

# PATIENT AS CO-CREATOR

## IPE Curriculum Toolkit

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A guide for interprofessional health sciences curriculum teams to include patients and caregivers as team members in the education and practice environments.



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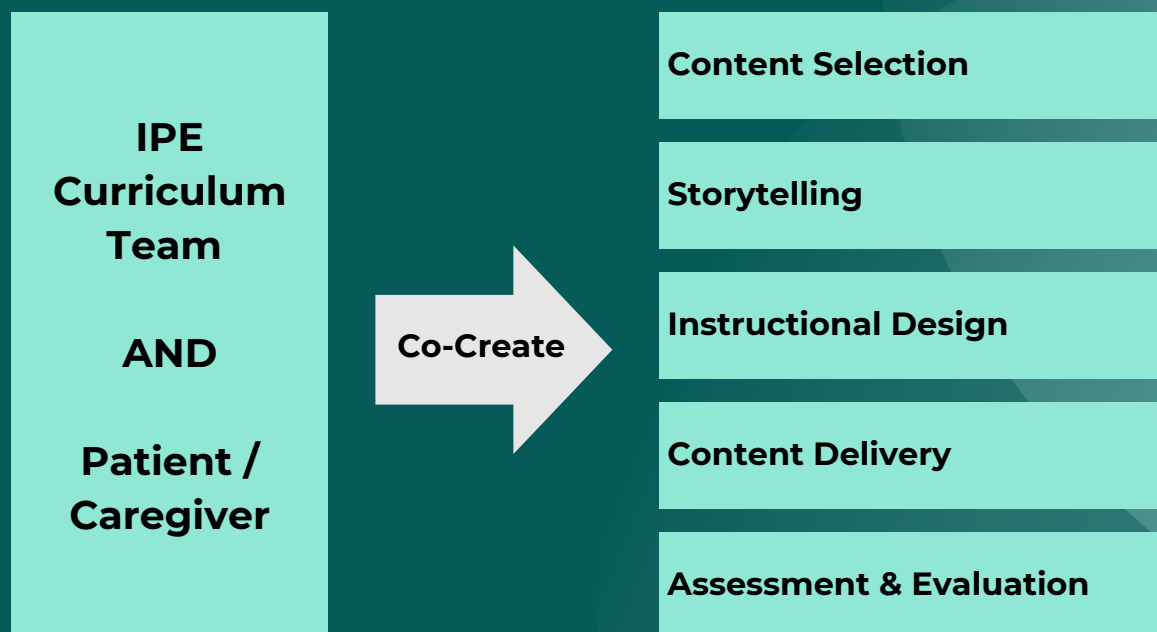
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# Introduction

“Nothing for me, without me.”

Borrowed from the disabilities-advocacy community, this slogan is the basis for embracing patients, caregivers, and their advocates as members of health teams. However, we understand there are many logistical concerns and training requirements to making this slogan a reality. This toolkit is a coordinated effort to survey national best practices for inclusive teamwork and educational experiences. Share your feedback and help us improve the next edition.



[ouhsc-ipe@ouhsc.edu](mailto:ouhsc-ipe@ouhsc.edu)

# Patient NOTES

**What I need educators to know  
about us, as patients**

**“Hearing my story,  
and including me in the team,  
are not the same thing.”**

**“I know my body better than you.”**

**“Patient-centered care is not the  
same as including me on the team.”**

**“I will teach you, if you will listen.”**

**“Please talk to each other.”**

**“Just because I’m different doesn’t  
mean I’m not intelligent.”**



# Introducing Our Co-Creator Team

Our team brings over 100 years of combined expertise in client-centered services.



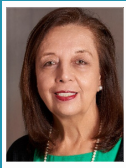
**Valerie N. Williams, PhD, MPA**

University of Oklahoma Health Sciences  
Vice Provost for Academic Affairs & Faculty Development  
Valerie-Williams@ouhsc.edu



**Pamela Allen, MD**

University of Oklahoma College of Medicine  
Carl J. Herzog Chair in Dermatology  
Pamela-Allen@ouhsc.edu



**Italia Folleco, MA**

Joe DiMaggio Children's Hospital  
Chair, Patient/Family Advisory Council  
Italiafolleco@att.net



**Wanda Felty**

University of Oklahoma Health Sciences  
Assistant Director, Community Leadership & Advocacy Coordinator,  
Oklahoma LEND Core Faculty, Parent/Family, Wanda-Felty@ouhsc.edu



**Katy Fisher-Cunningham, PhD, RN, CNE, CHSE**

University of Oklahoma Health Sciences  
Assistant Professor, Fran and Earl Ziegler College of Nursing  
Katy-FisherCunningham@ouhsc.edu



**Robert Salinas, MD, CAQ(G)**

University of Oklahoma College of Medicine  
Assistant Dean, Office of Access and Community Engagement  
Robert-Salinas@ouhsc.edu



**Margaret Robinson, M.Ed.**

University of Oklahoma Health Sciences  
Senior Associate Director, Office of Interdisciplinary Programs  
Margaret-Robinson@ouhsc.edu

# RATIONALE: Making the Case

## Benefits of Co-Creators

- Broaden the scope of educational content for learners.
- Provide depth of empathy in health sciences education.
- Connect the dots for learners between the human experience of health and the science of health care.

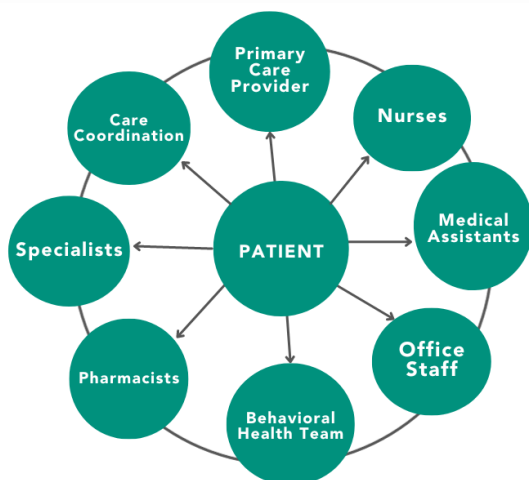
## Lessons Learned

Challenges include schedules and training of patients and caregivers as co-creators. Intentionality is key in ensuring successful outcomes of any partnership.

## Patients and Caregivers as Team Member

- Instead of the patient being the center, the patient/caregiver moves to equal partner with other health professionals.
- The health concern being addressed/taught becomes the focus.
- The patient is an expert with lived experience.

### Patient-Centered Care



Source: <https://www.southcoast.org/patient-centered-medical-home-pcmh/>

### Patient as Team Member



# IPEC Core Competencies

FIGURE 7. IPEC CORE COMPETENCIES FOR INTERPROFESSIONAL COLLABORATIVE PRACTICE: VERSION 3 (2023)



## ► Values and Ethics

Work with **team** members to maintain a climate of shared values, ethical conduct, and mutual respect.

## ► Roles and Responsibilities

Use the knowledge of one's own role and **team** members' expertise to address individual and population **health outcomes**.

## ► Communication

Communicate in a responsive, responsible, respectful, and compassionate manner with **team** members.

## ► Teams and Teamwork

Apply values and principles of the science of teamwork to adapt one's own role in a variety of **team** settings.

<https://www.ipeccollaborative.org/ipecc-core-competencies>

## Rationale in IPE Curriculum

### Values & Ethics

V&E Curriculum often requires intentionality and a focus on building trust: "Doing with each other, rather than to each other."

### Roles & Responsibilities

Patient / Caregiver as it's own profession emphasizes the patient/caregiver as the expert in their own health and health system experience.

### Teams/Teamwork

With patients/caregivers in curriculum teams, teamwork content can focus on commonly overlooked factors of resources, system structures, and accountability.

### Communication

With patients/caregivers as co-creators, IPE curriculum receives real-time feedback regarding clarity, cultural humility, listening skills, and power dynamics.

# Healthcare Improvement

## Rationale: Quintuple Aim

### Addressing Health Equity

The Social Determinants of Health affect up to 80% of a patient's health outcomes. Yet, we have only recently added health equity concerns to our framework to improve healthcare. Inclusion of the patient and caregiver in the health team provides an intentional platform for comprehensive wellness to be considered.



Image: <https://www.chesshealthsolutions.com/2023/08/01/the-quintuple-aim-what-is-it-and-why-does-it-matter/>

## Rationale in Healthcare Improvement

### Safety

Harm reduction and risk prevention is improved through mindful inclusion of patients / caregivers.

### Quality

System-wide approaches to quality improvement require inclusion of patients as team-member.

### Access

Identification of barriers to care or lack of trust are best found through input from intended patients.

For more information on the Institute for Healthcare Improvement (IHI), visit: <https://www.ihl.org/>

# Strategies

## Team Selection: Patients & Caregivers

STRATEGY	DO THIS	NOT THIS
Select patients/caregivers with availability	Consider their schedule. Put their wellness first.	Assume they are not available. Ask first, instead.
Select patients/caregivers with experience.	Understand patients are the top expert at knowing their experience.	Assume new onset equals inexperience, or vice versa.
Select patients/caregivers who are comfortable sharing.	Ask if they feel comfortable sharing their experience and let them express their limitations.	Assume everyone is comfortable sharing details about their life.
Select patient/caregivers who can be back-ups.	Select enough patients/caregivers to complete tasks in the event someone has to disengage.	Not plan to cross-train back-up members or alert back-up members of their role.
Select from advocates already involved in the community.	Partner with support groups or local advocacy groups to engage patients/caregivers already interested in leading change.	Recruit from patients with active medical emergencies / priorities.

# STRATEGIES: Start with Why

A common failure of including patients and caregivers is their invitation to join during the performing stage of team development. Instead, try these methods of starting with patients / caregivers at earlier stages.

**FORMING:**

Invite patients / caregivers as early as possible.

**STORMING:**

Purposefully create room for the voice of the patient / caregiver in team communication.

**NORMING:**

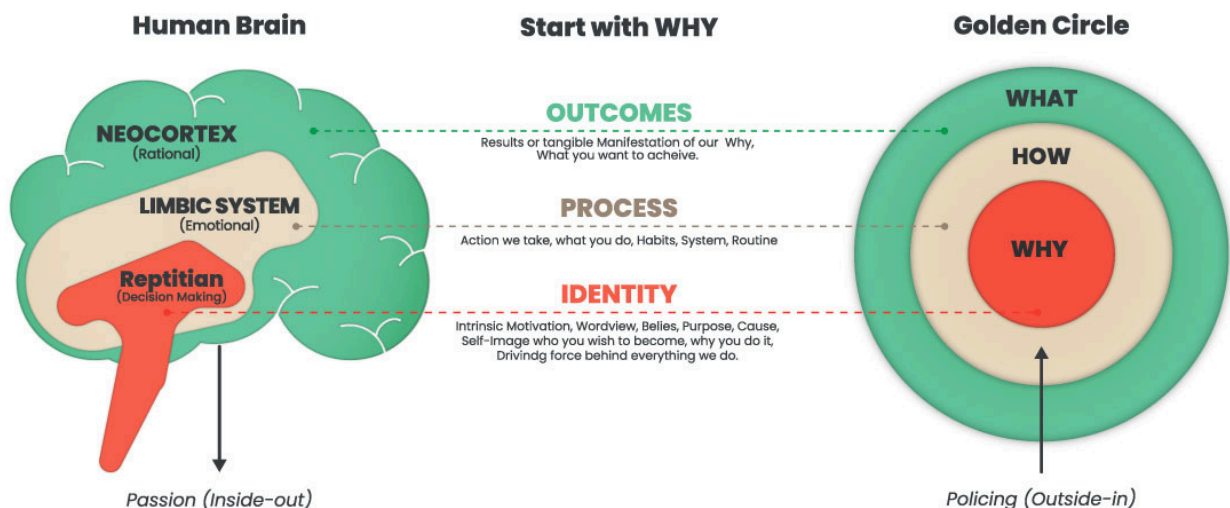
Patients / caregivers should have set roles and responsibilities known to the entire team.

## Lessons Learned

Intentionality is key. Schedule time early in the collaborative process to set shared goals, agree on processes, and ensure everyone knows the intended outcome and deliverables.

## THE GOLDEN CIRCLE AND THE BRAIN

Simon Sinek



Source: <https://www.gluedilimited.co.uk/brand-thinking/start-with-why/>



# Principles of Equal Partnerships

## A Patient Engagement Manifesto

6 Principles of Partnership

Marie Ennis-O'Connor

1. Engage Us in Ways That Are Personally Meaningful
2. Engage Us Where We Are – Not Where You Wish We Were
3. Engage Us Early in the Design Process
4. Engage Us in Progress Reports
5. Engage Us as Equal Partners
6. Engage Us Beyond Our Stories

<https://powerfulpatients.org/2018/09/19/a-patient-engagement-manifesto-6-principles-of-partnership/>

PATIENT PARTNER...



Chudyk, A.M., Stoddard, R., McCleary, N. et al. Exploring patient and caregiver perceptions of the meaning of the patient partner role: a qualitative study. *Res Involv Engagem* 9, 106 (2023). <https://doi.org/10.1186/s40900-023-00511-9>

# Support Programs

## Communication: Curriculum / Planning Teams

### Cultural Humility

- Use plain language whenever possible
- Use person-first language
- Hold each other accountable to ensuring psychological safety
- Active listening is necessary for all encounters
- Only ask questions that have actionable responses

### Story Bias

- One patient does not represent every patient
- Their story is not wrong - or right
- It is not the patient/caregiver's job to educate everyone
- Utilize patient/caregivers as equal content creator, not as sole subject matter expert

### Intersectionality of Representation:

- Patients and Caregivers are so much more than their disease or health concern
- While their team profession may be “patient,” their profession is not only “patient”
- Include the patient/caregiver in all aspects of the curriculum or planning team, not only delivery
- Maintain respect for lived experience and background

### Psychological Safety

- Intentionally schedule time to build rapport, relationships
- Listen to understand, not to respond
- Set ground rules and expectations
- Say what you mean and mean what you say
- Consider trauma informed care
- Embrace transparency

# Roles: Support Strategies

## Advisory Committee

- Give clear instruction
- Engage on a regular basis
- Ensure mechanisms are in place to utilize their advice

## Content Reviewer

- Give clear instruction
- Double-check content and get rid of “higher ed” words before sharing with co-creators. Accessibility checkers in MS Word can help identify words at various grade levels.
- Leave enough time to get input and use the feedback received

## Co-Educator

- They may want to choose how a lived experience is unfolded [revealed] for a learner audience
- Requires preparation as educator, not only story-teller
- Prepare learners to engage with patients
- Explain organizational structure and scope of the project
- Context of Social/Structural Determinants of Health

## Subject Matter Expert

- About their own experiences. family
- About their experience in the health system
- Have technical (learned experience), or poignant (lived experience) tips, tactics, or strategies to offer that may inform students in ways that prevent a misstep during a real patient encounter

## Guest Speaker or Panel Speaker

- A teaching guest may not want to re-live a traumatic experience on the fly
- Need to include the evidence/science to balance the patient’s lived experience
- Prepare questions in advance

## Food for Thought...

### Clinical Education

When doing a plan of care, is the actual patient at the table? And if so, under what conditions?

- Ambulatory or outpatient care/minor but more than 1-1 with a single clinician;
- Ambulatory or outpatient/major with multidisciplinary consultation that’s not quite interdisciplinary?
- Inpatient?
- Habilitative or Rehabilitative?
- Any situation with Social Determinants of Health (SDOH) concerns re support to follow through with plan of care? (such as people living unhoused; and people living in hard to reach areas (rural; frontier; ‘closed’ or difficult for non-members to access communities)

When is having patient participation most helpful/most necessary?

When does patient participation add stress to the patient’s treatment or recovery process?

# Preparing the Co-Educator

## PRE-BRIEF

1. Update the patient on the evidence base and what learners have already interacted with at their level of training
2. Prepare and review questions in advance that may come up
3. Acknowledge that patients are the expert in their experience, and their experience is not wrong
4. If possible, show the patient the learning environment and provide an opportunity to practice the activity

## DEBRIEF

1. Hear first from the patient about what worked, what didn't work, and what was learned
2. Provide feedback according to the pre-determined goals and expectations
3. Inform the patient what will happen next and how their participation will be used in the future
4. Follow-up with outcomes data

# Community-Based Participatory Research

## Including the patient in IPE Research

" Community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change."

<https://www.ahrq.gov/research/findings/factsheets/minority/cbprbrief/index.html>

1

### START WITH THE PATIENT

Determining the outcomes of team-based care requires additional evaluation on the role of the IPE or IPP intervention in patient outcomes. Patients can be included in the design of research studies from day-one as participants, not only as research subjects.

2

### RESEARCH QUESTIONS

Patients and caregivers provide valuable insight on the sought after outcomes of their relationship with the healthcare system. Patients can help teams in determining the scope and questions studied in IPE research.

3

### SHARE OUTCOMES

Subjects of health research rarely see the outcomes or the translation into future practice. Inclusion of the patient/caregiver in the research team respects the contributions made by those intended to benefit from the study.

4

### DISSEMINATE FINDINGS

IPE research teams are advised to include the patient / caregiver in their scholarship plans. This includes inviting them to co-author manuscripts and/or invite them to present at local, state, or national professional conferences.

# Teaming: Training & Preparation



## Training

Strategies include:

- Level the playing field for those without formal science/health education - include introductory training important to the scenario
- Cross-train and share information about what other patients as co-creators are being asked to contribute
- Invest time for additional training to be sure co-creators have time to think, reflect, and ask questions.
- Offer various training methods, include peer support
- Ensure your training coordinator is prepared to conduct educational training with non-clinicians

## Preparation

Strategies include:

- Send reminder emails. Maintain communication and send reminders.
- Translators/Interpreters should not be the patient/caregiver's child or minor
- Have Institutional Support Systems in Place - do not put the burden on the patient
- Tell them 'What to Expect'
- Host Huddle / Pre-Brief immediately before the activity
- Patient feedback to the team in the learning activity
- Debrief with Curriculum Team



# Values: Payment & Recognition

## Payment

Compensate co-creators for time and effort as you would any other employee or invited expert.

- Consider hourly pay for their time
- Supplemental honorariums
- Independent contractor agreements
- Contract with their advocacy organization
- Explore opportunities for payment to co-creators with your academic dean, research dean, or business manager

## Recognition

Contributions should be recognized for those who are giving outside their academic responsibilities. Patients / caregivers can be recognized by the IPE team by:

- Consider and acknowledge expertise in introductions
- Acknowledge verbally during IPE activities
- Send follow-up letters or feedback
- Recognize in scholarly products
- List as co-author in any publications

# Outcomes & Impact

- What, if anything, will you share with current patients/family members about advice from “patient/family” teaching partners that has been integrated into your work with them today?
- What feedback do you receive about the patient encounter that will inform your team about what worked and what didn’t work when involving the patient/family in plan-of-care planning and decision-making?
- How will you approach collecting data, including systematically collected data and anecdotal data (from on-the-spot feedback)
- What [de-identified or summary] data will you share with co-creators to inform your co-teaching activities with ‘patients’ as teachers?

## Learner Outcomes

Patients can be included in:

- Deciding the tool/instrument to be used to gather learner outcomes
- Setting objectives for the learner participants
- Reviewing the outcomes with the curriculum teams
- Informing formative and summative revisions based on the learner outcomes

## Co-Creator Outcomes

Patients can be included in:

- Is there mutual benefit
- Discussing how their participation will be assessed
- Determining their preferred outcomes of participation
- Reviewing student and IPE team feedback of their participation
- Receiving acknowledgement of their process metrics such as hours served or learners engaged

## Impact Evaluation

Patients can be included in:

- Setting learner goals
- Implementing longitudinal studies
- Providing feedback regarding their experience
- Recruitment of additional patients/caregiver participants

# Resources



## Seven Partner Values

## Siete Valores del Socio

**Recognize the Need to Partner...** by realizing they can't do it alone, involving others in a shared interest, issue or problem, and doing bigger, better and more useful things by working together.



**Reconocer la Necesidad de Asociarse...** al darse cuenta que ellos no lo pueden hacer solos, al involucrar a otros en un interés en común, asunto o problema, y al realizar cosas más grandes, mejores y más útiles por medio del trabajo en conjunto.

**Value and Respect Each Other...** by agreeing that the other partner's point of view and experiences are important and taking the time to let the partners express themselves (valuing what you say).



**Valorar y Respetar el Uno al Otro...** al ponerse de acuerdo que el punto de vista y las experiencias del socio son importantes y al dar el tiempo para dejar que los socios se expresen (valorando su opinión).

**Accept Each Other ...** by welcoming and encouraging people to bring different points of view and cultural perspectives to the partnership (valuing who you are).



**Aceptarse el Uno al Otro ...** al Otro al acoger y animar a las personas a brindar diferentes puntos de vista y perspectivas culturales a la asociación (valorando quien es).

**Set Clear Expectations ...** by listing what the partners need and want, giving partners direction and focus and a clear idea of how they will work together to accomplish something.



**Establecer Claras Expectativas ...** al hacer una lista de lo que los socios necesitan y desean, dando a los socios dirección y enfoque y una clara idea de cómo van a trabajar juntos para lograr algo.

**Provide Feedback ...** by having ongoing, two-way conversations about what each partner is doing to make the partnership work and making it safe to say what is going well and what is not going well.



**Proporcionar Reacciones ...** al tener conversaciones continuas de doble vía acerca de lo que cada socio está haciendo para que la asociación funcione y al hacer que sea un lugar seguro para poder decir lo que va bien y lo que no va bien.

**Expect Impact, Product or Outcome ...** by creating something that people can see, touch, or experience in real time that are the results of their work.



**Esperar Impacto, Producto o Resultado ...** al crear algo que las personas puedan ver, tocar, o experimentar en un tiempo real que son los resultados de su trabajo.

**Trust Each Other ...** by showing over time that there is a connection between what they say, what they do, and how they behave with each other and other people.



**Confíar el Uno en el Otro...** al demostrar a través del tiempo que hay una conexión entre lo que ellos dicen, lo que ellos hacen, y cómo ellos se comportan el uno con el otro y con otras personas.

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Learn more at:  
[www.ouhsc.edu/thecenter](http://www.ouhsc.edu/thecenter)

El Centro para el Aprendizaje y el Liderazgo es el Centro de la Universidad de Oklahoma para la Excelencia en Capacidades del Desarrollo.

Aprenda más en: [www.ouhsc.edu/thecenter](http://www.ouhsc.edu/thecenter)

# Family Advocates

The Family Mentors work to educate and prepare future professionals by allowing them time to learn from families regarding their day to day needs. Additionally, the Family Mentors provide an opportunity for future professionals to learn more about family advocacy and the impact of family professional partnership for advocacy and systems change.



<https://ouhsc.edu/thecenter/Projects/Training-and-Collaboration/OK-Family-Leadership-Network>

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# SAME/FAME IPE Simulation

Now in its 4th year, this virtual simulation training teaches interdisciplinary healthcare students basic information about patients with intellectual/developmental disabilities (I/DD), family caregivers, and the systems that shape their lives and experiences across the lifespan.

The course strengthens students' skills in communication and collaboration with patients with I/DD and family caregivers as part of the health care team. The course also allows students to consider societal attitudes towards diverse people with I/DD and families and the impact of those attitudes on health care.

Self-advocates and family advocates are key in planning, presenting, and evaluating the program.

SAME/FAME stands for Self-Advocates as Medical Educators/Family Advocates as Medical Educators.

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## DESIGN

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The SAME/FAME (Self Advocates and Family Advocates as Medical Educators) virtual training offers a collaborative, interdisciplinary educational experience for health profession preservice learners that aims to improve learners' knowledge, confidence, and attitudes about people with I/DD and family caregivers, with a specific focus on IPEC competency 3, Communication. The 6-hour training includes elements of Team Based Learning, a four-hour asynchronous didactic online component, I-RAT (Individual Readiness Assessment Test) and TRAT (Team Readiness Assessment Test), a virtual simulation provided by simulated patients and caregivers played by people with lived experience of I/DD and family caregiving, reflection, debrief, and feedback.

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## OBJECTIVE

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The SAME/FAME training seeks to improve the knowledge, confidence, and attitudes of interdisciplinary health profession learners through didactic content, elements of team-based learning, educational simulation activities, reflection, debrief, and feedback. Additionally, the SAME/FAME training is designed to use partnership and collaboration with multiple stakeholders in the community, such as people with I/DD, family caregivers, and interdisciplinary health care faculty and learners, to produce, deliver, evaluate, and disseminate educational content.

To collaborate on this IPE virtual simulation, visit:

<https://ouhsc.edu/thecenter/Projects/Training-and-Collaboration/SAME-FAME>



# UCEDD / LEND



## UCEDD

### How to engage with your local UCEDD Program:

Visit the “About University Centers for Excellence in Developmental Disabilities” on the Association of University Centers for Disabilities (AUCD) Website at this link:

<https://www.aucd.org/network-members>

Link to map of US **UCEDD** and **LEND** Programs:

<https://www.aucd.org/network-members>

## LEND

### How to engage with your local LEND Program:

Visit the “About Leadership Education in Neurodevelopmental Disabilities” on the Association of University Centers for Disabilities (AUCD) Website at this link:

<https://www.aucd.org/about-lends>

# Core Concepts

## Core Concepts of Patient- and Family-Centered Care

**Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

**Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

**Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

**Collaboration.** Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation; in research; facility design; and in professional education, as well as in the delivery of care.

Learn more about patient- and family-centered care at [www.ipfcc.org](http://www.ipfcc.org).

<https://www.ipfcc.org/bestpractices/sustainable-partnerships/background/pfcc-defined.html>



The screenshot shows the website header for the Institute for Patient- and Family-Centered Care (IPFCC). The logo is a stylized starburst. The tagline is "Transforming health care through partnerships". There is a search bar with "ENHANCED BY Google" and a magnifying glass icon. The navigation menu includes: Home, About Us, Our Services, Educational Programs, Resources, Profiles of Change, and PFCC Best Practices.

The main content area features a large blue banner with a colorful lightbulb icon on the left. The text on the banner reads: "A **Toolbox** for Creating Sustainable Partnerships with Patients and Families in Research".

Below the banner are three colored boxes with text:

- Project Background** (green box): Offers an overview of the project and those who contributed to the development of this Toolbox.
- How to Use This Toolbox** (orange box): Provides brief instructions for navigating the Toolbox.
- Engaging Patient and Family Advisors in Research** (purple box): Explores the different ways patient and family advisors can engage in research.

Visit: <https://www.ipfcc.org/bestpractices/sustainable-partnerships/index.html>

# PATIENT / CAREGIVER AS CO-CREATOR WORKSHEET

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ROLE(S) OF THE  
PATIENT IN THE  
TEAM

STRATEGIES TO  
INCLUDE THE  
PATIENT IN THE  
TEAM

DESIGN  
ELEMENTS AND  
SUPPORTS

RECOGNITION &  
REWARDS

EVALUATION &  
OUTCOMES

# MEETING GUIDE

**Collaborative meetings requires discussion of roles and responsibilities in meetings. Use this checklist to assign meeting management tasks.**

Task	Staff	Faculty	Patient
Schedule Meeting w/patient availability			
Create Agenda (include items/goals agreed to by all parties)			
Invite Attendees (confirm attendance)			
Reserve Meeting Space (easily accessible by all parties)			
Begin Meeting (introduce patient as equal team member)			
Review Agenda w/Team			
Discuss Agenda Items (speak with patient, not to)			
Call for decisions or consensus			
Timekeeper (respect the patient's time)			
Record Keeping (make records available to the patient)			
Table or Defer Items			
Adjourn Meeting			
Communicate Results to Stakeholders			

# PATIENT AS CO-EDUCATOR SIMULATION GUIDE

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## TRAINING

Prior to the simulation date, schedule time with the patient and any other facilitators to review the case, learning objectives, simulation structure, technology, possible questions and problems, and back-up plans.

## PRE-EVENT HUDDLE

Arrive early to review: event set-up, location of materials, confirm their role and assignments, trouble-shooting and back-up plans, and when/where to adjourn.

## EVENT INTRODUCTIONS

Consider if the patient will be introduced as a curricular leader or as a patient/caregiver / advocate. Consider the intended learning objectives with participants if the patient will be an educator, actor (simulated patient), or both.

## PATIENT AS ACTOR (SIMULATED PATIENT)

Have support faculty/staff available to assist the patient. Ensure learners are prepped on the learning goals and purpose of the simulation. Provide resources to the patient to assist with their delivery. Ensure back-up roles are aware of responsibilities and are on-call as needed.

## LEARNER FEEDBACK/DEBRIEF

Schedule time in the curriculum plan to allow the patient to provide feedback on the simulation encounter specifically as a patient. Introduce the patient and set the stage for their feedback. Invite the patient to stay for the simulation debrief.

## CURRICULUM TEAM DEBRIEF

Schedule time immediately following the simulation to debrief with the patient and curriculum team. Gather feedback from the patient regarding their experience and opportunities for improvement. Ensure psychological safety prior to adjournment.

# PATIENT AS CO-CREATOR

## IPE Curriculum Toolkit

Last Update: September, 2024

### Suggested Citation:

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Questions about information in this Toolkit can be directed to:

Margaret Robinson, M.Ed.  
OU Health Sciences Interdisciplinary Learning Building  
Office of the Vice Provost for Academic Affairs  
and Faculty Development,  
1600 North Phillips Avenue  
Oklahoma City, OK 73104  
or via e-mail to: [Margaret-Robinson@ouhsc.edu](mailto:Margaret-Robinson@ouhsc.edu)