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End-Stage Renal Disease Network of the South Atlantic
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Southeastern Kidney Transplant Coalition Quality Improvement Project: Referral Data Dictionary

Data Dictionary Version 1.4

Table of Contents

Table of Contents.....	1
Background	2
Definitions.....	2
Elements	3
Appendices.....	11
Data Submission Template	11
DAG ID (Data Access Group Identifier)	11
Optional Race Codes	12
Optional Ethnicity Codes.....	12
Project Workgroup Collaboration Space	12
Output File Specifications	13
Revision History	14



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Background

In support of the Southeastern Kidney Transplant Coalition's needs for transplant-center reported referral data from GA, NC, and SC, IPRO ESRD Network 6 has been tasked with collecting, reviewing, validating, and producing reports. This requirements document addresses the data upload requirements.

IPRO collects data using REDCap. If your institution or facility uses REDCap, one way to collect the required data is to copy IPRO's REDCap project to your facility's REDCap and populate your data locally. A quick export will then meet all requirements. Please contact us for more information. Otherwise, data collection will be via plain-text CSV.

IPRO operates a permissive, flexible data ingestion policy. If your facility data system cannot export data to the below requirements, please contact us so that we can review changes to the dictionary to accommodate your needs.

Definitions

Item	Definition
Data Portal	https://redcap.ipro.org
Frequency	Q2 2017 data submission will include referrals dated January 1, 2012 through December 31, 2016 (2012-01-01/2016-12-31). Subsequently, data is expected to be uploaded monthly by transplant centers.



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Elements

Element Name	Description	Data Type	Business Rules	Required?
record_id	Unique identifier for the record	Alphanumeric	dag_id-your_unique_identifier See Appendices to ascertain your unique dag_id. your-unique-identifier can be any unique value that your facility chooses to submit to ensure each row of your data is a unique record. For example, this can be a unique patient ID, a unique referral ID, or a unique ID created specifically for this collection. e.g. 1-12345678 1-ABCDEF 1-ABC123	Yes
last_name	Referred patient last name	Text	A-Z, a-z Will accept spaces and hyphens	Yes
first_name	Referred patient first name	Text	A-Z, a-z Will accept spaces and hyphens	Yes
date_of_birth	Referred patient date of birth	Date	YYYY-MM-DD e.g 2016-12-31	Yes



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Element Name	Description	Data Type	Business Rules	Required?
social_security_number	Referred patient social security number	SSN	xxx-xx-xxxx e.g. 123-45-6789 nine-filled is acceptable for blank/missing data i.e. 999-99-9999	Yes
referred_transplant_center	Center to which patient was referred	Alphanumeric	Facility CCN (preferred) OR Facility NPI OR from the following list: MSC or Medical University of South Carolina CHS or Carolinas Medical Center EMY or Emory University GHS or Medical College of Georgia PED or Piedmont Hospital UNC or UNC Hospital WFU or Wake Forest University DUK or Duke University Medical Center	No
race	Referred patient race	Alphanumeric	IPRO will accept any valid HL7 race code (e.g. http://hl7.org/fhir/v3/Race/cs.html) or a text entry as stored in the submitter's data store. IPRO cannot accept local system encoded data such as "0", "1" or "W", "B"; instead please submit the full text of the entry.	Yes



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Element Name	Description	Data Type	Business Rules	Required?
ethnicity	Referred patient ethnicity	Alphanumeric	IPRO will accept any HL7 Ethnicity code (e.g. http://hl7.org/fhir/v3/Ethnicity/cs.html) or one of the following: Hispanic, Non-Hispanic, Other, Unknown	Yes
sex	Referred patient sex	Text	IPRO will accept any text value. Numeric codes are not allowed. Preference is for one of: male, female, ambiguous, not-applicable, other, unknown OR one of: M, F, A, N, O, U	Yes
preemptive_referral	Was the patient referred for transplant prior to dialysis initiation?	Text	IPRO will accept any text value. Numeric codes are not allowed. Preference is for one of Yes, No, Unknown OR Y, N, U OR y, n, u	No



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Element Name	Description	Data Type	Business Rules	Required?
dialysis_start_date	<p>Date patient started maintenance dialysis. If the patient is not on dialysis or it is unknown whether the patient is on dialysis, leave this field blank.</p> <p>A missing dialysis date will be assumed to be truly missing if the preemptive referral field is also missing.</p>	Date	<p>YYYY-MM-DD e.g 2016-12-31</p>	No
dialysis_facility_name	Name of referring dialysis facility for patients who are on dialysis at time of referral only	Alphanumeric		No



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Element Name	Description	Data Type	Business Rules	Required?
dialysis_facility_address	Street number of referring dialysis facility for patients who are on dialysis at time of referral only	Alphanumeric	e.g. 123 Any Street	No
dialysis_facility_city	City of referring dialysis facility for patients who are on dialysis at time of referral only	Text		No
dialysis_facility_state	State of referring dialysis facility for patients who are on dialysis at time of referral only	Text	IPRO will accept the two letter state USPS code or the full text USPS display name, see: https://www.hl7.org/fhir/valueset-usps-state.html	No
dialysis_facility_zip_code	Zip code of referring dialysis facility for patients who are on dialysis at time of referral only	ZIP	Five digits e.g. 12345	No



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Element Name	Description	Data Type	Business Rules	Required?
dialysis_facility_ccn	Referring dialysis facility CMS Certification number for patients who are on dialysis at time of referral only	Numeric	Six digits e.g. 123456	No
referral_date	Date the referral form was received by the transplant center	Date	YYYY-MM-DD e.g 2016-12-31 Must be a valid date between 2012-01-01 and 2016-12-31	Yes
evaluation_start_date	Date when the referred patient physically starts a required component of the transplant evaluation. This may include a first visit to the transplant center, a satellite clinic, or a required education class.	Date	YYYY-MM-DD e.g 2016-12-31	Yes



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Element Name	Description	Data Type	Business Rules	Required?
evaluation_completion_date	Date that a decision was made by the transplant center to either waitlist the patient or to deny waitlisting approval	Date	YYYY-MM-DD e.g 2016-12-31	No
patient_street_address	Patient residential street number and name at time of referral; Billing address if residential is unavailable	Alphanumeric	e.g. 123 Any Street	No
patient_city	City of patient residence at time of referral	Text		No
patient_state	State of patient residence at time of referral	Text	IPRO will accept the two letter state USPS code or the full text USPS display name, see: https://www.hl7.org/fhir/valueset-usps-state.html	No
patient_zip_code	Zip code of patient residence at time of referral	ZIP	Five digits e.g. 12345	No



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Element Name	Description	Data Type	Business Rules	Required?
insurance_status	Patient primary insurance status at time of referral	Text	IPRO will accept any text identifiers with preference for one of Medicare, Medicaid, Private, Uninsured, Other	No
waitlisting_date	Date the patient was approved for waitlisting	Date	YYYY-MM-DD e.g 2016-12-31	No
referring_physician_name	Referring provider (MD) name	Text	This value expects First and Last Name combined e.g. Jane Smith	No
referring_physician_phone	Referring provider phone number	Phone	xxx-xxx-xxxx e.g. 123-456-7890	No



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Appendices

Data Submission Template

Data submission templates for current and previous collection periods as well as example files can be accessed at the collaboration Group: <http://jeny.ipro.org/group/9-sektx-quality-improvement-project>

The current data submission can be accessed at <https://redcap.ipro.org> - select this project and click “Data Import”. The template available will be for the current collection period only.

If you need help with the template or with accessing the collaboration Group on JENY please E-mail support@ipro.us

DAG ID (Data Access Group Identifier)

Each row must begin with a unique project row identifier which is comprised of your DAG ID, a hyphen, and your unique patient or referral identifier. If you are having trouble filling this field, IPRO can help. E-mail support@ipro.us to request file format support – do not send the data file. We will follow up on securely exchanging the file for us to work on.

Center	dag_id
Carolinas Health	4
Duke Medical	2
Emory Transplant	3
Georgia Regent	5
MUSC Transplant	6
Piedmont Transplant	7
UNC Center	8
Vidant Eastern	9
Wake Health	10



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Optional Race Codes

IPRO will accept any valid HL7 race code (e.g. <http://hl7.org/fhir/v3/Race/cs.html>) or a text entry as stored in the submitter’s data store. IPRO cannot accept local system encoded data such as “0”, “1” or “W”, “B”; instead please submit the full text of the entry. The following table may be of use.

Race	Code
American Indian or Alaska Native	1002-5
Asian	2028-9
Black or African American	2054-5
Native Hawaiian or Other Pacific Islander	2076-8
White	2106-3
Other Race	2131-1

Optional Ethnicity Codes

IPRO will accept any HL7 Ethnicity code (e.g. <http://hl7.org/fhir/v3/Ethnicity/cs.html>) or one of Hispanic, Non-Hispanic, Other, Unknown. The following table may be of use.

Race	Code
Hispanic or Latino	2135-2
Not Hispanic or Latino	2186-5

Project Workgroup Collaboration Space

<http://jeny.ipro.org/group/9-sektx-quality-improvement-project>

IPRO’s JENY is a private group collaboration space used for quality improvement program participants. Announcements and discussions pertaining to this QI activity can be accessed by signing in to JENY with your choice of log-in, and requesting access to the Group. Click the above link to begin the process, or E-mail support@ipro.us for help completing your registration.



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Output File Specifications

Requirement	Definition
Column Order	Columns should reflect the same order outlined in the requirements.
Column Titles	Columns should be labeled using the element name listed in the requirements.
Submission File Format	CSV (plain text comma separated values)



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Revision History

Date	Version #	Description	Updated By
2016-11-16	0.1	Draft of Requirements	Ariana Lucido
2016-11-30	1.0	Requirements Finalized	Ariana Lucido
2017-03-22	1.1	Updated to conform to REDCap data dictionary	Jaz-Michael King
2017-04-18	1.2	Reconciled data questions for final draft	Shannon Wright
2017-04-28	1.3	Changes to various elements per Coalition conference 2017-04-26. Removed elements referring_staff_name and referring_staff_phone. Added information to Appendices.	Jaz-Michael King
2017-05-04	1.4	Edited Hyperlinks referring to JENY forum Added patient_state field to data dictionary	Joseph Gulotta