



International Seminar on food allergy and coeliac disease

Milan, 11th September 2015



Association of European Coeliac Societies:

Networking to support people with coeliac disease

Tunde Koltai
AOECS Board, Chair

-
- European umbrella organisation of national coeliac societies in Europe
 - Independent NGO
 - Established in 1988
 - Registered seat in Brussels
 - 5 Board members
 - 35 members from 29 European countries
 - represents more than 300.000 coeliacs across Europe



AOECS



-
- Member of International networks: European Patients' Forum (EPF), International Alliance of Patients' Organisations (IAPO), International Society for the Study of Celiac Disease (ISSCD)
 - Partner scientific projects: PREVENTCD, CDMEDICS, TRAFOON, MEDICEL, ProCeDE
 - Partner of EU and national institutions

AOECS Aims

- To increase awareness of coeliac disease
- To facilitate the exchange of information relating to the coeliac condition
- To increase the availability and easily identifiable labelling of gluten-free products

2010 Survey

by the Netherlands Coeliac Society

Where can one find trustworthy information on Coeliac Disease?

1. Specialist
2. General Practitioners
3. Coeliac Society
4. Gluten-free producers
5. Dietitian
6. Health insurance companies

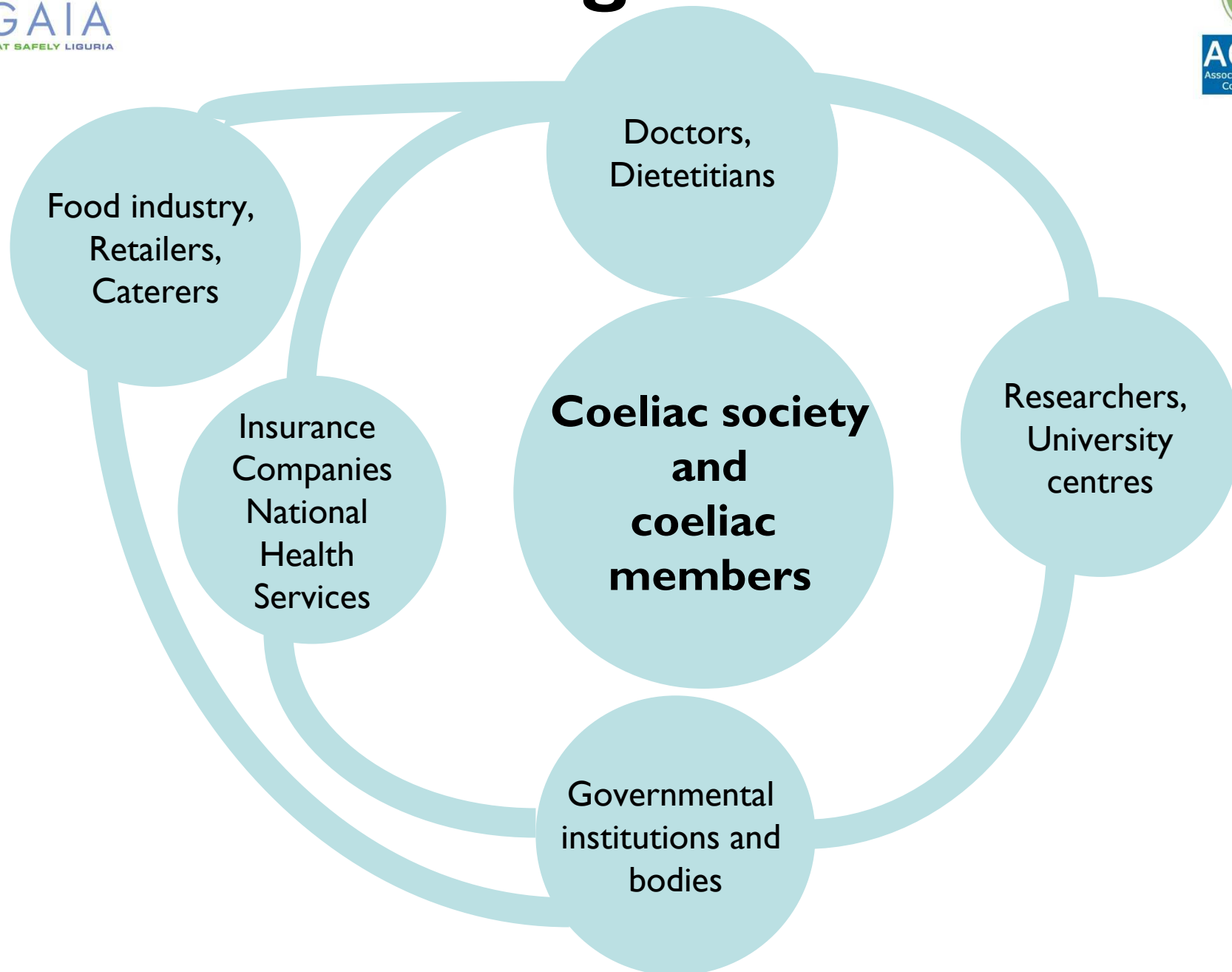
2014 Survey

by the Netherlands Coeliac Society

Where can one find trustworthy information about Coeliac Disease?

1. Specialist
2. Coeliac Society (↑)
3. Dietitian (↑)
4. General Practitioners (↓)
5. Gluten-free producers (↓)
6. Health insurance companies

Patient organisations 3.0



Gluten

Storage protein of cereals:

wheat, rye, barley and [oats*]

Can cause

- **Intolerance**

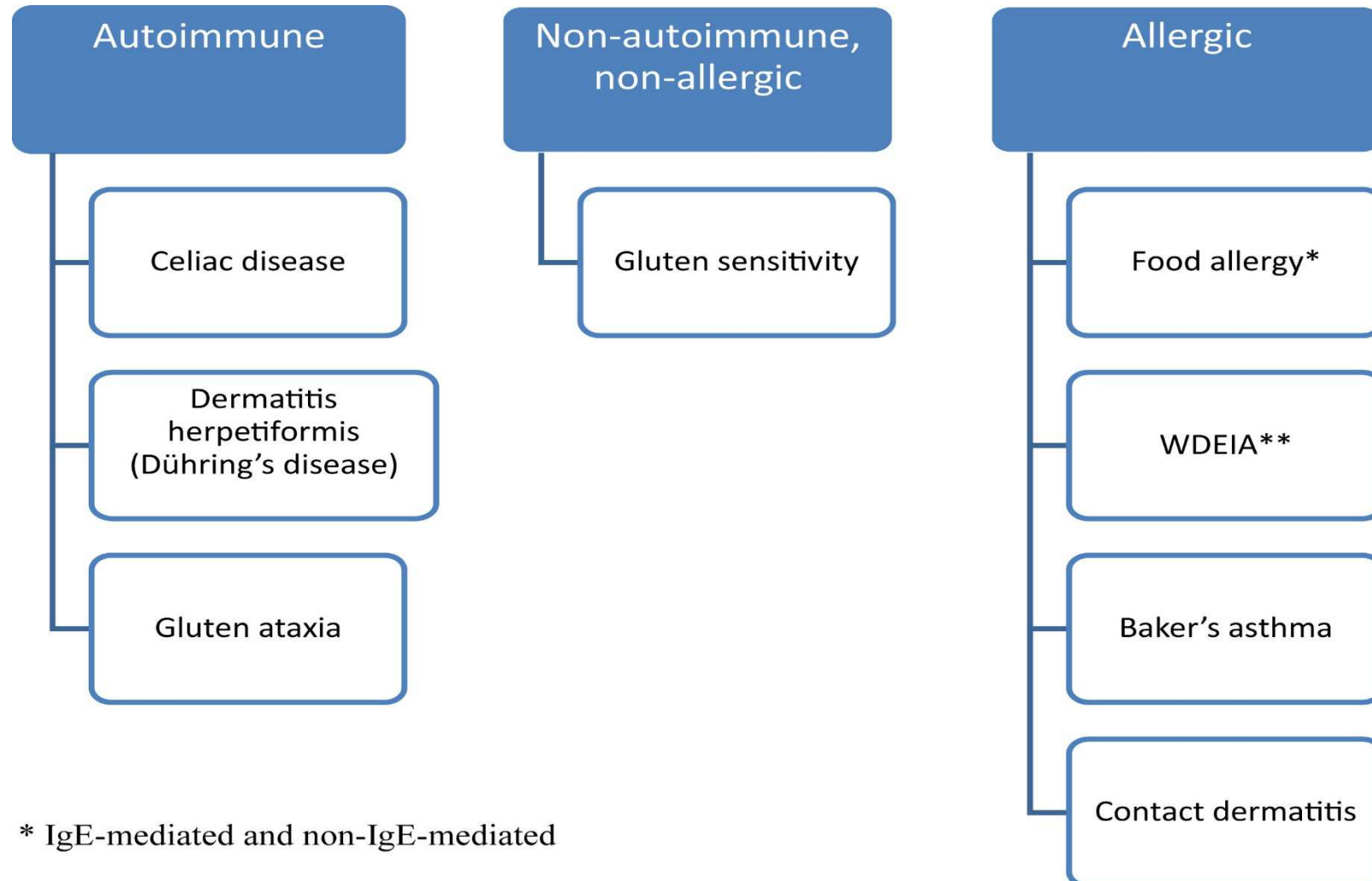
Threshold: 10 mg/day

- **Allergy** (is species specific)

Threshold: 0 (?!)/different sensitivity levels

* Oats can be tolerated by most but not all people who are intolerant to gluten. Therefore, the allowance of oats that are not contaminated with wheat, rye or barley in foods covered by this standard may be determined at the national level.

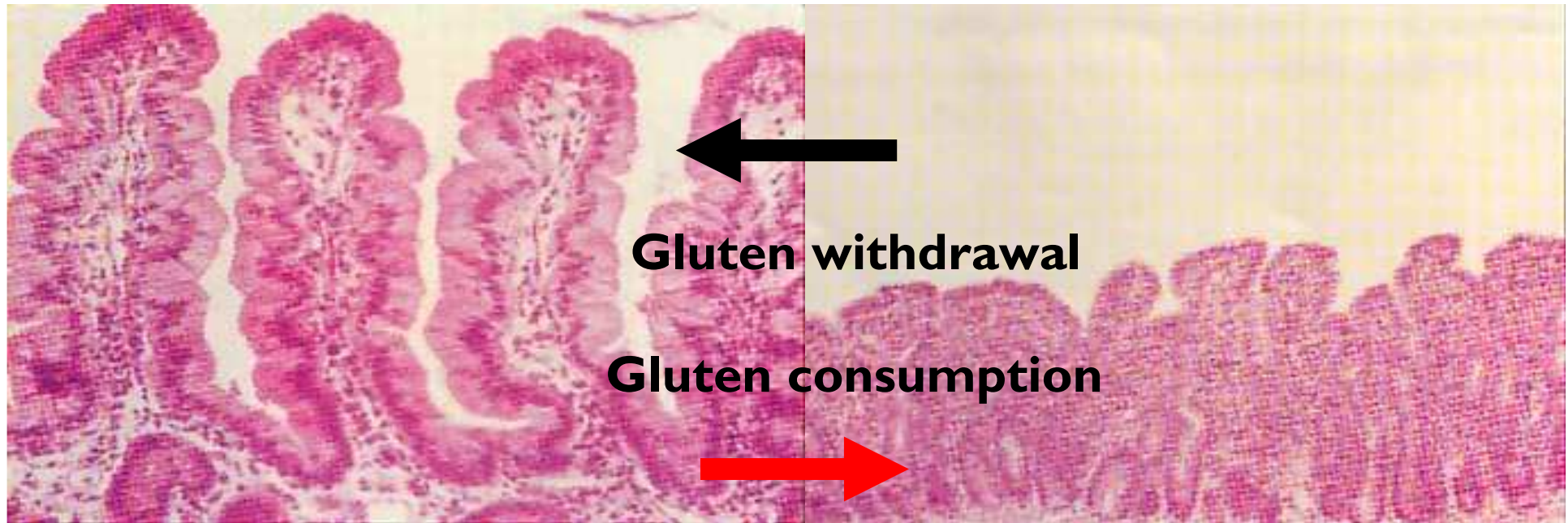
Gluten related disorders



* IgE-mediated and non-IgE-mediated

**wheat dependent exercise induced anaphylaxis

Coeliac disease is a medical, lifelong condition



Healthy villi

Villous atrophy of coeliac patients

Medication?



Treatment

The unique and evidence based treatment:

Lifelong and strict gluten-free diet

**Never start a gluten-free diet before the
diagnosis or exclusion of coeliac
disease or cereal (protein) allergy**

Challenges for coeliac patients

- Late diagnosis
- Frequent misdiagnosis
- Complications and associated diseases
- Psycho-social problems



Challenges of the gluten-free diet

- Maintaining a strict and lifelong avoidance of gluten
- Availability
- Cost
- Nutritional adequacy
- Identification of safe gluten-free products

Pricing of specialized gluten-free foods

The first step: „the Basket”

Based on their availability across Europe, five products of the Dr. Schaer company were selected:

- Pasta – penne - 500 g
- Flour 1 kg
- Baguette 2x175g
- Bread panini 200g
- Biscuits Frollini 200g



Pricing of specialized gluten-free foods



The second step: the costing survey

Working Group participants were asked to compile prices from supermarkets /groceries/ pharmacies in their capital cities during the same week, i.e. 23 February to 1 March 2015.

If a product was not available during the week of the survey, it could be replaced by a similar product in weight and type.

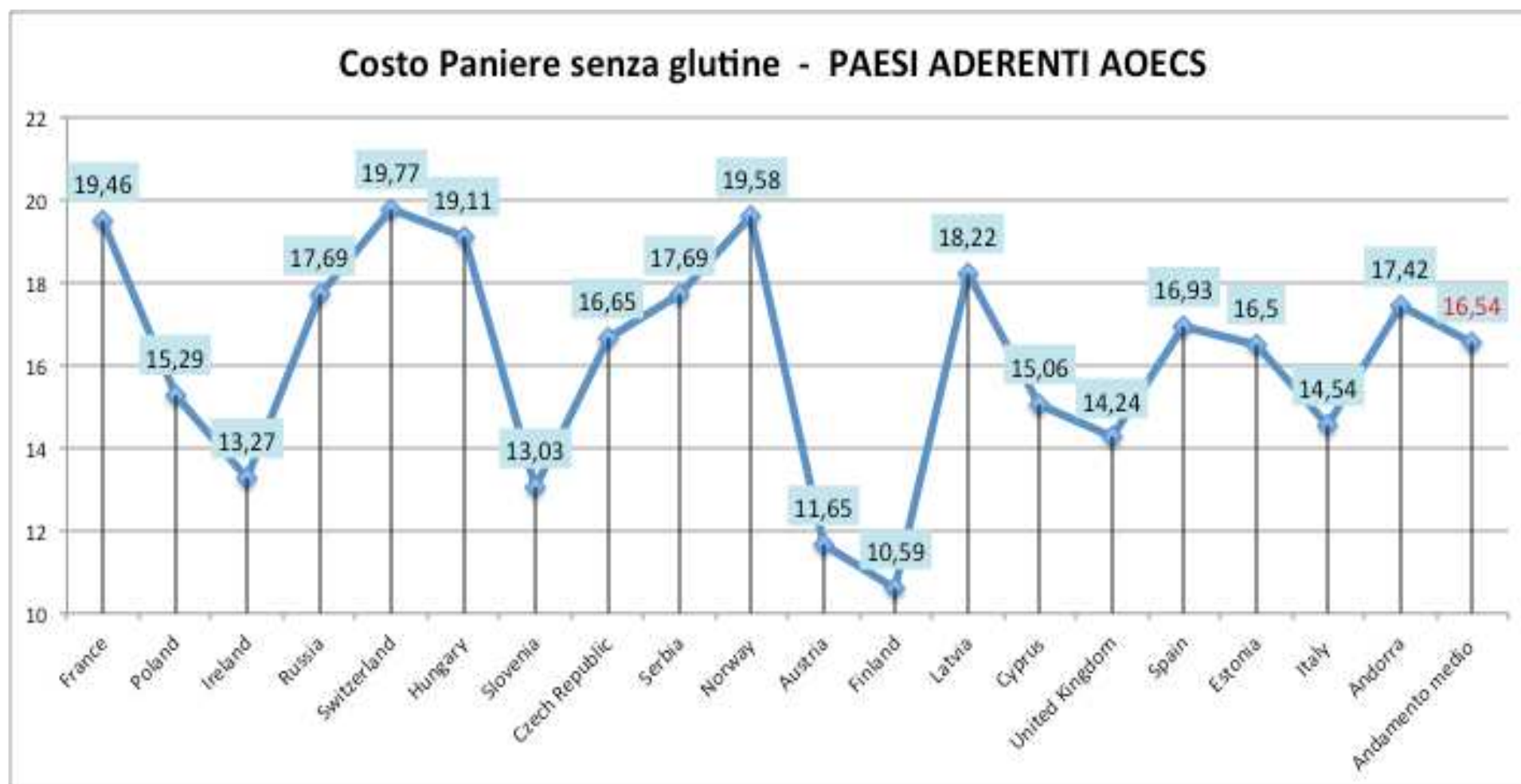
Pricing of specialized gluten-free foods

The third step: results

- Participating countries: France, Italy, Poland, Ireland, Russia, Switzerland, Hungary, Slovenia, Czech Republic, Serbia, Norway, Austria, Finland, Latvia, Cyprus, United Kingdom, Spain, Estonia, Andorra
- Prices obtained were converted into Euros (€) for reasons of comparison.

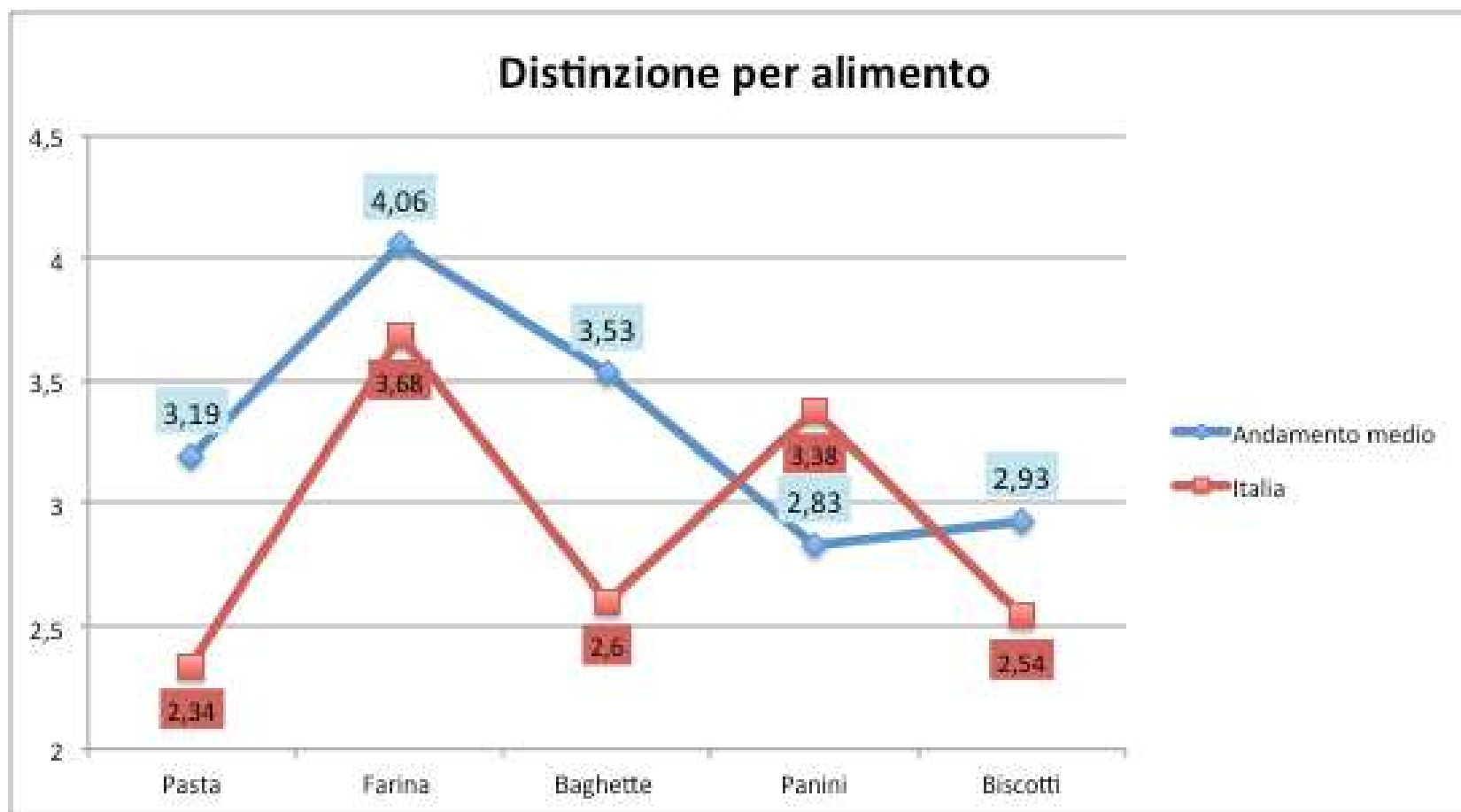
Pricing of specialized gluten-free foods

The total value of the basket



Pricing of specialized gluten-free foods

The average price of each item was compared to pricing in Italy





Pricing of specialized gluten-free foods



Conclusions:

- Countries in which the basket was more expensive: France, Hungary, Norway, Switzerland.
- Countries with lower prices were: Austria, Finland, Ireland and Slovenia.

It could be interesting to further assess the markets in order to understand market processes, learn best practices to be applied in other countries etc.



Pricing of specialized gluten-free foods



Proposals:

- Compare data collected vs. number of products available
- Compare GF food prices with the average cost of living in every country
- Repeat the survey every year
- Collect prices in a representative small city in each country

Gluten-free regulation



2008: Codex Standard 118-1979

World-wide



„Codex Standard for foods for special dietary use for persons intolerant to gluten”



EU regulations



COMMISSION REGULATION (EC)

No 41/2009 of 20 January 2009

**concerning the composition and labelling
of foodstuffs suitable for people intolerant
to gluten**

1169/2011 regulation (FIC)

Regulation (EU) 1169/2011 of the European Parliament and the Council of 25 October 2011

on the provision of food information to consumers, amending Regulations (EC) No 1924/2006 and (EC) No 1925/2006 of the European Parliament and of the Council, and repealing Commission Directive 87/250/EEC, Council Directive 90/496/EEC, Commission Directive 1999/10/EC, Directive 2000/13/EC of the European Parliament and of the Council, Commission Directives 2002/67/EC and 2008/5/EC and Commission Regulation (EC) No 608/2004

1169/2011 regulation (FIC)

Brings together existing regulations
regarding

- Labelling
- Nutrition
- Allergen information

Not only for pre-packed food

“Big 14” food allergens

Annex II

Gluten containing cereals



Crustaceans



Egg



Fish



Peanuts



Soybeans



Milk (casein and lactose)



Nuts



Celery



Mustard



Sesame seed

Lupin



Molluscs



SO₂ and sulfits



New PARNUT



Regulation (EU) No. 609/2013 of the European Parliament and the Council of 12 June 2013 on food intended for infants and young children, food for special medical purposes, and total diet replacement for weight control and repealing Council Directive 92/52/EEC, Commission Directives 96/8/EC, 1999/21/EC, 2006/125/EC and 2006/141/EC, Directive 2009/39/EC of the European Parliament and of the Council and Commission Regulations (EC) No 41/2009 and (EC) No 953/2009

New PARNUT

-
- (a) infant formula and follow-up formula
 - (b) processed cereal-based food and baby food
 - (c) food for special medical purposes
 - (d) total diet replacement for weight control

Gluten-free foods are no longer included in its scope.

Delegated regulation

COMMISSION DELEGATED REGULATION (EU) No 1155/2013 of 21 August 2013

amending Regulation (EU) No 1169/2011 of the European Parliament and of the Council on the provision of food information to consumers as regards information on the absence or reduced presence of gluten in food

Consequences

Commission Regulation (EC) No 41/2009 sets out harmonised rules on the information that is provided to consumers on the absence or reduced presence of gluten in food. Regulation (EU) No 609/2013 of the European Parliament and of the Council foresees the **repeal of Regulation (EC) No 41/2009 from 20 July 2016**

and

In the first subparagraph of **Article 36 of Regulation (EU) No 1169/2011**, the following point (d) is added:

‘(d) information on the absence or reduced presence of gluten in food.’

International Trade Mark



Registered by Coeliac UK and AOECS



European Licensing System (ELS)



- ✓ The ELS Charta was accepted by the AOECS General Assembly in Malta in 2009
- ✓ Regulates the use of the Crossed Grain Symbol on gf food products across all countries in which AOECS Member societies are located (AOECS territory)
- ✓ Permits the use of the Symbol across the entire AOECS territory with **one license contract**



European Licensing System (ELS)



- ✓ The Crossed Grain symbol conveys a safety guarantee for coeliacs by communicating that licensed GF products must comply with the AOECS Standard
- ✓ Provides unified licensing conditions across AOECS territory
- ✓ Increases availability of GF food products featuring the Symbol across Europe

European Licensing System (ELS)



License numbering
Country code-license code-product code

For example for Italy
IT-100-001



European Licensing System (ELS)



ELS components consist of:

- AOECS Standard
- AOECS Charta
- AOECS-Member society license contract for the sub-licensing of the Crossed Grain symbol
- AOECS Member-Producer license contract for the use of the Crossed Grain symbol



European Licensing System (ELS)



Data as per 31 December 2014

- 21 Member societies have signed the AOECS Charta
- +300 producer contracts signed
- +5000 gluten-free products licensed

GOOD GLUTEN-FREE

Majority of (daily) gluten-free products contain more salt, sugar and fat than regular products

„More than taking gluten out of your diet”



GOOD GLUTEN-FREE

For those who go GLUTEN-FREE as part of their life-style:

1. Organic
2. Healthy
3. Tasty
4. Safe
5. Available
6. Good price/value ratio

Gluten is everywhere!



Gluten-free accreditation of the catering sector



Coeliac UK

<https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/eating-out/gf-accreditation/>



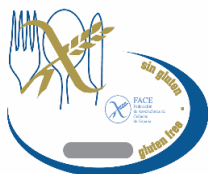
AIC Italy

<http://www.celiachia.it/dieta/Dieta.aspx?SS=95&M=1280>



DZG Germany

<http://www.dzg-online.de/glutenfreie-ernaehrung.7.0.html>



FACE Spain

<http://www.celiacos.org/restaurante.s.html>



SMAP Spain

https://www.celiacscatalunya.org/ca/establiments_certificats



IGZ Switzerland

<http://www.zoeliakie.ch/index.php/gastronomie-mitgliedschaft>



LEOE Hungary

<http://www.liszterzekeny.hu/tiki-index.php?page=%20GF%20Hotels%2C%20Restaurants%20and%20Pizzerias&structure=%20Gluten-free%20in%20Hungary>



AFDIAG France

<http://www.afdiag.fr/restaurateurs/>

Thank you for your kind attention!

www.aoecs.org

e-mail: theboard@aoecs.org
tunde.koltai@t-online.hu