

Using Unique Identifiers Within Syringe Services Programs

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Statement of purpose

This guide is intended for syringe services programs (SSPs) and SSP funders to support their understanding of data collection and monitoring. It provides an overview of the benefits and drawbacks of implementing unique identifiers (UID) as a method of data collection. The guide includes considerations for SSPs considering implementing a UID system and considerations for funders who are considering requiring individual-level data from grant recipients.

Background: What is a unique identifier (unique ID or UID)?

A unique identifier (UID) is a code assigned to a single participant that some SSPs use to distinguish individual participants. UIDs generally consist of elements of a participant's identity, such as a partial date of birth, initials, parents' name(s), etc. (See [Appendix A](#) for a table of common elements.) When they are derived from personal identifiers, UIDs are not truly anonymous.¹ A string of letters and digits may not be an obvious identifier to the general public, but a person with more information (such as birth certificate data) could decode it.

Background: Why do syringe services programs (SSPs) use unique IDs?

Unless local law requires it, SSPs should not collect full names or full dates of birth to create a unique ID, or require proof of identity, such as confirming information on a driver's license. Many SSPs choose to assign UIDs as a method for [tracking unique client encounters over time](#). When used in conjunction with a data system that allows for real-time reporting, unique ID systems can also be leveraged to follow up on services (e.g., need for annual HIV testing). They can also be used for program improvement purposes, such as reviewing program retention. Some programs may also be able to offer an "SSP card" to participants as protection in the event they need to demonstrate their participation at the SSP when interacting with police, or even after arrest.²

SSPs are sometimes required to use UIDs by local or state policy, a funder, or a local health department. SSPs may need to report de-duplicated data, like the number of participants to whom they provide syringes. While UID systems are often imprecise at quantifying exact numbers ([see here for details](#)) they offer closer approximations than encounter-based data systems. See [Appendix B](#) for more information about the benefits and drawbacks associated with funder requirements to implement UID systems.

³ "De-identified, coded or anonymous? How do I know?," UNC Office of Human Research Ethics, last modified May 1, 2020, <https://research.unc.edu/2020/05/01/de-identified-coded-or-anonymous-how-do-i-know/>.

²SSPs that do not use unique ID systems have found success protecting participants during police interactions by distributing proof of participation cards to participants without an associated code. If an SSP assigns codes for the purposes of protection, the SSP should ensure that there is some measurable benefit to the participant and not just to the organization tracking these data, due to the problems and security risks defined in Sections 2 and 3.

Pros and cons of implementing a unique ID system at SSPs: What are the benefits associated with using a unique ID at SSPs?

- SSPs can use unique IDs to observe program trends that are difficult to see without individual-level data.
 - If an SSP knows approximately how many participants they serve, the program can use stratification to track patterns of program utilization across and within subgroups.
 - SSPs tracking UIDs with demographic information can understand more about their reach among groups disproportionately impacted by drugs, such as BIPOC and queer communities.
- Using a unique ID can assist with program implementation and planning.
 - In some policy environments, UIDs may be required as part of compliance.
 - Knowing the number of unique clients served can be useful for designing programs, allocating resources, and budgeting. While encounter data can support supply projections, individual-level data can help programs understand patterns like the relationship between frequency of attendance and quantity of syringes provided.
- Using a unique ID offers individual-level longitudinal data, creating opportunities for improved continuity of care.
 - Longitudinal data can support a program in identifying how specific participants utilize program offerings over time.
 - Depending on the data systems and services offered, an SSP can implement alerts and/or reminders for follow-up appointments and information about previous encounters. (Note: This requires a higher level of technology and software than what many SSPs use, as well as more staff time.)
- Using a unique ID can improve communication with funders, partners, and the public.
 - Some grant applications and funders will ask for the number of participants an SSP serves. Having this information could make a grant application more competitive and simplify grant reporting.
 - Some SSPs work with their local health department or universities to mathematically estimate the population size of people who inject drugs in their community. Having a count of unique participants served may support this effort.
 - Some SSPs use the number of participants served as a demonstration of their impact to the public.

Pros and cons of implementing a unique ID system at SSPs: What are the drawbacks to using a unique ID at SSPs?

- Using a unique ID can increase barriers to accessing services.
 - Many UIDs rely on participants providing information about themselves they may feel uncomfortable giving, especially on their first visit. While staff can often effectively establish rapport and ease concerns about disclosing personal information by explaining the purpose of the data collection and how data will be protected, some participants may still find the process invasive. Additionally, setting up a UID may take longer than a typical encounter, which could also be a barrier.
 - While UID systems overall provide more reliable estimates of program participation than encounter data, some participants may provide false information when asked for the elements that will be used to generate a unique ID due to stigma and the nature of services that SSPs provide. This may result in recall difficulties for the participant for future visits. It also leads to inexact counts of participants served by the SSP.
- Using a unique ID system carries the risk of compromising a participant's identity.
 - If participants do not remember their code, they may be asked for the elements again at subsequent encounters. Because of the logistical barriers many SSPs face, like limited space, it can be difficult to prevent these conversations from being overheard.
 - Although unlikely, SSP records could be subpoenaed, or computers could be hacked or stolen, which would compromise participant records.
 - In communities with smaller populations, combinations of code elements that are tied to individual characteristics (such as partial date of birth, eye color, etc.) that make up the code are rarer, which means codes could be "breakable" if the elements are known.
- Unique ID systems can be burdensome for staff and peers.³
 - UID systems require more data entry. Programs with limited staff, or staff with limited literacy, may have difficulty completing data entry.
 - It is important that SSPs use the data they collect. Because they have more data, SSPs that generate UIDs should be prepared to spend more time analyzing their data. Additionally, some SSPs lack the technical expertise to effectively or efficiently analyze the quantity of data using UIDs may generate.
 - When used in conjunction with intake forms, programs that use UIDs should expect encounters at the first visit to be longer, which can be challenging to implement for SSPs with high volume. When collecting additional information at subsequent visits, these SSPs may have longer encounter times.

- Unique IDs cannot be tied to confidential records.
 - Client records that contain identifying information like full names and birth dates, such as case management and testing records cannot be tied to client codes without compromising the protection they offer. As a result, programs that offer medical services or case management should not use a participant's UID when documenting services or making referrals. These services require authorization (consent) to track and store personal health information.

Considerations when implementing a unique ID system : If we use a unique ID system, what program considerations should we make?

Blanket code: It is important that all SSPs who assign UIDs have a system in place that allows all participants to receive services, even if they do not want to provide the information for a unique ID. Otherwise, the UID becomes a deterrent to participation. As such, a blanket code can be used for any participant seeking services who does not wish to enroll at that time. Some SSPs may elect to utilize a catch-all or unknown code, which would be a code that is the same length as a normal code but cannot be assigned, such as one with all the same digits (e.g. 999999 for a 6-digit code). This also allows for all non-unique encounter data to be removed and analyzed separately from unique data. When describing their data, SSPs should be sure to identify the removal of these encounters and explain how this likely means their data is an undercount of their actual unique contacts.

Code lookup: SSPs who utilize UIDs should ensure there is a simple system for staff to look up codes as needed to confirm the existence of the code. For example, a participant may not remember whether or not they were at the SSP before, or may not remember their code, and staff should be able to verify before potentially creating a duplicate code. If an SSP prints a list of codes, they should follow relevant [HIPAA](#) protocols even if there is no personal health information (PHI) that can be connected to the codes.⁴

6 ⁴Guidance Regarding Methods for De-Identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule," HHS.gov, Last modified on November 26, 2012, <https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html>.

Considerations when implementing a unique ID system: If we use a unique ID system, what code should we use?

When developing a unique ID system, SSPs are responsible for ensuring a high level of security and continuity and a low level of duplication and bias. To do so, SSPs need to determine how many elements are necessary to include to strike that balance.

- **Security:** SSPs should consider combinations that cannot easily be deconstructed to identify a participant. Many code elements are based on distinguishing characteristics, such as initials or components of a birth date, which can compromise confidentiality. Some SSPs may wish to convert certain code elements to make hacking more difficult (also called 'hashing'), but they must weigh this with the burden on staff and/or technological capabilities. Hashing can be confusing to both staff and participants. See [Appendix C](#) for further explanation of hashing and additional resources.
- **Logistics:** Some code elements may require additional planning or preparation. For example, if an SSP chooses to use a conversion (to code an element that is obscured), like assigning a "1" to participants whose first names occur in the first half of the alphabet and a "2" to participants whose first names occur in the second half, they will need to ensure they support staff with a reminder, such as a visual cue like a sticky note taped onto the SSP counter. Alternatively, if an SSP uses a software-based or online converter, staff will need to be in front of a device with certain software and/or a connection to the internet.
- **Continuity:** Choose code elements that will make it likely that the participant will use the same code every time they attend the program, without having to verify their identity. For example, if a participant provides a different answer to the same question on two different days, they could get assigned multiple codes. This is called a "false split", when one person could be reflected as multiple people in a program's data set. This could occur as a result of difficulty recalling, mutability, and/or privacy concerns. Examples of elements and potential concerns can be found in [Appendix A](#).
- **Duplication:** Select a series of code elements that, when combined, have a low likelihood of being assigned to multiple people. For example, if all fields within a code are related to family of origin/birth date, twins would have the same code. SSPs should plan for what they will do if a participant enrolls and the fields for their code match a code already in existence, such as including an optional additional variable.
- **Bias:** SSPs should endeavor to use code elements that are non-discriminatory and non-triggering. To do so, consider using elements that are unlikely to impact some participants differently based on life experience. For example, some programs utilize maternal maiden name as a code element – consider if this may elicit a response from participants who may have nontraditional families.

Appendices

Appendix A: Code elements

Below is a table of some possible code elements for programs to consider incorporating. There is no perfect answer; it is not necessarily recommended that code elements be standard across programs. The more public the elements are, the easier it would be to break the code and identify the associated participants. Additionally, appropriate code elements may vary by local cultural context or with participant input.

While patient codes in electronic health records can be dozens of characters in length, codes longer than 8 digits are likely too long for a low-barrier SSP setting, while codes shorter than 6 digits would be considered too short. Overall, SSPs should aim to develop a code that is easily remembered by participants, with elements that are easy for staff to describe. Note that below, some potential code elements have many possible options (for example, 26 possibilities for an initial or 676 possibilities for a 2-letter string) while others have few (for example, 12 possibilities for a month of birth or fewer for race/gender), so that should be considered as well when creating a code formula.

SSPs should also note that all health information (such as medical history, test results, insurance information, demographic data, etc.) that contains at least one individual identifier is considered protected health information (PHI) under the HIPAA Privacy Rule.⁵ While not all SSPs are covered entities, it is generally considered best practice for SSPs to adhere to the “spirit” of HIPAA. The Privacy Rule names 18 individual identifiers that, when combined with health information, become PHI, which means that SSPs that store health information along with UIDs should consider them PHI. Common identifiers that SSPs may use include names, any component of an address, phone numbers, email addresses, and all elements of dates related to a participant *except* years. However, any other characteristic that could uniquely identify the participant should also be considered an individual identifier.

Table 1. Common code elements

Code element	Pros	Cons	Individual identifier?
First name - first or last letter(s)	Large # of potential variables, Easy to recall	Privacy concerns	Potentially
Last name - first or last letter(s)	Large # of potential variables, Easy to recall	Privacy concerns	Potentially
First or last initial in first or last half of alphabet	Easy to recall, potentially less breakable if the code elements are not public	Less unique	No
Mother's maiden name - first or last letter(s)	Large # of variables, invariant over lifetime of participant	Less trauma-informed	No
Parent's first name - first or last letter(s)	Large # of variables, relatively easy to acquire, invariant over lifetime of participant	Less trauma-informed	No
First letters of a chronological family member (e.g., first two letters of your oldest/youngest sibling's first name, oldest/youngest parent's, etc.)	Large # of potential variables	Difficult to recall, Less trauma-informed	No

Table 1. Common code elements (cont'd)

Code element	Pros	Cons	Individual identifier?
Zodiac sign - first _ letters	Potentially more difficult to reverse engineer if the code elements are not public	Lack of familiarity, Less unique, Potentially offensive	No
DOB - 2-digit day	Relatively easy for participant to remember/ answer, invariant over lifetime of participant	Privacy concerns, Less unique	Yes
DOB - 2-digit year	Relatively easy for participant to remember/ answer, invariant over lifetime of participant	Less unique	No
DOB - 2-digit month	Relatively easy for participant to remember/ answer, invariant over lifetime of participant	Less unique	Yes
DOB - day, year, or month odd or even	Relatively easy for participant to remember/ answer, invariant over lifetime of participant, potentially less breakable if the code elements are not public	Less unique	No
Eye color - first letters	Relatively easy for participant to remember/ answer	Privacy concerns	No

Table 1. Common code elements (cont'd)

Code element	Pros	Cons	Individual identifier?
Social Security Number – last number(s)*	Invariant over lifetime of participant	Privacy concerns	Potentially
Gender**	Could help differentiate if multiple people have similar codes	Less unique, Mutable, Less trauma-informed	Considered health information, which becomes PHI when stored in conjunction with an individual identifier
Race**	Could help differentiate if multiple people have similar codes	Less unique, Less trauma-informed	Considered health information, which becomes PHI when stored in conjunction with an individual identifier
Number of siblings (total, older, younger)	Relatively easy for participant to remember/ answer	Less trauma-informed, Less unique	No
City of birth – first letter(s)	Relatively easy for participant to remember/ answer	Less unique	No
First street name - first letter(s)	Potentially less breakable if the code elements are not public	Difficult to recall, Less trauma-informed	No
First phone number - last number(s)	Potentially less breakable if the code elements are not public	Difficult to recall, Less trauma-informed	Potentially

11*Not recommended due to the security risk.

**Not recommended due to potential insensitivity.

Example codes

- [National HIV Behavioral Surveillance \(NHBS\)](#) uses a 10-digit code:
 - First 2 letters last name
 - First letter first name
 - First letter mother's first name
 - 2-digit month of birth
 - 2-digit year of birth
 - Gender
 - Race
- **Project NEXUS, a health survey of people who use drugs recruited at SSPs**, uses a 10-digit code:
 - First 3 letters zodiac sign
 - First 3 letters eye color
 - First 2 letters city of birth
 - First 2 letters oldest parent's first name
- **Washington State Department of Health** uses a 7-digit code:
 - First 2 letters last name
 - First 2 letters first name
 - First letter mother's first name
 - 2-digit day of birth

Appendix B: Considerations for funders/policy-makers

As outlined above, de-duplicated data can facilitate trend analysis and provide insight into the population receiving services, making it a theoretically desirable metric for many funders and policymakers.

Below, we describe several considerations that we recommend funders and policymakers review before instituting requirements for de-duplicated data, to ensure their expectations are realistic and they get the most value out of instituting the requirement.

Consideration 1: Using a unique ID system does not guarantee that each code is representative of one participant.

Even when SSPs follow recommendations laid out in Section 3, participant codes are still susceptible to duplication (same code for two or more participants) and false splitting (multiple codes for the same participant). They also carry some risk to the program and the participant due to not being truly anonymous.

Recommendation: Explicitly communicate your understanding of these limitations and offer any additional privacy protection through data security or other measures. For example, proactively ask what IT support or systems they are lacking and consider if there are ways to incorporate that into your grant. While data security may not be meaningful to all participants, it is critical for SSPs. Ensuring that SSPs may offer a blanket code to participants who wish to not enroll will also improve participant comfort and reduce false splits.

Consideration 2: SSPs often reach many more participants than physically present to their program.

Even if the count of all unique participants seen at the SSP within a certain time frame is available, that still does not factor in participants served through secondary methods (e.g., a participant returning used syringes and/or receiving new syringes for others).

Recommendation: Define how you expect SSPs to count participants – and whether that should include people reached through secondary methods - and communicate that clearly. Where possible, include funding recipients in the development of this definition.

Consideration 3: Implementing a UID system requires a substantial overhaul of programmatic processes and service flow.

Changing from a system that does not use unique IDs to one that does impacts the delivery of services, including how staff interact with clients and how they document encounters. Additionally, it often requires technology and data management systems that require significant financial investment and staff training.

Recommendation: Offer ongoing financial incentives for SSPs who will be implementing a UID system for the first time to invest in data collection, management, and evaluation capacity. This should include lines for software, hardware, licensing, training, and personnel.

Consideration 4: Implementing a UID system does not guarantee that the SSP will be able to improve its program monitoring and evaluation.

Without resources and personnel, SSPs that did not previously have UID systems may not have the capacity to use the large amount of data they will generate to analyze trends and patterns, which will not benefit the program or the program participants. Additionally, SSPs are often not notified of how data they submit is being used, which can create a “black box” perception of the funder relationship.

Recommendation: Provide additional data analysis support to all SSPs if you are requiring unique data. For example, SSPs may not have the capacity to build dashboards or run statistical reports on their data. Consider if these are benefits you can offer.

Appendix C: Hashing

A conversion, or hashing, is when one digit is transformed to another value based on a predetermined conversion. It further obscures the code element and makes it more difficult for someone without the conversion information to identify the person. For example, one system would be converting an element of a code that uses letters to numbers (ex. A-E=1, F-J=2, K-O=3, P-T=4, U-Z=5). So, if the first element of a code was the first initial of the participant's last name and the participant's last name was Smith, the first element of their code would be 4.

Free online hashing systems include:

[SoundEx](#) and the [Double Metaphone Converter](#) will convert phonetic spellings of surnames, which can help ensure that names that might have multiple spellings result in the same code element.

[CRC16](#) will convert any string of digits into a 4-digit hash.

[Base 64](#) is intended to convert images and other attachments into strings of code, but you can use it to hash existing codes as well. The longer your code, the longer the hash will be.

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The [Supporting Harm Reduction Programs \(SHaRP\)](#) team at the University of Washington offers expert technical assistance about harm reduction data monitoring and evaluation. To reach out to the SHaRP team, please e-mail sharpta@uw.edu . Follow SHaRP on Instagram at [@UW_SHaRP](#) .

To request technical assistance from the National Harm Reduction Technical Assistance Center, go to <https://harmreductionhelp.cdc.gov/>.

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