Margin Status	☐ Negative (-)		procedure.	
		☐ Unknown		3114007	
31	Residual Tumor	□ RX	<b>□</b> R1	Using the patient's pathology/laboratory report, select the residual tumor status after the surgical resection.	
31	Residual Tulliol	□ R0	<b>□</b> R2	2608702	
	Necrosis of Total Tumor	□ 0% (no necrosis or no	mention of necrosis)	Using the patient's pathology/laboratory report, select the	
		□ <10% ("focal necrosis")		necrosis of the total tumor. If a specific percentage of necrosis is available, answer the following question.	
32		☐ Moderate Necrosis (		3300612	
		☐ Extensive Necrosis (	,		
		Complete or if listed (>99% or profound			
	_	therapy effect)		Indicate the percent necrosis of the entire tumor as recorded	
33	Percent Necrosis of			either at the time of resection or during subsequent analysis.	
	Total Tumor			<u>2841237</u>	
				Using the patient's pathology/laboratory report, provide the	
34	Mitotic Count		401:1	patient's mitotic count. This should be the number mitoses per 10 high powered fields (10 HPF $\cong$ 2.2 mm <sup>2</sup> ).	
		(number mitoses per	10 high power fields)	3227319	
		☐ Yes		Using the patient's pathology/laboratory report, indicate	
35	Is Disease Multifocal?	□ No		whether the disease was multifocal.	
		☐ Unknown		64356	
0.6	Number of			Using the patient's pathology/laboratory report, provide the	
36	Discontiguous Lesions			number of discontiguous lesions. 3162604	
Tur	Tumor Size: Include both well-differentiated and de-differentiated components.				
	(If there were multiple lesions, complete this question for each lesion)				
				Provide the length for this tumor, when available as reported	
		Radiologic Length	(cm)	on the CT scan or MRI, immediately preceding the surgical resection.	
				<u>3528021</u>	
				Provide the width for this tumor, when available as reported	
37	Radiologic Tumor Size	Radiologic Width	(cm)	on the CT scan or MRI, immediately preceding the surgical resection.	
				<u>3528033</u>	
				Provide the depth for this tumor, when available as reporte	
		Radiologic Depth	(cm)	on the CT scan or MRI, immediately preceding the surgical resection.	
				<u>3528032</u>	

#	Data Element	Entry Alt	ernatives	Working Instructions		
		Pathologic Length	(cm)	Provide the length for this tumor, when available as examined pathologically at the time of the surgical resection. 3528034		
38	Pathologic Tumor Size	Pathologic Width	(cm)	Provide the width for this tumor, when available as examined pathologically at the time of the surgical resection. 3528041		
		Pathologic Depth	(cm)	Provide the depth for this tumor, when available as examined pathologically at the time of the surgical resection. 3528040		
39	Radiologic Tumor Burden			Provide the sum of the maximum diameter of the primary tumors as reported on the CT scan or MRI immediately preceding surgical resection. This should include both well-differentiated and de-differentiated components.  3162636		
40	Pathologic Tumor Burden			Provide the sum of the maximum diameter of the primary tumors as examined pathologically at the time of the surgical resection. This should include both well-differentiated and dedifferentiated components.  3162641		
41	Locoregional Recurrence	☐ Yes ☐ No	□ Unknown	Indicate whether the patient had a local recurrence associated with the tumor submitted for TCGA.  62652		
42	Metastasis (Radiologic Evidence)	☐ Yes ☐ No ☐ Unknown		Indicate whether the patient was diagnosed with a distant metastasis with radiologic evidence.  65384		
43	Location of Metastasis	☐ Lung ☐ Bone ☐ Liver	☐ Unknown☐ Other, specify	If the patient had a metastatic tumor associated with the diagnosis of the tumor submitted for TCGA, provide the site of the metastasis. If there was more than one metastatic site, select all that apply.  3124499		
44	Other Location of Metastasis			If the site of the metastasis was not included in the list provided, please provide the site.  3124503		
45	Contiguous Organ/ Structure Resection	□ Adrenal □ Bladder □ Colon □ Inferior vena cava (IVC)	☐ Kidney ☐ Liver ☐ Small Bowel ☐ Spleen ☐ Unknown ☐ Other, specify	If the patient had a contiguous organ/ structure removed, indicate the location of the contiguous organ.  3162811		
46	Other Contiguous Organ/ Structure Resection			If the site of the contiguous organ/ structure was not included in the list provided, describe the organ. 3162812		
47	Contiguous Organ Invaded	☐ Yes ☐ No ☐ Unknown		Indicate whether the tumor invaded a contiguous organ. 3162817		
48	Dedifferentiated Liposarcoma: Prior Diagnosis of Well Differentiated Liposarcoma	☐ Yes ☐ No ☐ Unknown		Indicate whether the patient had a prior diagnosis of well differentiated liposarcoma.  3162681  Only answer this question if the histological subtype for tumor submitted to TCGA is dedifferentiated liposarcoma. All other subtypes can skip the remaining questions.		
Date	Date of <u>Primary Diagnosis</u> of Well Differentiated Liposarcoma					
49	Date Primary Diagnosis of Well Differentiated Liposarcoma	 Month Day	 	If the patient had a prior diagnosis of well differentiated liposarcoma, provide the date of this diagnosis.  3162688 (Month), 3162689 (Day), 3162690 (Year)		
Date	Date of Resection of Well Differentiated Liposarcoma					
50	Date Resection of Well Differentiated Liposarcoma		Year	If the patient had a prior diagnosis of well differentiated liposarcoma, provide the date the tumor was removed. 3162705 (Month), 3162706 (Day), 3162707 (Year)		

**New Tumor Event Information** Complete this section if the patient had a new tumor event. If the patient did not have a new tumor event (or if the TSS does not know) indicate this in the question below, and the remainder of this section can be skipped.

Note: The New Tumor Event section on OpenClinica can be completed multiple times, if the patient had multiple New Tumor Events.

## **Enrollment Form** Sarcoma (SARC)

#	Data Element	Entry Alternatives		Working Instructions
51	New Tumor Event After Initial Treatment?	☐ Yes ☐ No ☐ Unknown		Indicate whether the patient had a new tumor event (e.g. metastatic, recurrent, or new primary tumor) after their initial treatment. 3121376
52	Type of New Tumor Event	☐ Locoregional/Recurrence☐ Distant Metastasis☐ New Primary Tumor		Indicate whether the patient's new tumor event was a locoregional recurrence, a distant metastasis or a new primary tumor. 3119721
53	Site of New Tumor Event	☐ Lung ☐ Bone ☐ Liver	☐ Brain☐ Unknown☐ Other, specify	Indicate the site of this new tumor event. $\frac{3108271}{2}$
54	Other Site of New Tumor Event			If the patient had a new tumor event and the site of this tumor was not included in the provided list, describe the site. 3128033
Date	of New Tumor Event after l	nitial Treatment		
<u>55</u>	Date of New Tumor Event		 	If the patient had a new tumor event, provide the date of diagnosis for this new tumor event.  3104044 (Month), 3104042 (Day), 3104046 (Year)
<u>56</u>	Additional Surgery for New Tumor Event	☐ Yes ☐ No ☐ Unknown		Using the patient's medical records, indicate whether the patient had surgery for the new tumor event in question. 3427611
Date	e of Additional Surgery for I	New Tumor Event (when	applicable)	
<u>57</u>	Date of Additional Surgery for New Tumor Event			If the patient had surgery for the new tumor event, provide the date this surgery was performed.  3427612 (Month), 3427613 (Day), 3427614 (Year)
<u>58</u>	Residual Tumor after Surgery for New Tumor Event	□ RX □ R0	□ R1 □ R2	Using the patient's pathology/laboratory report, select the residual tumor status after the surgical resection for the new tumor event.  3104061
<u>59</u>	Is Disease Multifocal?	☐ Yes ☐ No ☐ Unknown		Using the patient's pathology/laboratory report, indicate whether the new tumor was multifocal.  3524937
<u>60</u>	Number of Discontiguous Lesions			Using the patient's pathology/laboratory report, provide the number of discontiguous lesions for the new tumor. 3526717
		Radiologic Length	(cm)	Provide the length for the new tumor, when available as reported on the CT scan or MRI, immediately preceding the surgical resection of the new tumor.  3527990
<u>61</u>	Radiologic Size of New Tumor	Radiologic Width	(cm)	Provide the width for the new tumor, when available as reported on the CT scan or MRI, immediately preceding the surgical resection of the new tumor.  3527997
		Radiologic Depth	(cm)	Provide the depth for the new tumor, when available as reported on the CT scan or MRI, immediately preceding the surgical resection of the new tumor.  3527996
	Pathologic Size of New Tumor	Pathologic Length	(cm)	Provide the length for the new tumor, when available as examined pathologically at the time of the surgical resection of the new tumor.  3528003
<u>62</u>		Pathologic Width	(cm)	Provide the width for the new tumor, when available as examined pathologically at the time of the surgical resection of the new tumor.  3528020
		Pathologic Depth	(cm)	Provide the depth for the new tumor, when available as examined pathologically at the time of the surgical resection of the new tumor.  3528004
<u>63</u>	Radiologic Burden of New Tumor			Provide the sum of the maximum diameter of the new tumors as reported on the CT scan or MRI immediately preceding surgical resection. This should include both well-differentiated and de-differentiated components.  3526720

#	Data Element	Entry Alternatives	Working Instructions
64	Pathologic Burden of New Tumor		Provide the sum of the maximum diameter of the new tumors as examined pathologically at the time of the surgical resection. This should include both well-differentiated and dedifferentiated components.  3526721
<u>65</u>	Is the New Tumor Well- Differentiated or De- Differentiated? (Check all that apply)	☐ Well-Differentiated ☐ De-Differentiated	Indicate whether the newly diagnosed tumor is well-differentiated or de-differentiated.  3194001
<u>66</u>	Additional treatment for New Tumor Event: Radiation Therapy	☐ Yes ☐ No ☐ Unknown	Indicate whether the patient received radiation treatment for this new tumor event. 3427615
<u>67</u>	Additional treatment for New Tumor Event: Pharmaceutical Therapy	☐ Yes ☐ No ☐ Unknown	Indicate whether the patient received pharmaceutical treatment for this new tumor event.  3427616
		estions are only to be answered if the Tissue Source S data if you have received permission from the NCI to provide ti	ite is unable to provide the dates requested on this form. me intervals as a substitute for requested dates on this form.
i	Has this TSS received permission from the NCI to provide time intervals as a substitute for requested dates on this form?	□ Yes □ No	Please Note: The time intervals must be recorded in place of dates where designated throughout this form if you have selected "yes" in the box. Provided time intervals must begin with the date of initial pathologic diagnosis (i.e., biopsy or resection).
ii	Number of Days from Date of Initial Pathological Diagnosis to Date of Birth	days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date of birth.  3008233
iii	Number of Days from Date of Initial Pathological Diagnosis to Date of Last Contact	days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date of last contact. 3008273
iv	Number of Days from Date of Initial Pathological Diagnosis to Date of Death	days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date of death 3165475
v	Age at Initial Diagnosis	days	Provide the age of the patient in years, at the time the patient was initially pathologically diagnosed with the tumor submitted for TCGA.  2006657
vi	Number of Days from Date of Initial Pathologic Diagnosis to Diagnosis of Well Differentiated Liposarcoma	days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date the patient was diagnosed with primary well differentiated liposarcoma. 3523205
vii	Number of Days from Date of Initial Pathologic Diagnosis to Resection of Well Differentiated Liposarcoma	days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease described on this form to the date of the resection of well differentiated liposarcoma.  3523210
viii	Number of Days from Date of Initial Pathological Diagnosis to Date of New Tumor Event After Initial	days	Provide the number of days from the date the patient was initially diagnosed pathologically with the disease to the date of new tumor event after initial treatment. 3392464

Treatment

Рад	ge 8	<b>Enrollment For</b> Sarcoma (SARC	
ix	Number of Days from Date of Initial Pathologic Diagnosis to Date of Additional Surgery for New Tumor	days	Provide the number of days from date of initial pathologic diagnosis to date of additional surgery for new tumor event 3008335
	Event Principa	l Investigator Signature	Date

 $\it I$  acknowledge that the above information provided by my institution is true and correct and has been quality controlled.