Goals of Care Conversations Training

Goals of Care Conversations about Life-Sustaining Treatments

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The Life-Sustaining Treatment (LST) Decisions Initiative

GOALS OF THE INITIATIVE:

The values, goals and life-sustaining treatment decisions of all high-risk patients are elicited, documented, and honored.

The initiative promotes:

• Goals of care conversations with high-risk patients - before a medical emergency or crisis.

• Easy-to-find documentation of the patient’s goals of care and treatment decisions through a new CPRS LST progress note and order set.
Steps necessary to honor the values, goals and treatment decisions of patients with serious illness.

- Proactively identify high-risk patients
- Prepare for goals of care conversations
- **CONDUCT A GOALS OF CARE CONVERSATION**
- Document goals of care and life-sustaining treatment decisions
- Honor the patient’s values, goals and treatment decisions

How do we define a **goals of care conversation (GoCC)**?

A discussion between a health care team member and a high-risk patient (or surrogate) that helps identify the patient’s values, health care goals and decisions about life-sustaining treatments and other care.
What is a life-sustaining treatment (LST)?

A medical treatment that is administered in an attempt to prolong the life of a patient who would be expected to die soon without the treatment.

Examples:
- Cardiopulmonary Resuscitation (CPR)
- Mechanical Ventilation
- Feeding Tubes
- Dialysis

Which patients are “high risk”? 

• At risk for a life-threatening clinical event within the next 1-2 years

• Can by identified through clinical judgment (“the surprise” question)
### ADVANCE DIRECTIVES vs POLST

<table>
<thead>
<tr>
<th>ADVANCE DIRECTIVES</th>
<th>POLST</th>
</tr>
</thead>
<tbody>
<tr>
<td>For anyone 18 and older</td>
<td>For persons with serious illness and/or limited life expectancy at any age and/or someone who want limits to life-sustaining interventions</td>
</tr>
<tr>
<td><strong>Instructions</strong> for <strong>FUTURE</strong> treatment</td>
<td><strong>Medical Orders</strong> for <strong>CURRENT</strong> treatment</td>
</tr>
<tr>
<td>Can be completed by the patient only</td>
<td>Can be completed by the patient or surrogate</td>
</tr>
<tr>
<td>Can appoint a Health Care Agent</td>
<td>Only legal mechanism for a Utahn to have a <em>Do Not Resuscitation (DNR)</em> order outside of a licensed health care facility</td>
</tr>
<tr>
<td>Does not guide Emergency Medical Personnel</td>
<td>Guides actions by Emergency Medical Personnel</td>
</tr>
<tr>
<td>Guides inpatient treatment decisions</td>
<td>Guides inpatient treatment decisions</td>
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</tbody>
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**Why are conversations about goals of care and life-sustaining treatment hard?**

- Don’t know the right words say
- Discussions are about death and sadness
- Emotions are strong, don’t know how to respond
- Uncertainty about outcomes
- Lack of a framework within which to enter the conversation
Required for Successful Goals of Care Conversations

Knowledge “The What”
• Steps
• Facts
• Data

Skills “The How”
• Words
• Clarity
• Empathy

What We Will Learn

✓ CAPTURES: A ‘Talking Map’
How We Will Learn

✓ Define skills (lecture)

✓ Observe skills in action (words that work)

What are some unintended consequences of the following questions/phrases when discussing LSTs?

✓ Would you like us to try to restart your heart?

✓ Would you like us to do everything possible if your father’s heart stops beating and he stops breathing?

✓ I think it is time to withdraw care.
What are some unintended consequences of the following when discussing LSTs?

Would you like us, in what would naturally be your final moments, to press on your chest and break your ribs, shove a tube down your throat and poke you with needles in lots of places in a chaotic attempt that has a very small chance of giving you more time to be technically alive but unlikely to ever return to meaningful communication with others?

Our role

Ensure patients receive treatment consistent with their values and goals by helping them...

- Define what is important to them
- Understand the possible outcomes of treatment
- Make informed decisions to support their goals
CAPTURES: A Talking Map for GoCCs about LST

› Capacity
› Authorized Surrogate and Advance Directives
› Perception of illness / prognosis
› Target: patient’s VALUES and GOALS
› Unite VALUES and GOALS with treatments
› Recommendations
› Empathize and Explore challenges
› Summarize the plan

CAPTURES: Capacity

› Capacity = A clinical judgment about a patient’s ability to make a particular health care decision at a particular point in time.
› A patient is considered to have decision-making capacity when they can do ALL of the following:

1. Understand the nature, extent or probable consequences of health status and health care alternatives;

2. Make a rational evaluation of the burdens, risks, benefits and alternatives of accepting or rejecting health care; and

3. Communicate a decision.
If the patient lacks decision-making capacity and a goals of care conversation is warranted, conduct the discussion with the patient’s authorized surrogate.

Capacity to make decisions about goals and life-sustaining treatments can be assessed throughout the goals of care conversation.

**CAPTURES: Authorized Surrogate, Advance Directives**

- Begin the conversation
- Give an overview of what you will discuss
- Ask for permission to proceed

*It’s important for me to understand what matters most to you as we look ahead and make plans for your care. This helps me make sure you get the care that helps you reach your goals.*

*Can we spend a little time talking about this?*
Verify who the patient wants to make decisions on their behalf if they lose decision-making capacity.

It’s helpful for me to know who you would like to make decisions for you if you were ever unable to make decisions for yourself. Have you thought about who you would like this to be?

Have you completed an advance directive to name this person as your decision maker?

Without an advance directive naming a health care agent, the patient’s authorized surrogate is the person at the top of the Utah surrogate hierarchy:

The Utah Surrogate Hierarchy:

1. A health care agent appointed by the adult.
2. Legal or special guardian appointed by a court of law.
3. Next of kin, 18+ years of age, in the following order of priority: spouse, child(ren), parent(s), sibling(s), grandchild(ren), grandparent(s).
4. An adult who has exhibited special care and concern for the patient and knows the patient and the patient’s personal values.
Since you haven’t completed an advance directive naming a health care agent, in certain circumstances, your health care team may need to turn to your [next of kin] to make health care decisions for you.

If you don’t want your [next of kin] to make health care decisions for you, you can name someone else in an advance directive. Would you like [our social worker] to help you with that?

NOTE: If the patient has Utah POLST orders, and has not given their surrogate leeway to make decisions – the surrogates should not be asked to make decisions.
Patients cannot make informed decisions about goals and treatments when they don’t know what to expect with their illness.

If the patient is not aware of their prognosis, discuss prognosis with them and allow them time to adjust to the news before proceeding with decisions, especially about life-sustaining treatment.

Goals of care should not be discussed at the same time as really serious news.

- What have other doctors have told you about your [name medical condition]?
- Tell me what you think the future might look like with your [medical condition].
If the patient has a different perception of their illness or prognosis then the medical team, spend time **reframing** prognosis.

The message:

You have an illness that could get worse in the coming days, weeks, or months - we need to think about the future.

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**Given where you are in your illness, it seems like a good time to talk about where to go from here.**

**We’re in a different place than we were [X] months ago.**
Most patients will have an emotional response to hearing the reframe. This is normal.

The emotional response may sound like a factual question:

- “Isn’t there something else you can do?”
- “Are you sure we’ve looked into everything?”

Respond to these questions with empathic statements.

Ask permission before moving on.

- I can see that you are really concerned.
- I get a sense that this is not what you were expecting to hear today.
- Is it OK for us to talk about what this means?
<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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<tr>
<td>8/25/2016</td>
<td>15</td>
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Reframe & Respond to Emotion

Tell me what you understand about your lung disease.

I’m not getting better with this treatment, but there’s got to be something else out there.

I wish we had more effective treatments.

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Reframe & Respond to Emotion

What is your sense about where things are?

I know I have COPD and my breathing has gotten worse over the last several weeks. But I’ve had this for quite a while, and it will probably get better...
<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>You’ve been living with this disease a long time, and I think we’re in a different place now.</td>
<td>So, what are you saying – that I’m supposed to give up?</td>
</tr>
<tr>
<td>I can’t imagine what it’s like to live with an illness that keeps getting worse.</td>
<td>I’m a fighter. I know I can still beat this thing.</td>
</tr>
</tbody>
</table>
Reframe and Respond to Emotion

Clinician

You are a fighter. I really admire your spirit and everything you’ve done to fight this illness. This must be tough.

Patient

I’ve just kept hoping that I would get better.

I can see how disappointing this is. Would it be all right if we talked about where we go from here?

I think that would be OK.

CAPTURES: Target ➔ Patient’s Goals

› You must know the patient’s goals and values before creating a plan with them. The only way to know is by asking.

› If asked correctly, the question makes sense and isn’t scary.

› The patient’s values and priorities will help determine which treatment plan is right for the patient.
Patient’s Goal = The Destination

Treatments = The Route

CAPTURES: Target => Patient’s Goals

• Given this situation, what matters the most to you?

• If it turns out that time is limited, what things would you want to do?

• As you think about the future, what are you worried about?
### Elicit and Explore Patient’s Goals

#### Example One

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Clinician Icon]</td>
<td>![Patient Icon]</td>
</tr>
<tr>
<td>Given this situation, what’s most important?</td>
<td>It’s important to me that I don’t give up – I don’t want to look back and regret that I didn’t give it everything I had.</td>
</tr>
<tr>
<td>I see that in you and admire your fight. Tell me what you mean when you say you don’t want to give up.</td>
<td></td>
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</tbody>
</table>

#### Example Two

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Clinician Icon]</td>
<td>![Patient Icon]</td>
</tr>
<tr>
<td>Given this situation, what’s most important?</td>
<td>I’m not sure what to tell you.</td>
</tr>
<tr>
<td>What if you start with the things in your life that matter to you?</td>
<td></td>
</tr>
</tbody>
</table>
### Elicit and Explore Patient’s Goals

**Example Three**

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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</thead>
<tbody>
<tr>
<td><img src="image" alt="Clinician Icon" /></td>
<td><img src="image" alt="Patient Icon" /></td>
</tr>
</tbody>
</table>

Given this situation, what’s most important?

This is a tough situation for anyone. What worries you most about talking about this?

I don’t feel ready to talk about this. It’s hard...

### Elicit and Explore Patient’s Goals

**Example Four**

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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</thead>
<tbody>
<tr>
<td><img src="image" alt="Clinician Icon" /></td>
<td><img src="image" alt="Patient Icon" /></td>
</tr>
</tbody>
</table>

As you think about the future, is there anything you worry about?

That helps me better understand what you’re thinking.

I worry that I’ll be too sick to take care of myself or stay at home. I don’t want to be stuck on machines in the hospital. I want to be at home with my family.
CAPTURES: Unite goals with treatment options

› Unite the patient’s goals/preferences with a treatment options that support their goals and are relevant to their medical condition.

› Don’t talk *only* about CPR.

› You may not want to *start* with CPR – discuss other LSTs first.

When uniting goals with life-sustaining treatment options...

› If the patient does not have a basic understanding of the LST, provide information to fill in the gaps.

› Be clear and direct.

› Avoid medical jargon.

› Give 1-2 pieces of information at a time, then stop and wait for the patient to respond.
CAPTURES: Recommendations

› Ask permission to make a recommendation – some patients want a recommendation and some don’t.
  • Recommend treatments that may help meet the goals
    – focus on what can be achieved
    – focus on what might be possible
    – discuss what you will not do because it will not meet the goal

CAPTURES: Recommendations

› When making a recommendation, repeat the patient’s goals using their own words, this conveys understanding.

› After making recommendation, ask if it makes sense, this ensures you have it right.
CAPTURES: Recommendations

› For medical trainees and some health care professionals, it may not be possible to immediately formulate a recommendation

› In these situations, map out goals

› Inform your team of the patient’s goal

› Return later with the recommendation from your team:

The information you shared with me about what matters most to you is very helpful. I’ll share this with [our team/your doctors/etc.] and [I/we] will meet with you [X timeframe] to talk about a plan.

CPR Example: Unite Goals with Treatment and Make Recommendation

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want to be sure you get the care that helps achieve your goals. It’s helpful to know in advance whether you would or wouldn’t want certain procedures. One of these procedures is CPR. Has anyone talked to you about CPR or have you seen it on TV?</td>
<td>No one has really talked about CPR with me. I’ve seen it on TV but I don’t know that much about it.</td>
</tr>
</tbody>
</table>
CPR is used only when someone’s heart and breathing have stopped. Sometimes the heart and breathing stop as a natural part of the dying process. Other times it happens unexpectedly.

Basic CPR involves forcefully pushing on the chest, and blowing air into the lungs to try to restart the heart and breathing. Advanced life support can include shocking the heart and putting a tube down the throat.

Would you like me to make a recommendation about CPR based on what you shared matters most to you and what I know about your health, or would you prefer to let me know your thoughts? A recommendation would be fine.
CPR Example: Unite Goals with Treatment and Make Recommendation

Clinician

Based on your goals to stay at home with your family, be able to take care of yourself, and not be stuck on machines, I would not recommend CPR. Does that sound right to you?

Patient

That sounds right.

CAPTURES: Empathize and Explore Challenges

› Remember these conversations can be emotional
› Clinicians must attend to emotion BEFORE moving on to anything else
› Emotional responses often sound like a factual question
› Do not respond to feelings with facts – respond with empathy
   – “NURSE” Statements
   – “I Wish” Statements
CAPTURES: Empathize and Explore Challenges

If a decision about LST appears inconsistent with the patient’s goals or the patient is hesitant to make decisions, explore the reasons why:

- Emotional response
- Lack of understanding of trade-offs or outcomes
- Other factors

Find out what will help the patient make a decision:

- Empathic responses and time
- Expected rates of survival or potential risks
- Information related to spiritual concerns

Tell me more about what you are hoping for with [intervention X].

Is there a situation you could imagine when you [would /would not] want [intervention X]?

Some people find it helpful to know how many people survive after receiving CPR, or what the risks might be. What information would be helpful to you as we talk about CPR?
CAPTURES: Explore
CPR Expected Rates of Survival and Potential Risks

- On average 17 out of 100 adults survive inpatient CPR to hospital discharge.
- Survival is lower for arrests in the outpatient setting.
- Factors associated with failure to survive CPR to hospital discharge:
  - Serum Creatinine >1.5 mg/dl
  - Metastatic Cancer
  - Dementia
  - Dependent Status
  - Sepsis the day prior to the CPR event
- Also see [http://www.gofarcalc.com](http://www.gofarcalc.com)

CAPTURES: Explore if additional information would be helpful

<table>
<thead>
<tr>
<th>Discharge Location</th>
<th>All who underwent CPR (n=42,566)</th>
<th>All who survived CPR (n=6972)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Died</td>
<td>84%</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Discharged Home</td>
<td>6.2%</td>
<td>40%</td>
</tr>
<tr>
<td>Discharged Inpatient Facility</td>
<td>9%</td>
<td>55.2%</td>
</tr>
<tr>
<td>Discharged Hospice</td>
<td>0.8%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Cognitive Status after CPR*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Died</td>
<td>84%</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Mild or No Neuro Disability</td>
<td>7.9%</td>
<td>48%</td>
</tr>
<tr>
<td>Moderate or Severe Neuro Disability</td>
<td>8.1%</td>
<td>52%</td>
</tr>
</tbody>
</table>

*Patients with good cognitive functioning prior to arrest had a lower risk of post-CPR cognitive disability (86% with good cognitive functioning on admission who survived CPR had good cognitive functioning upon discharge).
Explore When Choices Conflict with Goals
Example One

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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<tbody>
<tr>
<td>📧</td>
<td>📧</td>
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</tbody>
</table>

Would you like me to make a recommendation about CPR based on what you shared matters most to you and what I know about your health, or would you prefer to let me know your thoughts?

A recommendation would be fine.

Based on your goals to stay at home with your family, be able to take care of yourself, and not be stuck on machines, I would not recommend CPR. Does that sound right to you?

I think I would still want CPR.
### Explore When Choices Conflict with Goals
**Example One**

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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<tbody>
<tr>
<td>![Clinician Icon]</td>
<td>![Patient Icon]</td>
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</tbody>
</table>

**Clinician**

Tell me more about what you are hoping for with CPR.

**Patient**

I am not sure.

---

Some people find it helpful to know how many people with similar health problems survive after receiving CPR, or what the risks might be. What information would be helpful to you?

**Patient**

I guess I worry that saying no to CPR would be against my faith.
Explore When Choices Conflict with Goals

Example One

Clinician: It sounds like you might want to talk to someone who could help figure that out. Our chaplain would be able to provide some helpful information. Would you like to speak with him?

Patient: That would be helpful.

Explore When Choices Conflict with Goals

Example Two

Clinician: Tell me more about what you are hoping for with CPR.

Patient: CPR will bring me back, so why wouldn’t I want it?
Explore When Choices Conflict with Goals
Example Two

Clinician | Patient
---|---

Some people find it helpful to know how many people with similar health problems survive after receiving CPR, or what the risks might be. Would this information be helpful to you?

I thought it worked for just about everybody.

Explore When Choices Conflict with Goals
Example Two

Clinician | Patient
---|---

For people with health problems like yours, about X out of 100 people survive when they receive CPR in the hospital. That means that Y out of 100 people die. Survival is lower for CPR outside of the hospital.

That’s a lot less than I expected!

It surprises a lot of people.
### Example Two

#### Explore When Choices Conflict with Goals

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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<tbody>
<tr>
<td><img src="image1.png" alt="Clinician Icon" /></td>
<td><img src="image2.png" alt="Patient Icon" /></td>
</tr>
</tbody>
</table>

**What is your understanding of some of the problems that can occur after CPR?**

I’ve heard that CPR can break ribs.

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**Yes that’s right. There are also risks of permanent brain damage and disability after CPR. Although a person’s heart might restart, they may not be able to make decisions for themselves, recognize family, or return home. For people like you whose memory and thinking are sharp, these risks are low.**

I guess even if there’s just a small chance that CPR could help me live longer, I’d want to give it a shot.
### Explore When Choices Conflict with Goals

**Example Two**

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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<tbody>
<tr>
<td><img src="image" alt="Clinician" /></td>
<td><img src="image" alt="Patient" /></td>
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</table>

**Clinician:** Ok. Can you think of a situation when you wouldn’t want CPR?

**Patient:** If I couldn’t recognize my family or make decisions for myself, in that situation I wouldn’t want CPR.

**Clinician:** That’s very helpful to know. Let’s make sure [name of surrogate] knows what you want.

### Explore hesitations to discuss LSTs and make decisions [Not Urgent]

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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<tbody>
<tr>
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<td><img src="image" alt="Patient" /></td>
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</tbody>
</table>

**Clinician:** Can you tell me what worries you about talking about CPR?

**Patient:** I would just like some more time to think about it. I’d like to talk with my family before making any decisions.
### Explore hesitations to discuss LSTs and make decisions [Not Urgent]

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
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<tbody>
<tr>
<td>![Doctor Icon]</td>
<td>![Patient Icon]</td>
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</table>

This topic deserves time and attention. We don’t need to make decisions today.

Let’s set up a time to talk again when you are ready. In the meantime here is some material that you may like to review.

That sounds good. Thank you.

### Explore hesitations to discuss LSTs and make decisions [URGENT]

<table>
<thead>
<tr>
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<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Doctor Icon]</td>
<td>![Patient Icon]</td>
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</tbody>
</table>

Can you tell me what worries you about talking about CPR?

I’m just afraid to talk about this. I really prefer not to think about it at all.
Explore hesitations to discuss LSTs and make decisions [URGENT]

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Clinician Icon]</td>
<td>![Patient Icon]</td>
</tr>
</tbody>
</table>

It is hard to talk about this and it’s also very important so we understand your wishes. If you don’t want to talk about it, can I speak with [authorized surrogate] to help make decisions for you now since we need to make decisions right away?

Yes that would be fine.

CAPTURES: Summarize the plan

- To ensure shared understanding, summarize the plan and ask the patient to confirm.
- Repeat what the patient has just told you; communicates you have listened.
- Identify next steps.
**CAPTURES: Summarize the plan**

- **So it sounds like you [would/would not] want [X, Y, Z] [under A, B, C circumstances]. Do I have that right?**

- **I will put an order in your health record to make sure that staff knows what you want.**

- **Thank you for taking the time to have this important conversation with me.**

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**CAPTURES: A Talking Map for GoCCs about LST**

- **Capacity**
- **Authorized Surrogate and Advance Directives**
- **Perception of illness / prognosis**
- **Target: patient’s VALUES and GOALS**
- **Unite VALUES and GOALS with treatments**
- **Recommendations**
- **Empathize and Explore challenges**
- **Summarize the plan**
What surprised you?
Anywhere you might get stuck?
What do you want to take forward
(and try this week)?