FoRSE Data Validation Guidelines

The NAATP Foundation for Recovery Science and Education (FoRSE) is a 501(c)(3) nonprofit organization established in 2020 to improve addiction treatment through science, technology, and education. The primary work of FoRSE is operating the FoRSE Addiction Treatment Outcomes Program, which consists of a centralized repository of de-identified data describing discrete episodes of patient care occurring at treatment organizations ("FoRSE Data Sites") across the US and internationally. The data consist of information about:

- The **Patients** (e.g., demographics, diagnosis) who present for treatment,
- The **Services** provided (e.g., level of care, length of stay), and
- The short- and long-term **Outcomes** of those services (e.g., patient-reported symptoms, functioning, and quality of life).

FoRSE delivers an Annual Summary Report of de-identified data aggregated across these treatment episodes and organizations, as well as annual, confidential, site-specific reports to participating Data Sites.

In reporting data from the Outcomes Program, FoRSE strives to provide valid and useful information to the public as well as treatment providers about the impact of addiction healthcare. To reach this goal, FoRSE must ensure the quality of the data being submitted through an ongoing process of data validation, which is described in this document. This document provides practical guidance to FoRSE Data Sites and FoRSE Technology Partners to implement, establishing a base level of data validation for the Program. This implementation helps to ensure that reporting from FoRSE is most useful for purposes of business intelligence, quality improvement, and research.

Defining Data Validation

Data validation refers to the process of verifying the accuracy and quality of data before using it. If data are summarized, analyzed, or interpreted before validation, this often leads to invalid statistics and conclusions. Data validation consists of checking for errors such as missing data, duplicate data, and incorrect types of data, and resolving any inconsistencies in the data. Data validation is, therefore, a critical step in the data science process, verifying that the data meet quality standards and that conclusions derived from data analysis are valid and reliable.

In 2023, FoRSE delivered the first Annual Summary Report of de-identified data submitted by 55 distinct addiction treatment organizations ("FoRSE Data Sites"). This Report summarized data submitted to FoRSE between August 2021 through December 2022, representing 153,118 unique patient episodes of care that occurred at these organizations between 2002 and 2022.

Shortly after this Report was released publicly, FoRSE delivered confidential site-specific reports to each Data Site, summarizing de-identified data from 2022 admissions at that site, compared to aggregated data from other participating treatment centers. Throughout the process of completing the analysis and narrative for these reports, FoRSE identified several primary issues that must be addressed with additional data validation steps to improve the quality of FoRSE data and reporting.

FoRSE First-Year Data Quality Issues

The primary data quality issues identified by FoRSE during the first year of reporting include:

1. Missing Data, specifically missing values for the FoRSE Critical Data Elements [Age, Gender, Race & Ethnicity, Level of Care at Admission, Level of Care at Discharge, Discharge Type, Length of Stay/Engagement (days in each level of care), and Primary SUD Diagnostic Category]. These data points – located in the FoRSE "administrative surveys" (i.e., non-patient-facing) including FoRSE Demographic Information Form, FoRSE Admit Survey, and FoRSE Discharge Survey – describe key characteristics of the individuals being served in addiction treatment. Therefore, these data points are critical for FoRSE analyses. Without them, we cannot describe the set of persons being served or the services they receive, and we cannot examine demographic differences in service provision and treatment outcomes.

FoRSE Survey	Critical Data Element	% Missing in 2023 Annual Report
FoRSE Demographic Information Form	Age	1%
	Gender	9%
	Race and Ethnicity	42%
FoRSE Admit Survey	Level of Care at Admission	15%
FoRSE Discharge Survey	Level of Care at Discharge	38%
	Discharge Type	20%
	Length of Stay/Engagement	21%
	Primary SUD Category	14%

2. Duplicate Data, specifically having more than one of each type of FoRSE Administrative Survey per unique patient episode:
    - FoRSE Demographics Information Form
    - FoRSE Admit Survey
    - FoRSE Discharge Survey

   Only one of each of these surveys should be associated with a single patient episode. Duplicate FoRSE Demographic Information Forms were the primary issue.

FoRSE Survey	% of Surveys in 2023 Annual Report With Exact Duplicate Surveys Submitted
FoRSE Demographics Information Form	21%
FoRSE Admit Survey	0.25%
FoRSE Discharge Survey	2.7%

3. Unclear Timeline of survey completion. Each patient-facing survey submitted to FoRSE should have associated "timing indicators" that allow FoRSE to determine at what point in a patient's

treatment or early recovery a survey was completed. These timing indicators include:

- daysFromAdmit: Number of whole days between the admission date and the day a survey was completed.
- daysFromDischarge: Number of whole days between the discharge date and the day a survey was completed.

FoRSE does not collect any Protected Health Information (PHI), such as specific dates of service. Therefore, the FoRSE timing indicators are essential to examine changes in patient-reported symptoms and functioning over time.

In data analyzed for reports in 2023, 65% of all surveys submitted were missing the daysFromDischarge indicator. In such cases, it is impossible to determine if the survey was completed as part of Progress Measurement (during treatment) or Post-Discharge Outcomes Measurement.

FoRSE API Data Validation Guidelines

The best way to ensure the accuracy and completeness of FoRSE data is to update the Application Programming Interface (API) so that inaccurate and incomplete data will not be accepted. The following changes will be made to the FoRSE API on **January 1, 2024**. After that date, only data and surveys that follow these "V2" guidelines will be accepted. Surveys that do not follow specifications will be rejected. All changes are reflected in the updated FoRSE V2 API Documentation which can be found using this link: FoRSE V2 API Docs (https://naatpdata.com/v2/docs/APIdoc.php).

API changes to address the Missing Data challenge:

1. A FoRSE Demographic Information Form, which contains 3 of the FoRSE Critical Data Elements, is required for every new patient episode. If any type of survey is submitted for a new patient episode and there is no FoRSE Demographic Information Form corresponding to that patient episode, the survey will be rejected.
2. The FoRSE administrative surveys (FoRSE Demographic Information Form, FoRSE Admit Survey, and FoRSE Discharge Survey) must be 100% complete (all items endorsed), or they will be rejected. Some items on these surveys are FoRSE Critical Data Elements and must be endorsed with one of the available response options (see #3 below). For the NON-Critical items on these surveys, if the data point is not collected by the provider, the code from the technology vendor must endorse "NA."
3. All FoRSE Critical Data Elements are required. These data points are commonly collected across healthcare providers, and they are essential for FoRSE analyses. Survey responses must match exactly, or be converted into, FoRSE's available answer options. What this means:
    - A response for all Critical Data Elements (CDEs) must be selected from the available options, or the survey will be rejected. Because these variables are of critical importance, there is no "NA" option for these items. CDE's include:
        - On FoRSE Demographics Information Form:
            - Age (Q1)
            - Gender (Q2)
            - Race and Ethnicity (Q3)
            - Sexual Orientation (Q4)

        - On the FoRSE Admit Survey:
            - Level of care at admission (Q1)
        - On the FoRSE Discharge Survey:
            - Level of care at discharge (Q1)
            - Discharge type (Q2)
            - Length of stay/engagement (Q3a through Q3h) – no fields can be left blank; use 0 for no days in a given level of care
            - SUD category (Q5)
    - If the provider's response options do not match FoRSE's, they must be matched/mapped and converted to the FoRSE options. FoRSE can offer guidance in determining how site-specific categories (e.g., for Discharge Type) can be matched to FoRSE categories.
4. All patient-facing progress monitoring and outcome surveys must be 100% complete, or they will be rejected. This does NOT mean that clients must respond to every item on these patient-facing surveys. Rather, items must be assigned a "NA" value if they are not endorsed by the client.

To address the Duplicate Data challenge:

5. This is a clarification, not a change to the API: Each patient episode must be associated with only ONE of each type of FoRSE administrative survey (Demographics, Admit, and Discharge). Some EMRs have been sending, for example, more than one FoRSE Demographic Survey per patient episode. If data in the FoRSE Demographic Survey (or other administrative surveys) is updated, the survey should be re-sent with the same "sessionID," and the new submission will overwrite the first submission.

To address the Timeline challenge:

6. A new variable "completedWhile" is required for all outcome surveys – response options for this variable are inTreatment and postDischarge.
    a. If completedWhile = inTreatment, then daysFromAdmit must be an integer (>=0), AND daysFromDischarge must be -99.
    b. If completedWhile = postDischarge, daysFromAdmit must be -99, AND daysFromDischarge must be an integer (>=0).

    Note: Both daysFromAdmit and daysFromDischarge must have values or the survey will be rejected. Values must not be negative unless -99 as above.

Other Changes to FoRSE API

Several other changes have been made to FoRSE data elements and surveys in V2, primarily due to feedback from FoRSE Data Sites. The purpose of these changes is to improve clarity across providers and to reflect:

- Inclusivity in language describing patient demographics.
- Inclusivity in language used by different sectors of the SUD treatment and recovery space.
- Consistency with national standards.

Establishing healthcare interoperability (the ability of electronic systems to exchange and make use of health data) is essential to improve efficiency and effectiveness across healthcare settings. To achieve healthcare interoperability, providers and their health IT vendors must adhere to standards in how they record patient data electronically. Numerous entities have published sets of standards for use in healthcare settings. For example, the United States Core Data for Interoperability (USCDI), adopted through the 21st Century Cures Act (2016), is used by the Centers for Medicare and Medicaid and other federal and state partners. Some of the changes described below were made to conform to national standards.

Changes to the FoRSE Demographics Information Form

As awareness grows regarding diversity in definitions of personal identity, terms used to describe demographics including Gender, Race, Ethnicity, and Sexual Orientation (among many others), vary across patient assessment forms and electronic systems used by different providers. While some electronic systems have rigid, "hard-coded" options for these variables, some allow for customization. Providers sometimes choose to customize and offer many options, including a free-text option for patients to self-describe. While free text is ideal for the purpose of inclusivity in patient assessment, it can create a challenge for data aggregation and cross-agency research. FoRSE attempts to find a balance between promoting inclusivity in patient assessment with simplicity and consistency for research purposes.

Gender

7. The Gender data point in FoRSE has been changed from "Select one" to "Multi-select." Additionally, response options "Trans Woman" and "Trans Man" have been removed, and "Transgender" and "Unknown" have been added.

(Old labels; select one)	(New labels; multi-select)
Female	Female
Male	Male
Trans Female	Transgender
Trans Male	
Non-Binary	Nonbinary
Gender Not Listed	Gender Not Listed
Choose Not to Disclose	Unknown

A clarification of the coding for this element, as well as the rationale for this change, is included here. There is an urgent need to routinely capture in healthcare data the concepts of sex and gender in a safe and inclusive manner, as inconsistencies in the representation of diversity in sex and gender have led to fragmented and even harmful practices. The Gender Harmony Project (GHP) is "a collective, collaborative, international effort to help fulfill health care's responsibility to gender-marginalized people by specifying gender-inclusive standards that can be used by systems and clinicians in the provision of affirmative and quality person-centered care" (McClure et al., 2022). USCDI references GHPs data elements and response sets, as do the National Academies of Science, Engineering, and Medicine (NASEM, 2022) in their report, Measuring Sex, Gender Identity, and Sexual Orientation.

Following the guidance provided by the GHP and Kronk et al. (2022), the options Trans Female and Trans Male were removed from this item in the FoRSE database. Kronk et al. (2022) indicates that terms sometimes found in EMRs (e.g., "FTM" (female-to-male), "MTF" (male-to-female), "transgender male," "transgender female") are problematic due to major shifts in conceptualization of these terms in the past few decades. Instead, the authors suggest that EMRs can improve quality of both care and research with transgender patients by following one of two methods for patient gender self-identification:

- Direct one-step method: Patients can self-identify as transgender through a question such as, "Do you consider yourself transgender?" or "Does your gender identity match the gender you were assigned at birth?"
- Indirect two-step method: Patients self-identify as transgender through two questions: 1) What is your gender identity? And 2) What is your assigned gender at birth? The two-step method is supported by NASEM, CMS, and the CDC.

Providers can use either of these methods to ascertain a patient's transgender identity and endorse the "Transgender" option in the FoRSE Gender data point. Because the item is multi-select, this item can also capture other terms used by each individual.

The "Gender not listed" option can be endorsed to designate that a patient indicates that they use a different term for gender or sexual orientation than those listed. Best practice in presenting options to the patient is to provide a free-text response field which allows them to specify their preferred term.

The "Unknown" option is provided per McClure et al. (2022) to indicate that "The person's gender identity is not known at this time, for any of a variety of reasons."

Following GHP recommendations, personal pronouns and preferred name should also be included in assessment of gender (and in EMRs) for consistent, person-centered, and inclusive service provision.

<u>Race and Ethnicity</u>

8. The Race and Ethnicity data point in FoRSE has not been changed; however, a clarification of the coding for this element is included here, as some FoRSE Data Sites been sharing only race OR ethnicity data. Race and ethnicity are two separate, socially-constructed terms. The USCDI v4 standards specify that both Race and Ethnicity are domains that should be measured, including these categories at a minimum:
    - Race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White
    - Ethnicity: Hispanic or Latino; Not Hispanic or Latino (some prefer Latinx or Latine)

Race and Ethnicity are sometimes listed as two separate variables in electronic systems, and sometimes as one. In either case, a client should be able to select as many categories as they feel apply to them. In the FoRSE system, race and ethnicity are collapsed into one data point, with the option of selecting all that apply:

- American Indian or Alaska Native
- Asian
- Black or African-American

- Hispanic or Latine
- Native Hawaiian or Other Pacific Islander
- White
- Other

If a provider's EMR contains separate "Race" and "Ethnicity" data points, the selected combination of patient choices can easily be mapped onto the FoRSE categories within the single "Race and Ethnicity" data point. However, in this case, both data points (Race and Ethnicity) must be mapped onto the singular FoRSE element. If only one of these is mapped to the FoRSE element, key demographic data will not be represented.

Sexual Orientation

9. This data point has been added to the FoRSE Demographics Information Form and is a FoRSE Critical Data Element. Sexual orientation is an important component of personal identification, and people who identify as LGBTQ+ face societal discrimination and harm that increases risk for and prevalence of substance use disorders (SAMHSA, 2020). The answer options in the FoRSE system for this data point correspond to the recommendations of the Gender Harmony Project:
    - Bisexual
    - Lesbian or gay
    - Straight or heterosexual
    - Sexual orientation not listed here
    - Choose not to disclose
    - Unknown

The GHP (2022) recommends adding Asexual and Questioning or exploring; these options were not included in the recommendations by NASEM (2022) but may be added in future guidelines.

Changes to the FoRSE Admit Survey

10. Several data points in the FoRSE API documentation have been changed due to input from FoRSE Data Sites. Feedback was provided to FoRSE that Q1 in the FoRSE Admit Survey ("To what level of care is this client admitting?") requires a single response rather than "select all," and that clients may admit to more than one of the listed levels of care at a time (e.g., Intensive Outpatient and Sober Living). Therefore, one of these changes to this survey is to clarify that Q1 refers to the highest (most service-intensive) level of care to which the client is admitting.

(Old FoRSE item)	(New FoRSE item)
To what level of care is this client admitting?	What is the highest level of care this client is admitting into?

11. To help providers track readmissions to treatment, which is an important variable to payors, a new item has been added to the FoRSE Admit Survey as Q8:

    - Is the client readmitting within 90 days of a prior episode within this organization?

[Select one: No, Yes]

Changes to the FoRSE Discharge Survey

12. Also in response to feedback from FoRSE Data Sites, a new response option has been added to Q2 (Discharge Type) on the FoRSE Discharge Survey:

    - Financial (discharged/transferred due to personal financial restriction or insurance denial)

13. The Payment Type item (Q4) has been changed for several reasons: to clarify our interest in the *primary* form of payment each patient is using to fund their treatment; to clarify that *any type* of public funding can be represented; and to add a Data-Site-recommended response option (Scholarship):

    - Primary Payment Type
      [Select one: Self-Pay, Private Insurance, Medicaid/Medicare or Other Public Funding, Scholarship, Other]

14. The primary Substance Use Disorder category item (Q5) has been relabeled to clarify that the data of interest in the patient's primary SUD diagnosis, or (if diagnoses are not made by a provider, e.g., in a Sober Living setting) the individual's "primary drug." Additionally, a "None" option has been added, as some FoRSE Data Sites primarily treat individuals with mental health disorders other than SUDs.

    - What is the primary Substance Use Disorder category? (or "primary drug")
      [Select one: None, Alcohol, Cannabis, Hallucinogen, Inhalant, Opioid, Sedative/Hypnotic/Anxiolytic, Stimulant, Tobacco, Other]

15. The "MAT medications received" item (Q6) has been changed from "select one" to multi-select, as patients may receive more than one type of medication to assist them in their recovery. The term Medication-Assisted Treatment (MAT) generally refers to the use of medication(s) alongside counseling and therapy in the course of treatment. The medications used in treatment may include those approved by the FDA for substance use disorders, as well as those approved for the treatment of other mental health disorders. This data point is now multi-select, allowing for the collection and disaggregation of data for medications prescribed for SUD as well as other mental health issues.

    - MAT Medications Received
      [Multi-select: None, Acamprosate/Campral, Buprenorphine (Sublocade Injection), Buprenorphine (Subutex/Suboxone Film), Disulfiram/Antabuse, Naltrexone (ReVia Pill), Naltrexone (Vivitrol Injection), Methadone, Medications for co-occurring disorder (e.g. anxiety or depression), Medication not listed, Other]

Changes to Progress Monitoring and Outcome Surveys

16. Three standardized surveys have been added to the list of those accepted by FoRSE, including:
    - BAM-IOP: a version of the Brief Addiction Monitor that covers only the previous 7 days and can be used with patients on a weekly basis.
    - GAD-2: a screen for generalized anxiety with fewer items than the GAD-7
    - PHQ-2: a screen for depression with fewer items than the PHQ-9

The shortened forms of the GAD and PHQ have demonstrated appropriate reliability, validity, and sensitivity to change, comparing well to their longer forms (Bisby et al., 2022).

Changes to the FoRSE Outcomes Survey

17. The service utilization item in the FoRSE Outcomes Survey (Q1) has been changed from select-one to multi-select.

    - Over the last 30 days, have you used any of the following services?
      [Multi-select: None, Detox, Residential, Partial Hospitalization, Intensive Outpatient, Outpatient, Sober Living/Recovery Residence, Recovery Support]

18. As in #14 above, the "MAT medications received" item (Q4) has been changed from "Select one" option to "Multi-select":

    - Which of the following medications are you currently taking in support of your recovery?
      [Multi-select: None, Acamprosate/Campral, Buprenorphine (Subutex/Suboxone Film), Buprenorphine (Sublocade Injection), Disulfiram/Antabuse, Naltrexone (ReVia Pill), Naltrexone (Vivitrol Injection), Methadone, Medications for co-occurring disorder (e.g. anxiety or depression), Medication not listed, Other]

Summary

A summary of all changes made to FoRSE data elements and surveys can be found in the tables below.

Table 1. CHANGES TO CRITICAL DATA ELEMENTS (CDEs) AND SURVEYS

Updated Data Element or Survey	**Change/Specification(s)**	**Rationale**
FoRSE Demographics Information Form	Required for submission of any survey for a new patient episode	This survey contains several CDEs that are essential for FoRSE analyses
	Only one FoRSE Demographics Information Form per patient episode	This specification reduces duplicate data. Any changes in the patient's age, gender, race, or ethnicity identification can be captured by sending a new survey with the same clientID, instrumentID,

		and sessionID, which overwrites the previous submission.
Age at Admission (Q2 on FoRSE Demographics Information Form)	Required for submission of FoRSE Demographic Information Form	To allow for analyzing outcomes across age groups
Gender (Q3 on FoRSE Demographics Information Form)	Required for submission of FoRSE Demographic Information Form	To allow for analyzing outcomes across gender identity
	Response options updated	To conform to Gender Harmony Project and Kronk et al. (2022) recommendations
Race and Ethnicity (Q4 on FoRSE Demographics Information Form)	Required for submission of FoRSE Demographic Information Form	To allow for analyzing outcomes across race and ethnicity
Sexual Orientation (Q5 on FoRSE Demographics Information Form)	Required for submission of FoRSE Demographic Information Form	To allow for analyzing outcomes across sexual orientation
FoRSE Admit Survey	Only one FoRSE Admit Survey per patient episode	This specification reduces duplicate data. Any changes in data values can be captured by sending a new survey with the same clientID, instrumentID, and sessionID, which overwrites the previous submission.
Highest Level of Care at Admission (Q1 on FoRSE Admit Survey)	Required for submission of FoRSE Admit Survey	To allow for analyzing demographic and outcome data based on level of care at admission
	Changed to the highest level of care to which client is admitting	Patients may be admitting into multiple programs (e.g., IOP and recovery residence)
FoRSE Discharge Survey	Only one FoRSE Discharge Survey per patient episode	This specification reduces duplicate data. Any changes in data values can be captured by sending a new survey with the same clientID, instrumentID, and sessionID, which overwrites the previous submission.
Highest Level of Care at Discharge (Q1 on FoRSE Discharge Survey)	Required for submission of the FoRSE Discharge Survey	To allow for analyzing outcomes based on level of care at discharge
	Changed to reflect the highest level of care from which the client is discharging	Patients may be discharging from multiple programs (e.g., IOP and sober living)
Discharge Type (Q2 on FoRSE Discharge Survey)	Required for submission of FoRSE Discharge Survey	To allow for analyzing discharge types across demographics and to analyze outcomes based on discharge type

	Added Financial response option	To track the frequency of patient discharge due to financial issues
Length of Stay/ Engagement (Q3a-3h on FoRSE Discharge Survey)	Required for submission of FoRSE Discharge Survey	To allow for analyzing length of engagement across demographics and to compare outcomes based on length of engagement
Primary SUD Category (or "primary drug") (Q5 on FoRSE Discharge Survey)	Required for submission of FoRSE Discharge Survey	To allow for analyzing primary drug category across demographics and to compare outcomes based on primary drug
	"None" response option added	To allow for indication that the patient does not have a SUD
	"(or "primary drug")" added	To clarify that the data of interest in the primary substance category
completedWhile (new variable)	Required for submission of any survey	To identify when the survey was completed (during treatment or post-discharge)
daysFromAdmit	Required for submission of any survey	To identify when the survey was completed (during treatment or post-discharge)
	If completedWhile = inTreatment, value must be an integer (>=0), and if completedWhile = postDischarge, value must be -99	-99 is an additional validation indicator to identify when the survey was completed
daysFromDischarge	Required for submission of any survey	To identify when the survey was completed (during treatment or post-discharge)
	If completedWhile = inTreatment, value must be -99, and if completedWhile = postDischarge, value must be an integer (>=0)	-99 is an additional validation indicator to identify when the survey was completed
All progress monitoring and outcome surveys	Must be 100% complete (all items endorsed with a patient response or "NA"), or the survey will be rejected	An additional validation indicator to specify patient non-response to specific survey items

Table 2. CHANGES TO OTHER DATA ELEMENTS & SURVEYS

Data Element or Survey	**Change/Specification(s)**	**Rationale**
Readmission to treatment (Q8 on FoRSE Admit Survey)	Added as a question	Of interest to payors and providers for benchmarking

Primary Payment Type (Q4 on FoRSE Discharge Survey)	"Primary" added to indicate that the patient's primary form of payment should be selected	To allow for comparing outcomes across primary form of payment
	"Medicare/Medicaid" changed to "Medicaid/Medicare or Other Public Funding"	To include other forms of public funding
	"Scholarship" added as an option	To examine outcomes for patient episodes funded through scholarship
MAT Medications received (Q6 on FoRSE Discharge Survey)	"Select one" has been changed to "Multi-select"	To allow for the collection of data on medications prescribed for SUD and other mental health disorders
All progress monitoring and outcome surveys	Must be 100% complete (all items endorsed with a patient response or "NA"), or the survey will be rejected	An additional validation indicator to specify patient non-response to specific survey items
BAM-IOP	This survey is now accepted by FoRSE	The BAM-IOP covers only the previous seven (7) days and can be used with patients on a weekly basis.
GAD-2 PHQ-2	These surveys are now accepted by FoRSE	The GAD-2 and PHQ-2 are shorter versions of these screens for anxiety/depression and have acceptable psychometric properties.
FoRSE Outcomes Survey	Q1 (service utilization in past 30 days): "Select one" has been changed to "Multi-select"	To reflect possible participation in multiple service types
	Q4 (medications): "Select one" has been changed to "Multi-select"	To allow for the collection of data on medications prescribed for SUD and other mental health disorders

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