

South Carolina First Steps to School Readiness Client Information Data Collection Guide

Rationale for New Client Information Data Collection System

At the request of South Carolina First Steps, the Office of Research and Statistics (ORS) developed a client-based, web data collection tool to replace the current data collection method (Excel forms collected on disk). Protection of the identity of these clients falls under multiple state and federal laws with the two primary federal laws being Health Insurance Portability and Accountability Act (HIPAA) (Appendix 1), and the Family Educational Rights and Privacy Act (FERPA) (Appendix 2), and the state law South Carolina Family Privacy Protection Act of 2002.

Both HIPAA and FERPA have the same goal: to protect client information for healthcare and education, respectively. Data collection may fall under either or both of these laws. HIPAA and FERPA complement each other, which helps agencies meet regulations for protecting client information. In addition to federal legislation, the South Carolina Family Privacy Protection Act of 2002 provides for the protection of personal information not covered by either HIPAA or FERPA; it is less stringent than the two federal laws.

The new web enabled data collection system must be in compliance with all state and federal laws regarding client/patient privacy. With this in mind, current data collection process was reexamined. A series of meetings between SC First Steps to School Readiness (SCFS) and ORS was held to design this new system. As a result of these meetings:

- Procedures were developed for County First Steps Partnership Offices to implement the new client information data collection system.
- Forms were revised to protect client information at the administrative level. These forms are available in PDF files on the First Steps web site.

Collaboration with the Department of Education

SCFS, ORS and SDE-Office of Early Childhood Education met to reduce duplication between County Partnerships and local school districts regarding the protection of client information, since many program vendors are local school districts. The goal of these meetings were:

- To allow the use of uniform documents/forms for vendors participating in both the Family Literacy Online Information System (FLOIS) and the First Steps web-based data collection system.
- To develop forms (Confidentiality and Authorization/Consent Forms) that can be used by school districts participating in FLOIS and County First Steps Partnerships.

The Family Literacy Online Information System (FLOIS) will be implemented for all school district users at the start of the program year for FY 2006-2007. The Confidentiality and Authorization and Consent forms will be available to school districts for use in the Family Literacy programs. These forms were developed to ensure compliance with all federal and state laws regarding the protection of client information. Program vendors must maintain the original signed Confidentiality and

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Authorization and Consent forms *for First Steps clients* in their files. First Steps offices may have copies of the signed forms for First Steps clients in their files.

Contracts

Requirements of HIPPA, FERPA, and the Family Privacy Act mandated the amendment of the First Steps contract boilerplate. The contract between SCFS and ORS was amended to include language protecting the privacy of client information. For FY 2006-2007, contracts with program vendors will include language for compliance with federal/state regulations for data collection and security. Program vendors will be legally obligated to comply with these regulations as well.

Forms

Employee Confidentiality Form

Anyone who handles or views individual client/participant's information must maintain the privacy of that information. This form provides an explanation regarding the use of the data/information. By signing the form, the staff person pledges to maintain the privacy of this data. This form is similar to a form that was issued by SCFS is a "draft" employee manual in 2003 (Appendix 3).

Who Should Sign? All personnel in a county First Steps office who may come into contact with the data must read and sign this document. All program vendors and direct service staff must sign the Confidentiality Form. All forms should be filed at the county first steps office. If you have people that may view client data such as student interns or board members working on committees, the respective person must sign the confidentiality form.

When Should This Form Be Used? If you did not use the 2003 Confidentiality Form, please use the new form immediately. If you are using the 2003 Confidentiality Form, the new form must be signed at the beginning of the next fiscal year. The Confidentiality Form must be signed each year by staff, program vendors, direct service staff and board members.

Who Maintains This Form? County First Steps offices must keep the signed forms in their files. If school district personnel are program vendors, signed copies of these forms may be maintained with their school district administrator.

Client Authorization and Consent Form

This form provides the legal authority to collect client level data. Clients authorize the use of their personal information and consent to the release of information to the program (First Steps). The form clearly lists the reasons that data is being collected and the ways in which the data may be used. It also outlines the security practices that are used to keep this information private. A similar form was issued from SCFS in the past but was updated to comply with HIPAA/FERPA requirements and more fully explain the use of the clients' information (Appendix 4 and Appendix 5).

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Frequently Asked Questions

Who Should Sign The Form? All clients/participants¹ being served must be asked to sign the Client Authorization and Consent Form. Services cannot be denied to a client/participant if he/she does not sign this form or if he/she revokes consent.

This form cannot be used as a registration form. The Client Authorization and Consent form cannot be revised to include information unless authorized by SCFS. Any unauthorized revisions to this document may potentially change the legal intent of this form.

When Should This Form Be Used? The new form should be used as soon as possible and no later than the beginning of the next fiscal year. Once signed, this authorization is good for as long as the client participates in the program.

Who Maintains This Form? Program vendors need to keep the original forms in a locked file in their office.

Data Use Agreement/Access Request Form

All persons using the web client data collection system must sign the Data Use Agreement. This form:

- outlines the data user's responsibility as a user of the data system,
- obtains signatures from users, from the First Steps county office and from ORS to ensure all parties are aware of the users' interfacing with the data system, and
- provides ORS with enough specific information to issue a password to the user. Users are all vendors and county First Steps staff who use the on-line data system (Appendix 6)

Who Should Sign The Form? The First Steps data collection system has two parts: the Outputs data collection (which is currently in use) and the Client data collection system. Both will be housed together on a new server. Because both servers are housed together, HIPAA compliant passwords must be used to gain access to the server, all data users will need new passwords.

When Should This Form Be Used? The new system will be launched on July 1, 2006 and will include the Client data collection and the Outputs data collection web pages. During the month of June, ORS will issue passwords to counties after receipt of signed Data Use Agreement Forms (available on the First Steps web site). All Executive Directors will be notified when ORS will be processing these forms. The Data Use Agreement Form must be mailed (via US Post Office) to Mary Payson, Office of Research and Statistics, 1919 Blanding Street, Columbia, SC 29201.

Who Maintains This Form? ORS will keep signed originals and they will be kept in a locked file.

¹ The rule about collecting client data for only for programs serving clients face-to-face, multiple times is still in effect. That is, programs such as book distribution or child care quality enhancement are not currently required to collect client data.

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Frequently Asked Questions

How Should We Store The Information? Any media (disks, paper, CDs) with clients' information on them must be stored in a locked file.

Confidentiality Form- How Long Is It Effective? This form must be signed each year to ensure that employees are adequately informed of the confidentiality policy regarding client/participant information.

Can I Use My Existing Password? Passwords must be HIPAA compliant i.e. have a combination of specific characters. The current passwords will not be used. New passwords will be HIPAA compliant and user-friendly (e.g. passwords will be constructed using a familiar word or term). Passwords will have different levels of system access depending upon the user. Password access levels will be assigned based on information from the Executive Directors.

- Level 1 - Access will be given staff working with clients/participants (i.e. program vendors). Access at this level will allow the input client information and view/edit all client information. Client data will be downloaded into an Excel spreadsheet. Aggregate reports will be able to be viewed, printed and downloaded into Excel (Client and Output reports).
- Level 2 - Access will be given to county First Steps staff. Client information will not be viewed or edited; client names only will be viewable. Aggregate reports will be viewed, printed and downloaded into Excel (Client and Output reports).
- Level 3 - Access will be given to county First Steps staff or for vendor staff. Client information will not be viewed. Aggregate reports will be viewed, printed and downloaded into Excel (Client and Output reports).
- Level 4 - Access will be given to SCFS staff. Client information will not be viewed. Aggregate reports for any/all counties will be viewed, printed and downloaded into Excel (Client and Output reports).

Appendix 1

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA, which stands for the American Health Insurance Portability and Accountability Act of 1996, is a set of rules to be followed by doctors, hospitals and other health care providers. HIPAA took effect on April 14, 2003. HIPAA helps ensure that all medical records, medical billing, and patient accounts meet certain consistent standards with regard to documentation, handling and privacy.

In addition, HIPAA requires that all patients be able access their own medical records, correct errors or omissions, and be informed how personal information is shared used. Other provisions involve notification of privacy procedures to the patient. HIPAA provisions have led in many cases to extensive overhauling of medical records and billing systems.

Frequently Asked Questions on HIPAA

What are the main objectives of HIPAA?

1. **Accountability.** HIPAA hopefully will reduce waste, fraud, and abuse. New penalties will be imposed.
2. **Insurance Reform.** HIPAA offers continuity and portability of health insurance, as well as providing limits on pre-existing provisions.
3. **Administrative simplification.** HIPAA mandates standards on electronic data transactions in a confidential and secure manner.

Who must comply with HIPAA?

Any healthcare provider that *electronically* stores, processes or transmits medical records, medical claims, remittances, or certifications must comply with HIPAA regulations. HIPAA does not require a practice to purchase a computer-based system as it applies only to electronic medical transactions.

What is the difference between HIPAA-ready and HIPAA-compliant?

HIPAA-ready typically refers to software products used by healthcare providers, insurance companies and clearing houses that comply with HIPAA guidelines. HIPAA-compliant refers to the doctors, hospitals and insurance companies themselves that are in compliance with HIPAA regulations.

Does HIPAA specify how compliance is to be achieved?

No. HIPAA regulations give health-care organizations the decision to decide how they will implement HIPAA compliance, and are technology and software-neutral.

-Excerpted from "HIPAA-101.com"
HIPAA information web site

Appendix 2

Family Educational Rights and Privacy Act (FERPA)

The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.

FERPA gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Students to whom the rights have transferred are "eligible students."

- Parents or eligible students have the right to inspect and review the student's education records maintained by the school. Schools are not required to provide copies of records unless, for reasons such as great distance, it is impossible for parents or eligible students to review the records. Schools may charge a fee for copies.
- Parents or eligible students have the right to request that a school correct records that they believe to be inaccurate or misleading. If the school decides not to amend the record, the parent or eligible student then has the right to a formal hearing. After the hearing, if the school still decides not to amend the record, the parent or eligible student has the right to place a statement with the record setting forth his or her view about the contested information.
- Generally, schools must have written permission from the parent or eligible student in order to release any information from a student's education record. However, FERPA allows schools to disclose those records, without consent, to the following parties or under the following conditions (34 CFR § 99.31):
 - School officials with legitimate educational interest;
 - Other schools to which a student is transferring;
 - Specified officials for audit or evaluation purposes;
 - Appropriate parties in connection with financial aid to a student;
 - Organizations conducting certain studies for or on behalf of the school;
 - Accrediting organizations;
 - To comply with a judicial order or lawfully issued subpoena;
 - Appropriate officials in cases of health and safety emergencies; and
 - State and local authorities, within a juvenile justice system, pursuant to specific State law.

Schools may disclose, without consent, "directory" information such as a student's name, address, telephone number, date and place of birth, honors and awards, and dates of attendance. However, schools must tell parents and eligible students about directory information and allow parents and eligible students a reasonable amount of time to request that the school not disclose directory information about them. Schools must notify parents and eligible students annually of their rights under FERPA. The actual means of notification (special letter, inclusion in a PTA bulletin, student handbook, or newspaper article) is left to the discretion of each school.

- Excerpted from "ED.GOV"
US Department of Education web site

Appendix 3



Confidentiality Form

I understand and agree that as an employee of _____, I may occasionally view privileged and confidential information. I shall respect the privacy of the people we serve and hold in confidence all information obtained in the course of my employment, whether the information is obtained through reports, records, the web-based data or interactions with a participant. I understand that all participant information must be kept safe from loss, destruction, theft, and unauthorized use. I understand that the copying of information or removal thereof is strictly prohibited unless authorized for legitimate purposes by a supervisor. I understand that participant information may be released by authorized personnel and in accordance with the law. When my service with the agency is complete, I shall maintain participant and co-worker confidentiality, and I shall hold confidential information about any sensitive situations within this agency.

I further understand that the divulging of confidential information and computer access codes (passwords) to unauthorized persons may make me the subject of civil action, as well as disciplinary action up to and including termination.

Signature of Employee

Date

Signature of Supervisor

Date

County First Steps Affiliation

Name of Program (s)

FORMATO DE AUTORIZACIÓN Y CONSENTIMIENTO

Nombre del programa: _____

Se le pedirá información individual acerca de su hijo y su familia como edad, raza, sexo y fechas de nacimiento. La clase de información individual que es posible reunir incluye: tipos y números de servicios, fechas de participación en el programa, razón por la cual se terminaron los servicios, datos demográficos, datos de evaluación e información descriptiva acerca de su familia. Esa información se utilizará en informes para satisfacer de una manera mejor las necesidades de los niños de Carolina del Sur, para mostrar cómo funciona nuestro programa, para identificar cualquier necesidad no satisfecha y para ayudar al personal con la administración del programa.

Los informes son confidenciales y la información individual se mantendrá en un archivo bajo llave. Únicamente personal autorizado tendrá acceso a esa información. Además, los nombres y/o identidades nunca aparecerán en ningún reporte de distribución al público. La información se presentará sólo como parte de estadísticas (datos agregados) acerca de grupos de personas.

A través de mi firma, yo consiento el uso de mi información individual e información acerca de todos los participantes listados en este formato en formatos adicionales, junto con la información de otras familias, para contribuir al funcionamiento del programa. Autorizo a los miembros de su personal profesional a utilizar información para los fines mencionados arriba. Este consentimiento para recopilar información vence en el momento en que yo y/o mi hijo nos retiremos del programa. Entiendo que puedo revocar este consentimiento, salvo hasta el punto en que ya se haya tomado una acción.

Información del niño: Por favor escriba en letra de imprenta toda la siguiente información.

Nombre del Niño _____ Sexo _____ Raza _____ Fecha de Nacimiento del Niño _____

Nombre del Padre/Madre/Tutor _____ Parentesco con el Niño _____ # de Seguridad Social del Niño _____

Fecha _____ Firma de Padre/Madre/Tutor _____

Si aplica, responda:

Nombre del Maestro _____ Nombre de la Escuela _____ Nombre del Distrito Escolar _____

Información sobre el adulto: Por favor escriba en letra de imprenta toda la siguiente información.

Nombre del Adulto/Participante _____ Sexo _____ Raza _____ Fecha de Nacimiento del Adulto/Participante _____

Parentesco con el Niño _____ # de Seguridad Social del Adulto/Participante _____

Fecha _____ Firma del Adulto/Participante, (si es distinto del mencionado anteriormente) _____



Data Use Agreement for SC First Steps Data System Stored by the Office of Research and Statistics For Users

Appendix 5

1. The user will not move certificates authorizing access to the First Steps data system to any other computer without written approval by the ORS.
2. The user will not share logins and/or passwords. Anyone found to have shared a login and/or password will have access terminated to the First Steps data system.
3. The user will adhere to all federal and state requirements for privacy and security as presented in the educational training provided. The ORS will assist in identification of these requirements.
4. No attempt will be made to identify a client/person/patient indirectly using these aggregate data.
5. This agreement can be terminated in the event of extenuating circumstances by any party involved or any agency/organization submitting data
6. The user will direct all questions about the use of the data system for the agency to _____ (insert name and contact information of person who coordinates system access. First Steps Executive Directors may be the coordinator).
7. Access to the data system must be surrendered upon direction of the ORS

User Name (please print): _____

Organization/firm name (Branch, Division, Department, etc.): _____

Address (City, State and Zip): _____ *Telephone ()* _____

Email: _____ *County Number* _____

Optional: Program Code _____ *Vendor Number* _____

By signing this contract, I agree to comply with all the requirements indicated in this document.

Signature of User

Date

**South Carolina First Steps to School Readiness
Access Request Form**
(Please print or type clearly)

Program Code	
County Number	
Vendor Number	
Agency Name	
Name (Last, First)	
E-mail Address	
Telephone	

For security purposes, please fill in at least one:

Place of Birth	
Date of Birth	
Mother's Maiden Name	

First Steps Executive Director Approval:

_____	_____
(Signature and Title)	(Date)

Printed Name	

Health and Demographics Approval:

_____	_____
(Signature and Title)	(Date)

Printed Name	

Create Your Own Password

If you like, you may choose your own password. It must be at least 8 characters long with a maximum of 14. It must have at least 1 capital letter and 1 number. These may be at any part of the password. For example: appLetre3. It is subject to be changed if it doesn't meet the criteria. Print your password in the spaces below:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Your password must be at least 8 characters long ↗

ORS IT Use Only	
Username:	Password:
Date Certificate Request Approved:	
Date username and password sent to user:	