

"Combining optimal care, education and research: learnings from Cystic Fibrosis in children"

EFAD Conference September 29, 2018

Christina N. Katsagoni, PhD

Clinical Dietitian at Agia Sofia Children's Hospital,
Athens, Greece

Dietetic clinical practice should be based on evidence

- Evidence-based dietetics practice is about asking questions, systematically finding research evidence, and assessing the validity, applicability and importance of that evidence.
- This evidence-based information is then combined with the dietitian's expertise and judgment and the client's or community's unique values and circumstances to guide decision-making in dietetics.

Life-long Learning and Professional Development

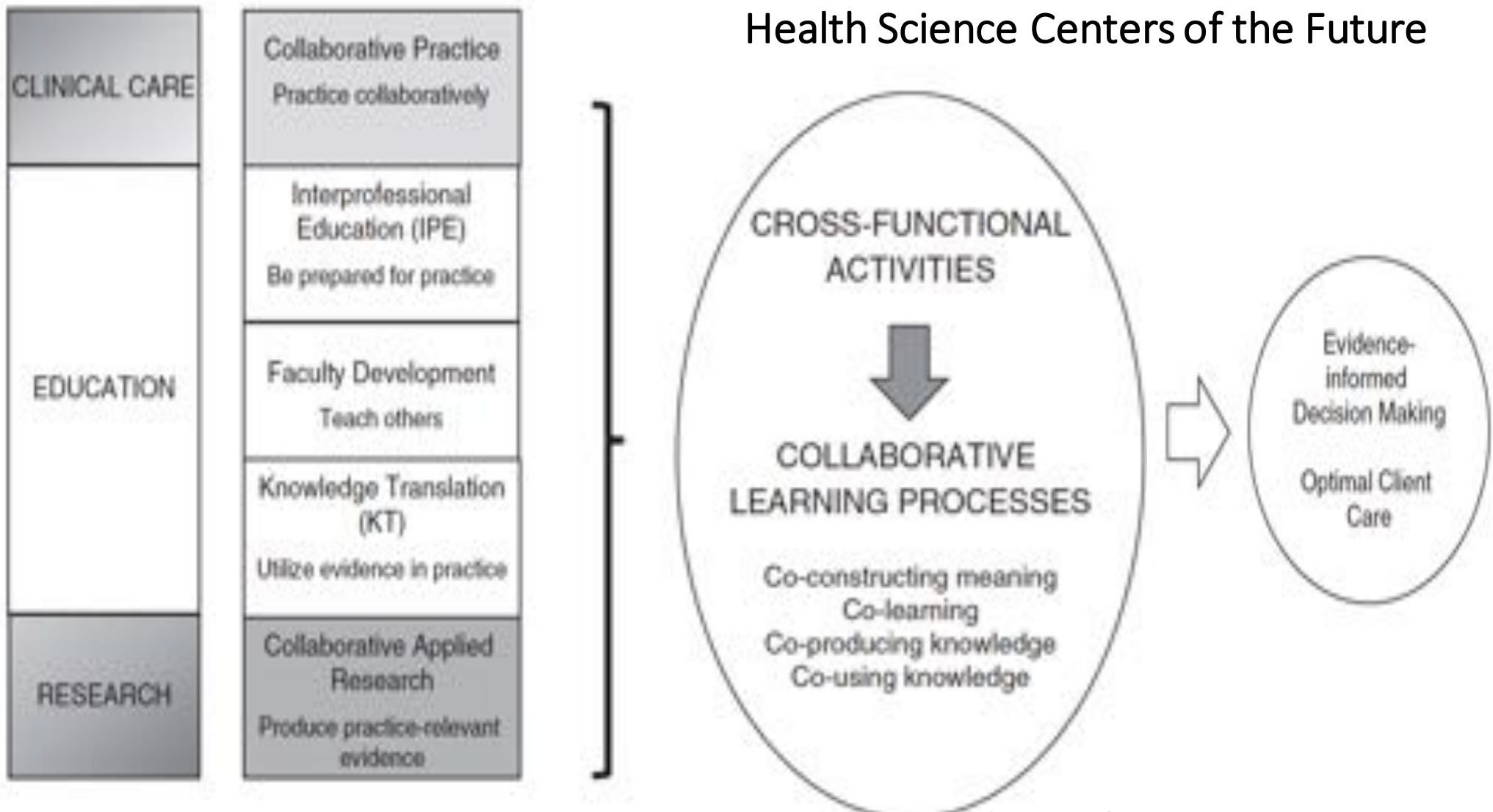


Adapted from the *Dietetics Career Development Guide*. For more information, please visit www.eatrightPRO.org/futurepractice

Utilities of this combination

- **Improving and promoting evidence-based decisions:** better use of the available evidence in combination with clinical expertise.
- **Enhancing workplace learning:** practice-based learnings (formal and informal learning activities)
- **“Collaborative advantages”:** a mechanism for self-organizing change, and improvements in organizational function, relational coordination, deliberative strategies.

Health Science Centers of the Future



King et al, 2016 Journal of Health Organization and Management

Teach Others - Professional Development

- ✓ Using Innovative and flexible ways to develop the level of education of current practitioners, such as problem-solving learning techniques.
- ✓ Engagement in activities that contribute to the academic agenda (such as renewing or assisting faculty in their teaching).

FROM THE ACADEMY

Position Paper

Position of the Academy of Nutrition and Dietetics: Interprofessional Education in Nutrition as an Essential Component of Medical Education

“The training and experience of RDNs make them uniquely qualified for the role of educating medical students about nutrition as it relates to health and disease”.

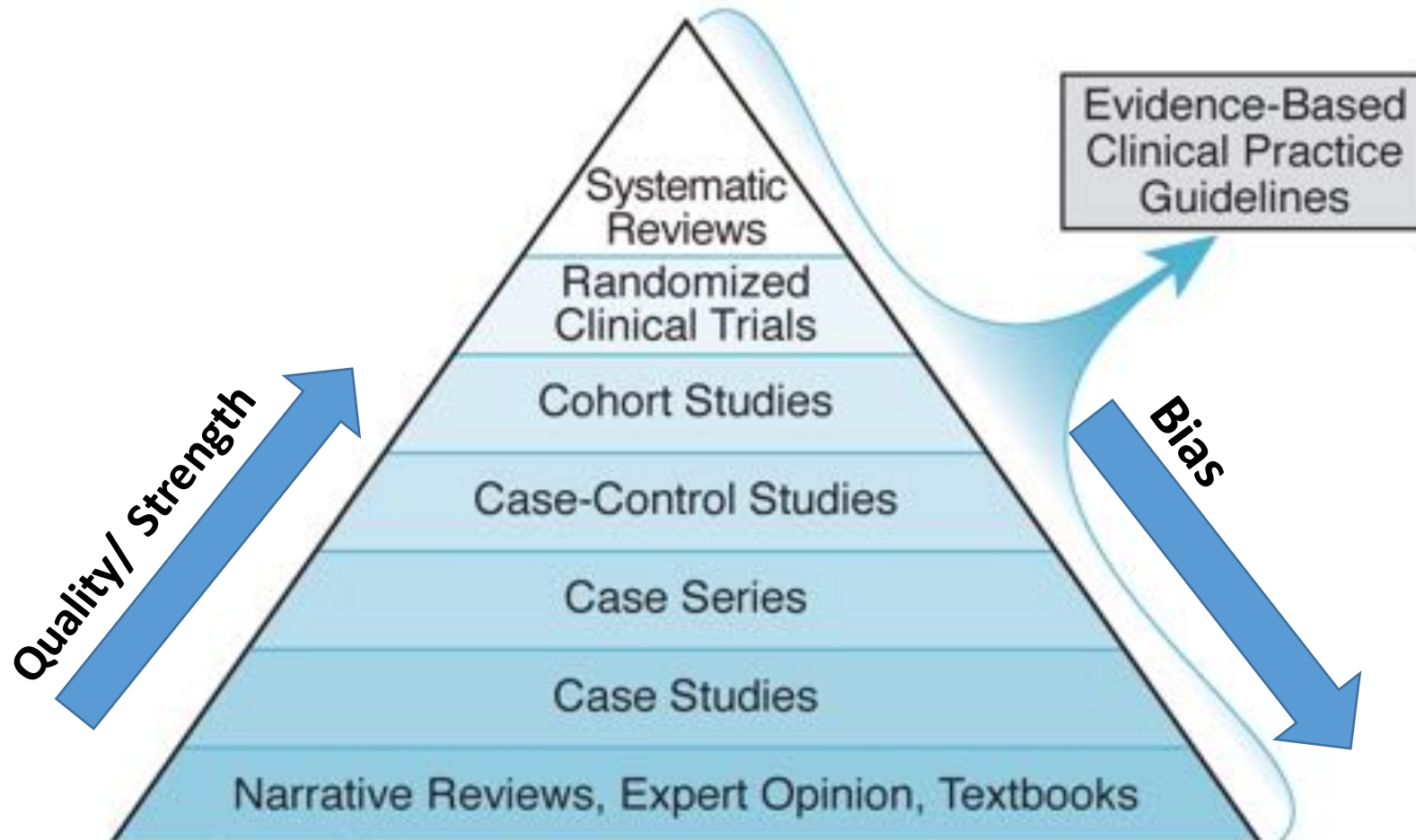
Utilize evidence in practice

- Its not easy! It takes an estimated 17 years to translate 14% of research discoveries into day-to-day practice!

So The degree to which the study bias is minimized so to produce valid estimates. **the translation of practice?** degree to which the y findings can be eralized to other populations.

- Understand the types of studies conducted.
- Understand the internal and external validity of a study.
- Interpretation of research results. The “strength of evidence pyramid”!

Research Evidence Pyramid
Intervention Studies



Source: Linda Fettes, Julie Tilson;
Evidence Based Physical Therapy,
www.FADavisPTCollection.com
Copyright © McGraw-Hill Education. All rights reserved.

Knowledge translation – Dietitians as communicators

- **Sharing of the knowledge generated from research and practice!**
- Share practical experiences and outcomes with budding professionals! Go beyond the syllabi and routine hospital internships...
- **How?**
- Public speaking/workshops.
- Use of information communication technologies.
- Educational material development.

Sharing best practices can raise the quality of dietetic education & practice!

Research: the backbone of dietetics

Are dietitians doing research?

- Actual participation is low (limited integration of research into practice).
- Even lower in activities higher on the research continuum, such as leading or supervising research projects.



Why?

Howard et al, 2013 J Hum Nutr Diet

Barriers to participation in research

Barriers to research ^a	Response				
	Major barrier	Barrier	Minor barrier	Not a barrier	Have not experienced
	n (%)				
Lack of interest in research (n=3,559)	272 (7.6)	514 (14.4)	786 (22.1)	1,467 (41.2)	520 (14.6)
Research seems overwhelming (n=3,555)	423 (11.9)	801 (22.5)	984 (27.70)	920 (25.9)	427 (12)
Structural barriers					
Lack of time (n=3,576)	1,069 (29.9)	1,287 (36)	585 (16.4)	271 (7.6)	364 (10.2)
Lack of ability to obtain funding (n=3,556)	738 (20.8)	910 (25.6)	593 (16.7)	277 (7.8)	1,038 (29.2)
Other work is more important (n=3,538)	979 (27.7)	1,108 (31.3)	717 (20.3)	364 (10.3)	370 (10.5)
Lack of administrative support to assist with process (n=3,564)	749 (21)	826 (23.2)	659 (18.5)	539 (15.1)	791 (22.2)
Lack of support from leadership at my place of employment (n=3,559)	676 (19)	654 (18.4)	621 (17.5)	723 (20.3)	885 (24.9)
Regulatory requirements such as human subjects' protection training (n=3,547)	329 (9.3)	502 (14.2)	673 (19)	1,093 (30.8)	950 (26.8)
Knowledge barriers					
Lack of understanding of research methodology (n=3,565)	275 (7.7)	726 (20.4)	1,039 (29.1)	1,113 (31.2)	412 (11.6)
Lack of understanding statistics (n=3,556)	346 (9.7)	807 (22.7)	1,177 (33.1)	825 (23.2)	401 (11.3)
Lack of understanding the IRB ^b process (n=3,559)	376 (10.6)	517 (14.5)	772 (21.7)	1,149 (32.3)	745 (20.9)
My training did not prepare me to conduct research (n=3,548)	358 (10.1)	467 (13.2)	781 (22)	1,285 (36.2)	657 (18.5)

^aTotal number of respondents to each question is specified in the first column.

^bIRB=Institutional Review Board.


Research capacity

Table 3 Department research capacity (scale: 1 = no skill/success to 10 = high skill/success)

Question: Please rate your team/department/unit's skill or success level for each of the following aspects selection a score on a 1–10 scale (1 = no skill/success and 10 = high skill/success): with respect to research, my department:	Overall, mean (SD) (n = 130)	Geographical location, mean (SD)		Research in role description, mean (SD)		Participation in research activities, mean (SD)	
		Metropolitan (n = 89)	Regional/rural/ remote (n = 41)	None (n = 98)	≥ 10% of position (n = 30)	0–4 activities (n = 107)	5+ activities (n = 24)
(i) Has adequate resources to support staff research training	5.0 (3.0)	5.7 (3.0)	3.8 (2.4)*	4.6 (2.9)	6.1 (2.6)*	4.9 (2.9)	5.5 (3.1)
(ii) Has funds, equipment or admin to support research activities	4.5 (2.8)	5.0 (2.8)	3.3 (2.3)*	4.1 (2.8)	5.6 (2.5)*	4.4 (2.7)	4.8 (3.0)
(iii) Has a plan or policy for research development	5.4 (3.0)	6.0 (2.9)	4.1 (2.7)**	5.0 (3.0)	6.5 (2.8)*	5.2 (2.9)	6.2 (3.3)
(iv) Has senior managers that support research	6.7 (3.0)	6.0 (2.9)	4.9 (3.0)***	5.4 (3.0)	6.4 (2.8)	5.5 (2.9)	6.2 (3.3)
(v) Ensures staff career pathways are available in research	6.9 (2.8)	7.3 (2.6)	6.1 (3.1)***	6.5 (2.9)	8.0 (2.2)*	6.8 (2.8)	7.2 (3.0)
(vi) Ensures organisational planning is guided by evidence	6.1 (2.9)	6.9 (2.7)	4.6 (2.6)**	5.7 (2.9)	7.4 (2.3)**	5.9 (2.8)	6.8 (3.0)***
(xv) Has regular forums/bulletins to present research findings	6.5 (2.7)	7.0 (2.4)	5.4 (2.9)*	6.2 (2.7)	7.4 (2.7)*	6.5 (2.6)	6.5 (3.2)
(xvi) Engages external partners (e.g. universities) in research	6.0 (2.8)	6.4 (2.7)	5.0 (2.9)***	5.6 (2.9)	6.9 (2.4)*	6.0 (2.8)	5.8 (3.1)
(xvii) Supports applications for research scholarships/degrees	6.6 (2.9)	7.3 (2.7)	5.1 (2.9)**	6.3 (3.0)	7.5 (2.5)***	6.4 (2.9)	7.4 (3.0)***
(xviii) Supports the peer-reviewed publication of research	7.0 (2.8)	7.6 (2.5)	5.7 (3.1)*	6.7 (2.9)	7.8 (2.4)***	6.8 (2.7)	7.6 (3.2)
(xix) Has software available to support research activities	5.0 (3.1)	5.7 (3.1)	3.5 (2.6)**	4.6 (3.0)	6.3 (3.0)**	4.8 (3.0)	6.0(3.4)***
Mean	6.1 (2.5)	6.7 (2.7)	4.9 (2.8)	5.8 (2.9)	7.1 (2.5)	6.0 (2.8)	6.6 (3.1)

Strategies to increase participation

- Get research on the agenda!
- Make research a priority.
- Build research knowledge and skills
 - Statistic knowledge
 - Knowledge of study design
 - writing proposals
- Collaborations/ Partnerships.



**More research,
better practice,
more acceptance of
new knowledge!**

Collaborative Applied Research

Which are your objectives?

- Develop new methodologies and approaches to address clinical challenges
- Improve the quality of the research.
- Maintain a clear focus on policy and practice.
- Support new researchers, and do so in a way that ensures that progress is maintained.

Collaborative practice

Is defined as a situation that occurs “when multiple health workers from different professional backgrounds work together with patients, families, carers, and communities to deliver the highest quality of care.”

World Health Organization 2010

What we can do?

- Which are the expectations of our team members.
- Assess the structure and communication of your unit during interprofessional meetings.
- Identify gaps.
- Plan opportunities to discuss how lack of interprofessional collaboration affects patient care.
- Initiate action to improve team competency in interprofessional collaboration.

Linda Bell, Am J Crit Care 2014

Cystic Fibrosis
in children



Our department experience!

The cystic fibrosis department

The Department was established in 1961 (57 years).

➤ **1961 – 1986 (as a clinic)**

~ 8.000 sweat tests, 415 CF patients

➤ **1987 – 2018 (as an autonomous department)**

>30.000 sweat tests, >650 CF patients



**300 CF
children
every year!**

Totally: Over 1000 CF patients!

The Multidisciplinary team of cystic fibrosis departments



Adapted from Cystic Fibrosis Foundation
<https://www.cff.org/Care/Your-CF-Care-Team/>

Our Multidisciplinary team

Parallel clinics twice a week.



2 dietitians in the cystic fibrosis clinic!

Dr. Ioanna Loukou - The last 2 years!

Collaborative practice

- Interprofessional discussions before and after clinics.
- Meet the expectations of our team members.
- Constantly assess the literature.



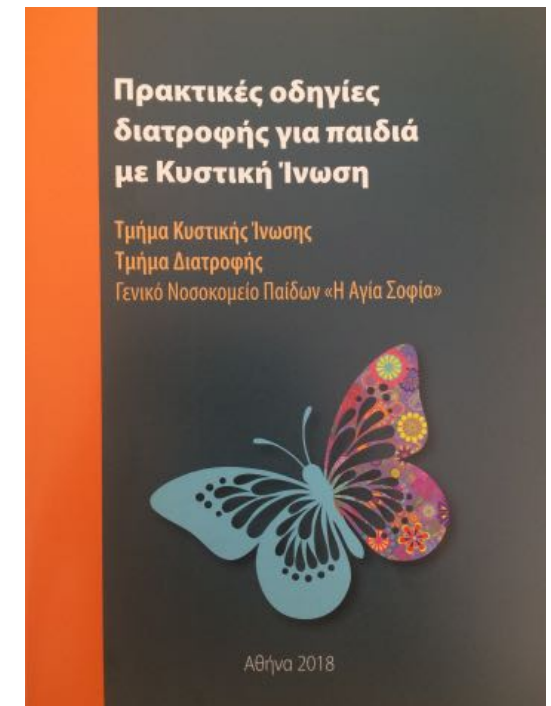
Education

- ✓ 1st workshop in cystic fibrosis (funding from several companies).
- ✓ Interprofessional education meetings once a month!
- ✓ Assisting university faculty in cystic fibrosis teaching every semester.



Education

- ✓ Development of appropriate educational material.



Next steps:

1. Create more internships positions.
2. Create a website with interactive education courses, presentations, videos etc.

Collaborative research

- Harokopio University of Athens, Greece
(Prof. Mary Yannakoulia)



Collaborative research

“Assessment of dietary habits and dietary patterns of children with Cystic Fibrosis and their association with clinical and laboratory characteristics of cystic fibrosis patients”.

Methods

At baseline and 1-year after the initial entry:

- Anthropometric and clinical assessments.
- Four 24-hour recalls at the beginning and and 1-year after the initial entry.
- Pancreatic enzyme replacement therapy assessments (in case of pancreatic insufficiency)
- Physical activity evaluation using the Self-Administered Activity Checklist.
- Blood collections (evaluation of biochemical markers, lipidemic profile, glucose metabolism and vitamin status).
- Evaluation of the pulmonary function (Forced Vital Capacity through spirometry).

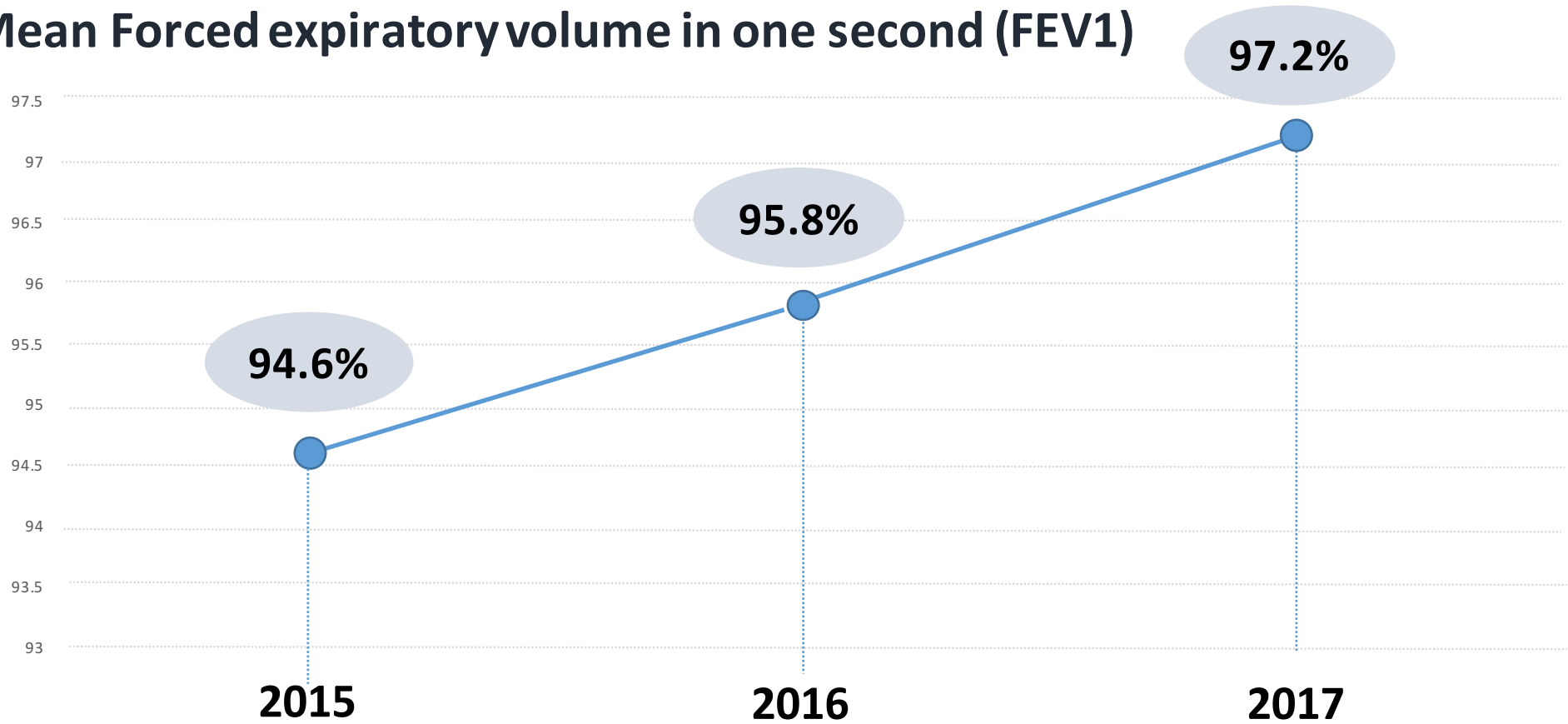
Preliminary findings (n=50)

Variable	Result	Guidelines
Energy intake based on EAR	130%	120-200% of EAR for energy
Energy from fat/day	45	35-40
Energy from Carbohydrates/day	40	40-45
Energy from protein/day	15	20

- 58% of our children have BMI above the 50th percentile.
- Children with pancreatic insufficiency have higher energy and protein intake compared to children with pancreatic sufficiency ($P < 0.05$). Energy comes from dairy products, eggs, olive-oil, sweets.
- Effective pancreatic enzyme replacement therapy. Lipase units per kg BW/ g of fat/ meal?
- Level of physical activity?

Does this hard work affect our patients?

Mean Forced expiratory volume in one second (FEV1)



Special thanks

Agia Sofia Children's Hospital

- Dr. Ioanna Loukou, MD
- Dr. Maria Moustaki, MD
- Dr. Argiri Petrocheilou, MD
- Ioanna Tokou, MSc
- Kimonas Sfigos
- Tzeni Troupi

Harokopio University of Athens

- Prof. Mary Yannakoulia
- Papachristou Eleftheria, MSc
- Kokkinou Elpida, BSc



Thank you very much
for your attention!