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| **NCI/Office of Communications and Public Liaison** |
| **APPENDIX 10** |
| **ELECTRONIC CONTACT RECORD FORM(ECRF) with SCREEN SHOTS** |

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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 MedicineCAM-Medical MarijuanaCAM-Biological Based ProductsCAM-Manual TherapiesCAM-Whole SystemsCAM-Mind Body/Spirituality/Energy Med. CAM-High Dose Vitamin C | *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)**Herbs, supplement/vitamins, food, special diets**Acupuncture, massage, chiropractic, reflexology**Homeopathy, naturopathy, Ayurveda**Hypnosis, Tai Chi, Reiki, therapeutic touch, yoga, meditation, visualization, relaxation, prayer* |
| 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**(QuitSTART replaced Quitpal)* |
| NCI-QuitSTART and other apps | *(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* |
|   | *i.e. SEER\*Stat databases; SEER\*Stat; Dictionary of SEER\*Stat Variables; SEER-Medicare linked Database* |
| SEER Datasets and Software |  |
| 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-19NCCAPS (NCI COVID study) | *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.* |
| CTCA Call (callers ref’d to us by CTCA) |  |
| VA Smoking ChatTMISTAll of Us Research ProgramDr. RosenbergAffordable Care Act (ACA) |  |
| In the News (anything people saw on TV e.g. Angelina Jolie, etc.) |  |
| Vice President’s Cancer InitiativeFirst in Human |  |
| CT Feedback (PIQ only) |  |
| Cancer Research Initiative Mailbox |  |
| Genomics Podcast |  |
| VA Lung Screening |  |
| Pediatric Petitions/Funding |  |
| FDA Referral (quit smoking) |  |
| Exceptional Responders |  |
| MATCHPed MATCH |  |
| Emperor of All Maladies |  |
| VM CallbackFB Live EventHurricaneDARTEvery Try CountsCell Phone RiskE2112 |  |
| PIQ Custom Phone ResponsePIQ Referred by DOCPIO Referred by Center for Global HealthPIQ 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 |  |