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A:CARE CONGRESS

# The paradox of non-adherence in symptomatic disease

**Prof. Matthias Löhr**

Professor of Gastroenterology & Hepatology at the Karolinska Institute & leads the Pancreatic Team at Karolinska University Hospital, Sweden

**Dr. Sheri Pruitt**

Clinical Psychologist and Behavioral Science Consultant, California, US

THE PARADOX OF NON-ADHERENCE IN SYMPTOMATIC DISEASE

# Pancreatic Exocrine Insufficiency

**Prof. Matthias Löhr**

Karolinska Institute
Karolinska University Hospital
Sweden

# Disclosures

## HONORARIA FROM ABBOTT, MYLAN/VIATRIS

# Pancreatic exocrine insufficiency Symptoms

**SYMPTOMS CAN BE**

**Irritating**
- Smelling
- Farting

**Severe**
- Opiod craving

**Incapacitating**
- Toilet in reach

**Life threatening**
- Vitamin deficiencies

**Diarrhoea**
- EPI can cause problems with undigested food moving too quickly through the digestive tract

**Gas and Bloating**
- People with EPI cannot properly digest the food they eat, which can result in uncomfortable symptoms like gas and bloating

**Stomach pain**
- Fat maldigestion due to EPI can lead to gas, bloating, and stomach pain

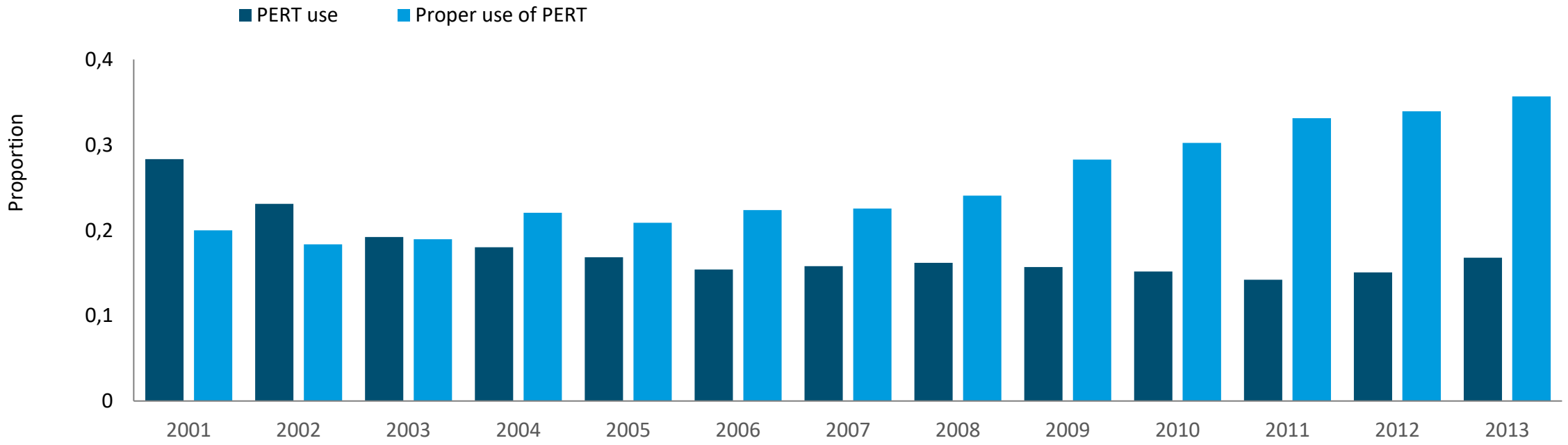
**Foul-smelling, greasy stools (steatorrhea)**
- Steatorrhea is a type of bowel movement that is oily, floats, smells really bad, and is difficult to flush. People with EPI are not able to absorb all of the fat that they eat, so undigested fat is excreted, resulting in stools that look oily or greasy. Not all people experience this symptom
- Talk to your doctor if you notice oil droplets floating in the toilet bowl or stools that float or stick to the sides of the bowl and are hard to flush; it may be a sign of EPI

**Weight Loss**
- EPI affects protein and carbohydrate digestion, but the greatest impact comes from fat maldigestion, which is the primary cause of weight loss in people with EPI

Ferrone M, Raimondo M, Scolapio JS. Pancreatic enzyme pharmacotherapy. *Pharmacotherapy*. 2007;27(6):910-920. 2. Domínguez-Muñoz JE.pancreatic exocrine insufficiency. Curr Gastroenterol Rep. 2007;9(2):116-122. 3. Alkaade S, Vareedayah AA. A primer on exocrine pancreatic insufficiency, abnormalities. *Am J Manag Care*. 2017;23(suppl 12):S203-S209.

# Propper use of enzymes low in the US

It’s slowly getting better




Forsmark CE, Tang G, Xu H, Tuft M, Hughes SJ, Yadav D. The use of pancreatic enzyme replacement therapy in patients with a diagnosis of chronic pancreatitis and pancreatic cancer in the US is infrequent and inconsistent. *Aliment Pharmacol Ther*. 2020;51(10):958-967. doi:10.1111/apt.15698

# The dilemma

**WHY WOULD A PATIENT WITH**




**NOT** follow physicians recommendations?!

# This is NOT a novel problem

CHILDREN's HEALTH CARE, 27(4), 259-264



**Unsuspected non-adherence with recommended pancreatic enzyme administration in patient with cystic fibrosis**

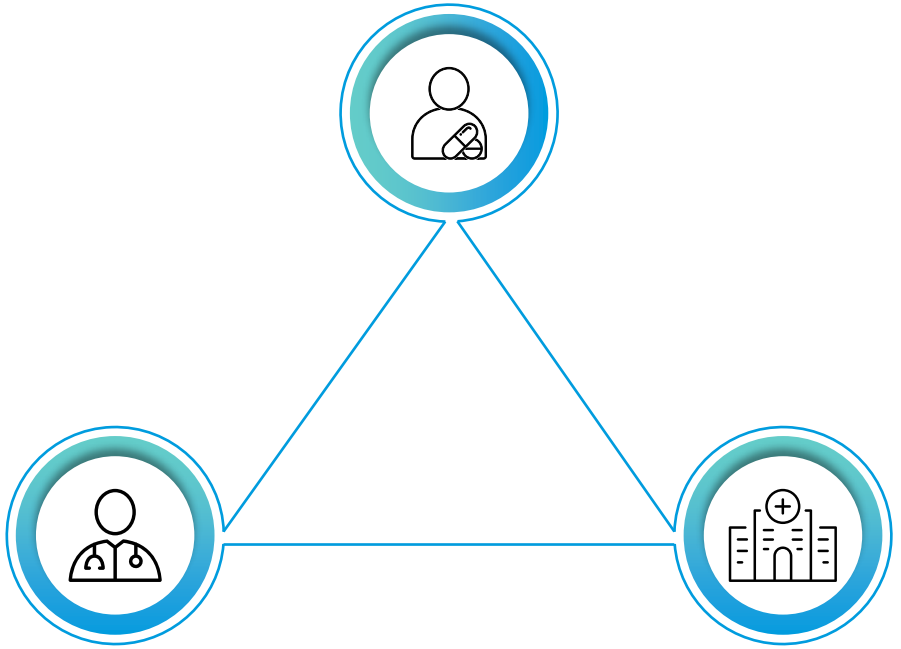
Lee S. Rusakow, Tami Miller, Catherine A McCarthy, William M. Gershan, and Mark L. Splaingard

# Factors influencing Non-adherence

- The patient
- The doctor
- The “system”

# Factors influencing Non-adherence

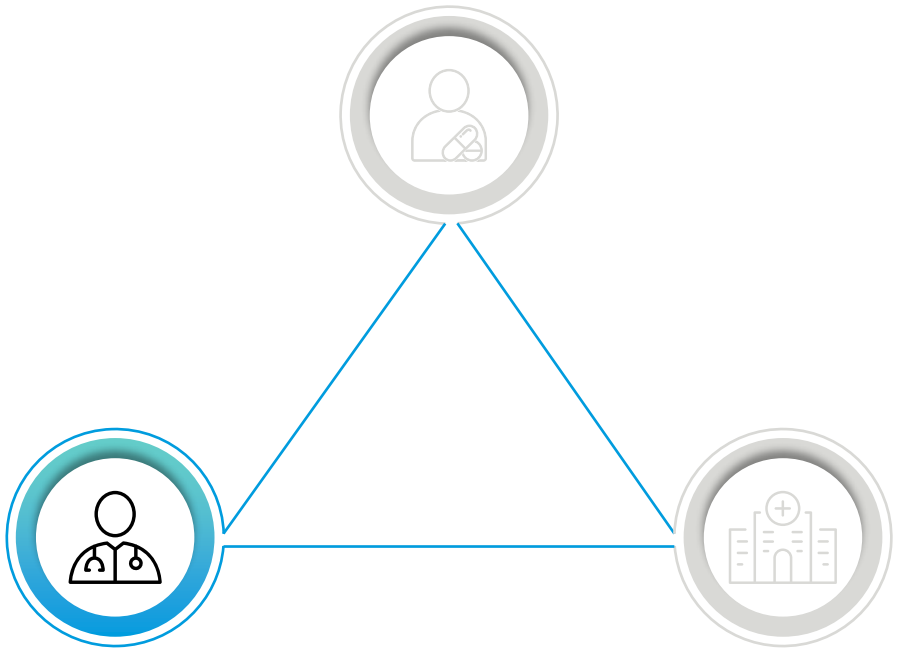
**The patient**



**The doctor**

**The “system”**

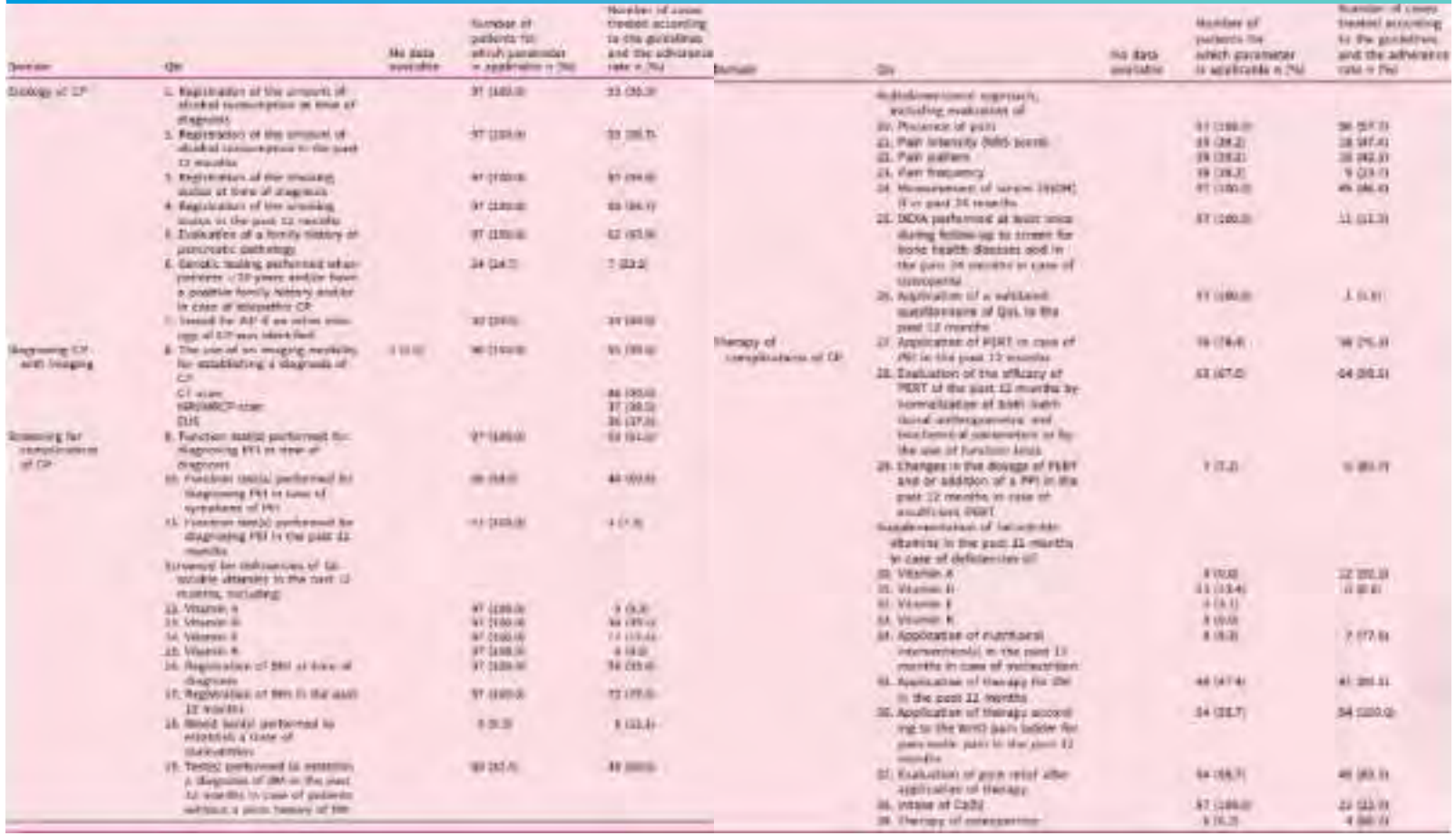
# Factors influencing Non-adherence



# Bad adherence to guidelines (1/2)

- Adherence varies across different area
  - Best in diagnosis
  - Worst in genetics and nutrition
- Academic hospital better than teaching hospital

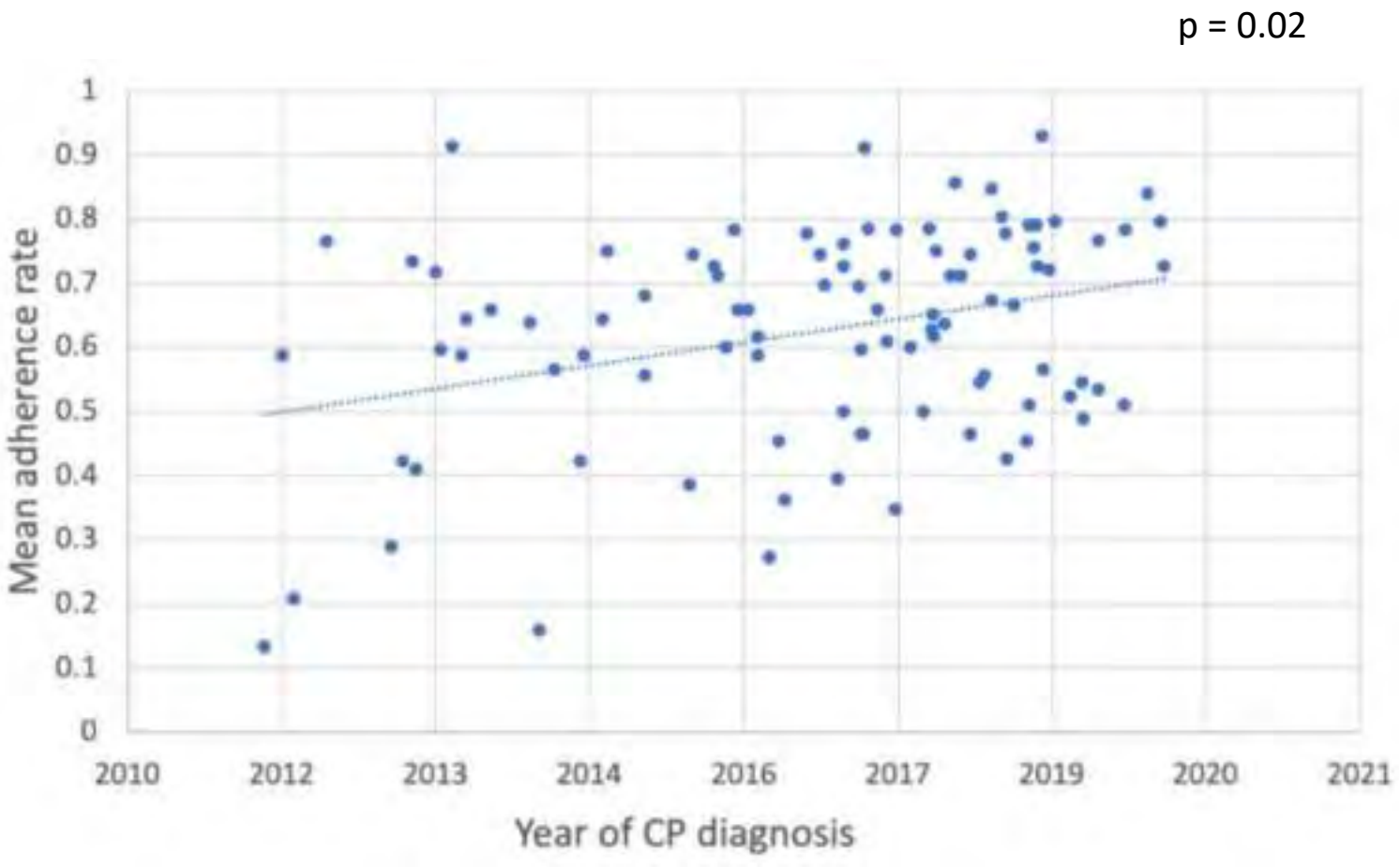
**AN OVERVIEW OF ALL THE QIS OF THE FOUR DOMAINS CONCERNING THE NON-INVASIVE MANAGEMENT OF CP AND ADHERENCE TO THE HAPANEU GUIDELINES**



1. Rijk FE, Kempeneers MA, Bruno MJ, et al. Suboptimal care for chronic pancreatitis patients revealed by moderate to low adherence to the United European Gastroenterology evidence-based guidelines (HaPanEU): A Netherlands nationwide analysis. *United European Gastroenterol J*. 2020;8(7):764-774. 2. Khan M, Rutkowski W, Vujasinovic M, Löhr JM. Adherence to European Guidelines for Treatment and Management of Pancreatic Exocrine Insufficiency in Chronic Pancreatitis Patients. *J Clin Med*. 2021 Jun 21;10(12):2737.

# Bad adherence to guidelines (2/2)

- Sex, age, etiology have no influence
- Adherence best for PERT (85%)
- Positive effect on
  - Iron
  - Vit D
- Overall adherences increases (slowly) with/after **HaPanEU**




Khan M, Rutkowski W, Vujasinovic M, Löhr JM. Adherence to European Guidelines for Treatment and Management of Pancreatic Exocrine Insufficiency in Chronic Pancreatitis Patients. *J Clin Med*. 2021 Jun 21;10(12):2737.

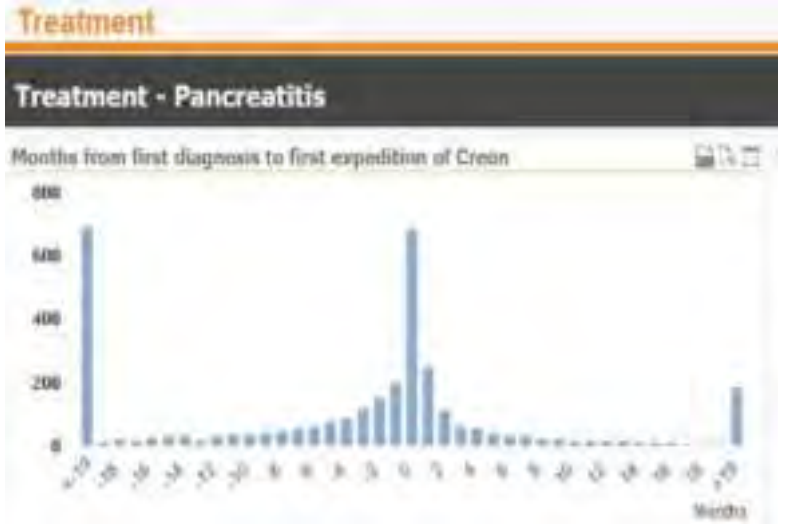
# Primary prescribers are surgeons

- Diagnosis is established mostly by **surgeons**
- PERT prescription is mostly initiated by surgeons, **but follow-up prescription is done mostly by general practitioners or gastroenterologists**
- Percentage patients **receiving PERT** is not increasing overall


Khan M, Rutkowski W, Vujasinovic M, Löhr JM. Adherence to European Guidelines for Treatment and Management of Pancreatic Exocrine Insufficiency in Chronic Pancreatitis Patients. *J Clin Med*. 2021 Jun 21;10(12):2737.

# Prescription dates vary

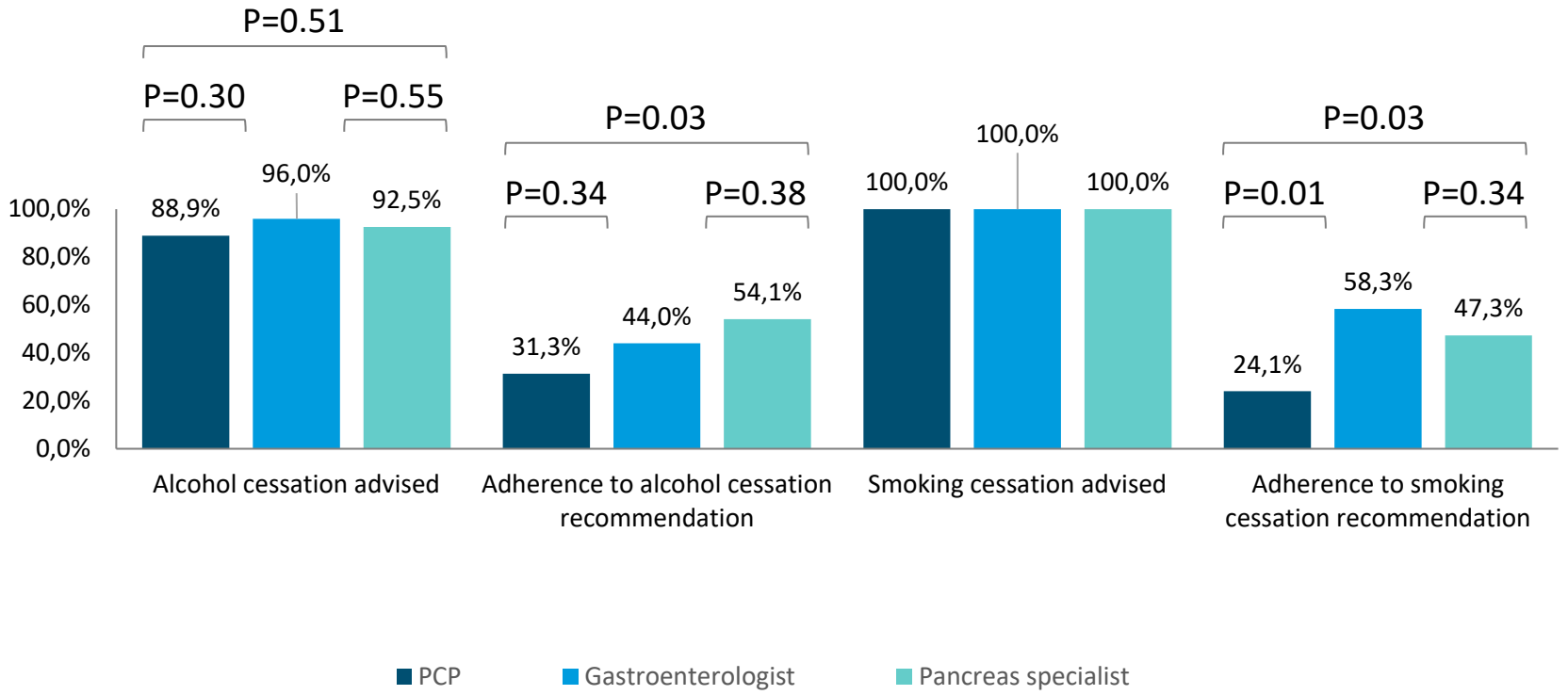
- Higher percentage **PERT prescription** by gastroenterologists (upper)
- Most patients receive prescription around the time of first diagnosis, but some receive it > 18 months before or after diagnosis of chronic pancreatitis




Khan M, Rutkowski W, Vujasinovic M, Löhr JM. Adherence to European Guidelines for Treatment and Management of Pancreatic Exocrine Insufficiency in Chronic Pancreatitis Patients. *J Clin Med*. 2021 Jun 21;10(12):2737.

# Specialist best in adherence to lifestyle recommendations

**LIFESTYLE MODIFICATION RECOMMENDATION AND ADHERENCE ACCORDING TO PROVIDER TYPE**

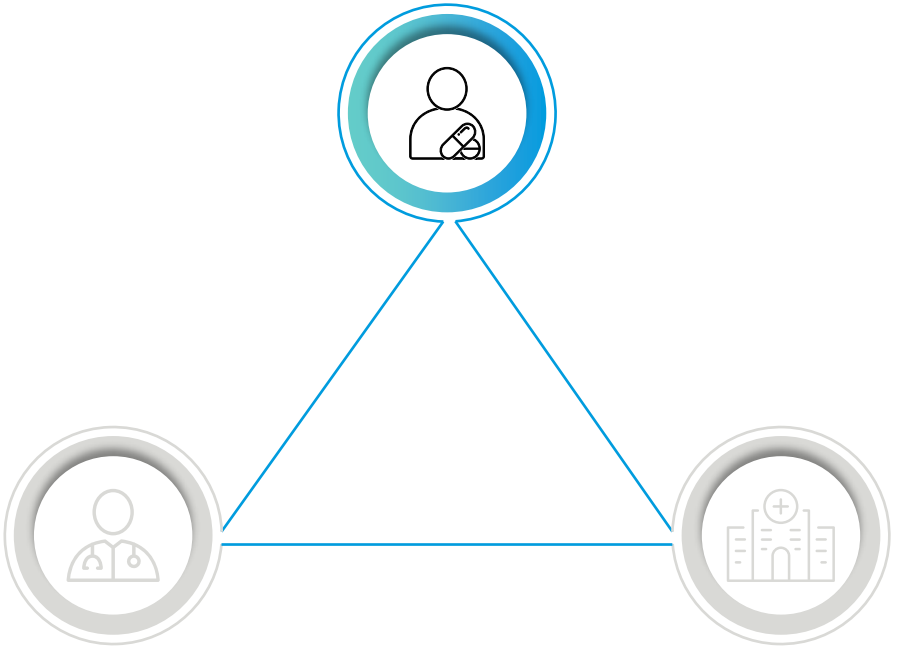



Pancreas specialist > gastroenterologist > primary care

Srivoleti P, Yang AL, Jin DX, Banks PA, McNabb-Baltar J. Provider type influences adherence to lifestyle changes in chronic pancreatitis. *Pancreatology*. 2021 Jan;21(1):42-45.

# Factors influencing Non-adherence

**The patient**



The doctor

The “system”

# Patient factors

**Socioeconomic status and environment**

**“Drug-seeking” behavior – dependency on**

- Alcohol
- Smoking
- Drugs

**Overall compliance**

Few published data on the noncompliance due to alcohol & smoking
**BUT** well-founded eminence-based experience!

Mössner J, Keim V, Niederau C, Büchler M, Singer MV, Lankisch PG, Göke B. Leitlinien zur Therapie der chronischen Pankreatitis. Konsensuskonferenz der Deutschen Gesellschaft für Verdauungs- und Stoffwechselkrankheiten. *Halle*, 21.-23. November 1996 [Guidelines for therapy of chronic pancreatitis. Consensus Conference of the German Society of Digestive and Metabolic Diseases. *Halle* 21-23 November 1996]. Z Gastroenterol. 1998 May;36(5):359-67. German. PMID: 9654702.

# Malnutrition after PERT in chronic pancreatitis: Risk factors in real world practice

## RESULTS

**Inclusion**

- 1006 CP patients from 8 centers were included for analysis

**Treatment adherence**

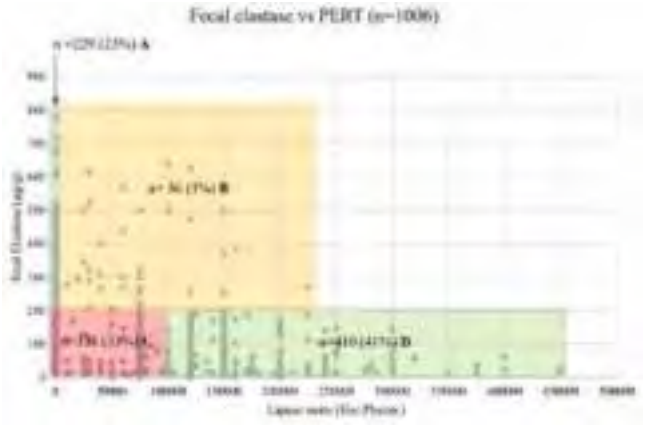
- 64% were correctly treated

**Patients with exocrine pancreas insufficiency**

- 25% were not taking PERT
- 45% were taking insufficient doses

**Pancreas sufficient patient**

- 14% were receiving PERT




## FACTORS ASSOCIATED TO POOR COMPLIANCE

**Current smoking** was associated with no treatment despite EPI

**Current heavy drinking** (>5 units/ day) was associated to under treatment of EPI

Associations between exposures, covariates and incorrect treatment

| | Factor | Univariate | | | Multivariate regression (Final Model) | | |
|---|---|---|---|---|---|---|---|
| | | OR | 95 % CI | p | OR | 95 % CI | p |
| Not treated | Current heavy drinking | 1.13 | 0.61, 2.09 | 0.69 | | | |
| | Current smoking | 2.17 | 1.55, 3.02 | <0.001 | 2.52 | 1.76, 3.61 | <0.001 |
| | Presence of pain | 1.31 | 0.94, 1.83 | 0.11 | | | |
| | Age* | | | | 1.00 | 0.99, 1.02 | 0.71 |
| | Sex (male) | | | | 1.01 | 0.70, 1.47 | 0.95 |
| | Disease duration* | | | | 0.95 | 0.91, 0.99 | 0.02 |
| Undertreated | Current heavy drinking | 2.57 | 1.44, 4.59 | 0.001 | 2.74 | 1.50, 5.02 | 0.001 |
| | Current smoking | 1.32 | 0.92, 1.90 | 0.14 | | | |
| | Presence of pain | 1.27 | 0.97, 1.68 | 0.09 | | | |
| | Age* | | | | 1.00 | 0.98 ,1.01 | 0.59 |
| | Sex (male) | | | | 0.82 | 0.54, 1.24 | 0.34 |
| | Disease duration* | | | | 1.04 | 1.01, 1.07 | 0.006 |

M. Arutla, S. Sarkar, M. Unnisa et al. *Pancreatology* 21 (2021) 34e41

# High adherence in pancreatic cancer patients

**ORIGINAL ARTICLE**

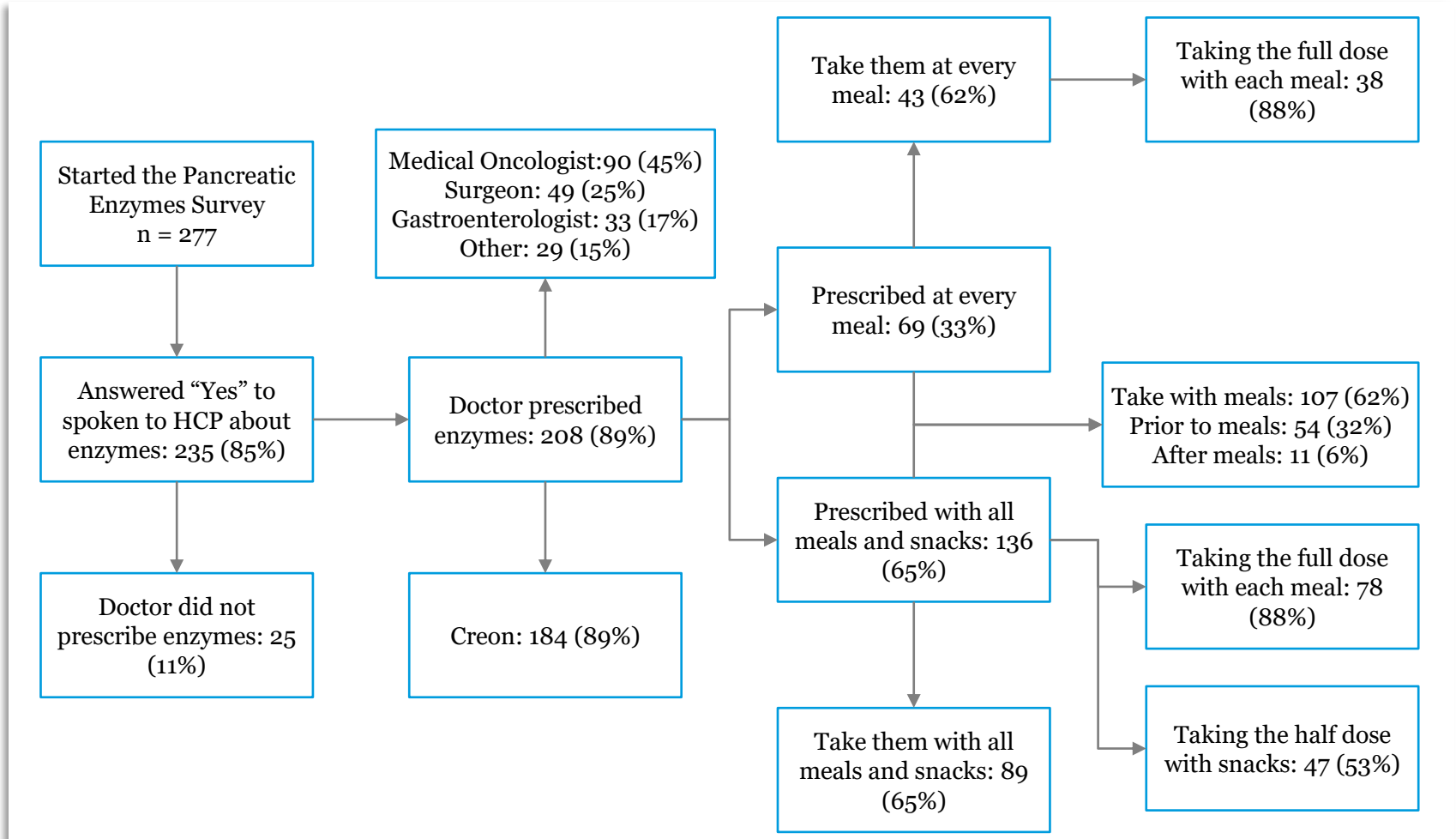
OPEN

**Frequency of Appropriate Use of Pancreatic Enzyme Replacement Therapy and Symptomatic Response in Pancreatic Cancer Patients**

Jodie A. Barkin, MD,[1] Amy Westermann, MPH,[2] William Hoos, MS, MBA,[2] Cassadie Moravek, BS,[2] Lynn Matrisian, PhD, MBA,[2] Hongwei Wang, MS,[3] Lynn Shemanski, PhD,[3] Jamie S. Barkin, MD,[1] and Lola Rahib, PhD[2]

**... despite contradicting factors such as**

- **Nausea**
- **Fatigue**
- **Chemotherapy**
- **Post surgical anatomy**

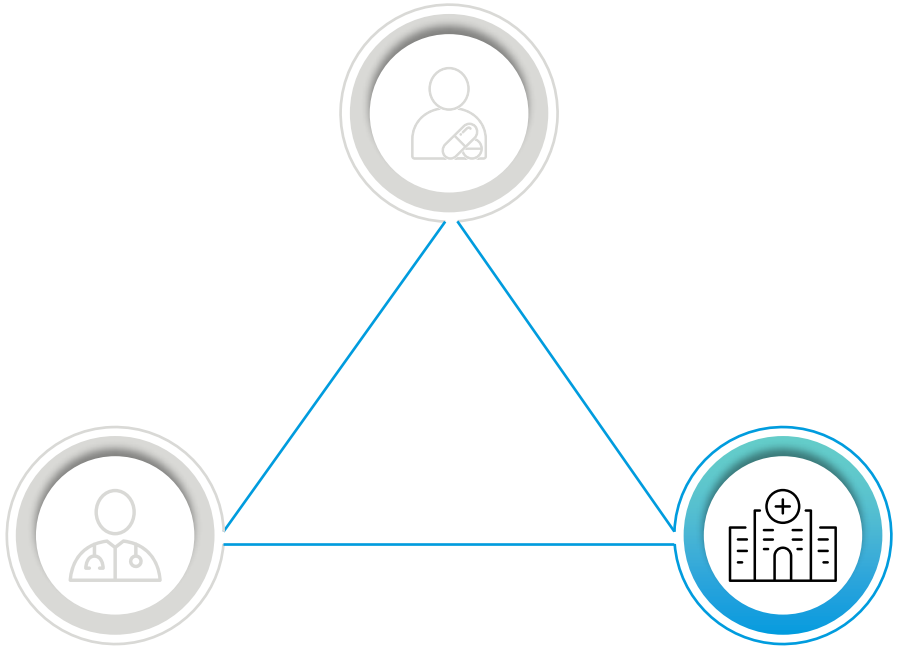



Results of questionnaire from PE survey (January 2016-January 2018)

1.Barkin JA, Westermann A, Hoos W, et al. Frequency of Appropriate Use of Pancreatic Enzyme Replacement Therapy and Symptomatic Response in Pancreatic Cancer Patients. *Pancreas*. 2019;48(6):780-786

# Factors influencing Non-adherence

The patient



The doctor

**The “system”**

# The cost of medication influences adherence

Pancreatology 21 (2021) 1009-1010

Contents lists available at ScienceDirect

**Pancreatology**

Journal homepage: www.elsevier.com/locate/pan

Projected 30- day out-of-pocket costs and total spending on pancreatic enzyme replacement therapy under Medicare part D[1]

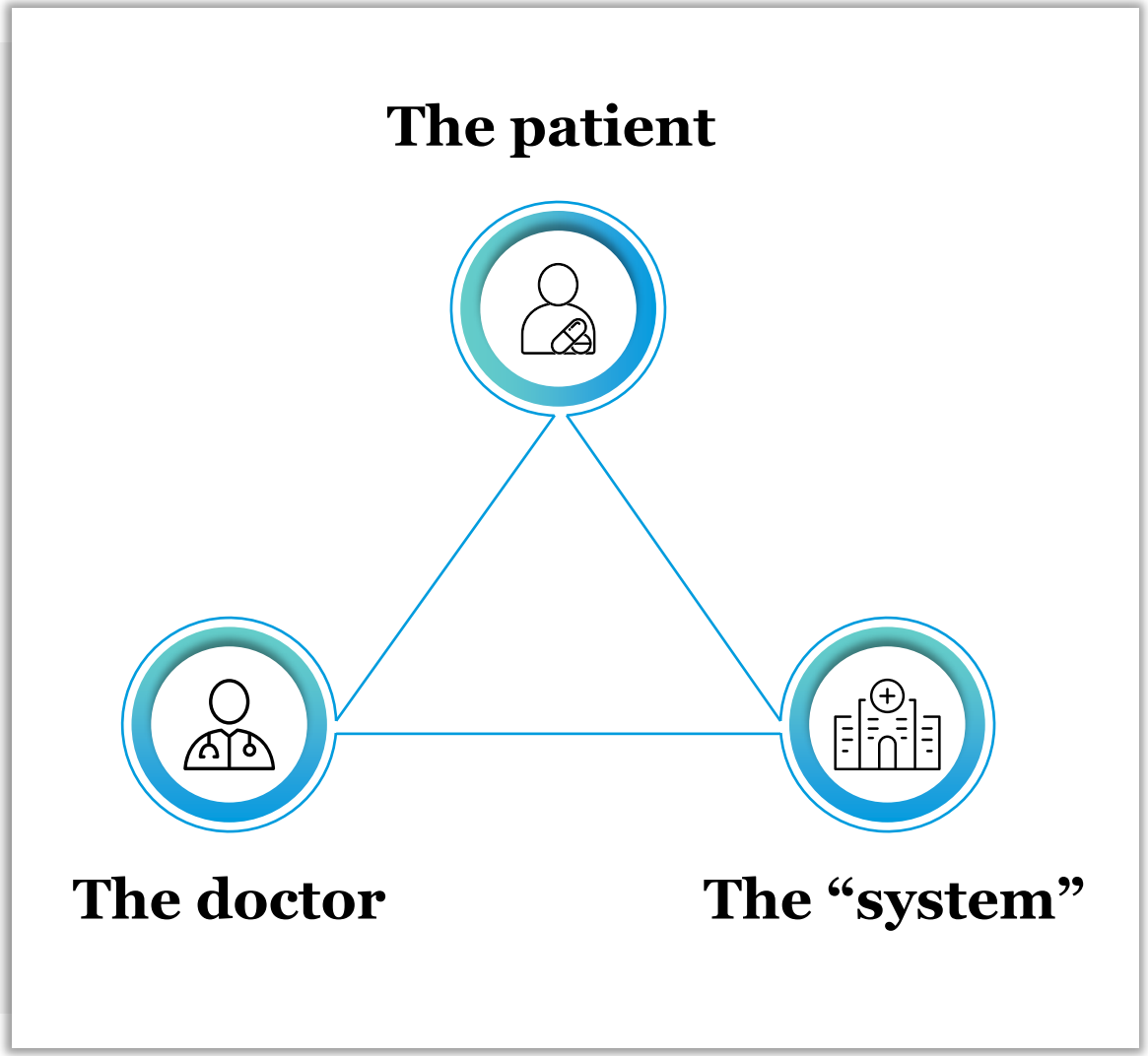
**AVERAGE (RANGE) OF 30-DAY OUT-OF-POCKET COSTS FOR PERT UNDER 3 SCENARIOS**

Progress through the year

| | | | |
|---|---|---|---|
| **Standard benefit** | **$999** | ($853-$1536) | $435 deductible, and 25% coinsurance after meeting deductible |
| **Coverage gap** | **$673** | ($527-$1210) | 25% coinsurance, after meeting the deductible and until spending $6,350 out-of-pocket |
| **Catastrophic coverage** | **$135** | ($105-$242) | (5% coinsurance) |

# Summary / conclusions

- All three factors (doctor, patient, system) influence adherence to evidence-based, guideline-compatible enzyme medication
- It starts with the physician
  - Right prescription
  - Follow-up & advice/adherence to life style changes (alcohol, smoking)
    Patient factors partly dependent on physician
  - Reimbursement major role in some countries



Abbott

a:care

THE PARADOX OF NON-ADHERENCE IN SYMPTOMATIC DISEASE

# Communication Strategies to Increase Adherence to Medical Advice

**Dr. Sheri Pruitt, PhD**

Clinical Psychologist and Behavioral Science Consultant
California, US

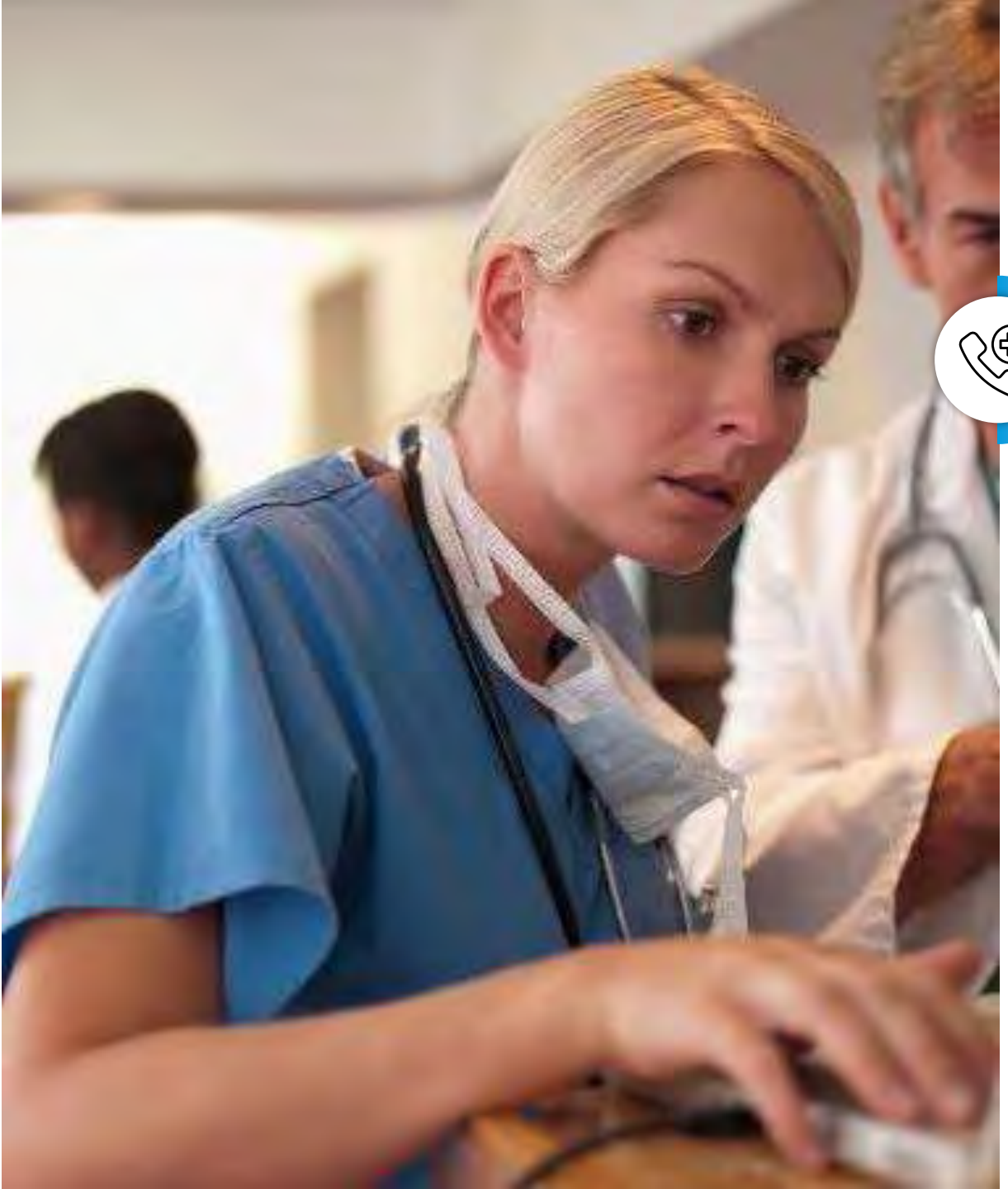
# Please let me know what you think!

## IN WHICH DISEASE CATEGORY DO YOU THINK ADHERENCE TO MEDICATION IS LOWER?


To participate in polling please exit full screen mode

THE ADHERENCE PROBLEM

# What we know



# Adherence often goes unrecognized

**Most providers think patients follow our excellent healthcare advice, but they don't!**

Why we think our patients adhere:

- Optimistic bias[1]
- Patients tend to exaggerate and want to please us[2]
- We think we can predict who will adhere[3]

1. Du Pasquier-Fediaevsky, Laurence, & Nadia Tubiana-Rufi.: Discordance between physician and adolescent assessments of adherence to treatment: influence of Hb[A.sub.1c] level. *Diabetes Care*, vol. 22, no. 9, September 1999, [Accessed October 2021], https://go.gale.com/ps/anonymous?id=GALE%7CA135564895&sid=googleScholar&v=2.1&it=r&linkaccess=abs&issn=01495992&p=AONE&sw=w; 2. Rand. C , Wise. R et al: Metered-Dose Inhaler Adherence in a Clinical Trial. *American Review of Respiratory Disease*, December 1992; 3. Gilbert. JR, Evans. CE, Haynes. RB, Tugwell. P: Predicting compliance with a regimen of digoxin therapy in family practice. *Can Med Assoc J*.123(2):119-122, August 1980

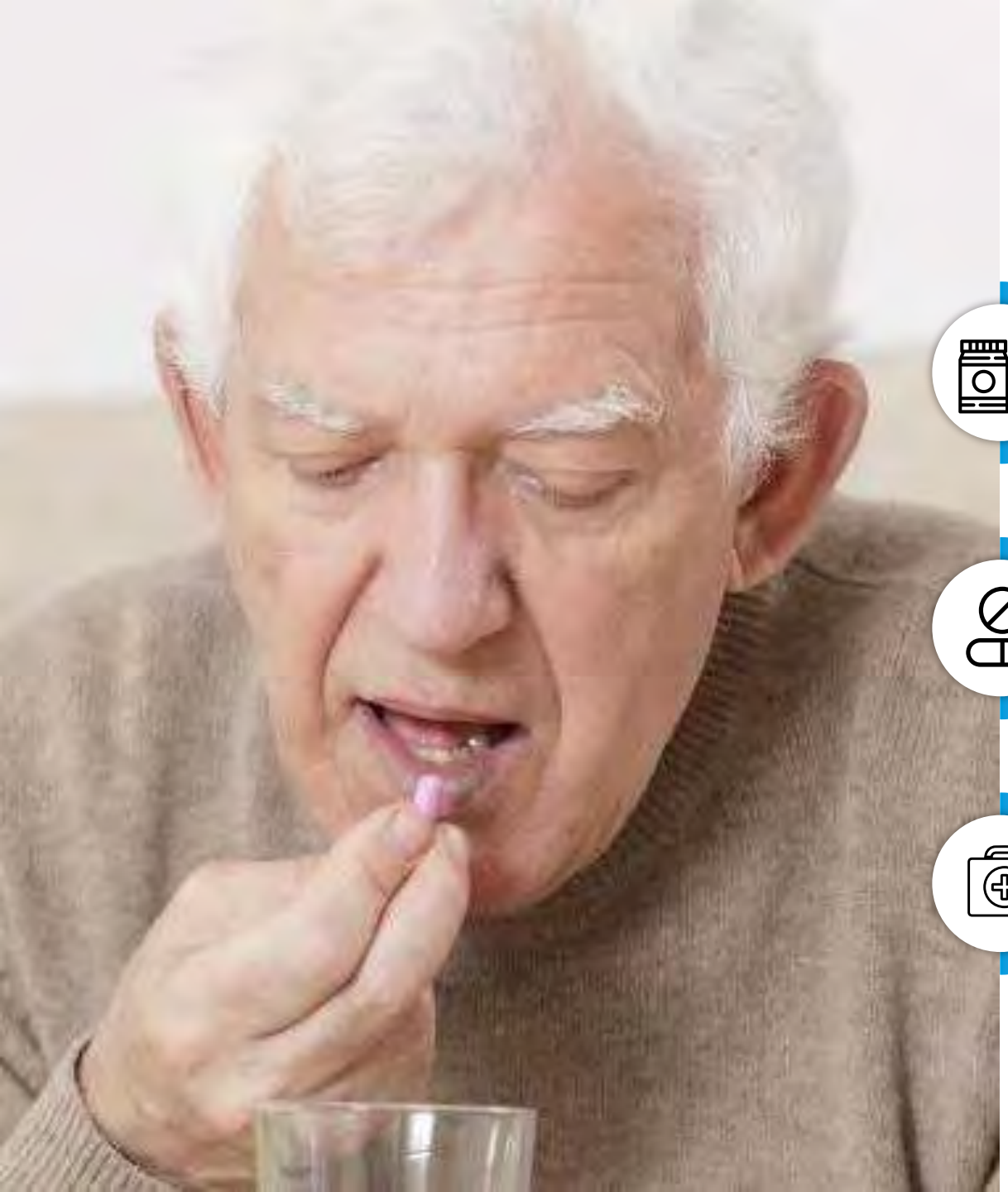
# Adherence and PEI

**Management of PEI has been reported as suboptimal; non-adherence is associated with higher costs and utilization[1]**

- Wrong timing of ingestion
- Inadequate dosage
- Cost[2]

1.Barkin JA, Westermann A, Hoos W, et al. Frequency of Appropriate Use of Pancreatic Enzyme Replacement Therapy and Symptomatic Response in Pancreatic Cancer Patients. *Pancreas*. 2019;48(6):780–786

2.Brown MT, Bussell JK. Medication adherence: WHO cares?. *Mayo Clin Proc*. 2011;86(4):304-314. doi:10.4065/mcp.2010.0575



# Adherence must be addressed

"Increasing the effectiveness of adherence interventions may have far greater impact on health than any improvements in specific medical treatments"[1]

How can we do better with the medications we have?

Is medical care more than writing a prescription?

1. Adherence to long-term therapies: Evidence for action, *WHO study*, 2003, [Accessed October 2021], https://www.who.int/chp/knowledge/publications/adherence_report/en/

WHAT PROVIDERS CAN DO TO IMPROVE ADHERENCE

# Providers can change their communication style

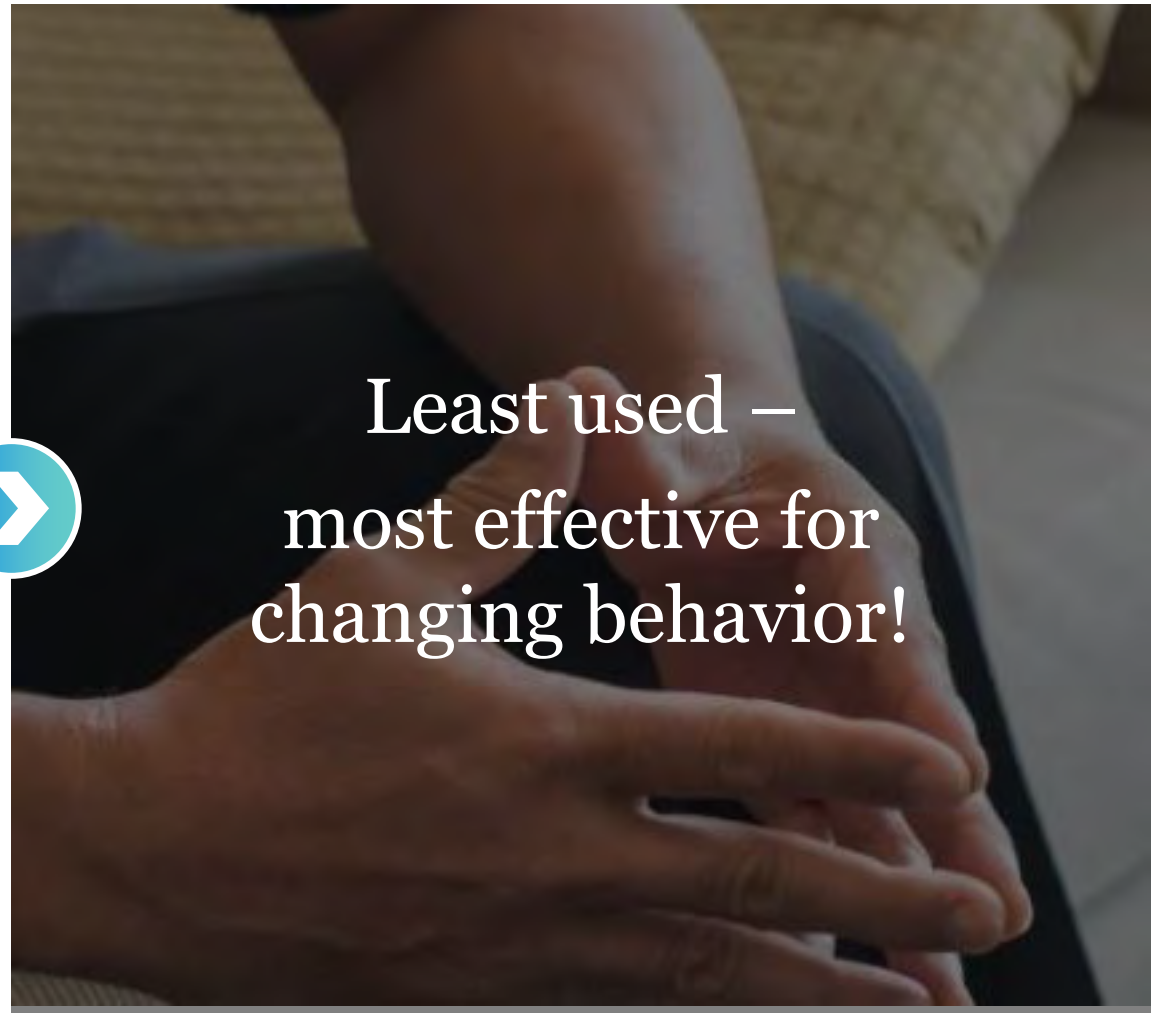
# Common communication strategies to influence others

## WHICH APPROACH DO YOU USE?

- Ordering, directing, demanding
- Warning or threatening
- Persuading with reason, logic, argument, or lecture
- Moralizing, preaching, telling what you “should” do
- Disagreeing, judging, criticizing, blaming
- Shaming, ridiculing, labeling

# Uncommon communication strategies to influence others

- Curious
- Nonjudgmental
- Other-focused
- Empathic
- Collaborative



# Three steps to integrate effective communication strategies

**1**

Strategic, open-ended questions to assess adherence

(curious, nonjudgmental, patient-focused)

**2**

Empathic response

"You must be feeling _____"

(empathy)

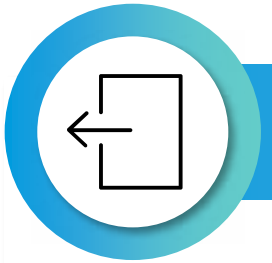
**3**

Promise of provider-patient partnership

"We can work together on this"

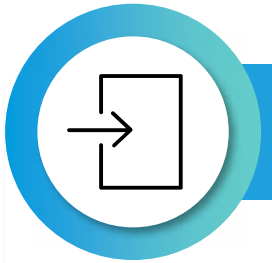
(collaborative)

# Step 1: Assess adherence with open-ended questions



## OPEN

"Some of my patients have difficulties taking the medications as they are supposed to be taken. Over the past 2 weeks, how many days do you think you missed a dose of your  medication?"



## CLOSED

"You are taking your medications, right?"

"Are you still taking the medicine I prescribed for you?"

Examples of what to say

# Step 2: Provide empathic responses

## EXAMPLES OF WHAT TO SAY

- This must be distressing for you
- It must be very difficult for you right now
- Things like this can be very tough
- This seems to be worrying you
- This is probably disappointing for you
- This seems to be challenging for you

# Step 3: Promise patient-provider partnership

## EXAMPLES OF WHAT TO SAY

- We can work on this problem together
- My goal as your doctor is to help you with taking your enzymes
- Let's work together so you can be as healthy as possible

# Example of patient-provider interaction

## USING THE THREE STEPS

1. **“Some of my patients have difficulties taking their medications as they are supposed to be taken. Over the past 2 weeks, how many times do you think you missed a dose?”**

Patient: “Well, I’ve missed quite a bit. I have to take so many of them and at different times and every time I eat. It’s a lot of work to get it right. And, I still don’t feel well.”

2. **“You must be frustrated. Taking these enzymes can be really difficult.”**

**PAUSE**

Patient: “Yes. I am frustrated. It just seems so hard to remember when and what to take.”

3. **“As your doctor, I want to help you be as healthy as possible. Let’s work together on this problem.”**

## FINAL THOUGHTS

Everyone in healthcare wants adherence to be better, but few of us want to change what we

If what we're doing isn't working, we need to change ourselves

When do you think you could try this new way of communicating about adherence?

# Which of the following statements describes what you are willing to do to improve adherence?

- I'll try one of the three steps with my next patient
- I'll try two of the three steps with my next patient
- I'll try all three steps with my next patient
- I don't think I can change my communication!

To participate in polling please exit full screen mode