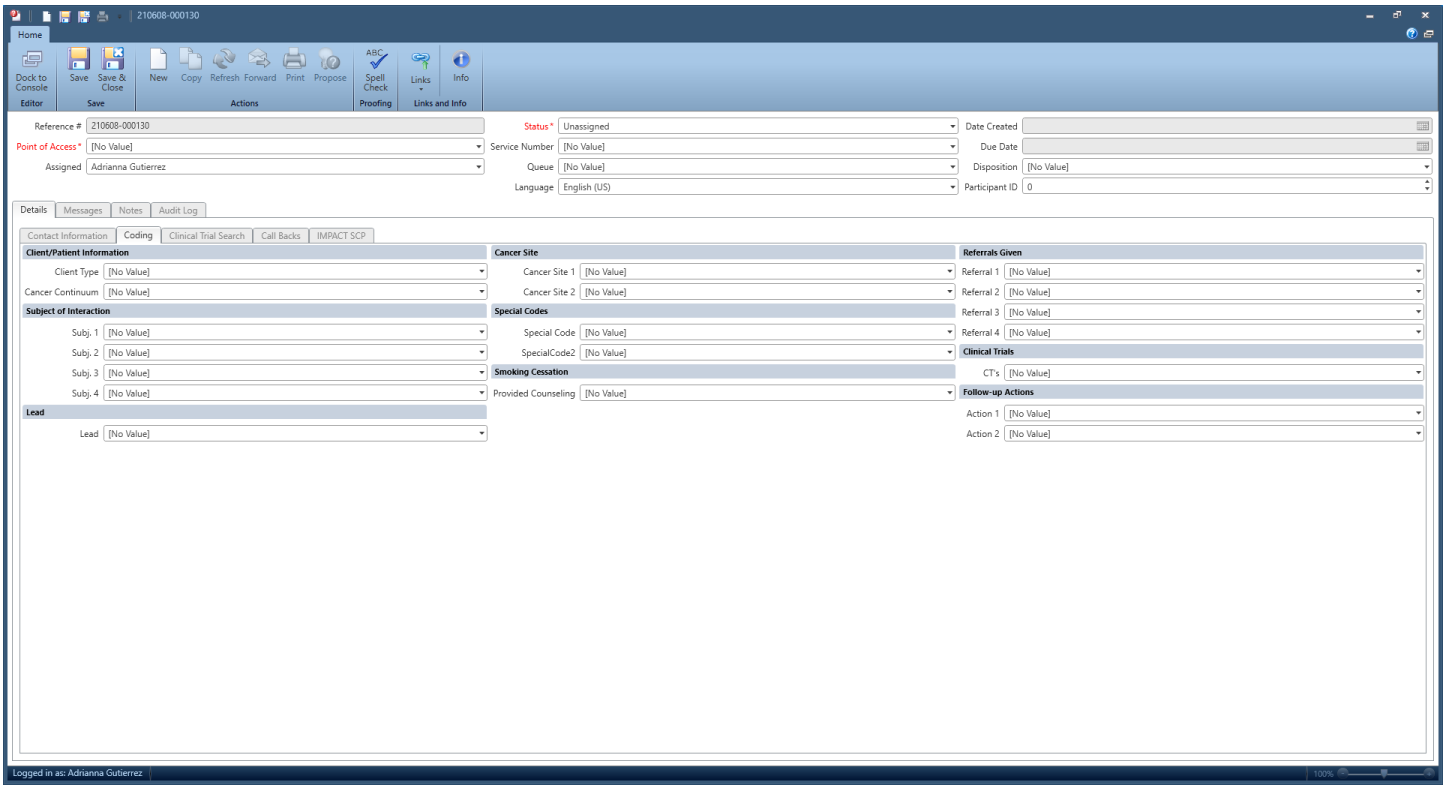
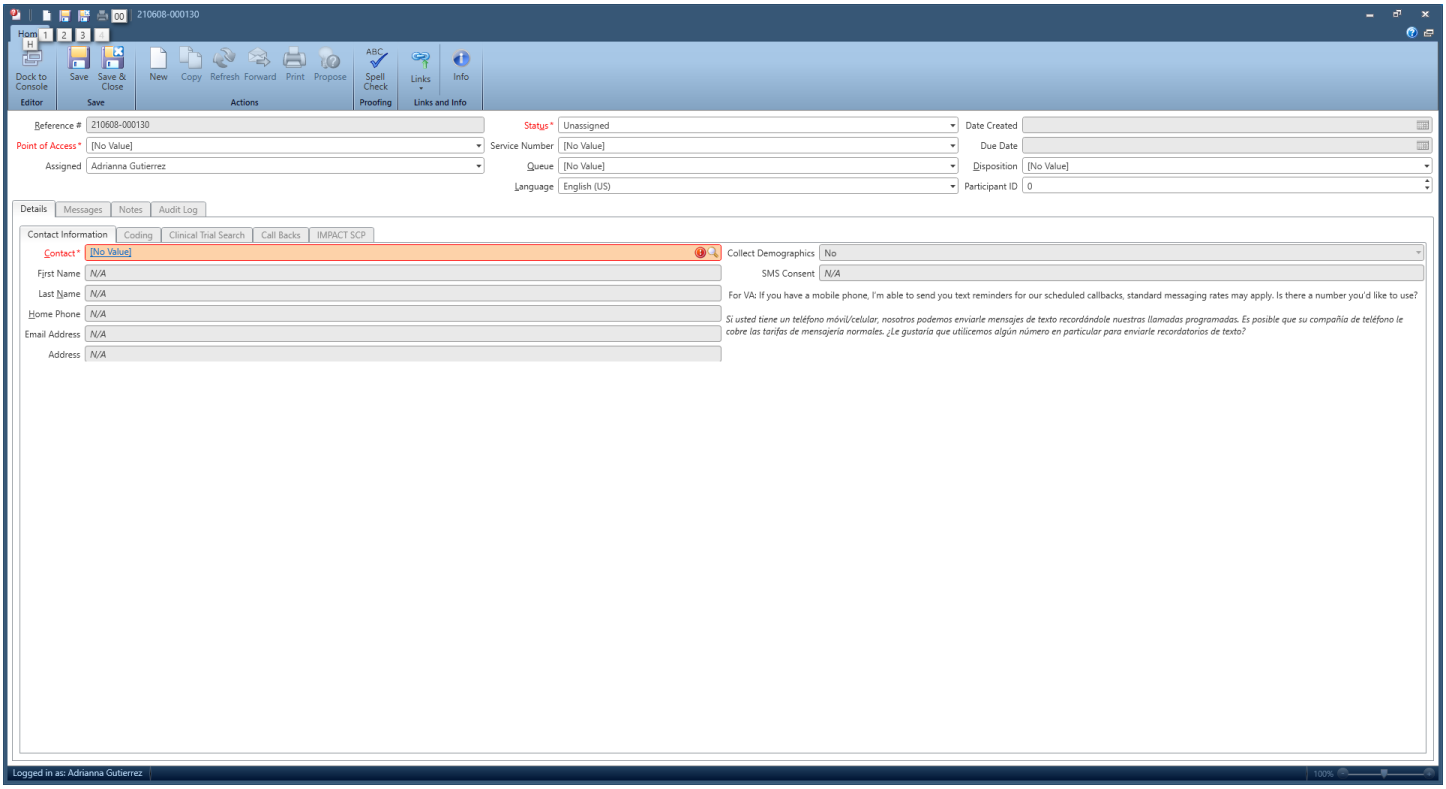
NCI/Office of Communications and Public Liaison

APPENDIX 10

ELECTRONIC CONTACT RECORD FORM(ECRF) with SCREEN SHOTS

Electric Coding Record Form (ECRF)





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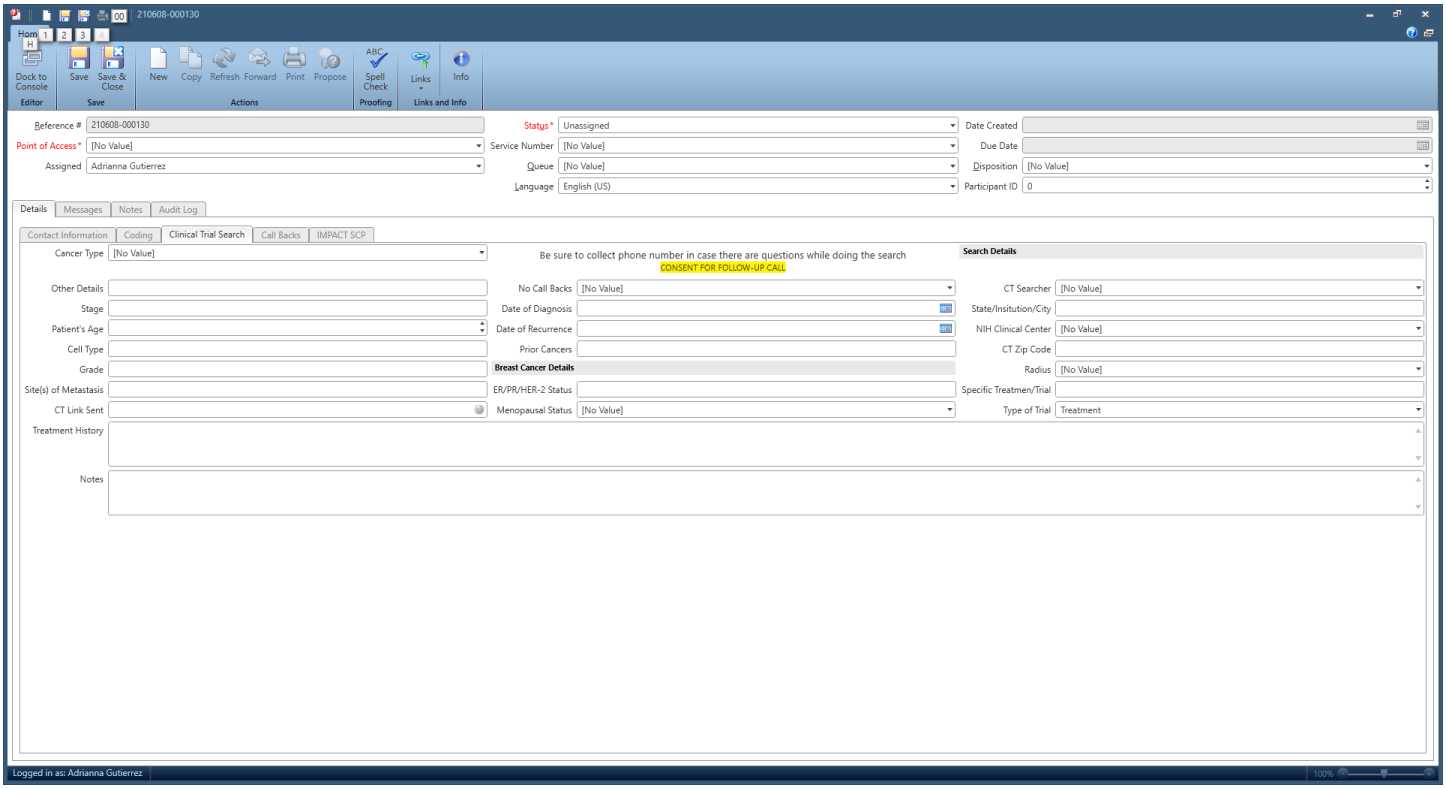

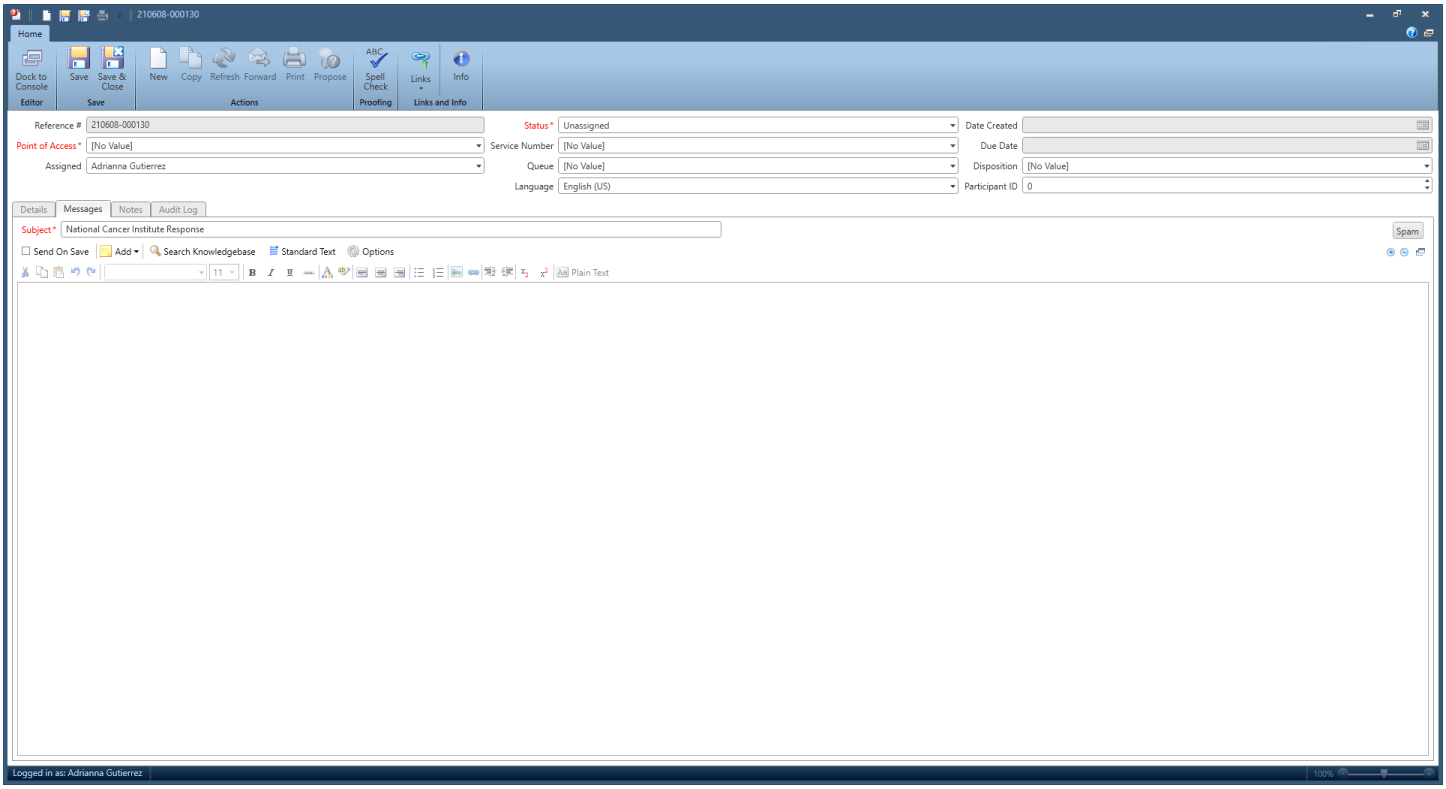

TYPE OF USER

Cancer Patient	*Patients along any point of the cancer continuum, recurrence or a new primary who were previously treated, started but not completed treatment. Includes cancer survivors and those with treated myeloproliferative and myelodysplastic disorders, and treated DCIS. Post-treatment maintenance, etc.*
Spouse, relative, friend of diagnosed cancer patient	*Includes relatives/friends of deceased cancer patients*
General Public	*Members of the public including: symptomatic people and their friends/relatives, inquiries about pets, precancerous or noncancerous conditions. (Includes all non-health professionals e.g. educators, clergy, librarian, lawyers, CPAs, insurance agents)*
Organization *	*Contacts from organizations, healthcare facilities, advocacy groups*
Health professional *	*MDs,RNs,PAs,PTs,NPs, social workers, nutritionists, and other allied health professionals, public health professionals, cancer registrar*
Scientist/Researcher *	*Includes researchers and scientists in training*
Media *	*Newspaper, television, radio, web – media*
Cigarette smoker – help to Quit	
Other tobacco user – help to Quit	
Relative/friend of tobacco user	
Students *	*Except researchers and scientist in training*
Government/Congressional *	*Congressional Aides; Federal Employee, etc.*
Other/Not able to ascertain	

*Do not ask demographics

Cancer Continuum

N/A	*Non-Cancer interactions, Cancer Continuum unknown, Patient is deceased, general questions not about a specific individual*
General Public/Undiagnosed	*symptoms questions, finding a health center*
Screening	*Questions about screening or finding a screening program*
Diagnostic	*People who have a symptom or have been referred for diagnostic testing, but have not yet received an official diagnosis*
Staging	*People who have been diagnosed but have not yet begun treatment because they are being staged*
Treatment	*Patients who are in treatment, this could be any stage of treatment*
Post-Treatment	*Any questions about life after treatment; follow-up care, recurrence rates, late effects, etc..*
End-of-Life	*Would include hospice/palliative or other end of life conversations*

SUBJECT OF INTERACTION

Understanding Cancer/General Cancer (G)	*Heading*
G-COVID-19	*Use when main topic of conversation is COVID-19. Also use Special Code COVID-19*
G-General Cancer Questions	*Topics related to cancer in general that are not specific to a type of treatment*
G-Symptoms	*Topics related to symptoms of cancer in general, specific types of cancer, metastasis, or symptoms for recurrence*
G-Cancer Statistics/Epidemiological Stats	*Statistical data (e.g. incidence rates) not related to specific cancer patient/prognosis*
G-Prognosis	*Questions about prognosis for cancer at any stage including survival statistics*
G-Research Donations	*Questions about making donations to research (tissue, body, blood, etc)*
G-General Donations	*Donations to NCI, other organizations, and inquiries about solicitations (e.g. take me off your mailing list)*
G-Suicidal Client	
G-Other Inquiries	*Any other questions that are not defined in list*
Causes and Prevention (CP)	*Heading*
CP-Risk Factors	*Questions about any type of risk factor for any type of cancer (e.g. HPV, Environmental, hormone use and cancer, EMF, etc.)*
CP-Genetics	*Questions about heredity/genetics as a risk factor or for cancer*

	treatment
CP-Prevention	*Any questions about how to prevent cancer (e.g. Diet and Nutrition – including preventing recurrence, exercise, etc)*
Tests	*Questions about any tests that are done to screen, diagnose, stage, monitor, follow-up for cancer, including risks and benefits of tests*
Treatment (TX)	*Heading*
TX-General Treatment	*Questions about treatment in general that are not specific to a type of treatment including healthy eating during treatment*
TX-Surgery	
TX-Radiation Therapy	
TX-Chemotherapy	
TX-Immunotherapy	*Includes CAR T-cell, TIL, Vaccines (such as Sipuleucel-T), checkpoint inhibitors, BCG*
TX-Targeted Therapy	*Includes Monoclonal Antibodies, Angiogenesis inhibitors, examples: Sutent, Gleevec, Avastin*
TX-Hormone Therapy	
TX-Stem Cell Transplant	
TX-Complementary and Alternative Medicine	*Any questions related to any type of CAM used as any type of treatment (Biological based products, Body, spirituality, energy medicine, Manual therapies, Whole systems, marijuana, nutrition as supplement)*
CAM-Medical Marijuana	
CAM-Biological Based Products	*Herbs, supplement/vitamins, food, special diets*
CAM-Manual Therapies	*Acupuncture, massage, chiropractic, reflexology*
CAM-Whole Systems	*Homeopathy, naturopathy, Ayurveda*
CAM-Mind Body/Spirituality/Energy Med.	*Hypnosis, Tai Chi, Reiki, therapeutic touch, yoga, meditation, visualization, relaxation, prayer*
CAM-High Dose Vitamin C	
Side Effects	*Includes any type of side effects from treatment. (Side effects from cancer itself-code symptoms)*
Clinical Trials (CT)	*Heading*
CT-General Information Only	*General information about clinical trials are discussed, CTs as a treatment option, cost, enrollment and eligibility information, etc.*
CT-General Information & Search	*Including searches that result in no matches. Does NOT include CCR trials. Also code CCR Clinical Trials for searches that include the Clinical Center. Code as 1st SOI when a search is needed*

CT-CCR Clinical Trials	*Educated about or searched for CCR trials (NIH Clinical Center)*
CT-Results & Outcomes	*Discussed results of trial (This does NOT refer to sharing clinical trial search result). Includes client wanting to know about results of a trial he/she participated in or heard about.*
Coping	*Use when listening to client talk about coping, providing emotional coping strategies, or giving significant emotional support (for depression, anxiety, distress or any other psychosocial issues)*
Managing Cancer Care (MC)	*Heading*
MC-Finding Health Care Services	*Use when helping client find any type of health care services (GP, Screening, Treatment, Genetics, etc) Includes finding support, transportation, lodging services*
MC-Managing Costs and Medical Information	*Use when providing information about costs and structure of health care system as well as financial assistance*
MC-Palliative/Hospice Care	
Publication Requests	*Also code Cancer Type*
Smoking Cessation (SM)	*Heading*
SM-Cigarettes	
SM-Cigars, Cigarillos, or Little Cigars	
SM-Pipes	*(not water or hookah)*
SM-Chewing Tobacco	
SM-Other Tobacco	
SM-Marijuana (recreational use)	**For medical marijuana, see CAM section*
SM-Cessation Counseling/Information	
SM-E-cigs	
SM-NRT (nicotine replacement therapy)	
NCI	*Heading*
NCI-About NCI	*Questions about NCI*
NCI-Key Initiatives	*Cancer Moonshot, Genomic Data Commons, NCTN, RAS, Bioinformatics*
NCI Budget	*Funding priorities, Budget, Getting funding, asking about/applying for grants*

NCI-Problems with a CT search	*User specifically states difficulty finding a CT or using the CT search form.*
NCI Permissions Requests	*Includes logo requests, artwork, text and licensing permissions/requests*
NCI – Other	*Includes product endorsement from NCI, employment verification, contacting NCI and NIH staff members, help with fund- raising or other events such as health fairs, scientific materials for researchers including cell lines, mice, etc.*
NCI Resources	*Questions about content, PDQ and cancer.gov comments and questions. Includes Breast, Colorectal and Melanoma RATs*
NCI-Risk Tools	*Includes Breast, Colorectal and Melanoma RATs*
NCI-QuitSTART and other apps	*(QuitSTART replaced Quitpal)* *(QuitSTART replaced Quitpal)*
SEER	*Heading*
SEER Cancer Statistics	*CSR Current and Archived, Stats tools: Fast Stats, State Cancer Profiles, SEER*Explorer, Cancer Query System, Cancer Stat Facts*
SEER Datasets and Software	*i.e. SEER*Stat databases; SEER*Stat; Dictionary of SEER*Stat Variables; SEER-Medicare linked Database*
SEER Manuals	*Coding and Staging Manual - Current and Archived and SEER Heme and Lymph Neop. Database Man.*
SEER Registries/Training etc.	*i.e. List of Registries; Cancer Registrars Training; SEER Quality Improvement documents*
SEER - other	
FB –Advertising (products/services)	
FB – Fundraising	
FB – Other Languages	
FB – CAM Cures	

PRIMARY CANCER SITE/TYPE

AIDS-related cancers	*AIDS-related lymphomas, Kaposi's sarcoma, and others*
ALL	*Acute Lymphocytic Leukemia*
AML	*Acute Myeloid Leukemia*

Anal	
Biliary Tract	*Gallbladder and bile ducts outside the liver. Does NOT include intrahepatic cholangiocarcinoma (code as Liver).*
Bladder	
Brain	
Breast	*Includes breast exam questions*
Carcinoma of unknown primary	*Physician has specified that the primary site cannot be determined and diagnosis is CUP. Includes metastatic squamous neck cancer with occult primary. NOTE: If there is no specific site discussed, code Not Applicable*
Cervical	*Includes cervical dysplasia*
CLL	*Chronic Lymphocytic Leukemia*
CML	*Chronic Myelogenous Leukemia*
Colorectal	
Endometrial/Uterine	
Esophageal	
Eye	*Includes intraocular melanoma and retinoblastoma.*
Gastrointestinal carcinoid tumor/GIST	
Head and Neck	*Includes lip and oral cavity, laryngeal, pharyngeal, paranasal sinus, nasal cavity, and salivary gland.*
Hodgkin Lymphoma	
Liver	*Includes intrahepatic cholangiocarcinoma*
Lung and Bronchus	
Melanoma	*Includes all non-ocular melanoma regardless of site.*
Myeloma/Plasma cell neoplasm	
Non-Hodgkin Lymphoma	*Includes CNS lymphomas and mycosis fungoides*
Ovarian	*Includes ovarian epithelial, germ cell, stromal*
Pancreas	
Prostate	

Renal (kidney) & renal pelvis	
Skin cancer (nonmelanoma)	*Includes Merkel cell*
Small Intestine	
Soft tissue	*Includes sarcomas/leiomyosarcomas, and heart, and uterine sarcoma*
Stomach/Gastric	
Thyroid	
Other – Central Nervous System	*Includes neuroblastoma*
Other – Digestive	
Other – Endocrine system	*Includes pituitary, islet cell, pheochromocytoma, adrenocortical, parathyroid, and peripheral neuroepithelioma*
Other – Hematologic system	*Includes myeloproliferative disorders and myelodysplastic syndromes*
Other – Leukemia	*Includes leukemias whose type is unknown or not specified, or any other than AML, ALL, CML, CLL*
Other – Lymphoma	*Includes lymphomas whose type is unknown or not specified. Otherwise, code as HL or NHL.*
Other – Musculoskeletal and connective tissue	*Includes bone and joints*
Other – Reproductive, female	*Includes labia, vulva, vagina, peritoneal carcinoma, and gestational trophoblastic tumors.*
Other – Reproductive, male	*Includes testicular, penile, and extragonadal germ cell tumors.*
Other – Respiratory	*Includes malignant Mesothelioma and thymoma*
Other – Urinary organs	*Includes Wilms tumor (also code Childhood cancers)*
Other Cancers	*Use for a specific site that does not fit in any of the categories; includes all non-intestinal carcinoid tumors and paraganglioma.* ***NOTE****: if Dr's diagnosis is CUP, see Carcinoma of Unknown Primary code*
Childhood Cancers	***NOTE****: When choosing this code, be sure to also choose an additional code for cancer type.*
Not applicable/no site mentioned	*Includes benign & non-cancer calls, general questions, site-unspecified calls, clients that are unsure about cancer site/type and questions related to pet/animal cancer. Use Solo.*

SPECIAL CODES

COVID-19	*Use whenever COVID-19 is part of the interaction, regardless of who initiates the conversation about COVID-19. Also includes when info about COVID-19 addressed only in f/u email.*

NCCAPS (NCI COVID study)

CTCA Call (callers ref'd to us by CTCA)

VA Smoking Chat

TMIST

All of Us Research Program

Dr. Rosenberg

Affordable Care Act (ACA)

In the News (anything people saw on TV e.g. Angelina Jolie, etc.)

Vice President's Cancer Initiative

First in Human

CT Feedback (PIQ only)

Cancer Research Initiative Mailbox

Genomics Podcast

VA Lung Screening

Pediatric Petitions/Funding

FDA Referral (quit smoking)

Exceptional Responders

MATCH

Ped MATCH

Emperor of All Maladies

VM Callback

FB Live Event

Hurricane

DART

Every Try Counts

Cell Phone Risk

E2112	
PIQ Custom Phone Response	
PIQ Referred by DOC	
PIO Referred by Center for Global Health	
PIQ Incarcerated Client	

ACTIONS: [up to 5]

None	
Sent information by mail	*Mail, letters, faxes, pubs, other printed material, PDQ stmts, CT searches, materials to walk-ins, or holding material for pick-up. Use when sending via NCI Pubs Locator.*
Emailed caller information	
Social Media Post	
Warm transferred to Organization/Federal agency	
Scheduled proactive callback	
Other	*Any other actions taken as follow-up (e.g. contacting POS for user)*

SMOKING CESSATION

Yes	
No	
Scheduled Intake	

REFERRALS GIVEN

Dr/Nurse/Pharmacist/SW/HP	*Includes referral to Social Worker, nurse, pharmacist or other HP*
NCI-Designated Cancer Center	
National or Community Org/Other Gov Program	*Use when referrals are made to community services, organizations, state and local gov't programs, and federal gov't programs other than NCI. Includes smokefree.gov.*
Other Healthcare Facility	*Includes hospitals, clinics, and screening facilities. Use when sending CoC hospitals or other facilities. Do NOT use when referring to BCCEDP programs, genetic services, NCI-designated cancer centers, or NCCCP hospitals.*
NCI Contact Center	*Inquiries referred to 1-800-4-CANCER*
Smoking Quitline	*Inquiries referred to 1-877-44U-QUIT*

Public Inquiries	
POS	*Publication Ordering Service*
NCI DOC/Program	*NCI Divisions Offices & Centers (DOCs) e.g. refs to DCEG, CTEP, DCCPS, TCGA, SEER, etc. Includes providing contact information for Dr. Sharpless or NCI researcher.*
NCI CCR/Clinical Center	
CDC-BCCEDP	*Use when a referral is given to Breast/Cervical Cancer Early Detection Program EXCEPT when referring to Missouri.*
Genetics Services	
International Referral	
CPEN Bulk Printing	
Other	
None	

CLINICAL TRIALS

N/A	*Clinical trials were not discussed*
Client Initiated	*The topic of clinical trials was presented by the client*
IS Initiated	*The topic of clinical trials was presented by the Information Specialist*

HOW FOUND OUT

REFERRAL

Relative/Friend	Incl. co-worker
Health Professional	
MEDIA	
TV	
Radio	
Huerta Radio Series	
Magazine	
Newspaper	
NCI	
NCI Publications	Incl. PDQ hard copy or fax
POS	
ORGANIZATIONS	
Organization/community group	Incl. hospitals, health agencies, CTCA
ACS	
CIS parent institution	FHCRC
CDC	
NCI-Designated Cancer Center	
Other 800 service	
State Health department	

DIRECTORIES/OTHER	
Phone book/directory assistance	
Other printed source	Incl. book, package insert, newsletter, prof journal, non-NCI pubs
Other	Source not listed elsewhere, incl. NCI, NIH
“I just know it”	
Internet	
LiveHelp	
Cancer.gov	
Direct mail	
NCI Facebook	
Other Facebook	
NCI Twitter	
Other Twitter	
NCI YouTube	
Other Youtube	
App	Incl. apps for IPhone, iPad, iTouch, Android, Blackberry, etc. NOTE: if specific app is listed, choose that code instead
Refusal	
Did not ask	