



Kern County Children and Families Commission (KCCFC)

CONFIDENTIALITY PROTOCOL:

Safe Handling and Security of Participant Information

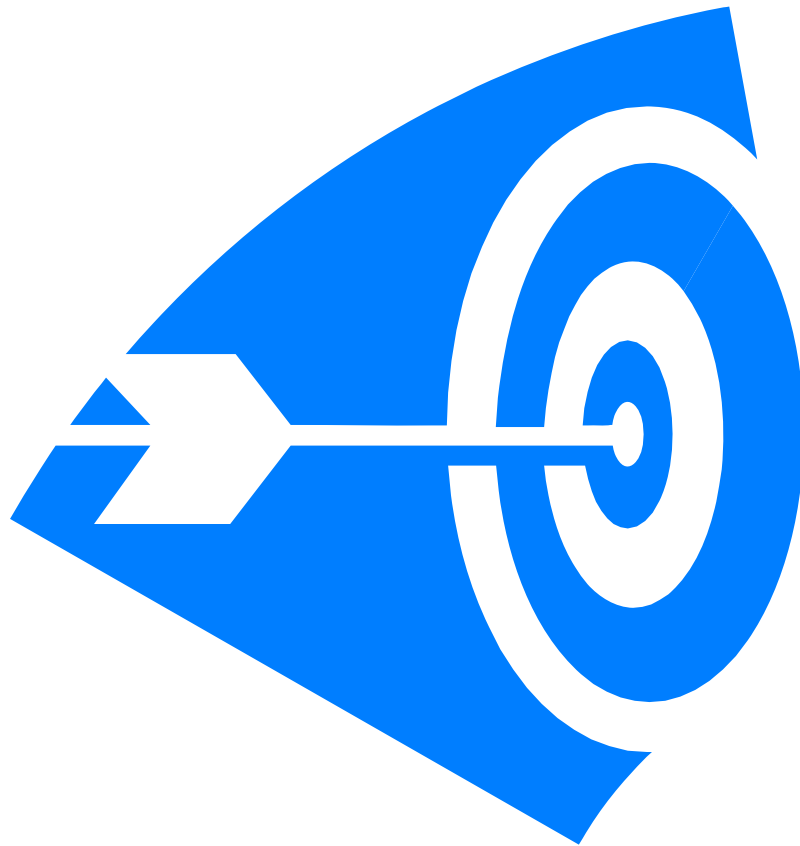
Procedures Manual

FIRST 5 KERN
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Introduction



Thank you for your attendance of the Kern County Children and Families Commission “First 5 Kern” Confidentiality Training. We appreciate your participation and willingness to assist First 5 Kern (F5K) in ensuring that appropriate participant information is maintained in a secure and confidential manner.

Goals:

- 1.** To increase knowledge and skills among programs funded by F5K in the area of confidentiality and data security.
- 2.** To ensure that all new F5K funded program-administered intakes are included in the evaluation.
- 3.** To protect participant confidentiality by ensuring that a signed consent is obtained from all participants (parents/legal guardians with children ages 0 to 5) from whom personal information is collected.

Objectives

- Instruct Informed Consent Form administrators from F5K-funded programs of the policies and procedures for obtaining informed consent.
- Instruct Informed Consent Form administrators from F5K-funded programs of the appropriate release of confidential participant information.
- Maximize the number of participants signing the Informed Consent Forms.
- Instruct trainees (program staff) in the security of confidential participant information.
- Instruct trainees (program staff) in good organizational security practices in general.

Section One:

Confidentiality Overview



Confidentiality: Philosophy, Policies, and Procedures

Philosophy

First 5 Kern's philosophy and policy for implementation of the confidentiality requirements are described in detail in this document. It is the responsibility of funded programs and their staff members, particularly the First 5 Kern Informed Consent Form administrators, to know and to adhere to the confidentiality philosophy and policies.

Most people expect that information regarding their personal lives will be kept private, especially as it relates to health and human services. Yet, the delivery of effective human services is often dependent upon the program's ability to use personal data effectively during case management and/or for the provision of services. An important basis for public trust is the perception that effective services will be provided and that personal information will be kept private.

Strict confidentiality regulations and procedures will be employed to avoid risks, discomforts or inconveniences for the children and families whose personal data are collected and reported. Inadvertent unauthorized disclosure or other compromise of personal data could result in embarrassment and a loss of public confidence in F5K, and must be prevented. Such a loss could deter families from seeking important early childhood services from funded programs.

Services will not be denied if a parent, or other legal representative of a child chooses not to consent to the release of personal information for evaluation collection and reporting purposes or withdraws such consent.

Policies

The following policies detail the commitment to the confidentiality and security philosophy of First 5 Kern:

Confidential Personal Information

Confidential personal information is personal data regarding a participant that must be kept confidential and controlled to guard individual privacy. Such data are obtained through written and verbal communication with the child, parents, or legal guardians, or by reviewing confidential personal records.

Personally Identifiable Information

Personally identifiable information is typically private information regarding a participant that allows those with access to determine the individual's identity. A child's name(s), birth date and place of birth, gender, and name(s) of other family members all are considered personally identifiable information in this protocol, also referred to as "personal data." HIPAA refers to the core identifiers (name, date of birth, place of birth, mother's maiden name) as "AB99".

Legal Representatives of Children

When a program identifies a child as in need of services, only *legally authorized* representatives of the child may approve access to or for the release of confidential information and records concerning the child and family. In addition, children themselves, if emancipated, may approve access to or for the release of confidential information and records.

Authorized representatives includes:

- Birth parent
- Legal Guardian
 - Court-approved legal guardians can include other related or unrelated family member, court liaison, adoptive parent, family friend, foster parent, etc.

Legal representatives of children who agree on their own and their child(ren)'s behalf to participate in F5K-funded services will be asked to provide personal identifying information that will be entered into Grant Evaluation and Management Solution (GEMS). Legal representatives must indicate their understanding and willingness to participate in this data-sharing system by signing the F5K Informed Consent Form,

If the legal representative's ability to understand and make decisions regarding the child(ren)'s and their own participation in F5K-funded services is uncertain (e.g., due to age, cognitive impairment, extreme stress, or other factors) then another legally authorized representative should make the decision regarding such participation.

Each program is responsible for developing and implementing a policy for verifying the legal status of parent/legal guardians. It is recommended that:

- Program intake staff ask for identification such as a driver's license or California I.D. card, birth certificate or other valid identification;
- The parent/legal guardian should be asked to sign a form testifying to their legal authority to obtain services for the child(ren);
- The parent/legal guardian should be asked to furnish at a later date, a court order which documents their legal status (if applicable); and
- In the spirit of Proposition 10, the policy should maximize the protection of confidentiality without delaying service in any way.

Limitation on Disclosure of Confidential Information

Participant information may be shared without participant authorization.

By law, if a program staff has reason to believe that the child is in imminent danger to him/herself or to others; or if the child is an alleged victim or perpetrator of child, elder, or dependent abuse, the staff will be required to disclose confidential information to the authorities without specific participant authorization.

Duration of the Informed Consent Authorization

The authorization to release confidential information will be effective until the child's eighteenth birthday. The Informed Consent remains valid for parents/legal guardians for ten years from the signature date. Written authorization may be revoked at anytime by (1) the parent or legal guardian signatory, or (2) the participant child, once the child obtains the capacity to consent pursuant to law. Action taken prior to the revocation and based on information already released may not be undone.

Need-to-Know

The portion of a child's record that contains personally identifiable information in GEMS will be available on a strict need-to-know basis to parties who are or have been contracted to provide F5K-funded services for the child or to provide program evaluation. Such authorization may be provided by the F5K Executive Director, Assistant Director, or Mosaic Network, Inc. Project Manager. Non-identifiable or aggregated data based on records stored in GEMS will be made available to those conducting program evaluations, needs assessments, planning activities, program audits, or research related to the children and families who have participated in F5K-funded services.

First 5 Kern Informed Consent Form

The First 5 Kern “Informed Consent to Release Confidential Information” is a form that documents the informed consent necessary to collect and use the personal information of children and their legal representatives. It provides the responsible legal representatives of the children with information regarding the purposes for which they are authorizing release of information, including data entry guidelines and the limits of data sharing. It designates the specific program or agencies to which the information will be provided. It affirms the children’s families’ rights and responsibilities regarding their own personal information in the custody of F5K, GEMS, and F5K-funded programs.

Program’s Performance Standards

The program’s performance standards include provision of full information to the child or the legal representative of the child on confidentiality, as well as services, etc. The program will enable the child or representative to have a full understanding of program confidentiality responsibilities, policies, and protocols.

For parents and other legal representatives to protect children’s best interests, they must be properly informed of their rights and responsibilities and those of the child. This requires the programs to inform legal representatives regarding the sharing of confidential participant and family information and how it will be used among F5K-funded programs and the evaluator.

The program staff will assure that:

Oral communication between program employees and the child or legal representative of the child, or oral communication between program employees concerning the child or the legal representative of the child as is necessary for professional consultation, can not be overheard in the interview setting by unauthorized staff, other program participants, or visitors.

The program staff should ask the child and parent or other legal guardian of the child, about the privacy comfort level of the interview setting. Program staff shall accommodate any request for a more private interview setting.

Procedures

Program staff members obtaining written authorization to release confidential information will fully explain the confidentiality policy and procedures, the authorization form, and the activities that will be undertaken on the child's behalf to the persons concerned. The following procedures reflect the implementation of the confidentiality and security philosophy and policies of First 5 Kern:

1. Administration

The Informed Consent Form is a required component (upon intake) when a child and/or parent seek services from a F5K-funded program, or in other settings where initial child-program interactions may occur. Each time the child is referred, or taken to, an additional service-providing program, a new Informed Consent Form will be administered by that program. In every case, a copy of the form will be maintained in the program's participant case file; a copy will be provided to the parent/legal guardian, and a copy will be forwarded to F5K. Informed Consent may be withdrawn at any time by the child's legal representative (per signed Informed Consent), using the form "Request to Remove Confidential Information", which should be explained on intake along with the Informed Consent Form.

2. Informing the Legal Guardian or Research Participant

The responsible program staff member will make sure that the orientation is provided in a language that the child and/or legal representative can fully understand. The Informed Consent is available in English and Spanish. If the legal representative does not speak English, then it is the responsibility of the staff collecting the information to provide an effective interpreter. If the child or legal representative cannot adequately read English or Spanish, the program will read the form aloud or arrange to have it read by a qualified interpreter. Interpreters must be over the age of 18 to ensure the ability to understand and convey all components of the informed consent process. In every case, program staff will explain any difficult wording. The responsible staff person will further respond fully, appropriately, and in a timely manner to the questions and concerns of the child and/or legal representative related to the Informed Consent Forms and the confidentiality policy and procedures.

3. Distribution of the Informed Consent Form

Program staff members must follow appropriate procedures for distribution and/or dissemination of Informed Consent forms and other participant files.

4. Referral to Other Agencies

Care must be taken when there is a referral to a subsequent program; the assisting program continues to protect the confidentiality of the participant using the appropriate procedures. Typically, agencies have a simple referral "okay" form that is signed by the parent/legal guardian, authorizing limited information sharing so that the program can complete the referral. The limited information usually includes names, phone numbers and the referral request. (It is recommended that each F5K-funded program maintain a written policy for making referrals. The policy should include provisions for protecting confidentiality, including specifications for any release of information.)

Section Two:

Legal Regulations



First 5 Kern, the funded program and all program staff, particularly those who administer the Informed Consent Form, are responsible for knowing and adhering to all program, local, state, and federal rules, regulations and laws regarding confidentiality and release of information relative to program participants.

Program Confidentiality Protocol

It is the responsibility of the First 5 Kern Informed Consent Form administrators to be familiar with their own program's written participant confidentiality policies and to have been trained in their implementation.

Programs will be required to develop a written, internal confidentiality protocol. The Informed Consent Form administrators should be familiar with this policy as well.

City and County Regulations

It is the responsibility of the F5K-funded programs and their Informed Consent Form administrators to be familiar with any city and/or county participant confidentiality policies.

Federal and State Regulations

It is the responsibility of the F5K-funded programs and their Informed Consent Form administrators to be familiar with any state and/or federal participant confidentiality regulations.

Selected applicable regulations include: Federal Privacy Regulations (i.e., 45 CFR Part 46, 45 CFR 160 and 164 [HIPAA Regulations.], 42 CFR Part 2, etc.), and California Privacy Laws and Regulations, including Health and Safety Codes such as Section 24172, the Research Participant Bill of Rights.

Section Three:

California Research Participants' Bill of Rights



The United States Bill of Rights outlines the rights and privileges of the people such as: freedom of speech, search and seizures, etc. These rights allow individuals to express their opinions without fear of reprimand or any negative actions against them. Similarly, individuals who participate in research studies or receive services from specific programs and agencies are afforded similar rights and protection under the California state laws. From time to time, agencies/programs may collect specific participant information for research and/or reporting purposes. Participants in these programs are protected from potential behaviors or practices that may harm or infringe upon their rights. The California Participant's Bill of Rights provides program participants with certain rights and privileges.

Any person who is asked to participate as a human subject in a research study or who is asked to consent on behalf of another has the following rights:

- (a) Be informed of the nature and purpose of the study.
- (b) Be given an explanation of the procedures to be followed in the study and any drug or device to be utilized.
- (c) Be given a description of any attendant discomforts and risks reasonably to be expected from the study.
- (d) Be given an explanation of any benefits to the subject reasonably to be expected from the study, if applicable.
- (e) Be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous to the subject, and their relative risks and benefits.
- (f) Be informed of the avenues of medical treatment, if any, available to the subject after the study if complications should arise.
- (g) Be given an opportunity to ask any questions concerning the study or the procedures involved.
- (h) Be instructed that consent to participate in the study may be withdrawn at any time and the subject may discontinue participation in the study without prejudice.
- (i) Be given a copy of the signed and dated written Consent Form.
- (j) Be given the opportunity to decide to consent or not to consent to a study without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on the subject's decision.

(California Health and Safety Code Section 24172)

Section Four:

Informed Consent Form Consent to Release Confidential Information



Consent forms included in this section have been approved by the Institutional Review Board of California State University, Bakersfield (CSUB). Whereas, one of the forms was designed for the data gatherings from children 0 to 5 years old, the other form was added for the Successful Application Stipend (SAS) program that extended the age boundary to 6 to 18 years old. Both consent forms are developed for use starting on July 1, 2010.

KERN COUNTY CHILDREN AND FAMILIES COMMISSION (KCCFC) "First 5 Kern"

Informed Consent to Provide Confidential Information

Purpose of this Agreement. I am providing personal information regarding my child(ren) and myself to facilitate coordination of services for my child(ren) and family, and to permit program evaluation that could lead to improved services for me, my child(ren), and the children and families of Kern County and the State of California.

Data Collection. Information will be collected on this form and others, such as: names, dates of birth, gender, race, place of birth, and other information, related to the services that my child(ren) and I will receive through the Program. These data and data in existing records and files, may be entered into the computer data system "Grant Evaluation and Management Solution" (GEMS). Upon request, I may be shown the data collection forms used to obtain information.

Data Sharing. I voluntarily agree to allow this Program to share information of my child(ren) and myself with F5K and its Principal Investigator "Dr. Jianjun Wang" authorized Proposition 10 service providers, and with the First 5 California evaluator for the purpose stated above.

Identifying Information will be kept private. My personal identifying information (i.e. names, address, phone) will be removed from any data reporting. Research reports will contain summarized data and never contain my personal identifying information. I understand that personal information may be released without my agreement if I am a victim, or person responsible for the abuse of children, seniors, or other dependants.

Several state (45 CFR 164.508(c)) and federal laws protect the personal and health information I share, including and beyond the federal privacy rule (Public Law 104-191). State and federal laws protect the personal and health information I share even if the Federal Privacy Rule does not do so. I understand that my approval to share my child's personal information will end on his / her eighteenth birthday, or when the research study ends, whichever comes first. At that time, all personal information about my child(ren) and myself will be restored. Mosaic Network, Inc. is responsible for investigation of the data and reserves the right of publication of results obtained from their analyses.

Voluntary Participation: I voluntarily agree to allow my personal information to be shared as described in this Informed Consent agreement. I understand that if I choose not to sign this Agreement, I will still receive services. If I sign this agreement, I will receive a copy of the signed Consent for my own use. A copy will be retained on file by the Program and F5K for at least three years. At the end of the retention period, Consent forms may be destroyed. Other F5K-funded Programs may only see my personal information if/when I sign Consent to share information with their program.

I may request to have my information removed from F5K's database at any time. I may also specify information about my child(ren) that I do not want to be recorded in the database. I may cancel this Agreement at anytime by completing the form entitled, "Request to Remove Confidential Information", which will be forwarded to First 5 Kern at 2724 "L" Street, Bakersfield, California 93301, for processing. Personal identifying information will be used by the database administrator (Mosaic Network, Inc.) for removal purposes upon participant's request. My child(ren) may also cancel this agreement in writing when he/she/they is/are of legal age.

Risks: There are no known risks for my child(ren) or myself by allowing personal information to be shared as specified in this document.

Contact Information:

- *For questions concerning the nature of the program and the results of this study:* Office of the First 5 Kern, 2724 "L" Street, Bakersfield, California 93301; Phone: (661) 328-8888.
- *For questions concerning issues of privacy and confidentiality:* Dr. Steve Suter, University Research Ethics Review Coordinator, Department of Psychology, California State University, Bakersfield, 9001 Stockdale Highway, Bakersfield, CA 93311; Phone: (661) 654-2373.
- Program Name & Contact Info.: _____

Print the birth name of the child(ren) (ages 0 – 5) for whom Consent is being requested:

Participant is pregnant Consent updated with child(ren) names ____/____/____ By (staff person) _____

1. First _____ Middle _____ Last _____ Date of Birth ____/____/____ Sex M F

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Data Collection. Information will be collected on this form and others, such as: names, dates of birth, gender, race, place of birth, and other information, related to the services that my child(ren) and I will receive through the Program. These data and data in existing records and files, may be entered into the computer data system "Grant Evaluation and Management Solution" (GEMS). Upon request, I may be shown the data collection forms used to obtain information.

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Risks: There are no known risks for my child(ren) or myself by allowing personal information to be shared as specified in this document.

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- Program Name & Contact Info.: _____

Print the birth name of the child(ren) (ages 0 - 18) for whom Consent is being requested:

Participant is pregnant Consent updated with child(ren) names ____/____/____ By (staff person) _____

1. First _____ Middle _____ Last _____ Date of Birth ____/____/____ Sex M F

1. First _____ Middle _____ Last _____ Date of Birth ____/____/____ Sex M F

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COMISIÓN PARA NIÑOS Y FAMILIAS DEL CONDADO DE KERN
“First 5 Kern”

Consentimiento fundamentado para suministrar información privada

Objetivo de este acuerdo. He suministrado información personal mía y sobre mis niños con el fin de facilitar la coordinación de servicios para mis niños y mi familia y con el fin de permitir una evaluación del programa que podría resultar en mejores servicios para mí, mis niños y los niños y familias del Condado de Kern y el Estado de California.

Recopilación de datos. Se recopila información en este formulario y en otros, tal como nombres, fechas de nacimiento, sexo, raza, lugar de nacimiento y demás información relacionada con los servicios que mis niños y yo vamos a recibir por medio del Programa. Estos datos y los datos en los registros y expedientes existentes se podrían ingresar al sistema de datos computarizado “Grant Evaluation and Management Solution” (GEMS). Previa solicitud, me pueden enseñar los formularios de recopilación de datos utilizados para obtener la información.

Para compartir los datos. De manera voluntaria estoy de acuerdo con permitir que este Programa comparta información personal mía y de mis niños con F5K y su Investigador Principal “Dr. Jianjun Wang”; los proveedores de servicios autorizados por la Proposición 10 y el evaluador de Primeros 5 California para los fines indicados anteriormente.

La información que nos identifica se mantendrá privada. Los datos míos que me identifiquen (por ejemplo, nombre, dirección, teléfono) se eliminarán de todos los informes con datos. Los informes de investigación contienen datos resumidos y nunca contienen información personal que me identifique. Comprendo que la información personal se puede divulgar sin mi consentimiento si soy víctima de o la persona responsable de abuso de niños, ancianos u otros a mi cargo.

Varias leyes estatales (45 CFR 164.508(c)) y federales protegen la información personal y de la salud que yo comparto, entre ellas la ley federal de privacidad (Ley pública 104-191) y otras. Las leyes estatales y federales protegen la información personal y de la salud que yo comparto aunque la Ley federal de privacidad no lo haga. Comprendo que mi aprobación para compartir la información personal de mis niños termina cuando cada uno cumpla los 18 años de edad, o cuando termine el estudio de investigación, el que ocurra primero. En ese momento toda la información personal de mis niños y la mía quedará eliminada. Mosaic Network, Inc. tiene la responsabilidad de investigar los datos y se reserva el derecho a publicar los resultados obtenidos de sus análisis.

Participación voluntaria: De manera voluntaria estoy de acuerdo con permitir que mi información personal se comparta como se describe en este Acuerdo de Consentimiento fundamentado. Entiendo que se elijo no firmar este Acuerdo, de todos modos recibo los servicios. Si firmo este Acuerdo, recibo una copia del Consentimiento firmado para mi propio uso. El programa y F5K retienen una copia durante por lo menos tres años. Al terminar este período, los Formularios de consentimiento se podrían destruir. Otros programas auspiciados por F5K pueden ver mi información personal solamente si/cuando yo firme un Consentimiento para compartir mi información con su programa.

Yo podría solicitar que se elimine mi información de la base de datos de F5K en cualquier momento. También podría indicar cierta información sobre mis niños que no deseo que se registre en la base de datos. Puedo cancelar este Acuerdo en cualquier momento si completo el formulario “Request to Remove Confidential Information” (Solicitud para eliminar información privada), el cual se enviará a First 5 Kern ubicado en 2724 “L” Street, Bakersfield, California 93301, para su procesamiento. La información personal que me identifica será utilizada por el administrador de la base de datos (Mosaic Network, Inc.) para fines de eliminarla previa solicitud del participante. Mis niños también pueden cancelar este Acuerdo por escrito cuando cumplan su edad legal.

Riesgos: No hay riesgos conocidos tanto para mis niños como para mí por el hecho de permitir que se comparta nuestra información personal como se indica en este documento.

Información de contacto:

1. **Si tiene dudas con respecto a la naturaleza del programa y los resultados de este estudio:** Office of the First 5 Kern, 2724 “L” Street, Bakersfield, California 93301; Teléfono: (661) 328-8888.
2. **Si tiene dudas con respecto a temas de privacidad o confidencialidad:** Dr. Steve Suter, University Research Ethics Review Coordinator, Department of Psychology, California State University, Bakersfield, 9001 Stockdale Highway, Bakersfield, CA 93311; Teléfono (661) 654-2373.
3. **Nombre del programa e información de contacto:** _____

Escriba en letra de molde el nombre de nacimiento de los niños (0 a 5 años de edad) para quienes se ha solicitado el Consentimiento:

Madre/Tutora legal embarazada Consentimiento actualizado con nombre de niños ____/____/____ Por (personal) _

1. Nombre _____	2º nombre _____	Apellido _____	Fecha de nac. ____/____/____	Sexo M F
2. Nombre _____	2º nombre _____	Apellido _____	Fecha de nac. ____/____/____	Sexo M F
3. Nombre _____	2º nombre _____	Apellido _____	Fecha de nac. ____/____/____	Sexo M F

Autenticación: (solamente UNO de los padres o tutor legal debe firmar)

Firma de uno de los padres o tutor legal* Fecha: ____/____/____

Firma de uno de los padres o tutor legal* Fecha: ____/____/____

Nombre en letra de molde

Nombre en letra de molde

Parentesco con los niños

Parentesco con los niños

*¿Qué constituye un "Tutor legal"? (por ejemplo, documento de la corte y fecha) _____

Intérprete: _____ Idioma: _____ Fecha de nacimiento del intérprete: ____/____/____
(nombre en letra de molde) (mm/dd/aaaa)

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Para compartir los datos. De manera voluntaria estoy de acuerdo con permitir que este Programa comparta información personal mía y de mis niños con F5K y su Investigador Principal “Dr. Jianjun Wang”; los proveedores de servicios autorizados por la Proposición 10 y el evaluador de Primeros 5 California para los fines indicados anteriormente.

La información que nos identifica se mantendrá privada. Los datos míos que me identifiquen (por ejemplo, nombre, dirección, teléfono) se eliminarán de todos los informes con datos. Los informes de investigación contienen datos resumidos y nunca contienen información personal que me identifique. Comprendo que la información personal se puede divulgar sin mi consentimiento si soy víctima de o la persona responsable de abuso de niños, ancianos u otros a mi cargo.

Varias leyes estatales (45 CFR 164.508(c)) y federales protegen la información personal y de la salud que yo comparto, entre ellas la ley federal de privacidad (Ley pública 104-191) y otras. Las leyes estatales y federales protegen la información personal y de la salud que yo comparto aunque la Ley federal de privacidad no lo haga. Comprendo que mi aprobación para compartir la información personal de mis niños termina cuando cada uno cumpla los 19 años de edad, o cuando termine el estudio de investigación, el que ocurra primero. En ese momento toda la información personal de mis niños y la mía quedará eliminada. Mosaic Network, Inc. tiene la responsabilidad de investigar los datos y se reserva el derecho a publicar los resultados obtenidos de sus análisis.

Participación voluntaria: De manera voluntaria estoy de acuerdo con permitir que mi información personal se comparta como se describe en este Acuerdo de Consentimiento fundamentado. Entiendo que se elijo no firmar este Acuerdo, de todos modos recibo los servicios. Si firmo este Acuerdo, recibo una copia del Consentimiento firmado para mi propio uso. El programa y F5K retienen una copia durante por lo menos tres años. Al terminar este período, los Formularios de consentimiento se podrían destruir. Otros programas auspiciados por F5K pueden ver mi información personal solamente si/cuando yo firme un Consentimiento para compartir mi información con su programa.

Yo podría solicitar que se elimine mi información de la base de datos de F5K en cualquier momento. También podría indicar cierta información sobre mis niños que no deseo que se registre en la base de datos. Puedo cancelar este Acuerdo en cualquier momento si completo el formulario “Request to Remove Confidential Information” (Solicitud para eliminar información privada), el cual se enviará a First 5 Kern ubicado en 2724 “L” Street, Bakersfield, California 93301, para su procesamiento. La información personal que me identifica será utilizada por el administrador de la base de datos (Mosaic Network, Inc.) para fines de eliminarla previa solicitud del participante. Mis niños también pueden cancelar este Acuerdo por escrito cuando cumplan su edad legal.

Riesgos: No hay riesgos conocidos tanto para mis niños como para mí por el hecho de permitir que se comparta nuestra información personal como se indica en este documento.

Información de contacto:

1. **Si tiene dudas con respecto a la naturaleza del programa y los resultados de este estudio:** Office of the First 5 Kern, 2724 “L” Street, Bakersfield, California 93301; Teléfono: (661) 328-8888.
2. **Si tiene dudas con respecto a temas de privacidad o confidencialidad:** Dr. Steve Suter, University Research Ethics Review Coordinator, Department of Psychology, California State University, Bakersfield, 9001 Stockdale Highway, Bakersfield, CA 93311; Teléfono (661) 654-2373.
3. **Nombre del programa e información de contacto:** _____

Escriba en letra de molde el nombre de nacimiento de los niños (0 a 18 años de edad) para quienes se ha solicitado el Consentimiento:

Madre/Tutora legal embarazada Consentimiento actualizado con nombre de niños ____/____/____ Por (personal) _

1. Nombre _____	2º nombre _____	Apellido _____	Fecha de nac. ____/____/____	Sexo M F
2. Nombre _____	2º nombre _____	Apellido _____	Fecha de nac. ____/____/____	Sexo M F
3. Nombre _____	2º nombre _____	Apellido _____	Fecha de nac. ____/____/____	Sexo M F

Autenticación: (solamente UNO de los padres o tutor legal debe firmar)

Firma de uno de los padres o tutor legal* Fecha: ____/____/____

Firma de uno de los padres o tutor legal* Fecha: ____/____/____

Nombre en letra de molde

Nombre en letra de molde

Parentesco con los niños

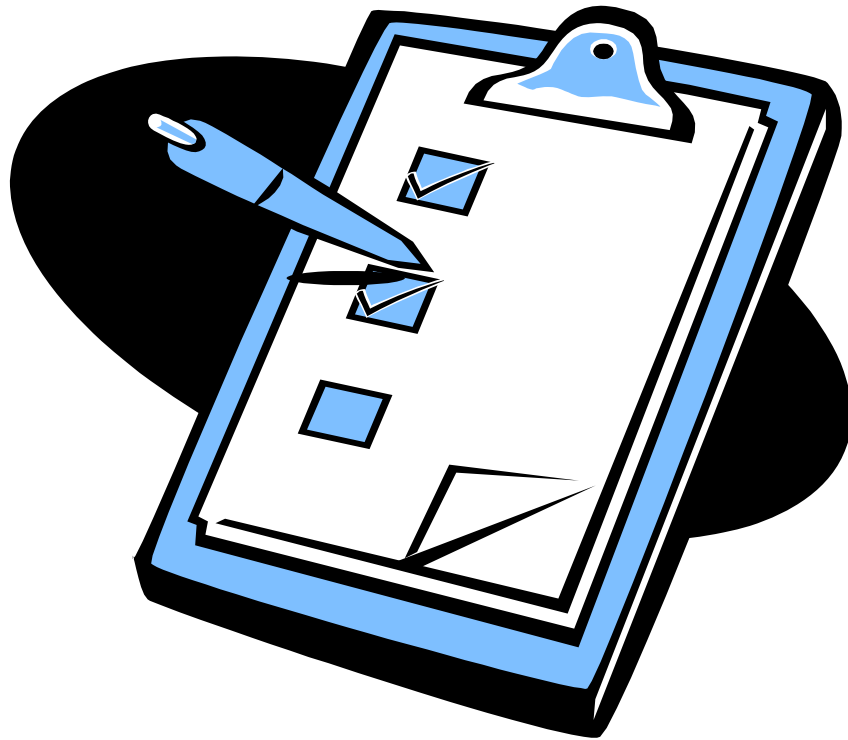
Parentesco con los niños

*¿Qué constituye un "Tutor legal"? (por ejemplo, documento de la corte y fecha) _____

Intérprete: _____ Idioma: _____ Fecha de nacimiento del intérprete: ____/____/____
(nombre en letra de molde) (mm/dd/aaaa)

Section Five:

Consent Administration



How to Administer the Informed Consent Form

I. Preparation for Implementation of First 5 Kern Informed Consent Forms

A. The program must identify the individuals within the program who will be directly responsible for all aspects of the First 5 Kern consent process including:

- Supervision of consent administration, secure storage and confidential dissemination
- Staff confidentiality agreements
- Actual administration of the Consent to the parent or legal guardian of child(ren) aged 0 to 5.

B. Provide appropriate training to responsible parties including:

- Identification of the qualifying child(ren) aged 0 to 5
- Program and personnel confidentiality obligations and responsibilities
- How to administer the First 5 Kern Informed Consent Form
- Who receives copies?
- Where are the signed forms stored?

C. Provide First 5 Kern Informed Consent Forms to appropriate individuals

- Implement the Informed Consent Form as part of the regular intake process
- Administer the form along with any program consent form
- Keep blank forms in easy to access place

D. All program personnel must sign the Staff Confidentiality Agreement

- Sign and date confidentiality pledge
- Store in appropriate place
- Make sure all new staff sign the Agreement at the request of the Confidentiality Training provider

II. Administration of the First 5 Kern Informed Consent Form

1. Administer at time of intake

The First 5 Kern Informed Consent Form should be administered as part of the routine intake process and for new intakes only. The blank Informed Consent Form should preclude the First 5 Kern intake packet (Family Demographics, Birth Intake Survey, and Core Data Elements forms). If your program has a consent form, administer it first then administer the First 5 Kern Informed Consent Form, and then the remaining intake packet.

2. Confirm that the adult is the parent or a legal guardian

It's likely that the legal status of the adult would have been established at the beginning of the intake process. Ask the adult if s/he is the parent/legal guardian of the child for whom the intake is being completed. If the adult is not the child's parent, but a legal guardian, written proof of such guardianship should be presented. If written proof is not immediately available and you have reason to believe that the adult is not the legal guardian, do not administer the Informed Consent Form or remaining intake packet. Determine who the legal guardian is and make arrangements for that person to sign, if possible, then continue with the intake process.

3. Explain the purpose and value of the F5K Informed Consent Form

The purpose of the First 5 Kern Informed Consent Form is to enable collection of useful data from individuals while protecting their rights.

4. Provide a copy of the F5K Informed Consent Form to parent/legal guardian

As you finish explaining the purpose and value, hand a copy of the First 5 Kern Informed Consent Form to the parent/legal guardian and ask them to read along with you. If you are using an interpreter, ask the interpreter to follow your words as closely as possible without abbreviation.

5. Read the form aloud

Read slowly, use an interesting voice, and keep the tone upbeat. Keep an eye on the parent/legal guardian to be sure that s/he is following and understanding. It can be very helpful to sit next to the individual and point to the section as it is being read aloud.

6. Ask parent/legal guardian if there are any questions

When you and the parent/legal guardian have finished reading the First 5 Kern Informed Consent Form, ask if s/he has any questions that you can answer. Then answer any and all questions as best you can using the script and training notes. It is critical to make the parent/legal guardian feel comfortable and safe when signing the form.

7. Fill in appropriate blanks for the parent/legal guardian

As you are answering questions, fill in all blanks on the Form, including program contact information; the name(s), birthdate(s), and gender of the child(ren); identify if the parent/legal guardian is pregnant (see item 18 below); legal guardian documentation, and any other requested information, so that the parent/legal guardian can merely sign and print their name, and provide the date.

- 8. Ask parent/legal guardian to sign the F5K Informed Consent Form**
Hand the partially-completed form to the parent/legal guardian with a pen, and ask her/him to sign and date in the appropriate places. Use your pen or a highlighter to show the parent/legal guardian where to sign.
- 9. Observe the writing of the signature and check for readability**
Observe the signing of the form to verify that it has been signed and dated in the correct places and that the signature and/or printed name are readable. Verify the accuracy of the date. The F5K Informed Consent Form is not useful if the parent/legal guardian's name is not readable. If the signature or the printed name is not legible, write the name underneath in legible handwriting, initial, and date your edits.
- 10. Tell parent/legal guardian that s/he will get a copy of the signed form**
Let parent/legal guardian know that s/he will receive a copy of the form upon completion. You are required to provide the parent/legal guardian with a copy of their signed Informed Consent. The Form provides the participant with important phone numbers for follow-up F5K Informed Consent questions.
- 11. Provide Copy Of The Signed F5K Informed Consent Form**
The Informed Consent Form is disseminated per instructions at the bottom of the form; white – program/case file, yellow – participant, pink – First 5 Kern audit copy.
- 12. Thank parent/legal guardian**
Thank the parent/legal guardian and assure her/him of the value of their participation.
- 13. Distribute and store First 5 Kern Informed Consent Form original and copies appropriately**
Following the completion of the intake, distribute the First 5 Kern Informed Consent Form original and copies to the appropriate parties.

SPECIAL ISSUES

14. Language/Translation Issues

It is important that translators/interpreters understand how important it is to accurately reflect both the Informed Consent Form and the messages being given by the person administering the Informed Consent Form. The translators must convey the same kind of safety and approachability as the Informed Consent Form administrator. The translator can have considerable influence on the process and can make or break whether or not a parent/legal guardian signs the form. The translator should be 18 or older, should not be a relative; must have signed the Staff Confidentiality Agreement, and should have received the F5K Confidentiality Training. If a family member is utilized, the individual providing the interpretation must understand the Informed Consent process; otherwise, a trained interpreter must be sought.

The translator must print their name on the form (in the designated area), along with the language translated, and their date of birth.

15. Multiple Children At Intake

An adult may request services for more than one child aged 0 to 5 of whom she/he is the parent or legal guardian. The Informed Consent Form can capture the names of up to three children aged 0 to 5). If the family size is greater than three children aged 0 to 5, attach an additional Informed Consent Form to accommodate all children aged 0 to 5 for whom services will also be provided.

16. If parent/legal guardian refuses to sign First 5 Kern Informed Consent Form

If the parent/legal guardian refuses to sign the First 5 Kern Informed Consent Form, try to understand why s/he does not want to sign. Ask if there are any questions you can answer that might make her/him feel more comfortable. Use the refusal guidelines developed in the training to try to persuade the parent/legal guardian to sign.

If the parent/legal guardian refuses:

- Thank her/him;
- Take back the form and flip it over to reveal the Refusal to Participate form.
- Complete the required information on the back side of the PINK copy only.
- Ask the parent/legal guardian to provide their signature where indicated.
- Sign the form as a “witness” and provide the date.
- Provide a photocopy of the signed Form to the parent/legal guardian.
- Provide a photocopy of the signed Form to F5K.
- Maintain the original 3-part copy in the participant's case file.

17. Minor parents

Minor parents (below age 18) are authorized by California and Federal law to complete and sign the F5K Informed Consent Form to authorize services for their child(ren) and/or themselves.

18. Prenatal consent

If the consenting adult is pregnant (checkbox selected on Consent), program staff must add the name of the child(ren) post birth to the program (white) copy of the

Consent, providing initials and date in designated fields. A photocopy of the revised Consent must be provided to F5K (at end of quarter), and participant (at next contact or by mail).

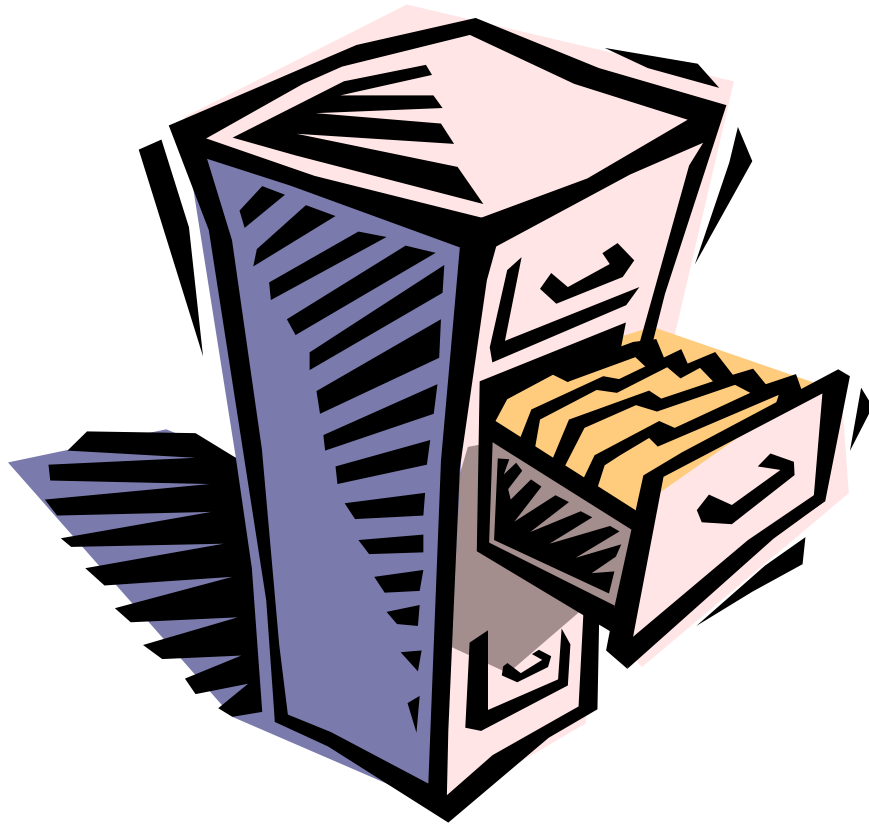
Section Six:

Informed Consent Refusal



Section Seven:

Informed Consent Handling



Dissemination of Copies

Informed Consent Form:

- The original/**WHITE** copy must be kept in paper form by the program who obtained it initially, in the participant's case file.
- The **YELLOW** copy must be provided to the child's legal representative upon completion.
- The **PINK** copy must be provided to First 5 Kern where it will be maintained in a master Informed Consent Form file.

Refusal:

- If the participant completes the Refusal form in lieu of the Informed Consent, the three NCR copies must remain together in the program's case file. Make a photocopy of the completed pink copy for the participant and another for First 5 Kern.

Appropriate Confidential Storage

Program Policy

Each program should have a detailed policy regarding appropriate confidential storage and dissemination of the Informed Consent forms in all settings.

Settings include:

1. *The program.*

Agencies/programs need to have an established process for gathering, storing, and disseminating consent forms and other participant confidential records. Such process must include: Who collects/gathers the forms? Where are these forms stored? Who has access to these records? Keys/locked storage?

2. *The intake staff office.*

Intake staff must be familiar with process for gathering, storing, and disseminating consent forms and other participant confidential records. Such process must be practiced and implemented at all times.

3. *Transporting of the documents from the field to the program.*

Consent forms and other participant forms transported from the field to the program must be maintained in a locked container with the program staff. It is also good practice to leave the locked container in the trunk of the car or other appropriate secure location within the vehicle.

4. *Transporting completed forms to First 5 Kern.*

The most appropriate method of delivering copies of completed Informed Consent Forms to First 5 Kern is by personal delivery. For programs located outside of Bakersfield, sending copies by registered mail through postal services is required. This method ensures safe handling and tracking of the package while in transport; thereby, safeguarding your participants' confidentiality. For either delivery method, the Forms must accompany the completed F5K Quarterly Progress Report (QPR) Cover Sheet.

5. *Transporting to referral agencies.*

See guidelines #3 and #4

6. *The participant home or other field settings.*

Program staff should only take forms that pertain to a particular participant with them when visiting the family. Records of other participants should never be taken into the home of another participant.

**** Informed Consent Forms and other intake records should never be taken home with program staff personnel.***

It is incumbent upon the funded program to set up a supervised and monitored system within the program to manage data handling efficiently.

Other Key Components:

Long-term storage

Programs should follow their agency's internal protocol for purging/destroying confidential participant documents. The program purging policy should provide for long-term storage as the documents are valid through the child's 18th birthday, which can require storage for many years. F5K requires the program to store signed Consents for a minimum of three years. F5K provides adequate storage of the F5K audit (pink) copy.

Long-term access

The program policy should provide for confidential access authorization and denial procedures over the "lifetime" of the forms.

Appropriate destruction

The program policy should detail the appropriate method of destruction and the timely date of destruction. The latter usually requires a tickler system that alerts the program when the documents are due for destruction.

Section Eight:

Informed Consent Withdrawal



Request to Remove Confidential Information

Children and Families Commission of Kern County (KCCFC) "First 5 Kern"

Request to Remove Confidential Information

As the legal representative of

Child's First Middle Last Name

I hereby request that First 5 Kern (F5K) remove all confidential information contained within the Grant Evaluation and Management Solution (GEMS) database, about the child identified above, my family, and myself.

Additionally, I hereby revoke the Informed Consent to Provide Confidential Information and prohibit F5K to obtain or share confidential information about the child identified above, my family or myself. However, I understand that this revocation does not apply to information that has already been released or reported under my previous consent.

I understand that I will not be excluded from services funded by the F5K if I choose to remove our confidential information from GEMS.

Please clearly type or print the following information to ensure the deletion of the correct records.

Child's Date of Birth (Month/Day/Year): _____ / _____ / _____ Sex of Child: M F

- If born in Kern County, CA, please identify hospital: _____
- If born in California (outside Kern), please identify county: _____
- If born in U.S. (outside CA), please identify state: _____
- If born outside of U.S., please identify country: _____

Birth Mother's Name _____

First Last Maiden Last Name

Authorized Signature _____
Date

Printed Name _____
Relationship to Child

Address

Person Accepting Removal Form:	Date:
Program Name:	

Please send this form to: First 5 Kern, 2724 "L" Street, Bakersfield, CA 93301;
Or fax this form to: (661) 328-8880

Section Nine:

Program Staff Requirements



Staff/Employee Training

Who Should be Trained?

- all program staff who administer the First 5 Kern Informed Consent Form
- their supervisors
- field staff who complete intakes outside of the program
- translators who will be present during intake
- staff who substitute for intake workers, even if only temporary substitution
- all data entry staff who will be entering confidential information into GEMS or other required database(s)
- all other First 5 Kern-funded program staff.

Follow-up training sessions

In recognition of the turnover that occurs in most programs, Confidentiality Training sessions are scheduled periodically. Programs will be notified of available Confidentiality Training sessions. Training may also be provided one-on-one on request.

Staff/Employee Agreement

Program Staff Confidentiality Agreement

The First 5 Kern Program Staff Confidentiality Agreement is a form to be signed by all present and future program employees who will have access to data in the GEMS system and/or have completed the Confidentiality Training. It documents that they understand and will abide by the confidentiality protocols of the program and F5K. This Agreement describes employee responsibilities and the liabilities resulting from the inappropriate, unauthorized, or illegal disclosure of participant information associated with a F5K-funded program. The person administering the Informed Consent Form also agrees not to disclose any confidential participant information to a third party without the written authorization from the child's parent or legally authorized representative.

Consequences of Violation of Confidentiality

Any violation of First 5 Kern's confidentiality protocol on the part of a program, that involves a participant's confidential information and records, may be grounds for contract revision or termination, and may expose the violator to civil and /or criminal penalties.

KERN COUNTY CHILDREN AND FAMILIES COMMISSION (KCCFC)
“First 5 Kern”
PROGRAM STAFF CONFIDENTIALITY AGREEMENT

- All staff members of First 5 Kern (F5K)-funded programs and projects (Providers) who are responsible for gathering or maintaining confidential information and records must read and sign this Agreement.
- The Program Staff Confidentiality Agreement will be signed by the staff person and her/his immediate supervisor, if applicable. The original will be maintained by First 5 Kern. Grant Evaluation and Management Solution (GEMS) user names and passwords will not be assigned until the Agreement has been signed.

RESPONSIBILITIES:

During the performance of my assigned duties related to F5K, I might have access to confidential participant information and records required for effective coordination and delivery of services to children (aged 0-5) and their families. All confidential discussions, deliberations, records, and information generated or maintained in connection with these activities shall be disclosed only to persons who have the need to know and authority to access confidential participant information or records. This includes information obtained and conveyed through all media including GEMS. I agree not to disclose any confidential child participant information to third party agencies without the written authorization from the child’s parent or legally authorized representative.

LEGAL LIABILITIES:

I have read and understand the following notice from the California Welfare and Institutions Code, Section 10850:

- ❑ *Notice: All applicable employees, agents, and subcontractors shall be notified of state requirements for confidentiality and also notified that any person knowingly or intentionally violating the provisions of the state law (W&I Code, Section 10850) is guilty of a misdemeanor.*
- ❑ *Records pertaining to any individual welfare recipient will be confidential and will not be open to examination for any purpose not directly connected with the administration of state authorized evaluation.*
- ❑ *No person will publish, disclose, use, or permit the use of, or cause to be published, disclosed or used, any confidential information pertaining to any individual public assistance recipient or person receiving public social services (e.g., child welfare services).*

If I make an unauthorized release of confidential information to a third party, it may expose me to personal civil penalties under the provisions of Welfare and Institutions Code, Section 5330; criminal action under Welfare and Institutions Code, Section 10850; and potentially a fine under Title 42, Code of Federal Regulations, Part 2. I understand that discussion of, or release of, information or records concerning a participant receiving F5K-funded services to any unauthorized person may also be grounds for disciplinary action.

ACKNOWLEDGEMENT:

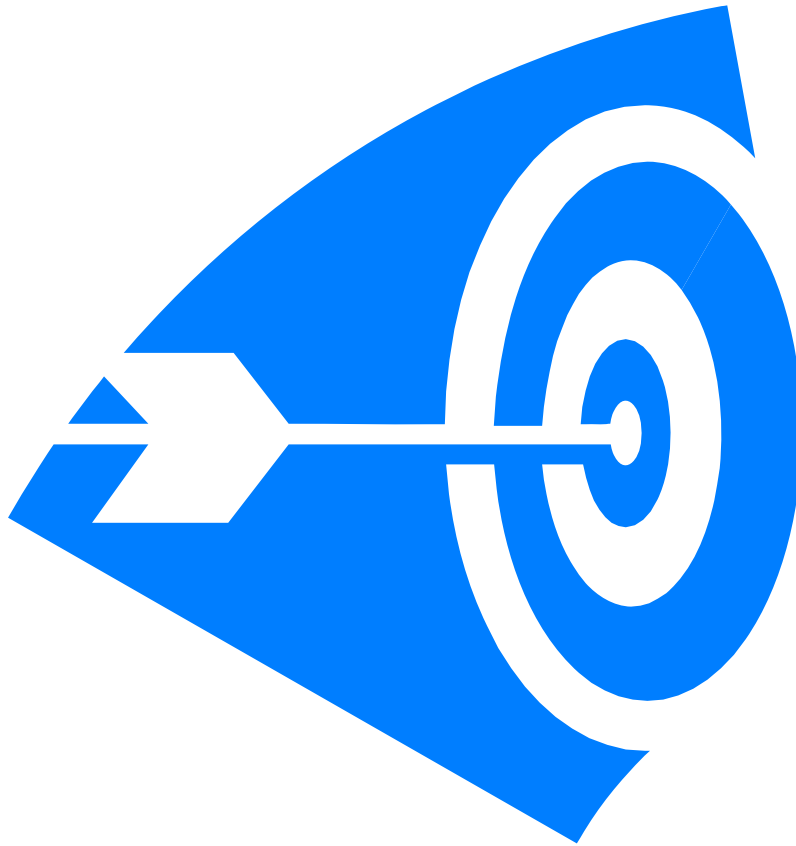
I acknowledge responsibility not to divulge any confidential information or records concerning participants of F5K-funded programs without proper written authorization.

I have received a copy of my employer’s Policy and Procedures regarding confidentiality and authority to release personal information, and have received instruction on the responsibilities and liabilities outlined in this Agreement.

I understand that I will receive a signed copy of this Agreement, and that the signed original will be placed in my personnel file.

Signature: _____ Date: ____/____/_____
Print Name: _____ Title: _____
Program Name: _____
Agency/Organization Name: _____

Summary and Conclusion



Summary/Conclusion

Once again the goals of this training manual have been:

1. to increase knowledge and skills among programs funded by First 5 Kern in the areas of confidentiality and data security;
2. to include all new, signed First 5 Kern Informed Consent Forms and intakes in the evaluation;
3. to protect participant confidentiality by ensuring that informed consent is obtained from all participants from whom personal information is collected.

Thank you for taking the time to review the First 5 Kern Confidentiality Protocol. We appreciate all that you do in providing services to children and families of Kern County. Thank You!