

# Improving Patient Advocate- Patient Communication

Amy Bruno-Lindner

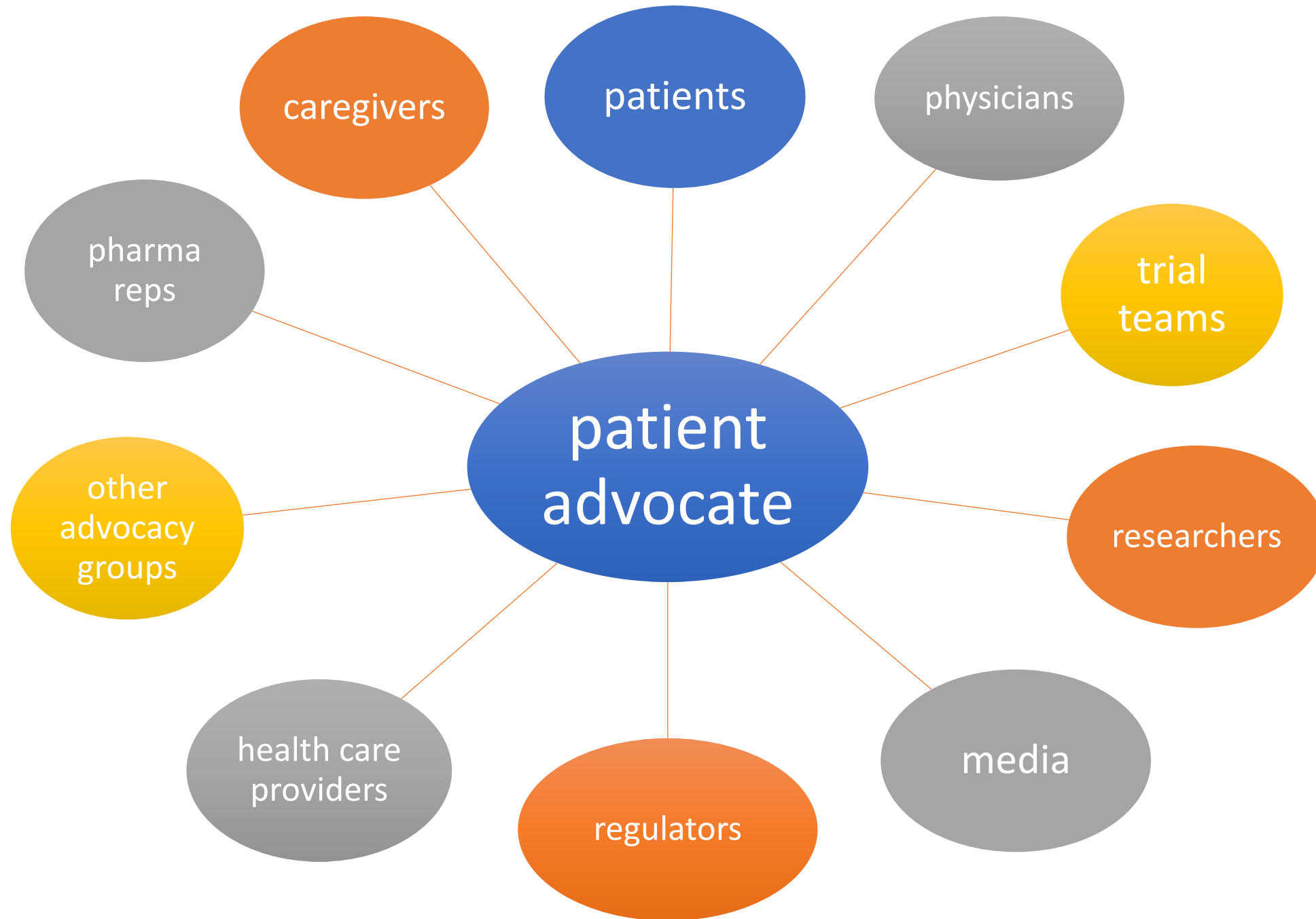


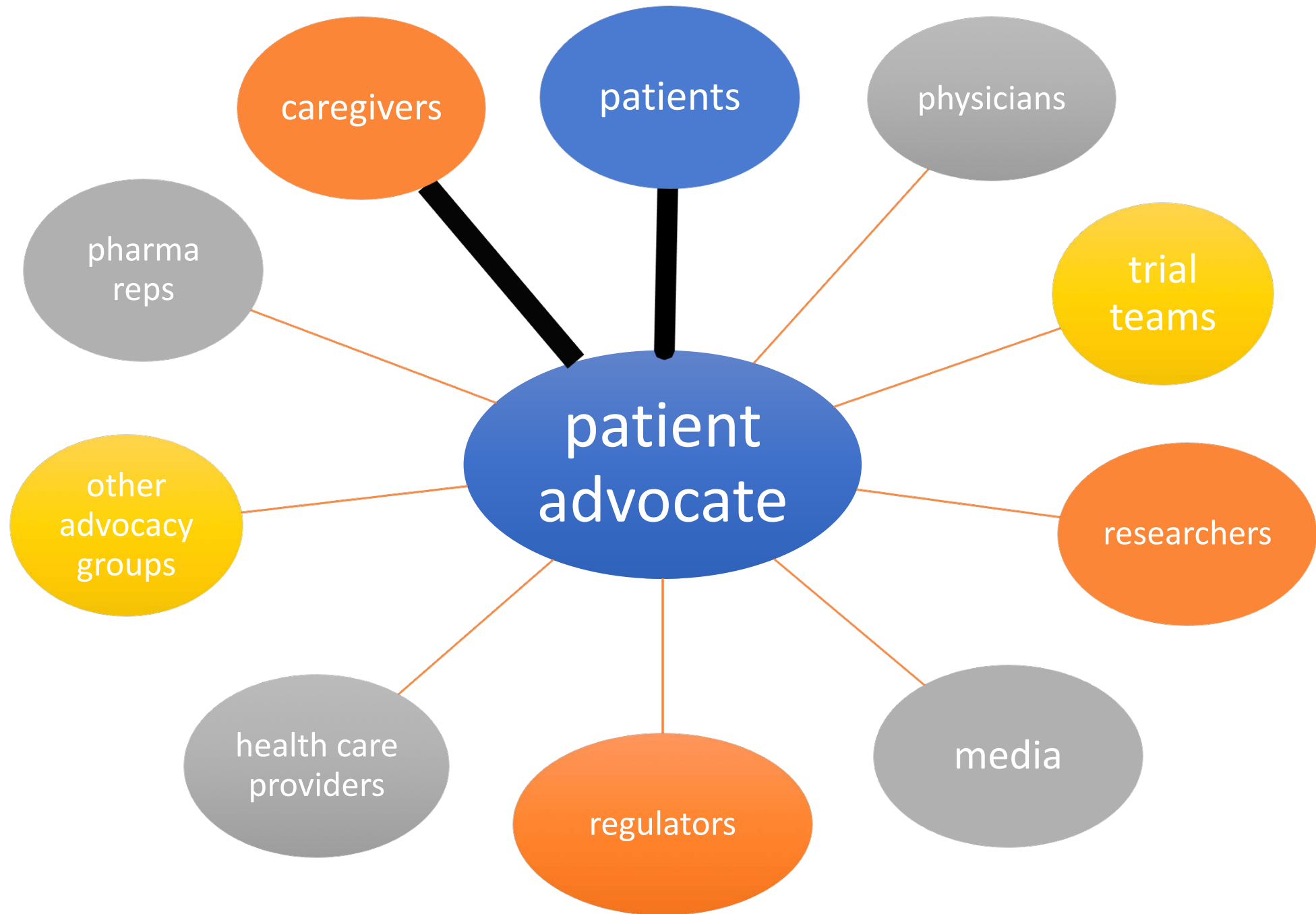
**GIST SUPPORT**  
ÖSTERREICH

advocacy work = communication

What I'd like to do this morning:

- Discuss our **aims**
- Ask for your **input**
- Share **principles** and **techniques** for effective communication





Many variables:

- written or spoken
- one-to-one or one-to-many
- public or private
- advocates may be patients or not, their communication partners likewise
- cultural parameters

# Aims

## INFORMATION

- explaining medical/scientific concepts
- informing about side effects, clinical trials, etc
- dispelling myths

## EMPATHY

- sharing good/bad news
- helping patients to express fears, concerns
- giving hope, perspective

## EMPOWERMENT

- preparing patients for physician appointments
- helping patients take responsibility
- encouraging self-advocacy

What communication challenges do you face  
in your advocacy work with patients?



information

empathy

empowerment

How can we overcome these challenges?

# Key principles

## INFORMATION

- simplicity
- visualization
- memorability, repetition

## EMPATHY

- openness
- mirroring, echoing
- personalization
- silence

## EMPOWERMENT

- action-orientation
- encouragement
- emphasis on patient rights

# Sharing Information: Principles and techniques

**Key principles:** simplicity, visualization, repetition

- Use plain language, avoid jargon
- Use analogies
- Formulate key messages and repeat them

# Examples of analogies

- **“KIT is like a gas pedal. Mutant KIT GIST has a stuck gas pedal.”**
- **“Checkpoint inhibitors take the brakes off the immune system.”**
- **“Imatinib fits like a key in a lock.”**
- **“Metastases are like the seeds of a dandelion.”**
- **“Cystic transformation makes a GIST tumor appear like a hole in Swiss cheese.”**

## Examples of key messages

- "Clinical trials are the way progress against cancer is made."
- "When you participate in a trial you are not a lab rat. You receive cutting-edge treatment under the care of leading experts."

# Expressing empathy: Principles and techniques

**Key principles:** openness, mirroring,  
personalization, silence

- Ask open-ended questions and listen actively
- Summarize what patient has said
- Personalize advice
- Share silence

# Fostering empowerment: Principles and techniques

**Key principles:** action-orientation, patient rights, encouragement

- Refer patients to sources of information
- Stress patient rights
- Coach patients to speak up/to take action



“The blockbuster drug of the century is an engaged patient.”

Leonard Kish