

Navigating Legal Parameters

for Cross-Sector Data

Collaboration

June 2018

Camden Coalition of Healthcare Providers

Cortney Bruno, MSW

Abigail Fallen, RHIA

Teagan Kuruna, MPH

Jacqueline Rodriguez, JD

San Diego Fire-Rescue

Department, City of San Diego

Anne Marie Jensen, BS, EMT-P

Navigating Legal Parameters for Cross-Sector Data Collaboration

Individuals with complex health and social needs* interact frequently with multiple healthcare providers and social service agencies.^{1,2} Despite repeated contact with these systems, these individuals can continue to experience significant barriers to health and well-being.^{3,4} Given their multi-system involvement, improving outcomes for this subset of the population requires care coordination and service integration, along with tailored programming aimed at addressing social barriers to wellness.^{2,4}

To address the needs of these individuals, providers first need to know who they are. Integrating data from multiple sectors, such as social services, education, criminal justice, and healthcare, can help providers identify individuals who are facing multi-sector barriers to wellness. The fuller picture provided by cross-sector data can illuminate a person's health and non-health needs, help improve communication among providers within and across sectors, and make a case for tailoring and integrating services.

While there are benefits to cross-sector data collaboration, establishing data sharing partnerships requires navigating legal and regulatory guidelines that have not kept up with current technology or were not designed with cross-sector collaboration in mind. Cross-sector collaboration, by nature, involves industries bound by different regulations. Potential partners may shy away

from sharing data because they are unclear about the legal and ethical implications of data sharing, or because they are wary of what the other partners may do with the data. Organizations may be concerned with client privacy or feel obligated to protect clients' information, especially because many cross-sector partnerships aim to address problems confronting vulnerable populations. Organizations may also view legal and regulatory frameworks as prohibitive to data sharing when, in fact, the regulations may allow for sharing data in certain circumstances.

Following are two case studies describing how the San Diego Fire-Rescue Department and the Camden Coalition of Healthcare Providers addressed legal and regulatory concerns while building cross-sector data sharing relationships. San Diego Fire-Rescue's Resource Access Program (RAP) developed a tool to help staff understand with whom they can share information, and under which circumstances data can be shared. The Camden Coalition of Healthcare Providers, as a partner in the Camden Promise Neighborhood initiative, built a cross-sector data sharing agreement that was appropriate for the program goals while complying with legal and regulatory requirements for each sector involved. Lessons from these organizations can help programs and initiatives navigate the legal issues at play while establishing data sharing partnerships.

* **Complex health and social needs** describe a combination of medical, behavioral, and social barriers to health and wellness. Patients experiencing this combination of needs often have poor health outcomes despite accounting for a high proportion of healthcare spending.

San Diego Fire-Rescue's Resource Access Program

Developing a tool to navigate legal and ethical implications of data sharing

One significant challenge that arises during data sharing collaborations is determining which data can be legally and ethically shared with which partners. For San Diego Fire-Rescue, this lack of clarity impeded communication among the various professionals in that same department. Emergency medical services are inherently multi-disciplinary, responding to emergencies that involve the overlapping systems of public safety, healthcare, and public health. Cross-sector professionals who work as coworkers in the department were unsure what could be shared among themselves. For example, an emergency medical services provider treating a burn victim may not know what information they can share with a police officer conducting an arson investigation for the same incident.

In response, RAP developed a matrix to guide staff through the legal and ethical implications of sharing various data with different stakeholders. Following is a description of the process RAP used to create, implement, and use the disclosure matrix. (See Appendix A for a copy of the matrix.)

1. Identify the need

Complying with the Health Insurance Portability and Accountability Act (HIPAA) is often one of the foremost concerns for data sharing partners. The most clear-cut way to ensure HIPAA compliance is to have individuals sign a data sharing consent or authorization form. However, because RAP often works with patients who are experiencing crises, requiring a signed form is not always a reasonable expectation. RAP was

specifically interested in developing a procedure that clarified how data can be shared when patients are unable to consent, such as during a medical emergency or when an individual is intoxicated.

About San Diego Fire-Rescue's Resource Access Program

The Resource Access Program (RAP) is the strategic social arm of San Diego Fire and EMS departments. RAP is a paramedic-based surveillance and case management system that intercepts high EMS users. The purpose of the program is to reduce dependence on EMS and acute care services by linking the individual with appropriate resources for their underlying medical, mental health, and social needs through integrated data and information sharing among partners. Prior to developing the matrix, colleagues in the Fire and EMS departments were often unsure of about the legal and ethical considerations of data sharing.

2. Perform a gap analysis

Drawing on strong organizational motivation, the program and legal staff at RAP conducted a gap analysis. It clarified its existing data sharing policies, gaining understanding about which information was already being shared; which information it wanted to share; and with whom it wanted to, but was not currently, sharing information. For example, RAP had policies in place regarding how to share medical information with families and how to disclose mental health information to healthcare entities. Through this gap analysis, staff noticed that the existing and potential policies had two components: *what* information

would be shared and *with whom* the information would be shared.

3. Create a disclosure matrix

Knowing each policy encompassed these two components, RAP created a matrix to organize the requirements of each policy in a user-friendly way so that providers could make decisions about data sharing when patients couldn't sign consent or authorization forms. The matrix consolidates the policies into a single tool that can be used as a guide for determining how to share information legally and ethically. RAP examined each policy to understand the type of recipient and type of information that the policy covered. To fill in the matrix, RAP's attorney provided the response for each information and recipient combination.

Because the information being shared are often about vulnerable individuals, considering not only the legal but the ethical implications of sharing information alongside the benefits is crucial. Simply asking *can I share this information?*, only allows for a yes/no response. Instead, RAP uses the matrix to answer the question *under which ethical and legal circumstances can this information be provided to this recipient?* This question allows for a wider range of answers, listed in the Disclosure Decision Matrix's "Matrix Legend" which are used by an attorney to complete the spaces correlating to type of information and type of recipient.

4. Support staff during implementation and use

While the matrix is a useful tool, RAP also recognized that staff need support to effectively navigate the relationships involved in sharing data across sectors. Establishing appropriate expectations about data sharing can help create relationships in which desire for information sharing is balanced with respect for patient privacy. It is, therefore, important to prepare healthcare

staff for interacting with professionals who are not bound by HIPAA, such as police or homeless outreach workers, and for conversations when they are unable to share requested information with cross-sector colleagues alongside whom they work regularly. RAP empowers staff to handle these scenarios by providing scripts with suggested language for responding to difficult requests, such as:

- When information cannot be shared: "Unfortunately, I can't share that information with you. I know it may not seem like a big deal, but we have to follow the laws about health information privacy very carefully or we could face some pretty serious penalties."
- When the provider needs time to consult the matrix: "Let me review the patient's file and get back to you."
- When discussing patient information via text message but need to switch to a phone call: "I'm not allowed to text you that information but let me call you later with details."

Camden Coalition's Promise Neighborhood Data Sharing Agreement

Creating a usable, flexible agreement for cross-sector data sharing

In support of the mission of the Center for Family Services' Camden Promise Neighborhood initiative, the Camden Coalition is building the data governance and infrastructure necessary for sharing and analyzing data. Building on its long-standing relationships with organizations throughout Camden, NJ, the Camden Coalition created data sharing agreements with an array of education and social service partners serving children and families to facilitate cross-sector collaboration. This case study outlines the process by which the Camden Promise Neighborhood data sharing agreement was drafted, signed, and implemented.

1. Determining which data sets are necessary and why

With the goals of the Camden Promise Neighborhood in mind, the Camden Coalition began by understanding the Promise Neighborhood's core partners and exploring which data sets they could provide. The Camden Coalition's legal and data security teams researched the federal and state laws and regulations that govern multiple data sets, including personally identifiable information from student education records, protected health information from healthcare data, and program data collected by social service agencies. The Camden Coalition considered the laws and regulations governing each type of data, knowing that the data sharing agreement would adhere to the strictest standard.

About the Camden Promise Neighborhood

Recognizing the strong link between low educational attainment and unmet social needs, the Camden Promise Neighborhood is "creating a comprehensive pipeline of services and a cradle through college to career path" for children in its catchment area. Led by the Center for Family Services, the Camden Promise Neighborhood brings together schools, non-profits, and other organizations to ensure that families are getting the social services they need. Data sharing is key to this endeavor, allowing partners to build connections between schools and social services.

2. Demonstrating reliability and ensuring privacy and security

Both the Center for Family Services and the Camden Coalition have been working with individuals and organizations in Camden for many years, and they were able to build on these long-standing relationships to create buy-in for the agreement. The Center for Family Services leadership drew on its track record of providing high quality services across the region to champion the data sharing agreements and articulate the Camden Promise Neighborhood vision, rallying partners toward the common goal of getting families the services they need. The Camden Coalition has been showing the value of data sharing and demonstrating trustworthiness for years through its community-based initiatives. The Camden Coalition brought not only the legal and technological expertise necessary to execute data sharing to link and analyze data sets, but also the credibility necessary to address partners' potential concerns. Robust language in the

data sharing agreement assured partners that data security was being taken seriously and that the agreement created shared responsibility for keeping information safe.

3. Creating an adaptable yet secure data sharing agreement

Guided by its understanding of the Camden Promise Neighborhood's needs, the laws and regulations, and data security requirements, the Camden Coalition created the data sharing agreement (See Appendix B). The agreement was designed to be broad, while maintaining necessary privacy standards, so that partners could feel comfortable signing it with only minor changes. When signed, the agreement gives the participating entities the ability to use data for two purposes: (1) case management (written consent required) and (2) research or evaluation purposes (written consent not required) (See Figure 1). This allows for flexibility as needs and priorities change while protecting sensitive or identifiable information such as personal information (e.g., name, address, date of birth, student ID number), FERPA-[†] protected information (student education records), HIPAA-protected information (individually identifiable health information), and confidential business information.

4. Negotiating with partners

Conversations around data sharing had been underway for over a year before the data sharing agreement was shared for approval and signature. As the partner organizations went through their review process, the Camden Coalition program managers handled questions that partners had about minor changes, such as contact information or the date the agreement would go into effect. The Camden Coalition's legal counsel conducted deeper legal research to address more substantive

questions and changes. For example, indemnification—the assignment of risk for potential legal issues—was a point of contention for one partner organization. This partner wanted the indemnification language changed because of state-level restrictions on its sector's ability to take on risk for certain types of data. After fully understanding the legal implications, the Camden Coalition changed the specific agreement for this partner removing the indemnity language so that the contract is “silent” and indemnity will only be addressed if a problem arises.

5. Current uses/issues with the agreement

All the major data sharing partners have signed the data sharing agreement. Recently, a question arose with one of the partner organizations. The agreement is written to allow two kinds of sharing: (1) Promise Neighborhood's case management process, which the agreement states requires written consent, and (2) research purposes, which the agreement does not state requires written consent. The Camden Coalition had a relationship with the partner's general counsel, and when that individual left the organization and a new person took the role, there were questions about whether data could in fact be shared for research and evaluation purposes without signed consent. Using its previous research on the laws and regulations governing this dataset, the Camden Coalition wrote a memo giving more context about the rules, clarifying how the data sharing agreement met those requirements.

As the organization responsible for the data sharing agreement, the Camden Coalition has responded to questions like this by recognizing where the apprehension comes from and helping to address the concerns through research. Partners often expect legal and regulatory frameworks to impede data sharing—but sometimes, regulation can help facilitate the data sharing process.

[†] FERPA – Family Educational Rights and Privacy Act.

Figure 1: Example language used in data sharing agreement

Purpose of data sharing	Written consent required?	Language used in the agreement
Case management	Yes	For inclusion in the Camden Promise Neighborhood case management system, which is a component of Camden ARISE and is used by Camden Promise Neighborhood Solutions ("Solutions") to coordinate, manage, track, and report on the services provided by all or some of the other Camden Promise Neighborhood Solutions to individuals and families. [NAME] agrees to allow the disclosure of personally identifiable information to the entities shown in Exhibit A to this Agreement provided that (i) appropriate consent or authorization, if required for use, has been obtained from the individual or the individual's parent or guardian; and (ii) a role-based access control is assigned as specified in Exhibit A.
Research	No	For research and evaluation purposes to study and report on the impact of services provided by Solutions and other organizations contributing data for inclusion in Camden ARISE ("Data Contributor(s)") to citizens of Camden City and Southern New Jersey on individuals and families in the area and to study and report on factors related to service provision, assessment of need, and topics relevant to innovating new approaches to benefit the citizens of Camden City and Southern New Jersey.

About the Brief

This brief, made possible by the Aetna Foundation, is one of a series of briefs and webinars outlining considerations for cross-sector data sharing to improve health and well-being. Each brief builds upon content presented in a webinar of the same topic. Find recordings of the webinars and the series of briefs at <https://www.nationalcomplex.care/blog/data-sharing/>.

The authors thank Bob Goerge of Chapin Hall for presenting in the webinar upon which this brief is based. The authors also thank Candice Dias of the Center for Family Services and Hannah Mogul-Adlin, Felicia Santiago, Aaron Truchil, Dawn Wiest, and Katie Wood of the Camden Coalition of Healthcare Providers for their valuable input.

About Us

The Camden Coalition of Healthcare Providers is a citywide coalition of over 25 hospitals, primary care providers, and community organizations working together to deliver better health care to vulnerable citizens in Camden, NJ. Founded by Dr. Jeffrey Brenner in 2002, the Coalition knits together a fragmented health care system for patients with complex needs and repeated, ineffective and expensive hospitalizations, using smart data and holistic, multi-disciplinary team care. We believe if we can deliver better care at lower cost here in Camden, it can be done for everyone, everywhere in America. Learn more about the Camden Coalition on our website: camdenhealth.org.

The National Center for Complex Health and Social Needs is an initiative of the Camden Coalition of Healthcare Providers in Camden, New Jersey. The National Center works to engage a wide range of national stakeholders across the spectrum of healthcare and health policy around improving care for high-cost, high-need consumers. The National Center is funded by the Robert Wood Johnson Foundation and the Atlantic Philanthropies. AARP is a founding member. Learn more about the National Center on our website: nationalcomplex.care.

References

1. Vickery KD, Bodurtha P, Winkelman TN, et al. Cross-sector service use among high health care utilizers In Minnesota after Medicaid expansion. *Health Affairs*. 2018;37(1):62-9. doi:10.1377/hlthaff.2017.0991.
2. The Commonwealth Fund and the London School of Economics and Political Science. Designing a high-performing health care system for patients with complex needs: Ten recommendations for policymakers, expanded and revised edition. Commonwealth Fund. <http://www.commonwealthfund.org/publications/fund-reports/2017/aug/ten-recommendations>. Accessed April 5, 2018.
3. Hayes SL, Salzberg CA, McCarthy D, et al. High-need, high-cost patients: Who are they and how do they use health care? A population-based comparison of demographics, health care use, and expenditures. Commonwealth Fund. <http://www.commonwealthfund.org/publications/issue-briefs/2016/aug/high-need-high-cost-patients-meps1>. Accessed April 5, 2018.
4. Blumenthal D, Anderson G, Burke, S, Fulmer T, Jha AK, Long P. Tailoring complex-care management, coordination, and integration for high-need, high-cost patients: A vital direction for health and health care. National Academy of Medicine. <https://nam.edu/tailoring-complex-care-management-coordination-and-integration-for-high-need-high-cost-patients-a-vital-direction-for-health-and-health-care/>. Accessed April 5, 2018.

Appendix A: San Diego Fire-Rescue's Disclosure Decision Matrix

10

		Covered Entity	Non-Covered Entity	Law Enforcement	Co-Responder	Family/Friends
	Disclosure	1	2	3	4	5
A	Demographics and Service Utilization					
B	Medical Information					
C	Electronic Medical Alert Subscriptions					
D	Mental Health Information					
E	Electronic Mental Health Alert Subscriptions					
F	Substance Abuse Information					
G	Electronic Substance Abuse Alert Subscription					
H	PHI for Minors Acting as Individuals					
I	PHI Information for Minors, Where Disclosure to Parent Poses a Threat or Harm to Minor					
J	Domestic Violence					
	Abuse or Neglect of a Child or Elder					
K	Hypothetical but probable threat to safety					
L	Electronic alert for hypothetical but probable threat to safety					
M	Time sensitive and immediate threat to safety					
N	Electronic alert for time sensitive, immediate threat to safety					

[Attorney to edit below!!!]

Guidance for Disclosures

The Disclosure Decision Matrix does not give you permission to share information in every circumstance. For the disclosure to be permitted under federal guidelines, it must:

1. Be necessary for treatment, referral, or placement for disclosures A -
2. Serve a compelling need related to public health, safety, or welfare for disclosures
3. Contain the minimum amount of information necessary for the intent of the disclosure for disclosures A-G
4. Be within the limitations of any formal agreement between EMS and the receiving agency.

Matrix Legend:

Y = Permitted

N = Not Permitted

P = Permitted with a formal partnership agreement, MOU, or BAA

A = Permitted with written authorization from the client or legal guardian

R = Permitted upon request

O = Permitted with permission from management or oversight agency

V = Permitted with verbal permission

PO = Permitted with a formal partnership agreement AND manager approval

PA = Permitted with written authorization from the client or legal guardian AND manager approval

M = Mandatory

Disclosure	Definition
Demographics and Service Utilization	Information regarding 911 use, including number of calls, location of calls, patterns of calls
Medical Information	Information about medical history, assessments, or treatment.
Electronic Medical Alert Subscriptions	Automatic, electronic alerts that contain medical information related to a current 911 call
Mental Health Information	Information about mental health history or assessments. See 45 C.F.R. § 164.508. See 45 C.F.R. § 164.501 for the definition of "psychotherapy notes."
Electronic Mental Health Alert Subscriptions	Automatic, electronic alerts that contain information related to a current 911 call that is algorithmically classified as behavioral/psychiatric
Substance Abuse Information	Substance abuse patient records and information that identifies an individual as an alcohol or drug abuser. See 42 U.S.C. § 290dd2, 42 C.F.R. Part 2
Electronic Substance Abuse Alert Subscription	Automatic, electronic alerts that contain information related to a current 911 call that is algorithmically classified as substance abuse
PHI for Minors Acting as Individuals	A minor is considered "the individual" who can exercise rights in one of three circumstances: 1) The minor has the right to consent to health care (associated with confidential or sensitive services like sexual and reproductive health care) and has consented , 2)The minor has received legal approval to receive services without parental consent, 3) The parent has assented to an agreement of confidentiality. (SB138, AB499, American Academy of Pediatrics v. Lungren, Confidentiality of Medical Information Act (CMIA), Ca Code of Regulations, Title 22, Section 5' 473.2, Family code section 6925, 6926, 6928, Health and safety code 123110, 123115, Federal Title X Family Planning Program
PHI Information for Minors, Where Disclosure to Parent Poses a Threat or Harm to Minor	The provider has reasonable belief that the parent has or may subject the minor to domestic violence, abuse or neglect, or believes treating the parent as the representative endangers the minor.
Domestic Violence	Law related to reporting of domestic violence?
Abuse or Neglect of a Child or Elder	45 CFR 164.512
Hypothetical but probable threat to safety	45 CFR 164.512
Electronic alert for hypothetical but probable threat to safety	45 CFR 164.512
Time sensitive and immediate threat to safety	45 CFR 164.512
Electronic alert for time sensitive, immediate threat to safety	45 CFR 164.512

Subject to change - For informational purposes only - Editable version available at <https://www.nationalcomplex.care/blog/data-sharing/>.

Appendix B: Camden Coalition's Promise Neighborhoods Data Sharing Agreement

Master Data Sharing Agreement

This Master Data Sharing Agreement ("Agreement") is entered by and among the **Camden Coalition of Healthcare Providers** ("Camden Coalition"), located at 800 Cooper St. 7th Floor, Camden, NJ 08102, **Center for Family Services** ("CFS") located at 584 Benson St., Camden, NJ 08103, and _____, that provides Solutions and support to the Camden Promise Neighborhood, and is located at _____, collectively "Parties". This Agreement shall be effective as of May 1, 2017 ("Effective Date").

1. PURPOSE AND INTENDED USE OF DATA SHARING. The purpose of this Agreement is to facilitate the submission of data to the Camden Coalition for the creation, use, and maintenance of a system of integrated social, health, and educational data concerning citizens of Camden City, Southern New Jersey, and the broader state of New Jersey in order to obtain a more complete understanding of the service needs, service gaps, and impact of services ("Camden ARISE"). The data will be used for the following purposes:

- a. For inclusion in the Camden Promise Neighborhood case management system, which is a component of Camden ARISE and is used by Camden Promise Neighborhood Solutions ("Solutions") to coordinate, manage, track, and report on the services provided by all or some of the other Camden Promise Neighborhood Solutions to individuals and families. [NAME] agrees to allow the disclosure of personally identifiable information to the entities shown in **Exhibit A** to this Agreement provided that (i) appropriate consent or authorization, if required for use, has been obtained from the individual or the individual's parent or guardian; and (ii) a role-based access control is assigned as specified in **Exhibit A**.
- b. For research and evaluation purposes to study and report on the impact of services provided by Solutions and other organizations contributing data for inclusion in Camden ARISE ("Data Contributor(s)") to citizens of Camden City and Southern New Jersey on individuals and families in the area and to study and report on factors related to service provision, assessment of need, and topics relevant to innovating new approaches to benefit the citizens of Camden City and Southern New Jersey.

2. DEFINITIONS

- a. Camden ARISE - A system of integrated social, health, and educational data concerning citizens of Camden City, Southern New Jersey, and the broader state of New Jersey
- b. Camden Promise Neighborhood – A project led by CFS which aims to create a comprehensive pipeline of services and a cradle through college to career path leading to positive change for the children and families
- c. Confidential Information – the [NAME] Data Set, Primary Data Set(s), the Case Management Data Set, Camden ARISE data or any part thereof
- d. Data Contributor(s) – Organization(s) that provide data for inclusion in Camden ARISE.
- e. Case Management Data Set – A data set comprised of data from all Solutions.

Page 1 of 14

- f. Solutions– Organizations which form a part of the Camden Promise Neighborhood and who (1) have active data sharing agreements with the Camden Coalition and; (2) contribute data for use in the Camden Promise Neighborhood case management system and Camden ARISE. The Parties anticipate that these organizations/programs will include insert names of partner organizations here. The Solutions that form a part of the Camden Promise Neighborhood may change during the term of this Agreement. The Coalition will maintain an active list of Solutions which will be made available upon request.
- g. [NAME] Data Set – Data set comprised only of data provided by [NAME]
- h. Primary Data Sets – Data sets provided by Solutions other than [NAME]

3. TERM AND TERMINATION.

- a. **Term.** This Agreement shall be in effect for five years from the Effective Date and thereafter shall renew for one year terms until terminated in accordance with 2b.
- b. **Termination.** This Agreement may be terminated by any party with thirty (30) days written notice to the other parties. In the event of the termination of the Agreement, the Parties shall, upon request, (1) delete all data containing individually identifying information obtained under this Agreement; and (2) certify in writing within ten (10) business days that all copies of the data stored on cloud-based or local servers, backup servers, backup media, or other media have been permanently erased or destroyed.

4. DESCRIPTION OF DATA

- a. [NAME] Data Set. [NAME] shall share with CFS and the Camden Coalition data according to the specifications set forth in Exhibit B. The data shared shall be limited to the data elements mutually agreed upon by the parties. The designated representative of each party will agree on specific data elements and data and record and file formats.
- b. Agreements with Solutions. Solutions will contribute and be given access to the Promise Neighborhood Case Management System and Camden ARISE after executing data sharing agreements with the Camden Coalition that contain substantially similar provisions as those contained in this Agreement.
- c. Other Data Sources Eligible for Linkage.
 - i. Each Solution will contribute a data set that shall be made part of the Promise Neighborhood Case Management System. The [NAME] Data Set will be linked with Primary Data Sets from all Solutions that choose to participate in the Case Management System to create a Case Management Data Set. The Primary Data Set from each Solution and/or the Case Management Data Set may be linked with data from Data Contributors that is available in Camden ARISE.

Page 2 of 14

ii. A data dictionary containing a list of all data elements in the [NAME], Primary, and Case Management Data Set will be available to Solutions and Data Contributors upon request.

- d. Adding to the [NAME] Data Set. Subject to applicable law, and provided there is mutual agreement of the Parties to this Agreement, content of the [NAME] Data Set may also include other records mutually agreed upon by the Camden Coalition, CFS and [NAME] to be necessary and appropriate for the proper execution of this Master Data Sharing Agreement or any approved Data Use Agreement executed under this Master Data Sharing Agreement.

5. CUSTODIAL RESPONSIBILITY AND DATA STEWARDSHIP.

- a. The Camden Coalition and CFS will be joint Custodians of the raw and linked data sets and will be responsible for the observance of all conditions for use and for establishment and maintenance of security arrangements as specified in this Agreement to prevent unauthorized use.
- b. Unless otherwise stated or modified in this Agreement, the Camden Coalition and CFS shall manage, link, and store data as specified in **Exhibit C** to this Agreement.
- c. [NAME] will not use Confidential Information for any purpose other than the purposes specified in this agreement. The Camden Coalition and CFS will fully cooperate with [NAME] in the event that an adult individual or the parent or guardian of a minor under 18 years old requests the opportunity to review his/her personally identifiable information disclosed to the Camden Coalition and/or CFS by [NAME] or wishes to revoke their consent to data sharing with the Camden Coalition and/or CFS. [NAME] will notify the Camden Coalition and CFS in the event it obtains written consent for data sharing with the Camden Coalition and CFS, a revocation of consent to share data with the Camden Coalition and CFS, or a request to review personally identifiable information stored by the Camden Coalition and CFS from an adult or parent/guardian of a minor under 18 years old.
- d. [NAME] will not release any data it receives as a result of its participation in this Agreement to any third parties not specifically authorized to have access to such data under this Agreement.

- 6. **ROLES AND RESPONSIBILITIES.** The Camden Coalition and CFS agree to provide appropriate staff support to execute its data stewardship, data management, custodial responsibilities, and analysis under this Agreement. The Camden Coalition and CFS agree to provide notice to [NAME] within thirty (30) days when additional Solutions or Data Contributors join Camden ARISE. [NAME] agrees to provide appropriate staff support to create and transmit the [NAME] Data Set to the Camden Promise Neighborhood case

Page 3 of 14

management system, which is a component of Camden ARISE, as specified in **Exhibit C** to this Agreement. The Camden Coalition and CFS will notify [NAME] and all other Solutions' staff member(s) of changes to any of the roles listed below within 30 days of receiving notice of the change. Notification via electronic mail to [NAME] and all other Solutions' staff member(s) will be sufficient.

- a. The following Camden Coalition staff member(s) is/are assigned to roles related to the proper management, processing, and distribution of the data under this Agreement:

Role Name, Title, and Organization Contact information

- b. The following CFS staff member(s) is/are assigned to roles related to the proper management, processing, and distribution of the data under this Agreement:

Role Name, Title, and Organization Contact information

- c. The following [NAME] staff member(s) is/are assigned to roles related to the proper management, processing, and distribution of the data under this Agreement:

Role Name, Title, and Organization Contact information

- d. Principal Investigator(s) or Lead Data Analyst(s) are individuals conducting research and evaluation, who will be vetted and approved through a governance structure developed by the Camden Coalition, CFS and all Solutions. All Principal Investigators or Lead Data Analyst(s) are Users, as defined in Exhibit C. Principal Investigators or Lead Data Analyst(s) will abide by any protocols and procedures established by the governance structure developed by the Camden Coalition, CFS and all Solutions. In addition, Principal Investigator(s) or Lead Data Analyst(s) may involve one or more researchers or student research assistants, working under the close supervision of the Principal Investigator(s) or Lead Data Analyst(s), to assist in a support role with various tasks under this Agreement and any approved data use agreements executed under this Agreement. Principal Investigator(s) will require any of its researcher(s) and/or student research assistants that create, receive, maintain, or transmit data to provide reasonable assurance, evidenced by written contract, that researcher(s) and/or student research assistants will comply with the same privacy and security obligations as Principal Investigator(s) with respect to the data.

7. PERMISSIBLE DATA USE, LINKING AND SHARING UNDER THIS AGREEMENT.

All data shared as part of this Agreement and/or any related data use agreements remains the property of the supplying Solution. This Agreement represents and warrants further that data covered under this Agreement shall not be disclosed, released, revealed, showed, sold, rented, leased, or loaned to any person or organization except (1) to other Solutions or Data Contributors; (2) as specified herein; (3) as approved in an executed data use agreement; (4) as otherwise authorized in writing by [NAME] or; (5) as required by law. Access to the data covered by this Agreement shall be limited to the minimum number of individuals necessary to achieve the purpose stated in this section and to those individuals on a need-to-know basis only.

- a. Authorized Linkage and Data Transfers for Program and Site Management. Access to

Page 4 of 14

limited identifiable individual-level data will be restricted to a tightly controlled data stream of “need to know” users at end service points and carefully selected organizational administrators (as specified in Exhibits A and C to this Agreement). Only records with a signed consent or authorization agreement will be transmitted for this purpose.

- b. Authorized Linkage and Data Transfers for Research and Evaluation. Uses of Confidential Information for research and evaluation shall be limited to the Principal Investigator(s)/Lead Data Analyst(s) with whom a signed data use agreement exists. Only de-identified data shall be released for this purpose. The Camden Coalition will manage all identifiable data contained with the Case Management Data Set as well as other Camden ARISE data. CFS will support the Camden Coalition in the management of the identifiable, linked data, as part of the broader data administration needs of the Camden Promise Neighborhood initiative. The Camden Coalition will establish external data sharing protocols with approval from the Solutions or Data Contributor(s). A data governance board, which will be established by the Camden Coalition, CFS, and the Solutions, will decide upon the process for de-identification. Data use agreements with Principal Investigator(s)/Lead Data Analyst(s) will include information about the de-identification process.
8. **NO WARRANTY FOR DATA OR LINKAGE QUALITY.** Both the accuracy of record linkage and the utility of administrative data for research and analytical purposes are dependent on the quality and consistency of the source data. Although the Camden Coalition and CFS will use reasonable efforts to promote accurate record linkage and the creation of appropriate data sets for analysis, no warranty is made as to the achievement of any particular match rate nor as to the ultimate accuracy or utility of any data contributed under this Agreement.
9. **PUBLICATION AND DISSEMINATION OF RESULTS.** The Camden Coalition and CFS shall provide [NAME] copies of written reports, analysis, or visuals produced or derived in whole or in part from [NAME]’s data prior to public dissemination. [NAME] will also be provided with final copies of these publications. Copies shall be submitted to the [NAME]’s primary contact for the administration of this Agreement as specified in Section 6 to this Agreement.
10. **MODIFICATION.** The Parties may amend this Agreement by mutual consent, in writing, at any time. This Agreement may be terminated by either party with thirty (30) days written notice.
11. **SIGNATURES.** By the signatures of their duly authorized representatives below, the Camden Coalition, CFS, and [NAME] agree to all of the provisions of this Master Data Sharing Agreement.

[Signatures on following page]

CAMDEN COALITION OF HEALTHCARE PROVIDERS

 By:
 Title: Chief Operating Officer
 Date:

CENTER FOR FAMILY SERVICES

 By:
 Title: Chief Operating Officer
 Date:

[Name]

 By:
 Title:
 Date:

List of Exhibits

EXHIBIT A: Participating Entities and Role-Based Data Access Controls

EXHIBIT B: Data Specification

EXHIBIT C: Standard Protocols and Procedures for the Use, Management, and Custodial Responsibilities for identifiable and Linked Primary Data Sets and Other Data Sources Eligible for Linkage

Exhibit A: Participating Entities and Role-Based Data Access Controls

Insert names of participating entities and role-based data access controls here.

Exhibit B: Data Specification

The matrix shows the categories of data to be shared with the Camden Coalition under this Master Data Sharing Agreement. Data will be shared on mutually agreed upon dates at the frequency listed below. The information in this Exhibit will be negotiated by the parties throughout the term of this Agreement and is subject to modification by mutual agreement.

Exhibit B: Data Specification

The matrix shows the data elements to be shared with Camden ARISE under this Master Data Sharing Agreement.

Individual-Level Data Sharing

Data Type	Update Frequency
Demographic Data	
Client ID	Monthly
First Name	Monthly
Middle Name	Monthly
Last Name	Monthly
Social Security Number	Monthly
Address	Monthly
Date of Birth	Monthly
Race	Monthly
Ethnicity	Monthly
Primary Language	Monthly
Gender	Monthly
Family Code	Monthly
Guardian Name(s)	Monthly
Guardian Relationship(s)	Monthly
Homeless	Monthly
Program Enrollment Data	

Page 9 of 14

Program Name	Monthly
Program Enrollment Date	Monthly
Program Outcome Date	Monthly
Program Outcome Type	Monthly
Assessment Data	
<u>Insert name(s) of relevant assessment(s) here.</u>	Annual
	Annual

Page 10 of 14

Exhibit C: Standard Protocols and Procedures for the Use, Management, and Custodial Responsibilities for identifiable and Linked Primary Data Sets and Other Data Sources Eligible for Linkage

This document describes protocols and procedures for the use, management, and custodial responsibilities for the Camden Coalition and CFS when accessing data meeting one or more of the following criteria:

- Data are in the form of individual records containing personally identifying information;
- Data are HIPAA or FERPA protected;
- Data are shared by one or more Solutions with the understanding and intent that records from the contributed data sets will be linked with records from other Solutions; or
- Data were provided under the terms of a Master Data Sharing Agreement between the Camden Coalition and Solutions and/or through obtaining consent or authorization from individuals to disclose their data.

This document will act as a core component to all agreements entered into between the Camden Coalition and CFS in which data meeting any of the above criteria are shared and will define how individual-level data will be secured and managed.

POLICY AND PROCEDURES FOR DATA SHARING

1. Terms and Definitions.

1.1. User. Includes any person with access to covered data.

1.2. Public Information is information that can be freely given to anyone.

1.3. Sensitive Information is all other information that is confidential, private, personal, or otherwise sensitive in nature. Sensitive Information includes the following:

Personally Identifiable Information, including an individual's name; address; date of birth; student ID number assigned by a school district, local education agency, or state education agency or partner organization.

1.4. Legislatively Protected Data are data subject to some government regulation or oversight. This includes, but not limited to, data as defined under:

- The Family Educational Rights and Privacy Act (FERPA)-student education records
- The Health Insurance Portability and Accountability Act (HIPAA)-individually identifiable health information

1.5. Other Sensitive Data are data where unauthorized disclosure could lead to a business, financial, or reputational loss. Examples include all intellectual property, research results, or information protected by a confidentiality agreement.

2. User Roles and Functions in Relation to data. For any Master Data Sharing Agreements executed under the terms of this document, Parties will assign (where applicable) an appropriate and qualified User for any of the following roles. Parties will inform each other in writing of the User(s) assigned to each role as well as to any changes in staffing for these

Page 11 of 14

roles. Parties agree that roles specified below may be performed by one or more staff.

2.1. Data Steward. The Data Steward has supervisory authority and is ultimately responsible for all tasks related to the management of data under this Agreement, any Master Data Sharing Agreements, and any Business Associate Agreements, and ensures compliance with all applicable agreements and regulatory requirements. The Data Steward reports any compliance issue or breach to the Camden Coalition a data governance board established by the Camden Coalition and the Solutions.

2.2. Database Administrator/Data Manager. The Database Administrator/Data Manager will be primarily responsible for (1) creating and maintaining appropriate data structures for secure warehousing of Confidential Information acquired under this Agreement; (2) facilitating secure transmission of Confidential Information between the Parties; (3) executing appropriate algorithms to standardize identifying data fields, de-identify the Confidential Information, and create unique linking IDs; (4) developing and executing appropriate data queries from Confidential Information to create linked, de-identified, and/or limited data sets; (5) monitoring and maintaining the server equipment and its security and overseeing regular data backups; (6) performing deletion or destruction of covered Confidential Information upon termination of applicable Agreements; and (7) deleting or permanently encrypting and archiving individually identifying data elements within active Confidential Information once it is determined that these elements are no longer needed in "clear text" (unencrypted) format to facilitate accurate record linkage. The Database Administrator/Data Manager reports any compliance issue or breach to the Data Steward.

3. Data Set Creation and Delivery

3.1. All creation, use, and/or transmittal of linked, de-identified, and/or limited data sets created under this Agreement is subject to the specific terms of this Agreement and any applicable Data Use Agreements. Under no circumstances will any data sets subject to the terms of this document be released to any party (including use by Solution) unless (a) the proposed use of the data set is explicitly authorized, either as part of the Master Data-Sharing Agreements executed by the Parties or by the execution of an approved Data Use Agreement covering the proposed Program and Site Management uses of the limited data set by all Solutions' whose data are included in the data set requested; and (b) approval is obtained from the data governance board to be established by the Camden Coalition and the Solutions for the proposed Program and Site Management uses of the limited data set.

4. Confidentiality and Data Security Safeguards

4.1. Parties agree to establish appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or physical or electronic access to it, and to report violations of this Agreement. Appropriate administrative, technical, and physical safeguards include, but are not limited to:

4.1.1. Users must not save Sensitive Information on personal computers that are not approved for storage of such information.

4.1.2. Users shall put in place reasonable safeguards and security procedures for its

Page 12 of 14

environment, including, but not limited to, using password protected spreadsheets, using password-protected computers, prohibiting password sharing among users, prohibiting unauthorized data downloads and distribution of data; requesting that users do not leave computer unattended and/or set a timeout to lock an unattended computer, installing antivirus software with current updates and a supported operating system with current patches and updates.

- 4.1.3. Parties shall provide periodic training for Users on internal security policies and procedures, and on applicable state and federal legal requirements for protecting the privacy of individuals.

5. Compliance

- 5.1. Compliance to this Agreement includes, but is not limited to:

- 5.1.1. Integrity Audits. To ensure compliance of this Agreement and the protection of Sensitive Data, the Data Manager shall have the right to make, via designated Users, unannounced visits to the Solution site for purposes of inspecting computer equipment and reviewing the security arrangements that the Program Administrator is maintaining with respect to Sensitive Information. Program Administrators will fully and promptly cooperate with the Data Manager and will assist them in completing those inspections. The Data Manager must coordinate access with the Data Steward.

- 5.2. Camden Coalition may temporarily suspend, block, or restrict access to Sensitive Information when it reasonably appears necessary to do so to protect the integrity, security, or functionality of Sensitive Data or to protect the organization from liability.

- 5.3. Statutory Breaches. If at any time a User of either party determines that there has been a breach of the security protocols or violation of this Agreement (including, but not limited to any unauthorized release, access use, or modifications of covered data), the User shall promptly take such reasonable steps as are necessary to prevent any future similar breaches and promptly notify the Data Steward and/or the Program/Contract Administrator and/or the Data Manager of the breach. The Data Manager and Program Administrator will identify the steps taken to prevent any future similar breaches and report to the Data Steward within 24 hours of their discovery.

- 5.4. Reported Violations. The Data Manager and Data Steward will issue a report identifying any privacy and security breach on covered data by a User. Party will have three (3) business days to comply and put in place corrective measures to prevent any future similar breaches. Failure to comply within this time frame will result in temporary or permanent termination of access to covered data and possibly termination of this Agreement.

6. Disposition of Data at Termination of Agreement. In the event of the termination of the Master Data-Sharing Agreement between the Camden Coalition and CFS, CFS shall (1) delete all Primary Data Sets containing individually identifying information obtained under this Agreement; and (2) certify in writing within five (5) business days that all copies of the data stored on local servers, backup servers, backup media, or other media have been permanently erased or destroyed.

Page 13 of 14

A downloadable version of this agreement is available at
<https://www.nationalcomplex.care/blog/data-sharing/>

Page 14 of 14