

**WELCOME! Please use the chat box to announce yourself  
by typing in first your state and then your – this will help  
speed things up in assigning breakout rooms!  
Thank you!**



**COLIN to Advance Care for  
Children with Medical Complexity  
State Team Webinar #3  
July 12, 2018  
Family Engagement**



# Housekeeping

- This webinar is being recorded
- CMC CoIIN public-facing website LAUNCHED!
  - <http://cahpp.org/project/CoIIN-CMC>
  - Thanks for reviewing state team info
- Shared workspace set up within the next month
- BU IRB application is in process
- Any other questions? – type into chat box anytime

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number #UJ6MC31113: *Health Care Delivery System Innovations for Children with Medical Complexity* (\$2,700,000 annually). This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsement be inferred, by HRSA, HHS or the U.S. government. Anna Maria Padlan, HRSA/MCHB Project Officer

# State Team Updates

What's been your biggest success since the May webinar?



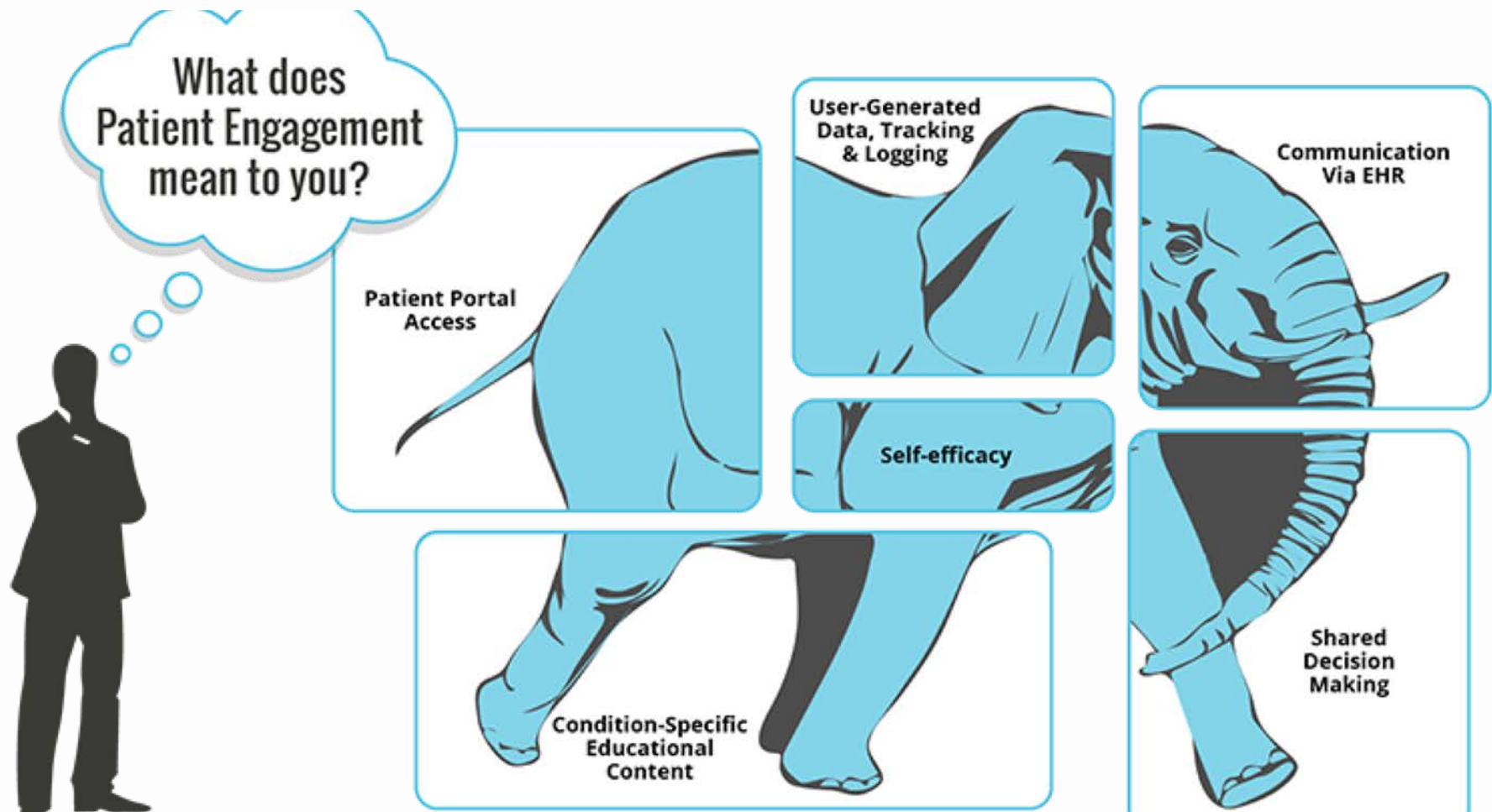
# Cowboys, CMC CollN & Herding Cats??

- <https://www.youtube.com/watch?v=Pk7yqlTMvp8>

## Webinar Objectives/Outline:

- Share/ highlight ongoing Family Engagement (FE)
- Step back: shared understanding of FE
- Aha Moments of FE
- Questions- Operationalizing FE

# Let's get on the same page- what is family engagement?



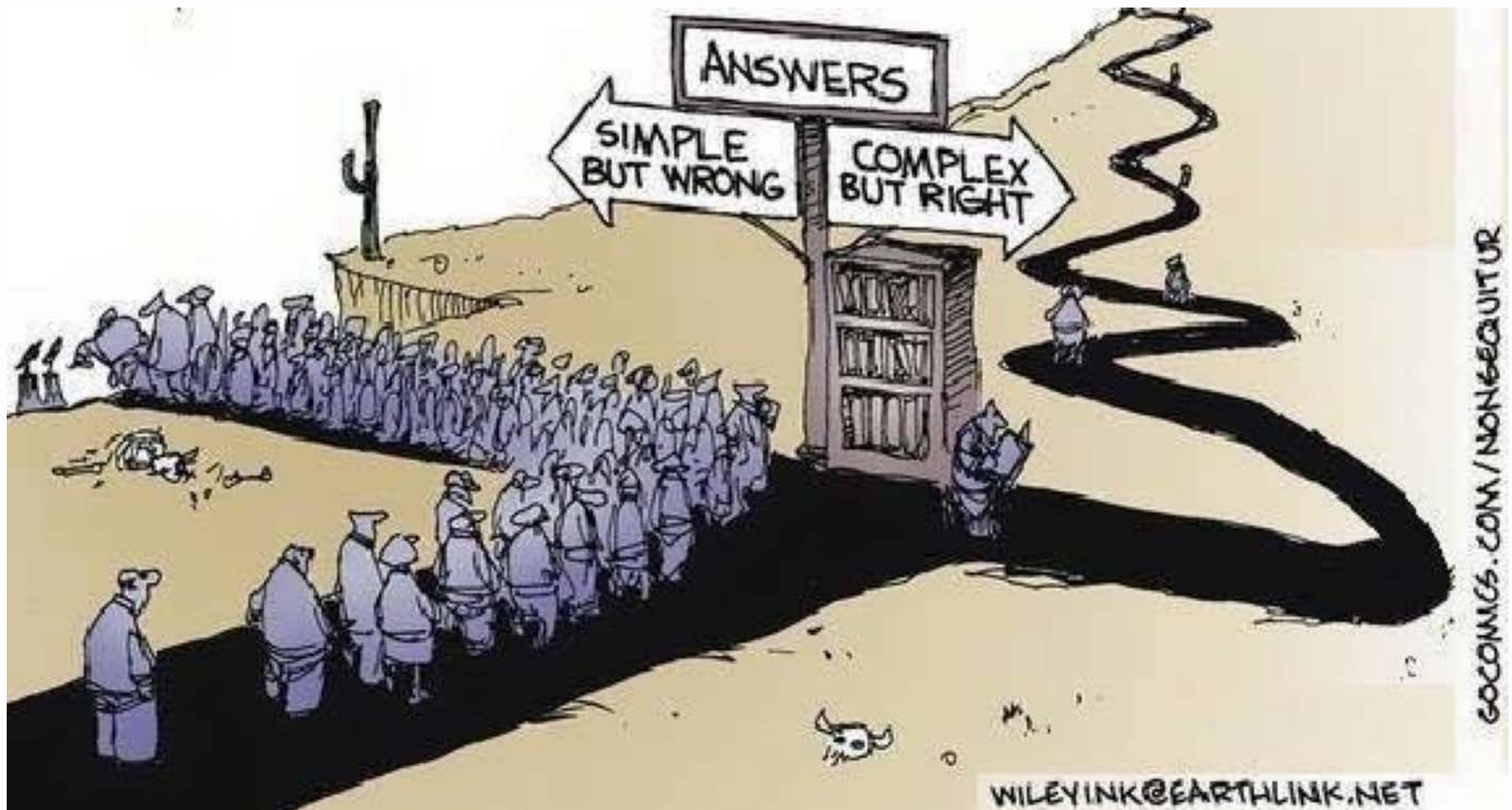
# We're Engaged!!



# Family Engagement (formally) defined

*“An authentic partnership between professionals and family leaders who reflect the diversity of the communities they represent, working together at the systems level to develop better policies and practices.”*

# Story of healthcare system for CMC..



# Domains to guide FE in systems

- Representation
  - Diversity of community
  - Family led orgs and CBOs
- Transparency
  - Access
  - Partnership in all stages
- Impact
  - Change? In general and with families
- Commitment
  - Core values

# *AHA Moments*

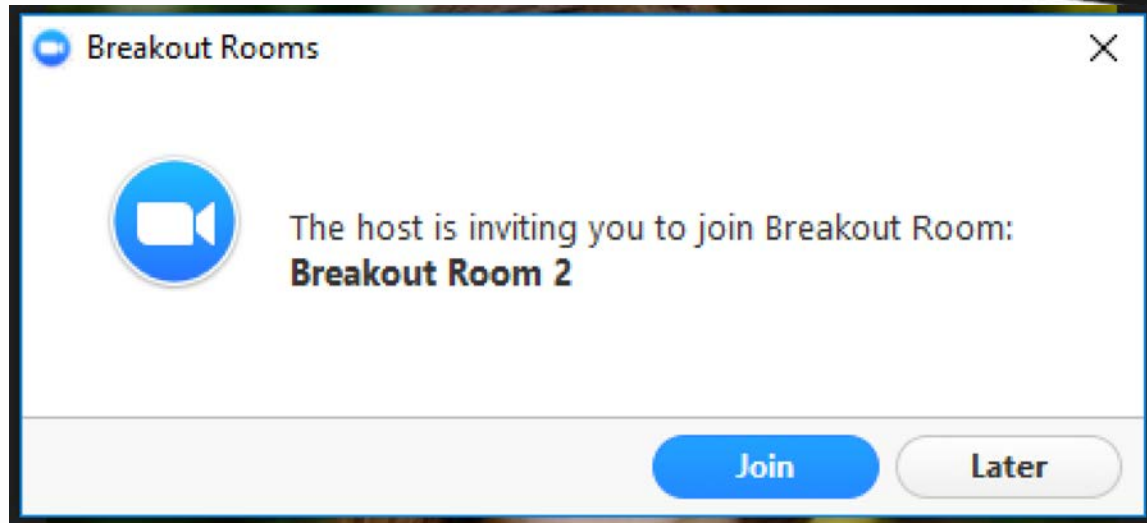


- <https://www.youtube.com/watch?v=rw9c8CSnDaU>

# State Team Breakouts

- Share your *aha moments* with each other
- Nominate one person to share their aha moment with the larger group (as time allows)

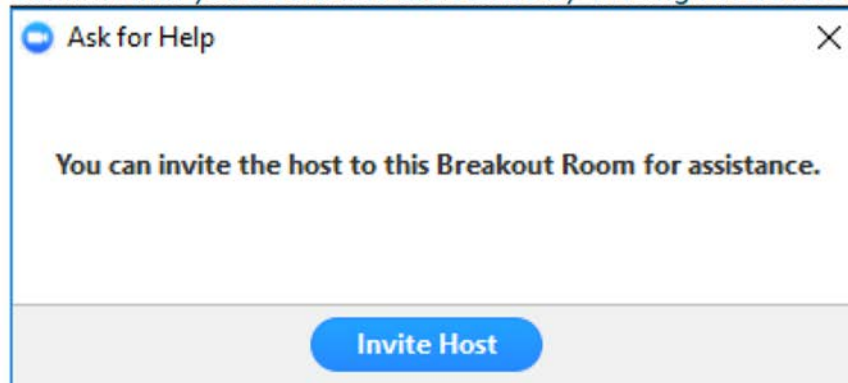
# Breakout – How-to Instructions



Click **Ask for Help** in the meeting controls.



Confirm that you would like assistance by clicking **Invite Host**.



## ALLOWED IN



## BUY-IN



Tell me and I forget. Teach me  
and I remember. Involve me  
and I learn.

- Benjamin Franklin



# How do we “operationalize” family engagement?



# Resources on Family Engagement

[https://drive.google.com/open?id=1YyCYyPBp\\_ZujmVTL1ygrzr-z7f2lnkg4](https://drive.google.com/open?id=1YyCYyPBp_ZujmVTL1ygrzr-z7f2lnkg4)



## Families of Children With Medical Complexity: A View From the Front Lines

This article, written for a group of experienced parents of children with medical complexity (CMC), provides an overview of the demands of managing care from the front lines. It explores the challenges that these parents face, including the need to coordinate care across multiple providers, the need to advocate for their child's needs, and the need to manage the emotional and financial burden of caring for a child with CMC. The article also discusses the importance of family engagement in the care of children with CMC and provides strategies for how families can effectively engage with their child's care team.



## PREPARING FOR PATIENT AND FAMILY ADVISOR PARTICIPATION ON QUALITY IMPROVEMENT AND SAFETY INITIATIVES

There are many benefits to involving patient and family advisor on quality improvement and safety initiatives, including increased transparency, improved patient and family engagement, and improved patient and family satisfaction. However, there are also challenges to involving patient and family advisors, including the need to ensure that the process is transparent and that the advisors are properly trained and supported. This document provides a guide to preparing for patient and family advisor participation on quality improvement and safety initiatives.

Notes	
<b>Making Key Decisions about Advisor Participation</b>	
The committee sponsor and/or the family/QI champion of the project/committee have identified the experience and value of advisor participation.	
The committee sponsor is prepared to communicate that support in words and actions with other members, staff, and clinicians for the involvement of advisors on the project team/committee.	
The role of patient and family advisor has been defined for this particular project team/committee. Consider the following options: Full team member, Not a team member, Committee/Reviewers, or Guest Speaker?	
Resources	
The number of advisors needed for this project team/committee has been determined. Remaining two or more advisors to be added.	
The special skills and experience needed for advisors to effectively participate have been identified (e.g., patients with experience in a topic relevant to the initiative, or program).	
The time commitment and length of participation anticipated for advisors to serve on the project team/committee have been determined.	
The meetings have been scheduled at times that make advisor participation possible.	
The role of existing project team/committee members cannot be changed, flexibility was for advisors to be meaningful participants have been identified and adopted (e.g., participation by conference call, Skype, etc.).	



## TIPS FOR GROUP LEADERS AND FACILITATORS ON INVOLVING PATIENTS AND FAMILIES ON COMMITTEES AND TASK FORCES

### Selecting Patients and Families to Serve as Advisors

- Look for people who are:
  - involved in the topic being addressed by the committee or task force;
  - comfortable in speaking to a group with confidence;
  - able to use their personal experience constructively and
  - able to listen and hear differing opinions.
- Having just one patient or family member on a committee is not usually successful. Some for patients and family members to be one-third to one-half of the committee's membership.
- Remember that serving as a patient or family advisor is a new role for many people. Some patients and family members will need more support than others. Recognize the individuals can grow and develop in this role.

### Preparation for Meetings

- Consider the committee and schedules of patients and families as well as in planning the time and location for meetings.
- Send agendas and minutes ahead of time to all committee members, encouraging to allow time for material to reach patients and families they may not have (fax machines, email, etc.).
- Provide a list of committee members with a brief description of each person.
- Offer a support, experienced patient or family advisor or another committee member to support a new advisor.
- Offer to have someone come to the first meeting with a new member and debrief afterwards.
- Remember that this type of collaboration is new for many people in preparation and orientation is important for staff, as well as patients and family members.

## Enhancing Family Engagement through Quality Improvement

### Lessons Learned from the Family Engagement Quality Improvement Project

Family engagement is an innovative approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.

Family engagement and family involvement can improve patient and family outcomes, increase family and clinician satisfaction, decrease health care costs, and increase efficiency of health care delivery.

The National Family Engagement Quality Improvement Project developed strategies to the following:

• Increase family engagement in patient and family care

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## FAMILY VOICES

### Communicating the Tools of the Change Package with Families

Developing partnerships with families requires unique communication skills that demonstrates the importance of the team working together and recognizes that everyone on the team brings expertise and experience that is unique, but has equal value.

Quality improvement teams have the opportunity to learn from families about what is and is not working and then use the quality improvement framework to make improvements. The quality improvement team may want to think about their questions:

- How are staff/providers partnering with families in developing the change package tools for the individual child?
- How are staff/providers helping families understand the QI and RMC to use these tools?
- What small tools of change can the QI team use to improve how staff/providers are improving these processes and how they are communicating with families?

These teams get at the heart of the existing principles of the change package. When the clinic staff and providers are really partnering with families to develop the tools individually for their child, the family will become invested in the quality and outcomes of the tool, and as part of the process. If staff/providers are talking about and give examples of how families can use the tool, and using basic teach-back communication skills the family will learn how to use the tool.

For example some ideas for staff working with families:

- As the provider and family are creating the care plan – the discussion about the child's conditions helps the family understand the child's conditions and are able to discuss things such as:
  - How the conditions are impacting the child.
  - How are the medications working or not working.
  - What are upcoming specialty visits.
  - Are upcoming procedures.
  - How are things going at school.
  - Are there medical supports at school and at home.
- As they are creating the Diabetes Care Team – they are discussing:
  - What is the value of having an identified DCM, how have other families used this idea.
  - What are the most important specialists in the family and child?
  - Are there community people who should be on the team? (It would be like to know if any parents have community members on the DCM team at home care nursing agency, home care nurse, PCA, grandchild/grandson, etc.)
- As they are creating the Access Plan – they are discussing:
  - What are some of the anticipated complications that might be expected and what should the parent do if complications develop, who to call, when to call.
  - What are some complications that have occurred in the past, what did we learn from those complications, how should they be handled in the future by staff.
  - Are there concerns the family/parent has about their child's health status how should these concerns be handled in the future by staff.
  - Are there equipment issues that could be addressed to have adequate back up on needed.

When the team is having these types of discussions with the family they are doing a number of things:

- They are really recognizing the families experience and concerns and are therefore learning from the family more about the child.
- They are giving the family the opportunity to learn why and how to use their tools.
- Usually this should be done at a specific call dedicated to this work.

# Next Steps

- Continue this fundamental work as a team
  - Coaching calls for guidance/support/TA
  - Ask BU anytime re: expert TA on family engagement
  - State cross-sharing support through coaches

# Next Steps (cont'd)

- Upcoming Dates of Note
  - Fri, July 27: Next team update form due
  - Sept 17, 12p-1:30p EST: Webinar #4 (Topic TBD)
  - M/T Oct 29/30, 8:30a-4:30p: In-person state team meeting @ Chicago
    - State team input request, including top 3 team-specific objectives out of the meeting
    - Poll – Sunday evening start?
  - Nov 29, 1:30p-3p EST: State team webinar #5

# Lucille Packard Foundation webinar

## JOIN US

**A Conversation on Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?**

Date and time: July 26, 2018 10-11 am PST

Care coordination is an important approach to addressing the fragmented care that children with medical complexity often encounter. What are optimal care coordination services? How does care coordination intersect with care integration and case management? Learn best practices and how to implement a process that will achieve improved outcomes and value for children with special health care needs and their families.

Join us for a lively discussion on the article, [Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?](#) The lead author and experts in the field will review the article's key content and discuss why care coordination is vital to improving the system of care. We suggest attendees read the article prior to the event. Audience Q&A is highly encouraged. Attendees can listen via web or phone. [Read more.](#)

**REGISTER**

<https://register.gotowebinar.com/register/6314492371449423875>

# REMINDER: CSHCN Challenge

## HRSA MCHB Care Coordination for Children with Special Health Care Needs (CSHCN) Challenge

- The Care Coordination for CSHCN Challenge will award \$375,000 in prizes to support the creation of tech innovations to help families and case managers with the care and coordination of children with special health care needs.
- This Challenge will support the development and testing of low-cost, scalable tech innovations to meet the information needs of families of CSHCN, particularly those with complex medical conditions, and case managers. These innovations should improve the quality of care and enhance patient and family engagement and health care quality while saving costs to families and the health care system.
- Launch date August, 2018. Click here to learn more:  
<https://mchbgrandchallenges.hrsa.gov/challenges/care-coordination-children-complex-needs>

# And one last thing ...

WEBINAR EVALUATION:

<https://www.surveymonkey.com/r/BCS6F97>



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