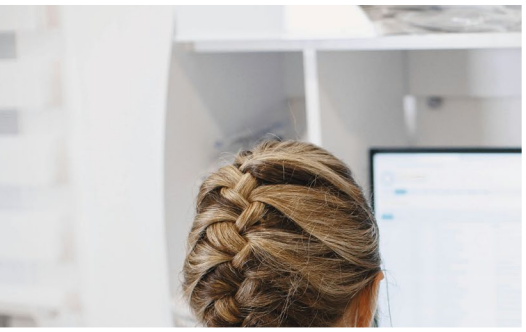
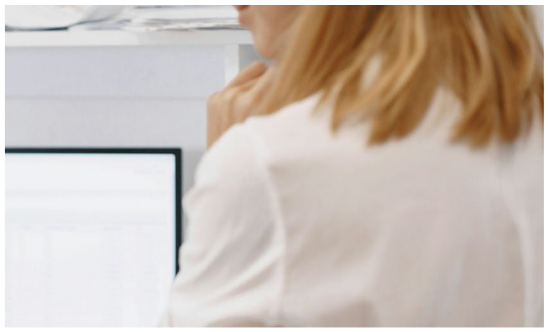
Data Management: Person-Directed Approaches and Perspectives

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Data Collection

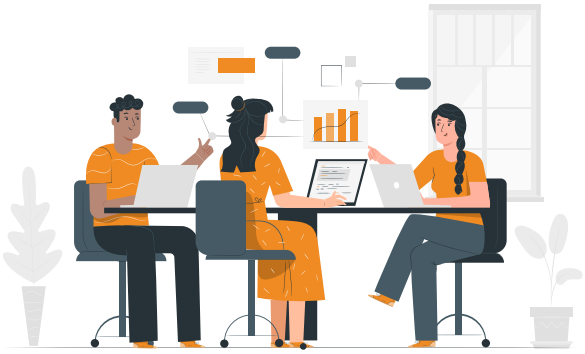
OVERVIEW

Center the patient's experience and perspective. Data must have clear use for, above all, improving patient's health and outcomes as well as overall health center performance.

Telling one's story over and over is often unnecessary and harmful when data is already collected and securely sharing is an option. Data elements are repetitive, outdated, or not meaningful to patient, provider, or organization.

Tools and instruments are available to help guide data collection and streamline registration processes and check-ins with discretion and respect. Qualitative data from patients and providers are important too.

POTENTIAL PITFALL:
Staying Current with Data Collection



CHALLENGES

- When was the last time we reviewed our intake forms?
- Which elements are tied to funder requirements? How do they differ from similar questions for other funders?
- How are data on patient conditions and health impacts collected? Used?
- Data elements on those forms may no longer be used for anything, contain outdated language, or are out of synch with current care practices

SOLUTIONS

Understand the current state

- Review data collection processes and paperwork
- Inventory all data elements: who, when, how, why
- Link data collection to patient outcomes and performance
- Plan to communicate results to funders and leadership
- Identify duplication and overlap

Centering patients and providers

- Data collection is more than forms
- Patient care starts at check-in
- Training
- Build systems that share data with patients
- Let patients answer for themselves

Data Use

OVERVIEW

Data collected and shared must benefit the health outcomes of patients individually and collectively.

From data analysis, risk assessments, population health management, and organization performance, patients' experience must be incorporated to gain context.

Providers and organizations must think critically about how even seemingly innocuous uses of data could create a great deal of harm.

POTENTIAL PITFALL:
Data Collected, Not Used

CHALLENGES

- Even with proper collection procedures, sharing practices, infrastructure, training, and instruments if data are not used there is no value
- Organizations lack the data management structure to clean, store, access, and retrieve data collected
- Staff may not have time to conduct necessary analysis and develop key resources (e.g., policies and procedures)
- Data collection and analysis are detached from action to improve outcomes

SOLUTIONS

Building an analytical framework

- Develop/review organizational Key Performance Indicators (KPI) ensuring direct connection to data elements collected
- Set baselines and objectives around these KPIs, consider incorporating a Continuous Quality Improvement (CQI) approach
- Close the gap in gathering patient perspective
- Analysis and interpretation of data is a team sport

How could this hurt or help patients?

- Health centers need to be viewed as trusted partners in the community and are stewards of sensitive data
- Engagement with patients is a key element of informing health and services you provide
- How might connecting certain data points to outreach about services be helpful? How could it be harmful?
- Always center the patient experience, how would patients receive information given individual circumstances and could data be used to engage in a more tailored way?

Data Access + Sharing

OVERVIEW

Virtually all health centers (and health care more broadly) have adopted EHRs, now encompassing extensive data collection and documentation.

Patient and provider access have increased through a number of initiatives promoting interoperability. Increasing adoption of digital tools that support access to patient records, such as patient portal and HIE.

These concurrent trends and initiatives have led to increasing access to and sharing of patient data documented in the patient's record, some of which may be sensitive.

POTENTIAL PITFALL:
Increasing Importance of Consent Processes

CHALLENGES	SOLUTIONS
Trauma survivors' records may contain sensitive information	Consent management is critical
Sharing without consent can: • Be against law and regulation • Increase risk of stigma • Interfere with patient-provider relationships in other contexts	Information Blocking Rule: requires sharing of information unless one of eight exceptions is met Discuss options with patients (e.g., blocking records). Team conversation improves understanding

POTENTIAL PITFALL:
Information Does Not Represent Patient

CHALLENGES	SOLUTIONS
Sometimes info entered does not reflect patient's own responses	Train staff to ask demographics directly, not infer
Examples: • Patient characteristics added without review, later seen in portal • Notes include details not discussed or misrepresent visit	Avoid shortcuts/copy-paste that add inaccurate info Have a process through which patients can request a change to their record and that process works!

Data Access + Sharing (cont)

POTENTIAL PITFALL:
Open Notes Mean Patients See More

CHALLENGES	SOLUTIONS
Open notes = more patient access	Consider all end-users when documenting patient information- not only the single clinic or provider who documented the information is going to see it!
Document carefully patients see what's written	Let the patient know that anyone who is authorized (you [the patient], your other providers, and anyone else you designate) may access EHI.
Example: Patients have long received visit summaries; now they may elect to have access to the their full record. This means that they will see chief complaints, progress notes, and other information such as communication between the providers that may use language that is unfamiliar or troubling to patients.	

POTENTIAL PITFALL:
Heightened Security Concerns

CHALLENGES	SOLUTIONS
More integrations & access = higher cybersecurity risk	Cybersecurity is everyone's job
Data breaches more harmful due to increased sensitive info in EHR	Move beyond basic privacy & outdated security measures
	Train & retrain to avoid phishing (main ransomware entry point)
	Prevent EHR snooping: • Use role-based access controls • Send alerts for unauthorized access

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