ASCO's Quality Training Program

Integrating Family Caregivers into Gynecologic Cancer Education & Support Services

Michelle Boisen, Grace Campbell, Heidi Donovan, Lauren Hand, Nora Lersch, & Barb Suchonic

Magee Women's Hospital of UPMC

12/5/18

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Institutional Overview

- Academic regional referral center - Pittsburgh, PA
- National Center of Excellence in Women's Health
- NCI-designated Comprehensive Cancer Center
- 300 Inpatient beds
- Average of 10,800 clinic visits/year over past 3 years
- 10 GynOncs, 2 MedOncs, 7NPs & PAs

Team Members

Core Team Members: Dr. Michelle Boisen & Dr. Lauren Hand (Team Leaders); Heidi Donovan, PhD, RN; Grace Campbell, PhD, MSW, RN (Facilitators); Barb Suchonic, Director of Operations; Nora Lersch, MSN, NP	**EHR Medical Director:** Glenn Updike, MD **UPMC Patient Reported Outcomes:** Janel Hanmer, MD
Caregiver Advocate: Scott Harrison	**Medical Assistants and Intake Staff:** Alexis Morris; Kelsey Onufrey
Palliative Care: Lisa Podgurski, MD; Lisa Griffiths, RN	**Patient/family Navigator:** Alex Ley, MSW, LSW
Infusion Center: Annette Smith, RN **Collaborative Practice Nursing:** Cathy Jackson, RN	**Patient Care Coordinator:** Robin Minich, RN
Diversity & Inclusion: Susan Baida Director, UPMC Community Engagement:	**QTP Improvement Coach:** Stephanie Amport

Project sponsors:

- Dr. Robert Edwards, Chair, OB/GYN
- Dr. Joseph Kelley, Division Director, GYN Oncology
- Troy Treanor, Program Administrator, Women's Cancer Services
- Tami Minnier, RN, Chief Quality Officer, UPMC
- James Taylor, UPMC Diversity

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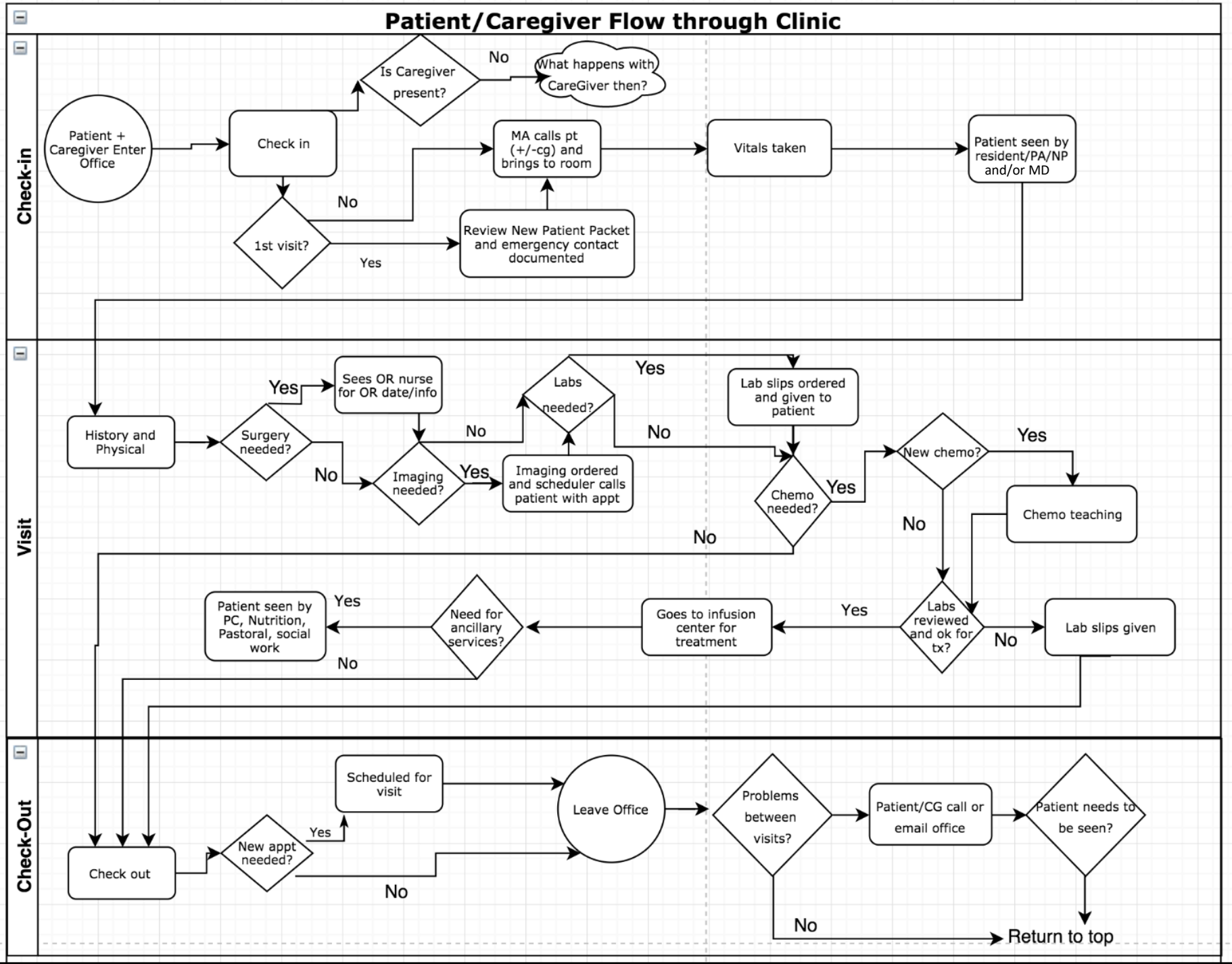
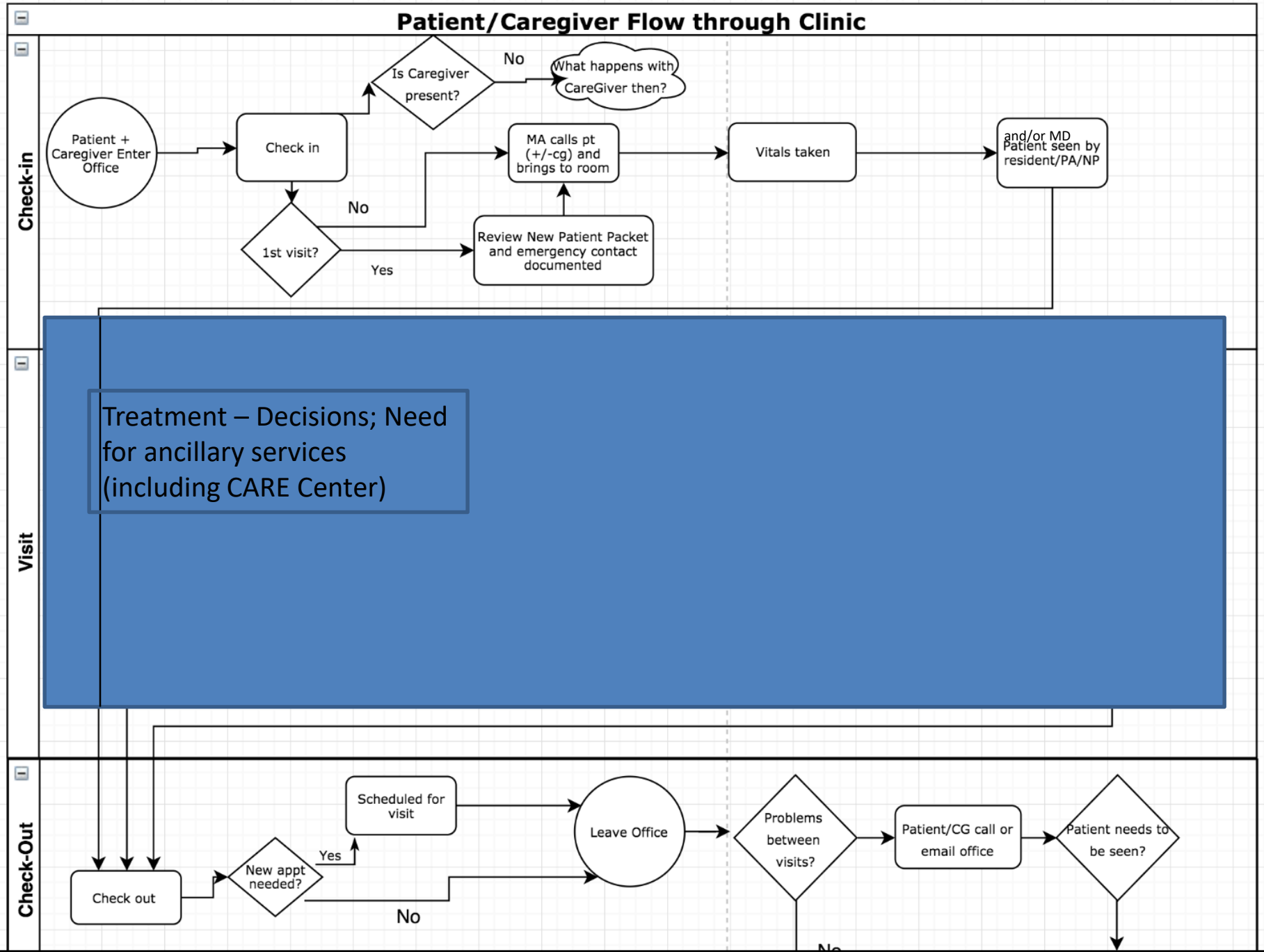
Problem Statement

- Based on a medical record review of gyn onc patients receiving chemotherapy during a one-week period in July, 2018, only ***19% of charts included any documentation of a family member and no (0%) charts included documentation of caregiver concerns or needs*** (n=36).

- Based on a needs assessment of family caregivers conducted between 9/17 and 12/17, ***50% of caregivers report 9 or more distressing unmet needs*** *(n=56, score of ≥ 4 on 0-10 scale)*.

- These data suggest that family caregivers are not receiving the support they need in the gynecologic cancer program to effectively care for themselves and their loved ones.


Patient/Caregiver Flow through Clinic
Check-in
Patient + Caregiver Enter Office
Check in
Is Caregiver present?
No
What happens with CareGiver then?
1st visit?
No
Yes
MA calls pt (+/-cg) and brings to room
Review New Patient Packet and emergency contact documented
Vitals taken
Patient seen by resident/PA/NP and/or MD
Visit
History and Physical
Surgery needed?
Yes
Sees OR nurse for OR date/info
No
Imaging needed?
Yes
Imaging ordered and scheduler calls patient with appt
Labs needed?
Yes
No
Lab slips ordered and given to patient
Chemo needed?
Yes
No
New chemo?
Yes
Chemo teaching
No
Labs reviewed and ok for tx?
Yes
No
Lab slips given
Goes to infusion center for treatment
Need for ancillary services?
Yes
No
Patient seen by PC, Nutrition, Pastoral, social work
Check-Out
Check out
New appt needed?
Yes
No
Scheduled for visit
Leave Office
Problems between visits?
Patient/CG call or email office
Patient needs to be seen?
No
Return to top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Is Caregiver present?
No
What happens with CareGiver then?
1st visit?
No
Yes
Review New Patient Packet and emergency contact documented
MA calls pt (+/-cg) and brings to room
Vitals taken
and/or MD
Patient seen by resident/PA/NP
Visit
Treatment – Decisions; Need for ancillary services (including CARE Center)
Check-Out
Check out
New appt needed?
Yes
No
Scheduled for visit
Leave Office
Problems between visits?
Patient/CG call or email office
Patient needs to be seen?

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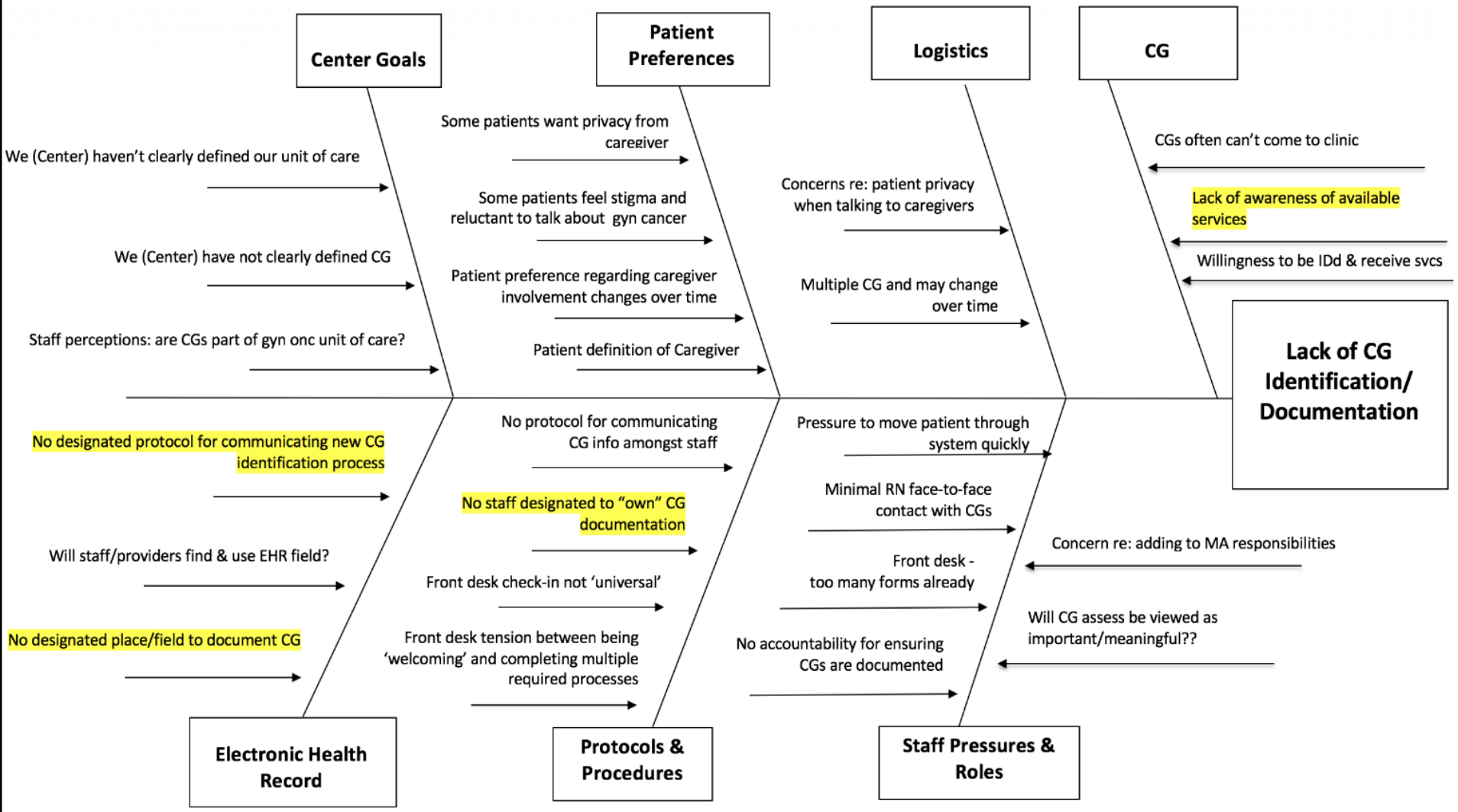
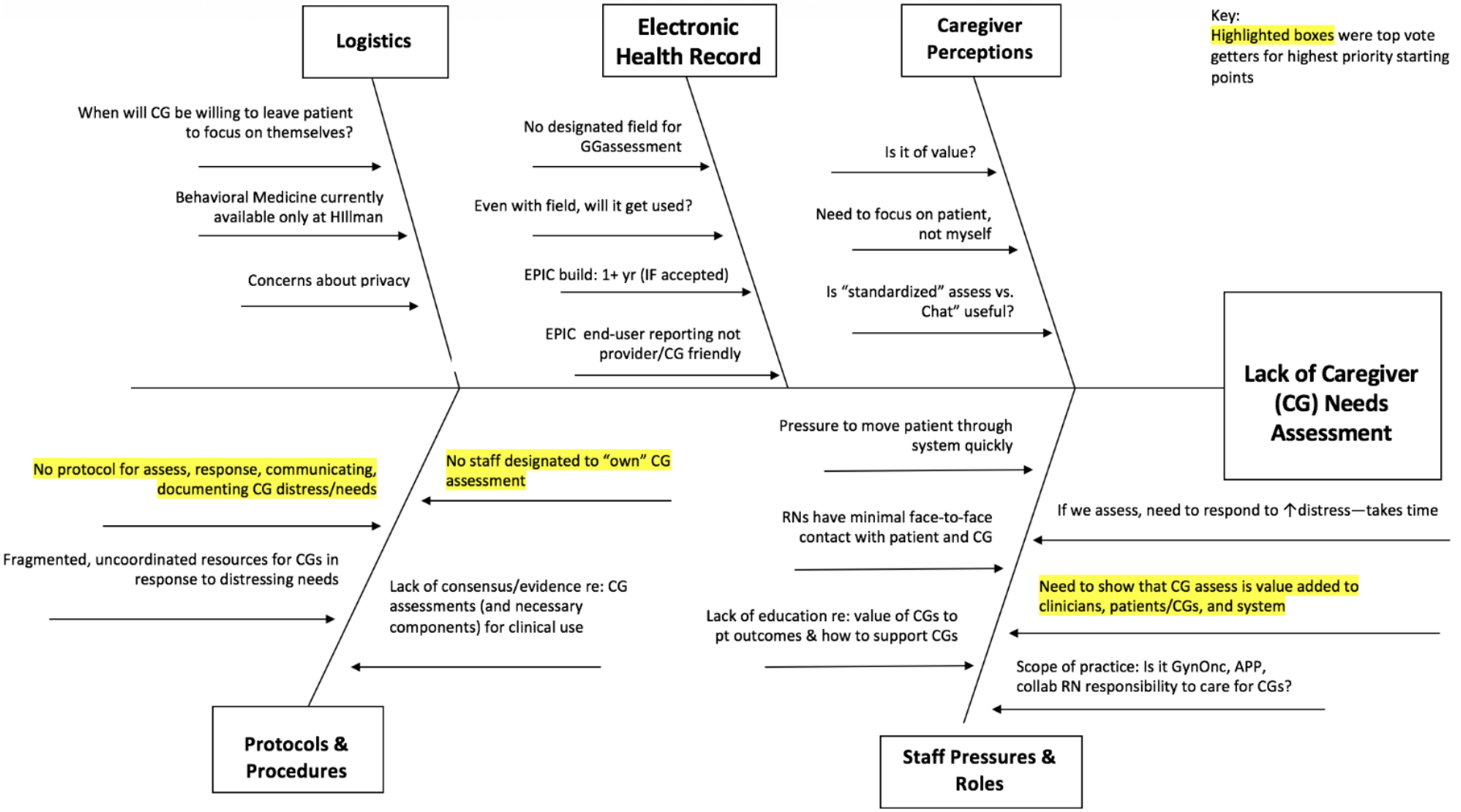
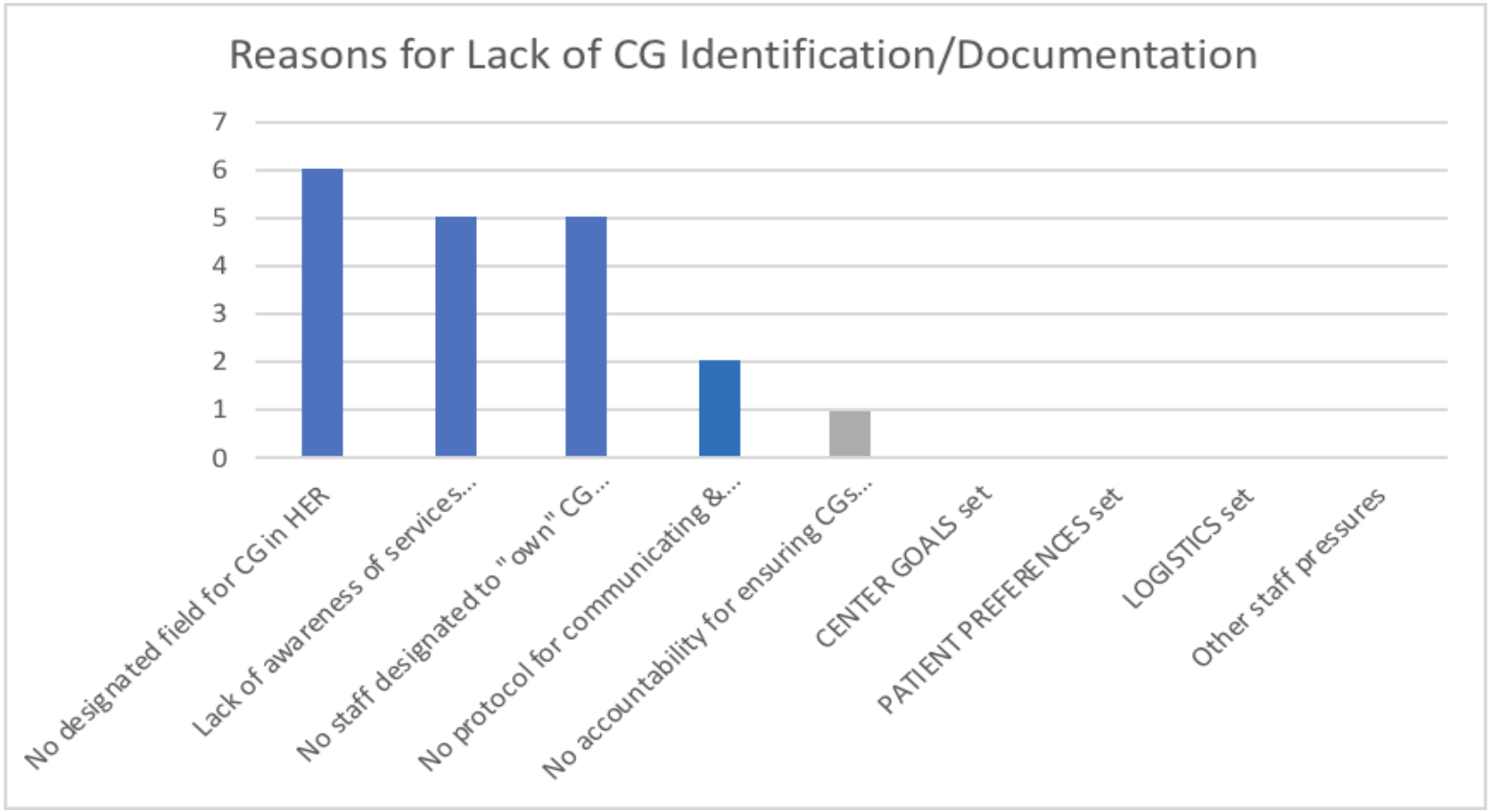
Cause & Effect Diagram - Caregiver Identification



Cause & Effect Diagram - Caregiver Assessment



Diagnostic Data - Caregiver Identification



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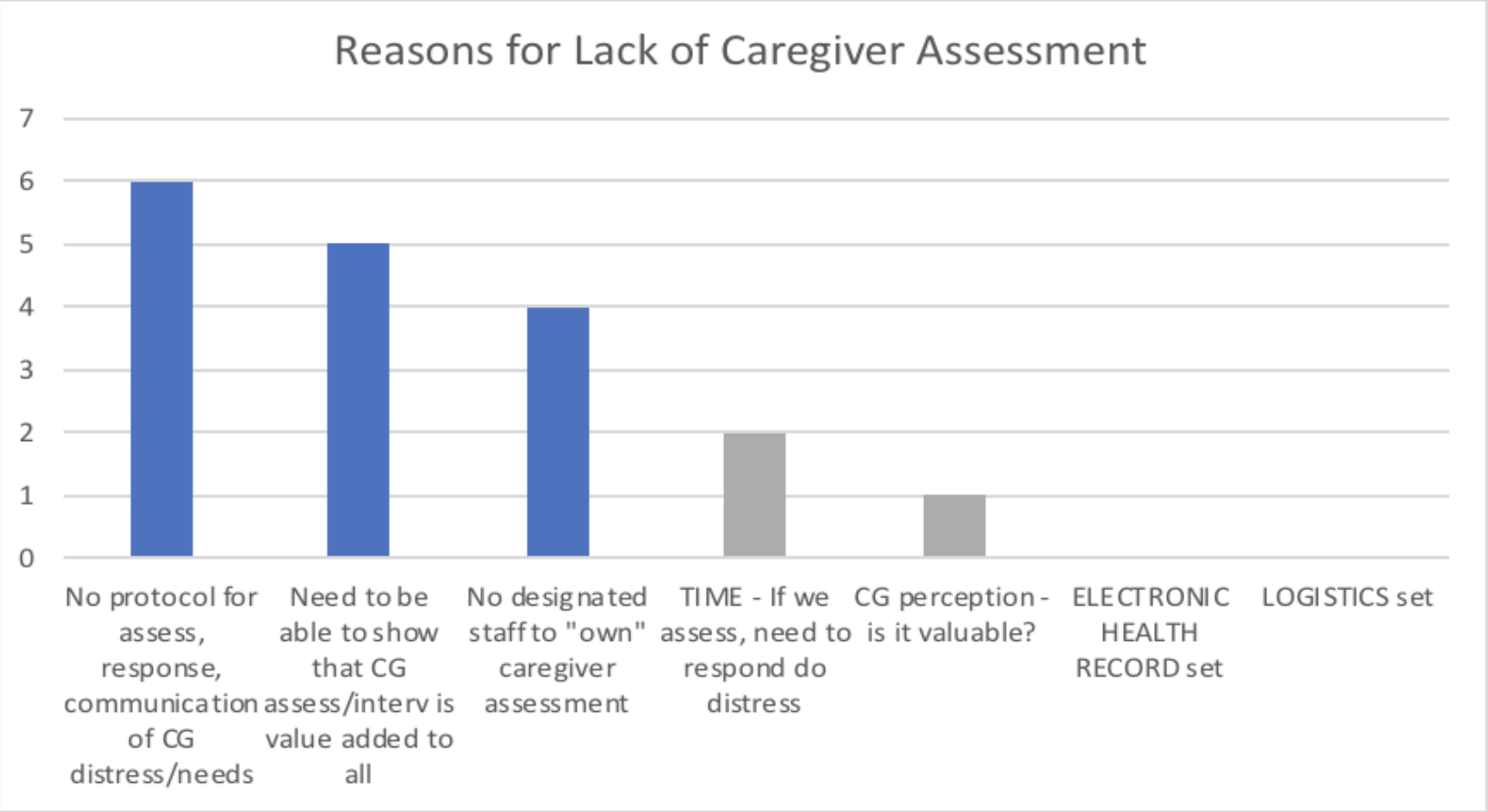
Diagnostic Data - Caregiver Assessment



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Aim Statement

By December 1, 2018:

- 85 % of Magee Gynecologic Cancer Program patients will have an identified and documented primary caregiver within 2 clinic visits of receiving a confirmed diagnosis of gynecologic cancer, and
- 75% of caregivers will have distress level and sources of distress assessed within 2 weeks of caregiver identification.

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Measures

Measure(s) & Calculation Methodology:

1. EPIC Query
   a. % Caregiver documentation
2. Survey (% = #positive response/#completing surveyx100)
   a. Did anyone in the clinic ask you about your needs as a caregiver today?
   b. Did provider give you education or support today?
   c. To what extent did info/support meet your needs? [0-4 Likert type scale;0=not at all; 4=completely (Mean score)
   d. Distress Thermometer - Level of distress over past week [Mean Score] [0-10 scale; 0=no distress - 10=as much distress as I can imagine]

- Patient population: All patients seen in gynecologic oncology clinic

Measures

- Data collection frequency:
  - 5 days/month; once on each day of the week
  - Pre & post implementation then annually
- Data quality (any limitations):
  - Not able to capture everyone in busy clinic
  - Caregiver reluctant to provide information on his/her distress when patient is not there
  - CGs consider any info provided to them and to patient as CG education/support education

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Baseline Data n=166

1. 28% of Caregivers reported being asked about their needs as a family caregiver
2. 45% of Caregivers reported receiving information from a provider
3. Extent to which info met needs: 2.7 (range: 0-4)
4. Mean Caregiver Distress score: 2.9 (range: 0-10)
    - 38% of CGs scored >4 on distress thermometer

Priority Matrix—Caregiver Identification

Impact	Easy	Difficult
High	1) Printed materials (posters; flyers in new patient packets; pamphlets) 2) Educate all levels of staff about services/program 3) Staff meeting and division meeting agendas/minutes every 3 months (sustaining gain and visibility) 4) New staff orientation agendas 5) Process for caregiver identification in clinic	1) Educate providers about value of including caregiver on care team 2) Monthly audits of identification and documentation to sustain the process 3) Develop caregiver data base for center to organize and search by caregiver, patient, service date, MD
Low	1) Implement wording of identification question/invitation: "Is anyone with you today? Please join us."	1) Educate entire organization (hospital; health system) on program 2) Designate field for caregivers in eRecord (that is not redundant with existing fields)

Ease of Implementation

Priority Matrix—Caregiver Assessment

Impact	Easy	Difficult
High	1) Staff the center 5 days per week 2) Develop protocol for telephone education, counseling and referral 3) Assess caregiver information needs 4) Targeted caregiver assessment w/in 2 weeks of identification (NCCN distress, emotional well-being, problem list, resources)	1) Assess caregiver financial resources, insurance coverage 2) Assess what relationship caregiver is to patient and what kinds of support that person provides 3) Ongoing assessment of metrics to demonstrate value 4) Documentation template for caregiver assessment/notes in patient chart 5) Ongoing feedback to clinicians re: caregiver follow up to show value
Low	1) Assess technical/medical 'literacy' of caregiver	1) Develop protocol and decision points for referrals to behavioral medicine, crisis lines, etc.

Ease of Implementation

PDSA Plan (Test of Change)

Date of PDSA Cycle	Description of Intervention	Results	Action Steps
Cycle 1: October 1- October 19	1) Define standard process for identifying caregiver 2) Identify/define standard location for documenting caregiver(s) in patient eRecord	1) Standard process and location identified and agreed upon by full project team.	
Cycle 2: October 20- November 2	1) Redecorate former exam room in clinic with comfortable seating, lighting; refreshments for caregivers; storage/displays for caregiver resources	1) Caregiver center decorated and furnished by 10/30/18.	1) Obtain CARECenter email address 2) Obtain direct phone line for CARECenter

PDSA Plan (Test of Change)

Date of PDSA Cycle	Description of Intervention	Results	Action Steps
Cycle 2: October 20-November 2 (cont'd)	2) "Soft opening" two days prior to official center opening to educate staff about caregiver identification process, documentation location 3) Daily promotional/ 'spirit' activities (bagels; popcorn, lunch) during first week of clinic to increase staff awareness, investment, and buy-in	2 & 3) Soft opening included 5 'spirit-building' activities for staff (1 activity daily for first 5 days) to increase staff excitement and educate about Center.	

PDSA Plan (Test of Change) - ID

Date of PDSA Cycle	Description of Intervention	Results	Action Steps

Cycle 3: November 9-November 23	1) Staff center 5 days/week
	2) Develop protocol for notifying center staff of caregivers to be assessed
	3) Develop protocol for completing phone assessment
	4) Implement targeted CG assessment (NCCN distress, emotional well being, problem list, resources
		1) Final CG identifications through 11/29 (with ”mini PDSAs):
		• 174 CGs documented
		  • 116 return pts
		  • 49 new patients
		  • 4 new recurrences
		  • 5 no cancer
			1) Need to refocus our priorities on CGs of new patients or patients in transition; not bog down center staff.

PDSA Plan (Test of Change) - Assess

Date of PDSA Cycle	Description of Intervention	Results	Action Steps
Cycle 3: November 9-November 23	1) Staff center 5 days/week 2) Develop protocol for notifying center staff of caregivers to be assessed 3) Develop protocol for completing phone assessment 4) Implement targeted CG assessment (NCCN distress, emotional well being, problem list, resources	2) Outreach initiated with 61 patients • 30 emails with info about center • 10 phone messages left • 21 phone conversations (cg &/or patient) • Only 4 full assessments done	

PDSA Plan (Test of Change)

Date of PDSA Cycle	Description of Intervention	Results	Action Steps
Cycle 4: November 26-December 2	1) Streamline Center's CG data base 2) Streamline/refine process for entering into Center data base 3) Refine role/responsibility for each member of Center staff to ensure efficient, effective CG assessment	1) Began working with IT to develop CARE Center documentation template in HER (work in progress) 2) Role definitions begun and are ongoing	1) Re-organize CG spreadsheet ("data base") for easier tracking of priority follow ups 2) Create new posters that define CG better 3) Create a flyer for new patient packet that is both a form be completed AND information about the center.

PDSA Plan (Test of Change)

Date of PDSA Cycle	Description of Intervention	Results	Action Steps
Cycle 5 (planned): December 10-December 20	1) Increase education, marketing of center to: Providers/staff Patients Caregivers 2) Develop protocols for patient/caregiver case finding and outreach 3) Develop protocols for direct referrals to CARE Center from clinicians 4) Continue refining protocols for following up		1) Switch to active CG identification for new patients only

Materials Developed (optional)

Date: _____
My Name is: _____
My closest support person, or "caregiver" (CG) is my _____ (mother, sister, husband, partner, daughter, son, friend).
CG Name:_____
CG Phone:_____
CG Email: _____

GynOnc CARE Center Guides

Cancer Reaches Beyond the patient; So Should Cancer Care

Maintaining Your Emotional Health as a Family Caregiver

"Family Caregiver" means anyone (friend or family member) who provides day-to-day support for a woman with gynecologic cancer

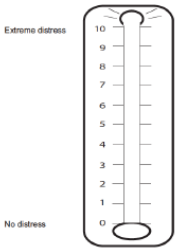
Emotional health refers to your sense of well-being. People who provide support to a woman with gynecologic cancer face many of their own physical and emotional challenges as they deal with their loved one's illness. This is often a very overwhelming time.

Many caregivers feel unprepared for all the things they need to learn and manage. Even though

GynOnc Family CARE

Cancer Reaches Beyond the Patient; So Should Cancer Care

Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing **in the past week, including today**.



Caregiver (CG) Name:_____
CG Phone:_____
CG Email: _____
I am supporting my _____ who has cancer (mother, sister, wife, partner, daughter, friend).

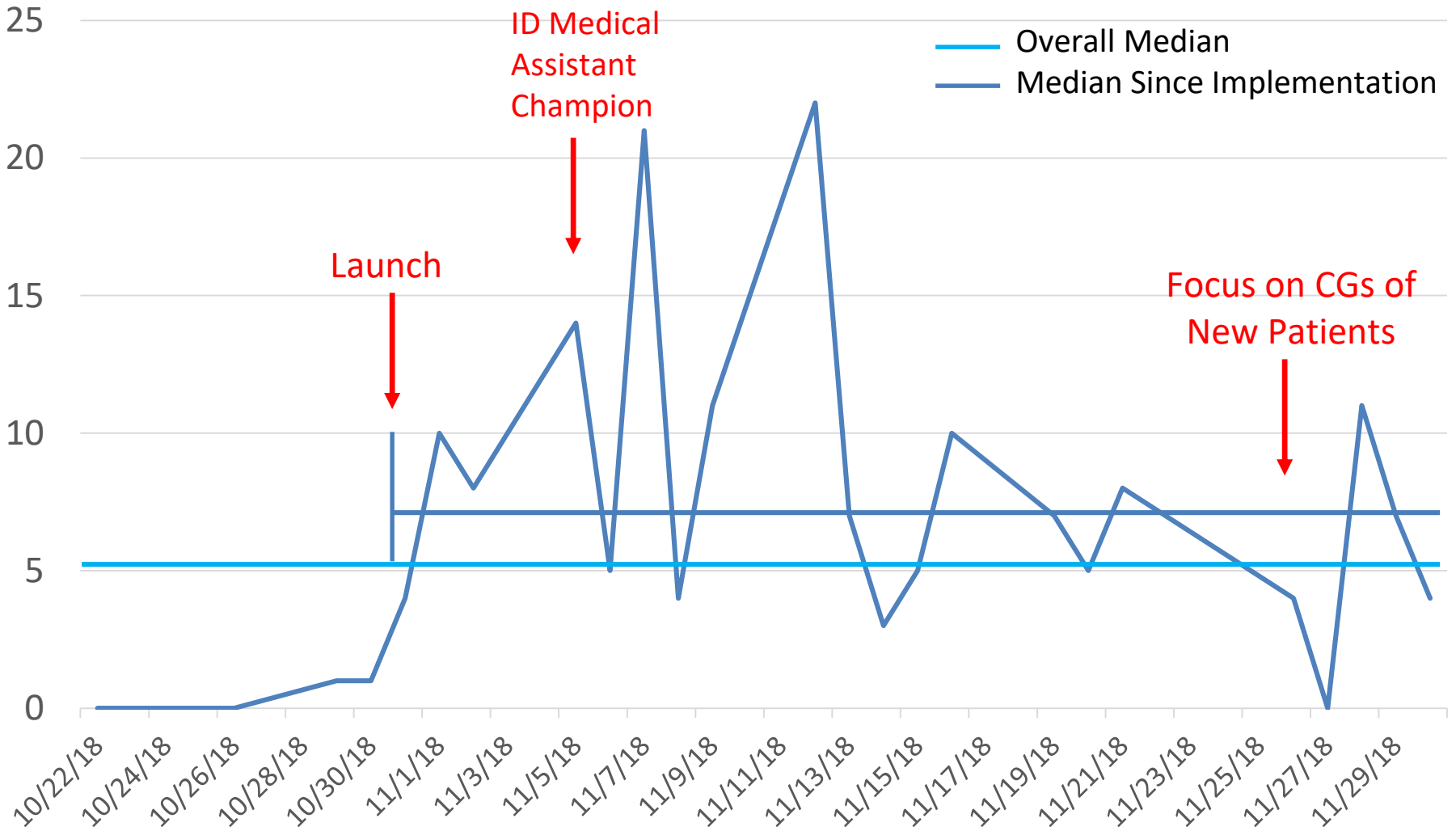
Caregiver Problem Checklist
Please check all of the following items that have been a concern or problem for you **in the past week, including today.**

For any concerns that you have, please tell us how stressful that concern is for you on a scale of **0 (not at all stressful) to 10 (as stressful as you can imagine)**

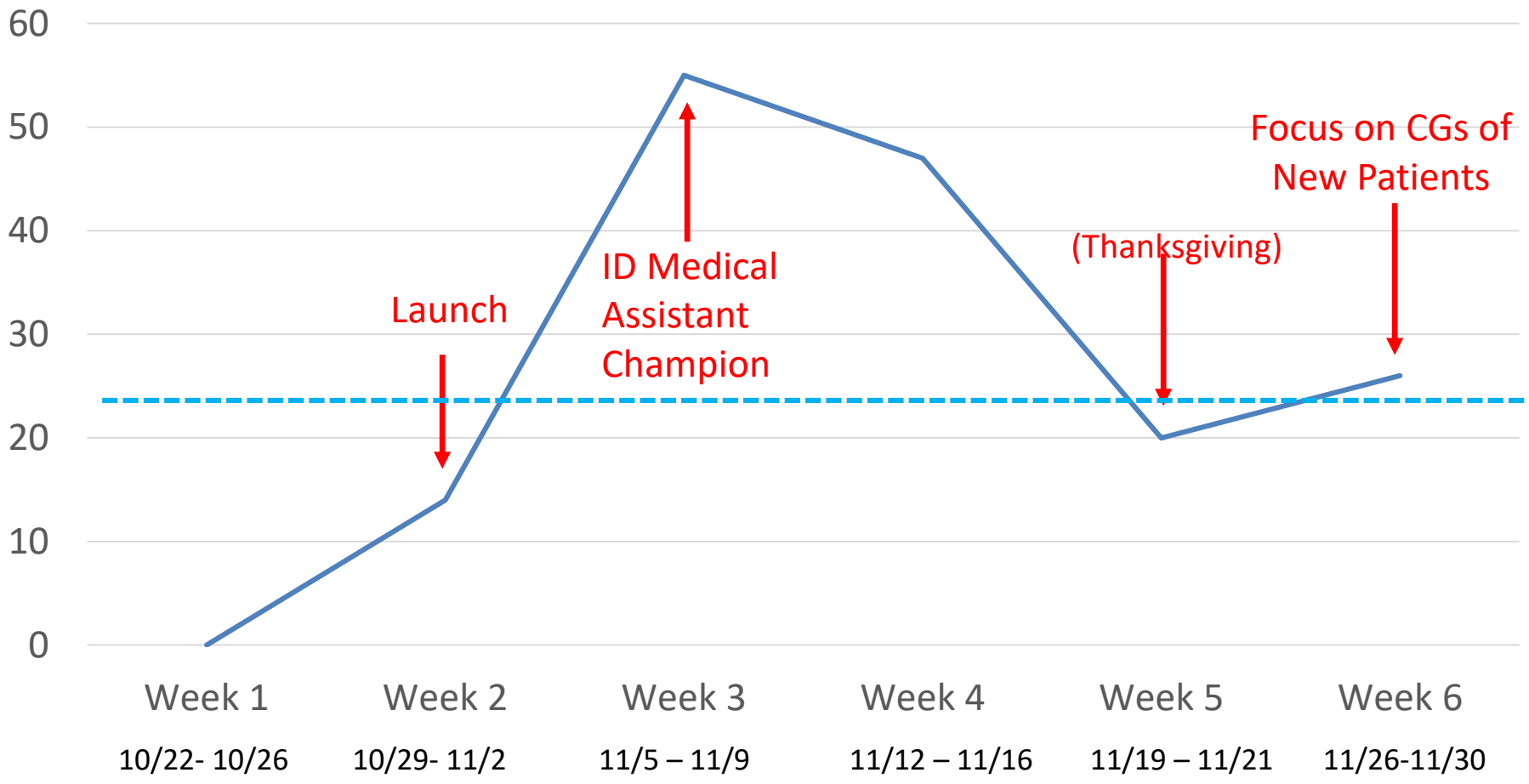
Self-Care	
☐ Maintaining your emotional health	0 1 2 3 4 5 6 7 8 9 10
☐ Maintaining your physical health	0 1 2 3 4 5 6 7 8 9 10
☐ Finding time for yourself	0 1 2 3 4 5 6 7 8 9 10
☐ Spiritual Concerns	0 1 2 3 4 5 6 7 8 9 10
Information	
☐ About the disease	0 1 2 3 4 5 6 7 8 9 10
☐ About the treatment	0 1 2 3 4 5 6 7 8 9 10
Practical	
☐ Finances	0 1 2 3 4 5 6 7 8 9 10
☐ Legal Issues	0 1 2 3 4 5 6 7 8 9 10
☐ Transportation/Parking	0 1 2 3 4 5 6 7 8 9 10
☐ Work	0 1 2 3 4 5 6 7 8 9 10
Patient Care	
☐ Managing patient symptoms	0 1 2 3 4 5 6 7 8 9 10
☐ Managing patient medication	0 1 2 3 4 5 6 7 8 9 10
☐ Self-Confidence as a caregiver	0 1 2 3 4 5 6 7 8 9 10
Relationships	
☐ Communicating with providers	0 1 2 3 4 5 6 7 8 9 10
☐ Talking with others about cancer	0 1 2 3 4 5 6 7 8 9 10
☐ Relationship with patient	0 1 2 3 4 5 6 7 8 9 10
☐ Family Dynamics	0 1 2 3 4 5 6 7 8 9 10

Patient Information

Change Data – Number of Caregivers Identified per Day



Change Data – Number of Caregivers Identified per Week



Exemplar

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Conclusions

- Aim: Met/Not met???
- Implementation process, outcomes data suggest positive benefits
- Distal quality indicators (e.g. ED visits; patient satisfaction) yet to be assessed
- Center adds value to patients, caregivers, clinicians (Exemplar)
- Labor-intensive for Center staff (QTP Team) but labor-saving for clinical staff

Next Steps/Plan for Sustainability

- Simplify and clarify Center processes
- Simplify measures; data collection
  - Optimize EHR documentation to streamline?
  - Continue improving tracking via data base for easier prioritization of follow up
- Finalize Center staff role descriptions
- Active referrals vs. case finding
- Integrate clinic screening and referrals into overall clinic work flow