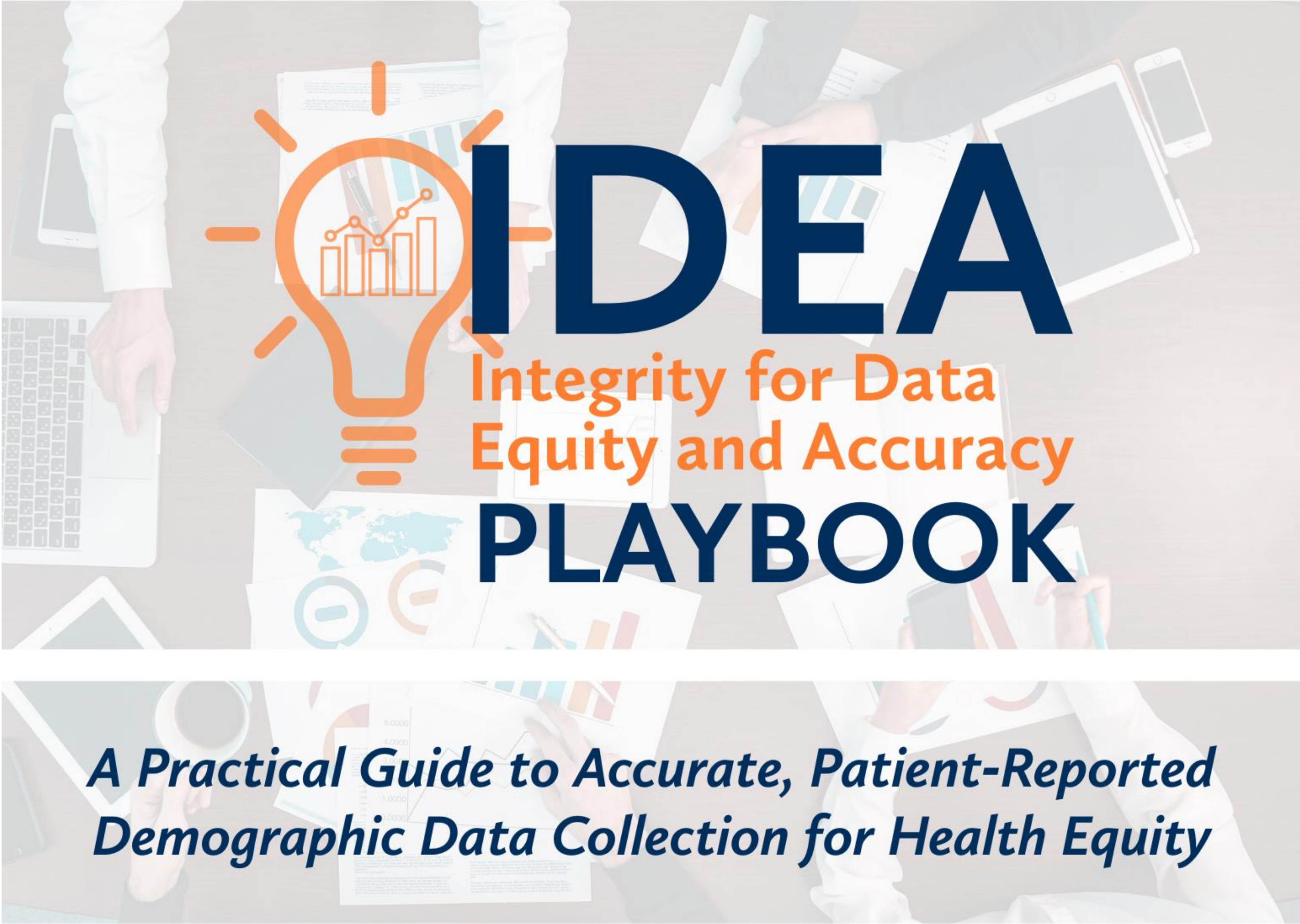

IDEA
Integrity for Data Equity and Accuracy
PLAYBOOK

A Practical Guide to Accurate, Patient-Reported Demographic Data Collection for Health Equity

WHA WISCONSIN HOSPITAL ASSOCIATION

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Executive Summary

Accurate, patient-reported demographic data is foundational to health equity. This playbook synthesizes insights from field practice and national guidance to help organizations design, implement, and sustain reliable collection of Race, Ethnicity, and Language (REaL), Sexual Orientation and Gender Identity (SOGI), and other key demographics. It outlines governance, standardized question sets, staff and community education, EHR configurations, quality assurance, and metrics to drive improvement.

- Why now: Incomplete and inaccurate demographic data obscures disparities and limits effective interventions; updated federal standards elevate the urgency for quality, patient-reported data.
- What this playbook provides: Standard operating procedures, scripts, training plans, IT build guidance, KPIs, and checklists to move from intent to sustainable practice.
- Who should use it: Registration, clinical, quality, IT/analytics, compliance, and leadership teams working together through a formal governance structure.

How to Use This Playbook

1. Review Section 1 to align on core concepts and the case for change.
2. Stand up a cross-functional governance team and complete the baseline assessment (Sections 2 & 7).
3. Configure EHR data elements and workflows (Section 6).
4. Train staff and prepare patient-facing materials (Sections 4 & 5).
5. Launch, measure, and iterate using the KPIs and QA routines (Sections 7 & 8).
6. Document lessons learned and share outcomes (Section 10).

Section 1: Health Equity & Demographic Data Collection

1.1 Key Concepts

- Health equity: Everyone has a fair and just opportunity to be as healthy as possible by removing obstacles to health.
- Health disparities: Differences in health outcomes across populations; tracking disparities is essential to equity progress.
- Patient-reported data: Self-identification is the most accurate and consistent method for demographic data.

1.2 Why Accurate Demographic Data Matters

- Enables identification of inequities in access, experience, and outcomes.
- Improves language access, accessibility support, and culturally responsive care.
- Informs targeted quality improvement and community partnerships.

Section 2: Governance, Roles, and RACI

2.1 Create a Cross-Functional Team

- Include senior leadership, registration/front desk, clinical operations, quality/safety, health information management, IT/EHR analysts, analytics, compliance/privacy, and community engagement.
- Engage patient and community advisors to co-design materials and review patient experience.

2.2 RACI Overview

Workstream	Responsible (R)	Accountable (A)	Consulted (C)	Informed (I)
Policy & Standards	Equity Lead; Compliance	Chief Quality Officer	Legal; Community Advisors	All Staff
EHR Build & Data Model	IT Analysts; Data Architect	CIO/CMIO	Registration; Clinical Ops	Steering Committee
Training & Competency	Education Dept.; DEI Lead	Chief Nursing/COO	Registration Supervisors	All Staff
Patient Communications	Marketing/Comms	Chief Experience Officer	Community Advisors	All Patients
Data Quality & Reporting	Analytics; Quality	Chief Quality Officer	IT; Operations	Leadership

Section 3: Standards & Question Sets (REaL and SOGI)

3.1 Principles

- Use a combined race/ethnicity question that allows multiple selections.
- Collect English proficiency and preferred language for care; support write-ins for specificity.
- Whenever possible, enable “self-describe” write-ins to honor identity and improve data utility.

3.2 Recommended REaL Items

- Which of the following best describes your racial or ethnic group? (Select all that apply) — with detailed checkboxes and write-ins for American Indian or Alaska Native; Asian; Black or African American; Hispanic or Latino; Middle Eastern or North African; Native Hawaiian or Pacific Islander; White.
- How well do you speak English? (Very well; Well; Not well; Not at all).
- Preferred spoken language for care (include write-in option).
- Do you speak a language other than English at home? If yes, which language?

3.3 Recommended SOGI Items

- Sex assigned at birth (e.g., male, female, intersex, another term, prefer not to answer).
- Gender identity (e.g., woman, man, transgender woman, transgender man, non-binary, another term [write-in], prefer not to answer).
- Sexual orientation (e.g., straight/heterosexual, lesbian, gay, bisexual, queer, another term [write-in], prefer not to answer).
- Reminders: Explain purpose, privacy, and access; questions are voluntary and may be skipped.

Section 4: Staff Training & Competency

- All patients are asked standard demographic questions; do not assume based on appearance or name.
- Role-play intake scenarios; practice responses to common questions and concerns.
- Provide just-in-time job aids and a supervisor escalation path for complex situations.

Training Element	Audience	Format	Cadence	Completion/Competency
Foundations of Health Equity & Demographic Data	Registration; Clinical; Supervisors	eLearning (30–45 min)	Onboarding + Annual	≥ 90% score on post-test
Standard Question Sets & Scripts	Registration/Intake	Instructor-led + Role-play	Quarterly refresh	Observation checklist: competent/needs coaching
Privacy & Handling Sensitive Info	All staff handling data	eLearning (20–30 min)	Annual	Attestation + knowledge check
Using Data in Care & QI	Clinicians; Quality	Workshop	Semi-annual	QI project participation

Section 5: Patient & Community Education Toolkit

- Core message: “We Ask Because We Care.”
- Emphasize purpose, confidentiality, who can access information, and that responses are voluntary.
- Offer multi-channel materials: posters, brochures, portal messages, IVR prompts, website FAQ.

Patient Question	Recommended Response
Who will see this information? How will it be shared?	Your information is confidential and protected, like all health information. Only your care team and authorized staff may access it. For research and reports, data are de-identified and combined.
I am only here for a quick test. Why is this relevant?	Knowing who we serve helps us plan services, provide interpreters, and ensure equitable care—today and in the future.
Do I have to answer?	No. These questions are voluntary. You may choose “prefer not to answer,” and this will not affect your care.
How does this benefit me?	It helps tailor care, improve access (e.g., interpreters), and identify gaps so we can improve quality for everyone.

Section 6: EHR/IT Configuration Guidance

- Use a single, combined race/ethnicity question allowing multi-select with detailed write-ins; store both minimum categories and detailed values.
- Create discrete fields for English proficiency, preferred spoken language, SOGI, and “prefer not to answer.”
- Enable patient portal and kiosk/clipboard workflows for self-reporting; default collection at registration with clinical validation as needed.
- Add hard stops or soft-stops to reduce “unknown” and “refused” while preserving patient choice.
- Version and audit data elements; maintain mappings to reporting standards. Document change control.

Data Element	Field Type	Allowed Values (examples)	Notes
Race/Ethnicity (combined)	Multi-select + write-ins	AIAN; Asian; Black; Hispanic/Latino; MENA; NH/PI; White; write-in detail	Store min category + detail; allow multiple selections
English Proficiency	Single-select	Very well; Well; Not well; Not at all	Patient-reported
Preferred Spoken Language	Single-select + write-in	Spanish; Hmong; Somali; Other (write-in)	Use International Organization for Standardization (ISO) codes if available
Sex Assigned at Birth	Single-select	Male; Female; Intersex; Another term; Prefer not to answer	Separate from gender identity
Gender Identity	Single-select + write-in	Woman; Man; Transgender woman/man; Non-binary; Another term; Prefer not to answer	Display help text on privacy/intended use

Sexual Orientation	Single-select + write-in	Straight; Lesbian; Gay; Bisexual; Queer; Another term; Prefer not to answer	Include a self-describe option

Section 7: Baseline Assessment & Data Quality Plan

- Conduct workflow observation at registration and care settings to document when and how questions are asked.
- Profile current data: % complete by element, distribution of "unknown/refused," and multi-select usage; stratify by location/department.
- Validate storage and reporting logic against the standard question sets.

KPI	**Definition**	**Target (Year 1)**	**Monitoring**
Demographic completeness	% encounters with all core fields populated (REaL + SOGI when applicable)	≥ 85%	Monthly dashboard
"Prefer not to answer" rate	Rate by element and location	≤ 10% (without coercion)	Monthly, investigate outliers
Data accuracy/validation	Concordance checks (e.g., portal vs. intake)	≥ 95% concordance	Quarterly audit
Language services utilization	% LEP encounters with interpreter documented	≥ 95%	Monthly quality review
Staff competency	% staff passing post-test and observation checklist	≥ 95%	Quarterly
Quality Routine	**Description**	**Cadence**	**Owner**
Field audits	Sample 50–100 recent encounters per site; verify presence/accuracy of REaL/SOGI	Monthly	Quality + Registration Supervisors
Report validation	Compare operational vs. analytics extracts; verify mappings/aggregation	Quarterly	Analytics
Feedback loop	Share findings with sites; coach; update scripts/job aids	Monthly	Equity Lead + Education

Section 8: Implementation Timeline

Phase	**Timeframe**	**Milestones**
Phase 0 – Mobilize	Weeks 0–2	Form governance; confirm standards; approve question sets; plan communications
Phase 1 – Build	Weeks 3–8	EHR configuration; reports; job aids; training content; community materials
Phase 2 – Train & Validate	Weeks 9–12	Staff training; dry-runs; data validation; go-live readiness review

Phase 3 – Go-Live	Week 13	Launch across intake points; activate dashboards; support command center
Phase 4 – Stabilize & Improve	Weeks 14–26	Monitor KPIs; PDSA cycles; update materials; share progress

Section 9: Risks & Mitigations

Risk	**Impact**	**Mitigation**
High "refused/unknown" rates	Incomplete data; limited insights	Script coaching; patient education; soft stops; multiple collection modes (portal, intake)
Workflow burden at registration	Delays; staff resistance	Lean redesign; pre-visit collection; kiosks/portal; concise scripts
EHR inconsistency across sites	Reporting errors	Standardized build; change control; regression testing
Privacy concerns	Lower trust and response rates	Clear messaging on access and use; privacy training; limit access appropriately

Section 10: Program Aims & Workplans

Aim 1: Collaborate with Leaders

- Establish an advisory team with leadership, staff, community members, and patient advocates.
- Convene regular meetings to align procedures, IT configurations, and patient-facing materials.
- Standardize auditing and validation across sites; review completeness and integrity routinely.

Aim 2: Provide Tailored Education and Training

- Develop training emphasizing the why, what, and how of REaL and SOGI collection.
- Use pre-/post-assessments and observation checklists to verify knowledge and skills.

Aim 3: Offer IT Support

- Create EMR-specific build guidance, including data elements, value sets, and mappings.
- IT office hours during go-live; collect feedback to refine build.

Aim 4: Document and Share a Project Summary

- Compile outcomes, lessons learned, and a resource compendium for broader dissemination.

Section 11: Scripts & Communication Examples

Situation/Question	**Suggested Language**

“What does this have to do with my care?”	We ask everyone these questions to provide the best, most equitable care. For example, if you prefer a language other than English, we will arrange an interpreter.
“I am here for a quick appointment.”	This information helps for today and any future visits, so we can tailor services to your needs.
“This does not apply to me.”	We do not make assumptions, so we ask all patients the same questions. You may select the options that fit or choose “prefer not to answer.”
“I do not want to answer.”	That is okay. Would you like me to mark “prefer not to answer” for these questions?

Section 12: Measurement & Evaluation

- Use pre-/post-training evaluations for training impact; collect qualitative feedback; allow anonymous responses.
- Follow up at 30/60/90 days to assess retention and behavior change; observe intake encounters.
- Share dashboards stratified by site and service line; celebrate progress and address gaps.

Section 13: Organizational Commitment

- Leadership sponsorship and routine communication to all staff and the community.
- Policies endorsing standardized collection and respectful, patient-centered communication.
- Sustained resources for training, quality monitoring, and community engagement.

Section 14: Resources

- Patient and staff brochure templates: “We Ask Because We Care.”
- Staff job aids: Standardized scripting, definitions, and privacy talking points.
- Quality tools: PDSA worksheets, audit data templates

Section 15: Glossary (Selected)

- **Health Equity:** Fair and just opportunity to be as healthy as possible; remove obstacles to health.
- **Health Inequity:** Unjust, avoidable differences in resources and conditions that lead to disparities.
- **Disparities:** Differences in health outcomes across population groups.
- **Social Drivers of Health (SDOH):** Nonmedical factors influencing health outcomes.
- **Sex Assigned at Birth:** Information used for clinical decision support and screenings.
- **Gender Identity:** Personal, internal sense of gender; may differ from sex assigned at birth.

- **Sexual Orientation:** Emotional/romantic/sexual attraction (e.g., heterosexual, gay, lesbian, bisexual, queer).

Appendix A: Go-Live Readiness Checklist

- Approved question sets and scripts in place
- EHR fields configured with write-ins and “prefer not to answer”
- Portal and intake workflows tested
- Training completion ≥ 95%
- Dashboards validated and scheduled
- Patient communications live (posters, portal, website)

Appendix B: Data Audit Template

Element	Completeness %	Prefer-Not-to-Answer %	Notes/Actions
Race/Ethnicity (combined)			
English Proficiency			
Preferred Language			
Sex Assigned at Birth			
Gender Identity			
Sexual Orientation			

Appendix C: PDSA Worksheet (Summary)

Plan	Do	Study	Act