



# A RADICAL PROPOSAL

## Transforming Patient & Family Engagement

February 15, 2024 | 10 – 11am



## FIRST...

With gratitude to Optima and Haley Flower for bringing us together!

## FOR...

A radical proposal to re-boot  
“engagement” to achieve safer care

*Practical tips & tools to get there:  
simple, do-able, economical!*



## Karen Curtiss

Board Certified Patient Advocate  
Certified Patient Experience Coach  
Founder, The Care Partner Project  
Formerly, President, Strategic Research

- 20+ years in market research, Fortune 500 clients
- Thousands of focus groups! (hundreds of surveys)
- All laser focused on language
- How language impacts attitudes and behaviors
- Left behind for...

## Family healthcare crisis



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**Bill Aydt, married to Margaret 51 years  
6 children, 9 grandchildren**

**IPF :**  
**Devastating Diagnosis**  
**Successful lung transplant at SuperStar**

**CURED!**

Fall	MRSA...again
VAP	C diff...again
MRSA	Step 2 Pressure Wound
C diff	
DVT	
PE	



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**Bill Aydt, married to Margaret 51 years  
6 children, 9 grandchildren**

**IPF:  
CURED!**

## **OUTCOME**

7 months and 1 day

Never left the hospital

Family bedside every day

Highly “engaged”

Completely clueless





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# Shared Grief





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***“We cannot  
solve our  
problems with  
the same  
thinking we  
used when we  
created them.”***

**—Albert Einstein**





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## Problems to solve...

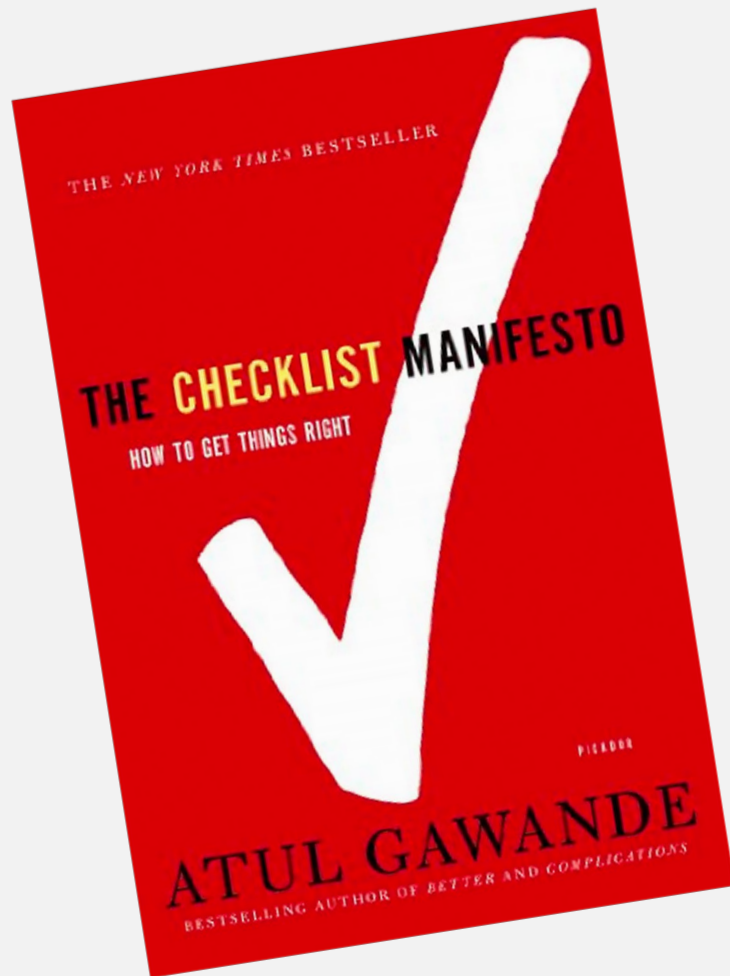
- ZERO education on how to be a patient
- ZERO education on health care systems
- Almost ZERO common vocabulary between patients and clinicians
- Unbalanced power relationship between patients and providers
- Almost ZERO resources to remedy, either by patients or clinicians
- Patients and clinicians alike can be severely compromised:  
stress, sleep, nutrition (and more for patients)





## Let's cure the root cause with new thinking...

- Healthcare literacy must improve significantly for truly meaningful engagement to occur – especially for patient safety.
- Healthcare literacy must be a cultural imperative.
- Healthcare literacy begins with hospitals, trusted partners to the greatest number and most vulnerable.



*“We have trained, hired, and rewarded people to be cowboys, but it is pit crews that we need – pit crews for patients.”* — Atul Gawande, MD



**Train these pit crews for patients.**  
*Who could be more patient-centered?*



“Everyone who is receiving treatment from the health care system needs an advocate — that is, someone (whether family, friend or a professional) to provide support to the patient and family, and to guard against any of the many mishaps that make medical error one of the leading causes of preventable death in this country.”



# Grief into Good

[Contact Us](#) [Resources for Professional Advocates](#)



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## The Care Partner Project

Know what professional patient advocates know



How to support your loved ones' safe & sound care



[TheCarePartnerProject.org](http://TheCarePartnerProject.org)

## Checklists put everyone on the same page for patients

- ✓ Self-guided
- ✓ Directed to Care Partners
- ✓ “On the fly”/”just-in-time” learning
- ✓ Quick, simple information
- ✓ Simple “To-do’s” that *activate toward results*
- ✓ Cover 3 learning styles  
(using accessible electronic formatting)





## The Keystone Study

- Checklists virtually eliminated CLABSIs in ICU's in University of Michigan Hospitals.
- Checklists reduced mortality rate overall by 10% in the system.

**Why *not* checklists for the “pit crews” for patients?**





# Your Own Checklist

- Agree on communication goals, tools & resources
- Know your audience/s, get them involved (PFACs!)
- Key in on words that support your goals: words shape perceptions and motivate actions!
- Organize your words: compose and format with purpose (perceptions & behaviors)
- Speak to different learning styles: support your words with graphics
- Distribute, share, promote!



# Communication Goals?

*Check the boxes that match your goals*

- Welcoming
- Direct, simple
- Factual, accurate
- Easy to understand
- Motivating, positive
- Promote Action
- Collaborative
- Trusted
- Can be used with confidence
- Effective → Safe & Sound care



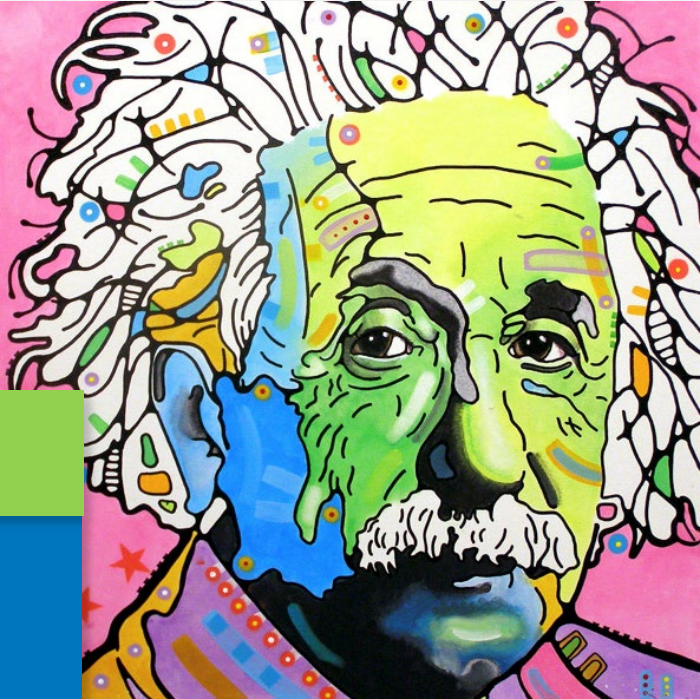
# New Words for New Thinking

## INSTEAD OF...

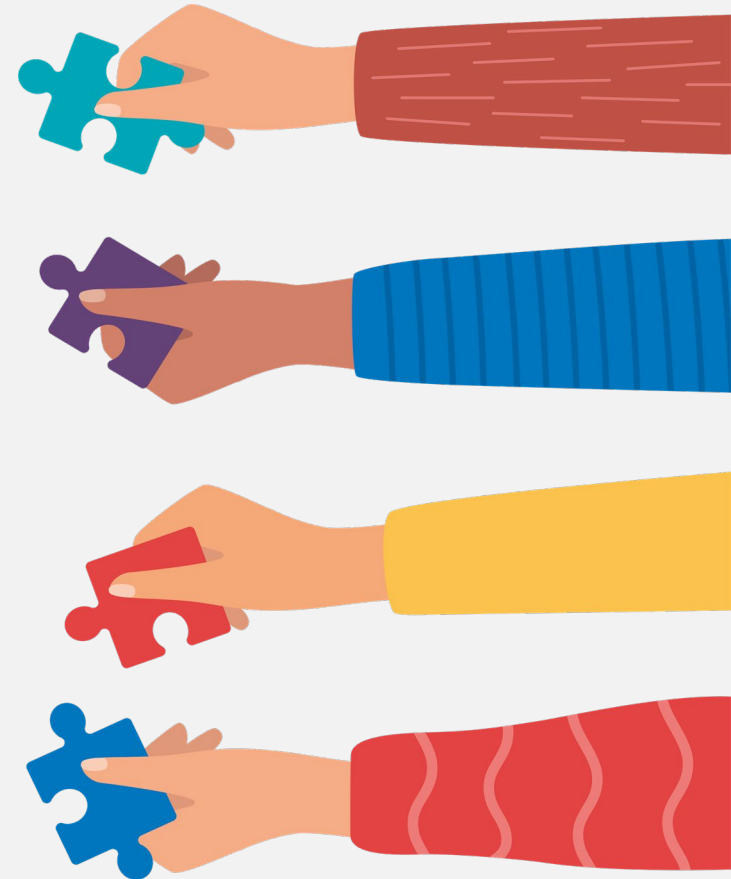
Engagement  
Engage  
Educate

## USE...

Activation  
Activate  
Inform



- **PATIENT:** person in your care
- **FAMILY:** anyone a patient trusts or relies on to help them
- **CARE PARTNER:** anyone a patient trusts who wishes to be helpful to patient and clinicians
- **ADVOCATE:** a *professional* patient support staff person or professional hired by the patient or family



# More Words That Matter





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## CLINICIANS SAY

- Decubitus ulcer, pressure wound
- Heart Failure
- MRSA
- Isolation precautions
- Jaundice
- Up fluids
- PCP

## EVERYONE ELSE...

- Bed sore
- OMG!!!! About to die!
- Infection, bad germs, “staff”
- ?????
- Yellow
- Drink more water
- Main doctor (or... angel dust, a street drug)





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“Plain language lets people read with less effort. It reduces frustration and makes it easier for people to access services.

“People also trust information that’s easy to understand.”



*State of California, Design Systems*

<https://designsystem.webstandards.ca.gov/style/content/write-in-plain-language/index.html>



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# Writing Tips

- Simple, short sentences — but not brusque! (It's an art.)
- Active voice
- Avoid compound phrases
- Plain terms, 6<sup>th</sup> grade literacy level, or lower.
- Quick rule of thumb:
  - ✓ 1 and 2-syllable words, but verify
  - ✓ Use Flesch-Kincaid tools, others
  - ✓ Grammarly Go can be helpful
- Common terms: “Bed sores”, *not* “pressure ulcers” OR “decubitus ulcer”
- Enlist your marketing department





# Good Design Tips

(to support good words)

- Lots of white space
- Uncluttered
- Casual and friendly
- Icons, Images
- Consistency
- Colors appropriate to topic, context
- Sans Serif font – No Times New Roman!
- 4-color
- Good paper when printing! 32#, consider gloss or coating





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# Same topic: which will be read?

**FAQs**  
(frequently asked questions)

about  
**"Catheter-Associated Bloodstream Infections"**  
(also known as "Central Line-Associated Bloodstream Infections")

**What is a catheter-associated bloodstream infection?**  
A "central line" or "central catheter" is a tube that is placed into a patient's large vein, usually in the neck, chest, arm, or groin. The catheter is often used to draw blood, or give fluids or medications. It may be left in place for several weeks. A bloodstream infection can occur when bacteria or other germs travel down a "central line" and enter the blood. If you develop a catheter-associated bloodstream infection you may become ill with fevers and chills or the skin around the catheter may become sore and red.

**Can a catheter-related bloodstream infection be treated?**  
A catheter-associated bloodstream infection is serious, but often can be successfully treated with antibiotics. The catheter might need to be removed if you develop an infection.

**What are some of the things that hospitals are doing to prevent catheter-associated bloodstream infections?**  
To prevent catheter-associated bloodstream infections doctors and nurses will:

- Choose a vein where the catheter can be safely inserted and where the risk for infection is small.
- Clean their hands with soap and water or an alcohol based hand rub before putting in the catheter.
- Wear a mask, cap, sterile gown, and sterile gloves when putting in the catheter to keep it sterile. The patient will be covered with a sterile sheet.
- Clean the patient's skin with an antiseptic cleanser before putting in the catheter.
- Clean their hands, wear gloves, and clean the catheter opening with an antiseptic solution before using the catheter to draw blood or give medications. Healthcare providers also clean their hands and wear gloves when changing the bandage that covers the area where the catheter enters the skin.
- Decide every day if the patient still needs to have the catheter. The catheter will be removed as soon as it is no longer needed.
- Carefully handle medications and fluids that are given through the catheter.

**What can I do to help prevent a catheter-associated bloodstream infection?**

- Ask your doctors and nurses to explain why you need the catheter and how long you will have it.

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**HOW TO HELP**

**PREVENT SEPSIS:**

- When a central line is inserted, ask: "Are you using a central line bundle and checklist?"
- Watch to make sure that nurses and doctors always:
  - Wash their hands thoroughly before touching your loved one.
  - Use sterile instruments and supplies.
  - Clean the skin with an alcohol wipe.
  - Choose the safest spot. (Ask, "Why?" if groin is chosen.)
  - Use a clean sheet to drape your loved one's body
  - Wear a mask.
  - Cover the area with a sterile pad.
- Make sure any openings in the skin are kept covered at all times.

**COMMON LOCATIONS FOR CENTRAL LINES AND IVS:**

**GET A NURSE IF:**  
Your loved one shows signs of (or complains about) the following:

- Chills.
- Headache.
- Extreme pain.
- Shivering.
- Diarrhea.
- Fast breathing.
- Confusion.
- Nausea.
- Fast heartbeat.

**ABOUT SEPSIS**  
(Bloodstream Infection):  
Germs can invade the body through cuts or breaks in the skin, resulting in serious infection, called Sepsis, that's carried through the body in the bloodstream.

**RISK FACTORS:**  
Use of a tube and bag system called an IV or "Central Line" to deliver fluids is a common risk. However, any break in the skin or intestinal tract can be a risk. Also, sepsis can occur when someone is suffering from multiple infections.

**CHECK OUT**  
EndSepsis.org.

**REMEMBER, IT'S OKAY TO SPEAK UP!**

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# Defuse Defensiveness



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**HOW TO HELP  
PREVENT FALLS:**

**ABOUT FALLING:**  
Falls can happen to anyone in an unfamiliar place. Most patients are tired, weak, or sleepy from medications, or suffering from conditions affecting balance.

**RISK FACTORS:**  
**ALL PATIENTS—regardless of age or strength—are at risk for falls.**  
Past history of falling or problems with balance carry extra risk.

**REMEMBER, IT'S OKAY TO SPEAK UP!**

**HOW TO HELP PREVENT FALLS:**

- Look for things in your loved one's room** that might cause a trip and fall.
  - Point out all furniture and equipment on wheels.
  - Discuss ways to move around the room without leaning on wheeled items for support.
- If your loved one has a history of falling** or any problems with their balance:
  - Ask about getting a cane or walker, and using bed rails.
  - Ask about the hospital's fall protection equipment, such as low beds, floor padding, and bed alarm.
  - Discuss the possibility of a room for your loved one close to the nurses' station.
- Make sure someone helps your loved one** go back and forth to the bathroom or commode, and that someone is on standby in your loved one's room for every trip.
- Hang our "CAUTION" signs** in can't-miss spots in your loved one's room, such as on doors or over the head of the bed.
- Ask for non-skid socks**, or bring slippers, for your loved one to wear out of bed.
- If you are able, lend your arm for support** when your loved one walks. *Please don't risk injury to yourself—it's okay to ask for help.*
- Watch to make sure** the hospital gown and any IV tubes won't trip your loved one.

**GET A NURSE IF YOUR LOVED ONE FALLS...**

- Hit a call button immediately.
- Put a blanket over her/him.
- Go in the hall and call for help, if necessary.
- Do not move your loved one.
- Ask for a meeting with your loved one's nurses and a nursing supervisor to discuss:
  1. How the fall happened, and
  2. What will be done to help make sure your loved one doesn't fall again.

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“Falls can happen to anyone in an unfamiliar place. Most patients are tired, or sleepy from medications or suffering from conditions affecting balance.”



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**Thanks for  
washing your  
hands...and  
using clean  
equipment!**

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**Awwww...  
thank you for caring  
about my safety  
and cleaning  
your hands!**



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**¡POR FAVOR!**



**¡GRACIAS  
por lavarse las manos!**

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### **Keeping You Safe from Germs**

At UTMB, your safe care is #1! Everyone should have clean hands when they touch a patient.

*Thanks for washing your hands, too!*



**Learn More**



**Aprende Más**



### **Manténgase a salvo de los microbios**

¡En UTMB, su seguridad es lo primero! Todos deben tener las manos limpias cuando toquen a un paciente.

*¡Gracias por lavarse las manos también!*





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**“Since my husband and I are both in our middle 80's, probably one of us will be in the hospital sometime.**

**“I carefully went through the checklists...these records would be very helpful!!**

**“It will bring comfort and peace.”**

**— Joanne Cerling**





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**Because  
we care  
about  
YOU!**



[TheCarePartnerProject.org](http://TheCarePartnerProject.org)



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**It's OK TO ASK...  
"Have you washed  
your hands?"**



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# THE CARE PARTNER

## MEDICINES TO TAKE AFTER LEAVING THE HOSPITAL

*(Be sure to include non-prescription medicines and other remedies used at home.)*



FOR: \_\_\_\_\_

DATE: \_\_\_\_\_

Name of Medicine, What It Looks Like, Dose (units on label, i.e. mg)	Why Taking This Medicine	How Much to Take Each Time	At What Time/s?	How to Take This Medicine (by mouth, on skin, with food, on empty stomach, etc.)	Taken at Discharge? <input type="checkbox"/> YES <input type="checkbox"/> NO
Prescribed by Dr. _____					Need to Be Filled? <input type="checkbox"/> YES <input type="checkbox"/> NO If yes, where? _____ When to Take Next Dose: _____ DAY / HOUR AM/PM
Prescribed by Dr. _____					Taken at Discharge? <input type="checkbox"/> YES <input type="checkbox"/> NO Need to Be Filled? <input type="checkbox"/> YES <input type="checkbox"/> NO If yes, where? _____ When to Take Next Dose: _____ DAY / HOUR AM/PM
Prescribed by Dr. _____					Taken at Discharge? <input type="checkbox"/> YES <input type="checkbox"/> NO Need to Be Filled? <input type="checkbox"/> YES <input type="checkbox"/> NO If yes, where? _____ When to Take Next Dose: _____ DAY / HOUR AM/PM
Prescribed by Dr. _____					Taken at Discharge? <input type="checkbox"/> YES <input type="checkbox"/> NO Need to Be Filled? <input type="checkbox"/> YES <input type="checkbox"/> NO If yes, where? _____ When to Take Next Dose: _____ DAY / HOUR AM/PM

- Look up every medicine at: [MedlinePlus](#).
- If 65 or older, check the [Beers List](#) for medicines that may be harmful for seniors to take.

For children, check the [KIDS' List](#) for medicines that may be harmful for children to take.

**QUESTIONS? CONC**  
Please speak up! It's okay to ask your doctor later for answers.

One East Erie Street, Suite 525-411, Chicago, IL 60611 | 847.208.6074 | TheCarePartnerProject.org

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# Partner Up with Meredith!

## No need to reinvent the wheel:



### Meredith Masel, PhD, MSW

Dr. Masel provides leadership and management of the Oliver Center for Patient Safety and Quality Health Care.

She sees the Oliver Center as an incubator for patient-centered programs that make the experience of being a patient, care partner, and/or provider easier and safer.



[mcmasel@utmb.edu](mailto:mcmasel@utmb.edu)  
409-747-6009





# THE CARE PARTNER PROJECT™

utmb Health

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## How to help prevent:

Please make a selection...



Bed Sores (Pressure Ulcers)



Blood Clots



C. Diff (Infection)



Falls



Medication Mixups



Sepsis



Superbug Infections



UTIs



Ventilator Pneumonia

## How to Support Your Loved One:

Please make a selection...



During Pregnancy



Labor and Delivery



Recovery from Childbirth



From Afar



Caretaker Self-care



Diagnosis and Treatment Options



Make a Decision about Surgery



Choose a Surgeon, Hospital, and a Date for Surgery



Prepare for Surgery



Support Good Communication



Manage Medications



Day of Surgery



People seem hungry for healthcare information.

“Checklist page”  
accounted for 68%  
increase in traffic on  
site overall

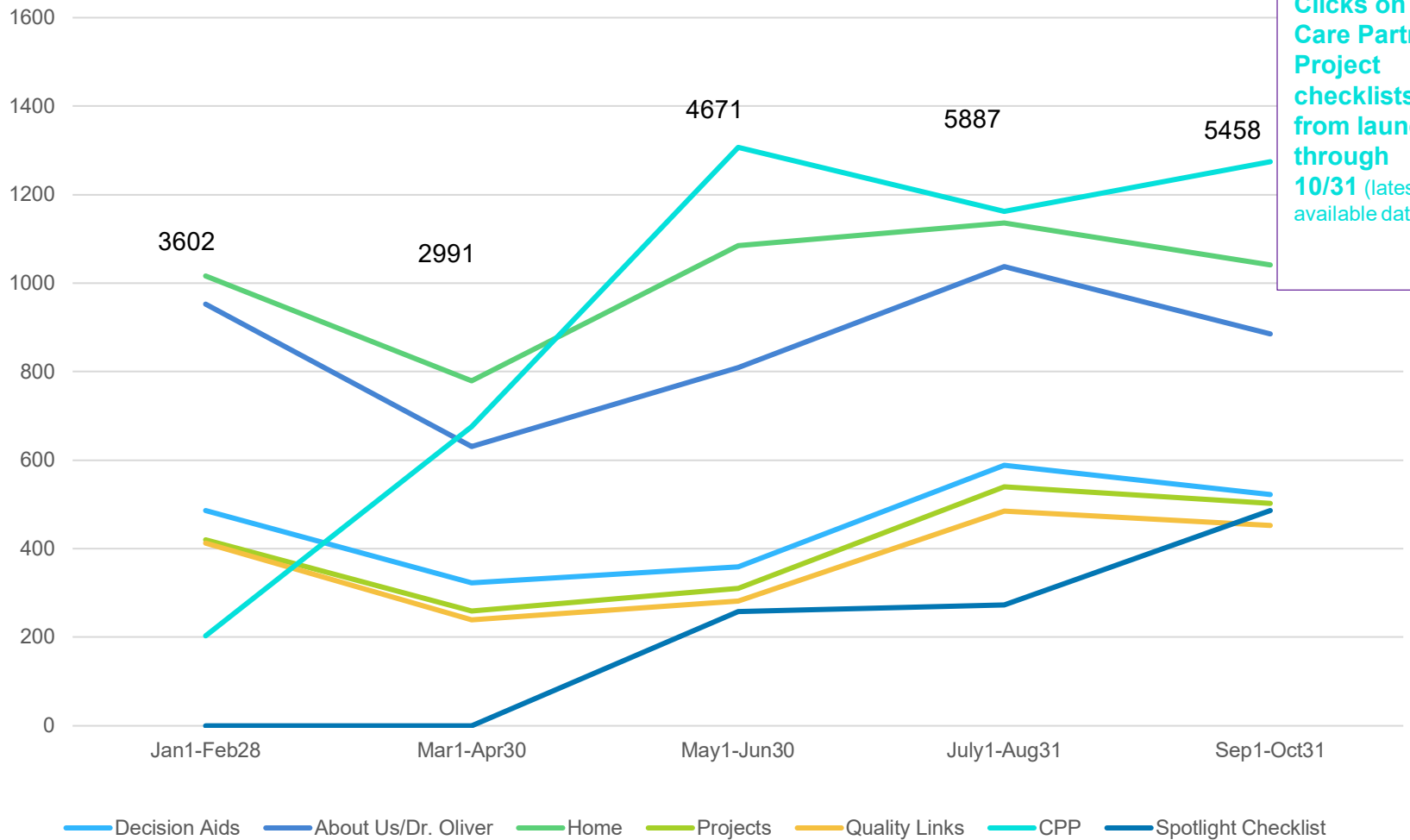


TheCarePartnerProject.org



# Evidence?

Website Traffic Care Partners 2023



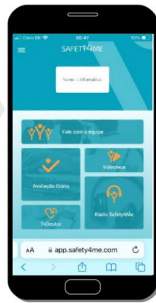


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## SAFETY4ME

Safety4me is a platform to connect patients, families and caregivers, with the safest care, enhancing their experience while in treatment.



- 1 Education for patients and care partners – The 6 International Patient Safety Goals – Videos and Podcasts
- 2 Communication channel – real time connection for patients and care partners with their providers.
- 3 Patient Safety Perception Index – patients review about providers compliance on the 6 international safety goals
- 4 Patient experience review through text message or whatsapp

Developed by a physician, Salvador Gullo MD

Used in 25 hospitals in Brazil

Distributed by 11 payers to covered patients worldwide

Launching in the US, with The Care Partner Project content

**Who wants to test? Contact Haley or Karen!**



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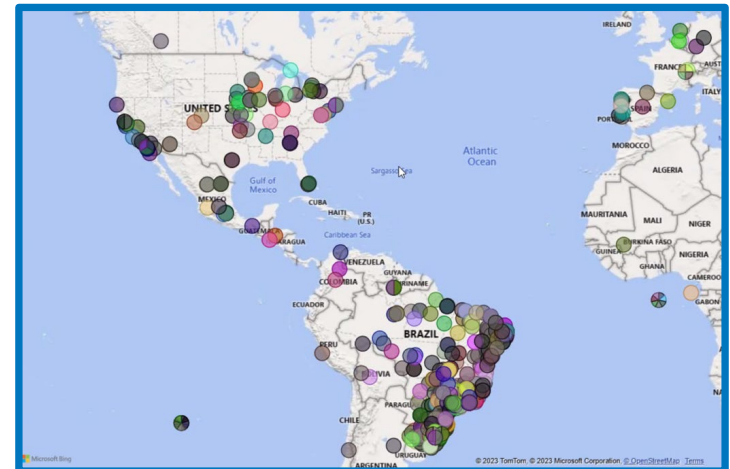
# Building on Success

Proven patient safety platform that informs and activates patients in their care

Promotes good communication

Provider dashboard to:

- Spot and avert harm in real-time
- Evaluate QI processes at every point of care to adjust, refine, re-train





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# Cliff Notes



HEAD

Simple  
Facts



HEART

Friendly Tone  
& Graphics



HANDS

Something  
To Do





# Thank you for your time and care.

Safe & Sound Patient and Family Engagement™



RESOURCES TO SUPPORT YOUR PATIENT-CENTERED CARE



PFE Resources



Checklist Samples

Karen Curtiss

[Karen.Curtiss@CarePartnerProject.org](mailto:Karen.Curtiss@CarePartnerProject.org)

847.208.6074

