Patients for Patient Safety US
Policy Priorities

Patient Advocacy in Washington

September 2024

Patients for Patient Safety US

Patients for Patient Safety US (**PFPS US**) is an activist network of people and organizations aligned with the World Health Organization and focused on making healthcare safe in the United States.

We are led by people who have experienced preventable harm as a patient or in our families.

PFPS US is committed to supporting partners, policies, and protocols which ensure that patient safety standards are incorporated across all healthcare, public health, and industry platforms for a safer and healthier system for all.

Who We Are

Our network:

- Individuals with diverse backgrounds, experiences and skill sets, residing in almost every U.S. State
- Organizations that advance patient safety in the public and private sectors

Our Goals

Patient and Family Engagement

1. Establish policies, structures, funding criteria, strategies, and budgets that require and support diverse PFE
2. Redesign mechanisms that effectively engage and learn from patients/families
3. Require co-development (design, measurement, and oversight) of safety of clinical practices and prevention of diagnostic errors
4. Engage, orient, and train diverse patients and family members to form a skilled community of diverse patient and family member partners

Transparency and Reporting

1. Require and enforce transparency in reporting harm
2. Improve the quality and integration of data to understand harm better
3. Establish Communication and Resolution Programs (CRPs) as the standard of care
4. Ensure patient access to medical records
5. Expand the spectrum of patient safety events that must be collected and publicly reported

Accountability and Oversight

1. Reassert patient safety and equity as a strategic priority
2. Create and coordinate legislative and executive oversight and commitment to advance safety priorities
3. Build awareness of safety through the annual World Patient Safety Day march and social media
4. Coordinate proposed rules and guidance in the federal register to advance safety oversight

PFPS 2024 Policy Engagement Strategy

Raise Awareness

- Raise Awareness of Patient Safety as a Persistent Problem

Calls for Congressional and Executive Action

- Identify areas for Improvement of Federal Policy, Budget and Oversight to Support Better Safety

Build a Network of Supporters

- Establish PFPS Network of Hill 'Friends for Safety'

The State of Patient Safety

Medical errors and harm are almost always unintentional and are the result of a SYSTEM failure.

No doctor, nurse or caregiver wants to give poor care to any patient .

Patients and Providers want trusted relationships and to give and receive good care.

The State of Safety

Harm happens
FREQUENTLY
in US Healthcare!

- One in 4 patients is at risk for harm across healthcare settings from hospitals to nursing homes to rehab centers (OIG)
- This is the equivalent of a jumbo jet crashing every day!
- Wide variation from setting to setting and among various patient populations

The State of Safety

Why does preventable harm happen so often in healthcare?

Healthcare is complex.

Harm is hidden because there is not a culture or a mandate for reporting.

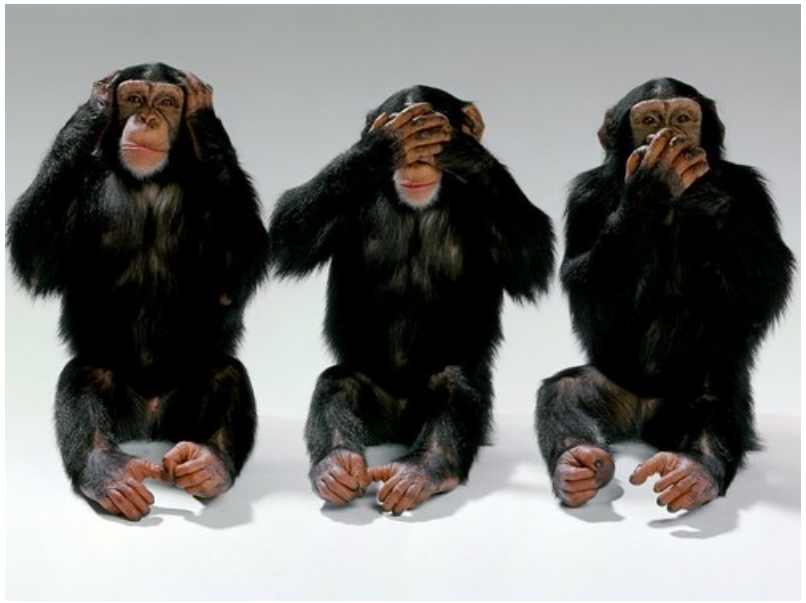
When harm is reported, liability decreases and shared learning increases

Patients can not directly input their experiences of harm.

Healthcare systems and providers *still get paid* for harm!

There are almost no consequences to hiding harm – financial, reputational, operational. So why invest in improving it?

The State of Safety



Hiding harm:

Prevents oversight, learning and improvement!

Is taxpayer fraud!

Is costly and devastating to patients!

The State of Safety

Patients are not asking for perfection.
Patients want transparency and accountability for learning and improvement.
Patients want their harm to be prevented from happening to others.

PFPS US Patient Policy Priorities

See the Harm

Include Me

Don’t Pay for Harm

Fix Law Loopholes

Patient Safety Proposals for Budget, Measurement and Payment in Governmental advocacy

Issue	Concern
"See the Harm"	Harm is not being reported within healthcare facility, externally (PSO/other organizations), state health departments, and federally (CMS/CDC/AHRQ) as required. Hiding harm impedes work to solve underlying issues to reduce harm.
"Include Me"	Patients are not told of harm that may have occurred to them, do not have a clear way to report harm, and have no mechanism to provide input into their harm event analysis
"Don't Pay for Harm"	Currently, most places of care do not report (as required) the majority of harm events. Then, they then charge for those events. Hiding harm causes the federal government to pay for care that, by law, it should not pay for and is fraud to taxpayers.
"Fix Safety Law Loopholes"	Fix Broken 2005 Statute that inadvertently created loopholes for Safety reporting

Patient Safety Proposals for Budget, Measurement and Payment in Governmental advocacy

Issue	Concern
"See the Harm"	Harm is not being reported within healthcare facility, externally (PSO/other organizations), state health departments, and federally (CMS/CDC/AHRQ) as required. Hiding harm impedes work to solve underlying issues to harm.

Specific improvements / recommendations:

- Mandate CMS to require providers to report of patient harm as part of the Conditions of Participation (CoP). Add diagnostic and digital harm for classification as other new categories of harm.
- Just like in aviation, patient harm should be reported nationally in a de-identified manner to best learn from and prevent error. AHRQ maintains the national Network of Patient Safety Databases (NPSD) of event reports. Patient safety organizations (PSOs) should be required to report to NPSD. Of the 100+ PSOs, less than 10 report to the NPSD currently! This requires a revision of the Patient Safety Act of 2005 and funding to advance the analytics and capabilities of reporting and hold PSOs accountable for improvement.
- Direct ONC- ASTP to accelerate standards for digital reporting to ensure more robust and timely information and the layering advanced analytic and AI tools to improve safety.
- Ensure public reporting of harm is at an individual facility level (NOT by CMS Certification Number (CCN) – aka. aggregated by system to hide harm / reduce accountability). Aggregated harm misleads patients.
- Adjust CMS guidance so that survey, certification, and payment for Medicare/Medicaid participation track required reporting of harm, ongoing evaluation of safety, resourcing improvement of safety, and timeliness of incident reporting.

Patient Safety Proposals for Budget, Measurement and Payment in Governmental advocacy

Issue	Concern
"Include Me"	Patients are not told of harm that may have occurred to them, do not have a clear way to report harm, and have no mechanism to provide input into their harm event analysis

Specific improvements / recommendations:

- Mandate CMS to include reporting of harm TO THE PATIENT in the Conditions of Partipation (CoP). Hiding harm is information blocking.
- Create direct pathways for patient reporting of harm. Fund a patient direct harm reporting to a national database (e.g. the Consumer Financial Protection Bureau, Consumer Product Safety Commission).
- Establish patient reported harm experience in quality reporting (e.g., ARHQ should adjust its CAHPS questions to add validated questions about safety, diagnosis, and bias in care).
- Require CMS to include Communication and Resolution Programs (CRP) as part of the Conditions of Participation.
- Ensure through the Conditions of Participation that all patients have unrestricted access to their medical information AND the ability to suggest correction. This is imperative as AI integrates into medical decision making.

Patient Safety Proposals for Budget, Measurement and Payment in Governmental advocacy

Issue	Concern
"Don't Pay for Harm"	Currently, most places of care do not report (as required) the majority of harm events. Then, they then charge for those events. Hiding harm causes the federal government to pay for care that it should not pay for and is fraud to taxpayers.

Specific improvements / recommendations:

- Establish for CMS the authority to impose civil monetary penalties for hiding harm from patients and payors. This would be similar to the NTSB and ONC for information blocking.
- Expand CMS payment discretion consequence for harm and allow CMS to include the entire care episode as a payment consequence. This requires revision of the 2005 Deficit Reduction Act.
- Direct CMS to oversee that healthcare ranking systems (such as CMS star ratings) to give higher weight to safety and that the lowest safety scoring providers not be allowed to get 4-5 stars (misleads consumers).
- Establish increased payment incentives for high safety performance and transparent reporting.

Patient Safety Proposals for Budget, Measurement and Payment in Governmental advocacy

Issue	Concern
"Fix Safety Law Loopholes"	Fix Broken 2005 Statute that inadvertently created loopholes for Safety reporting

Specific improvements / recommendations:

- PSOs are not useful to improving safety in their current state because of loophole in the way the law was written. Most PSOs have become a repository to hide error and a 'black box' for reporting error without accountability to spread improvement of safety.
- Change 2005 Patient Safety Act loophole and set a statutory requirement for PSOs to report to the National Patient Safety Database by 2025 or they lose should the PSO legal protection.
- Establish and clarify ONC/CMS standards for health data use that do not take private patient information from portals and share it / sell it without specific patient consent (i.e. no broad waivers). Support federal funding to establish standards for patient data health privacy.
- Ensure coordination for safety oversight among federal agencies.

It’s time to improve patient care and save lives!

WE NEED YOU!

PFPS US

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https://www.pfps.us/

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