



# Coeliac disease: the patient perspective

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## About Coeliac UK



We are the oldest and largest coeliac disease charity in the world.

We have been working for people with coeliac disease and dermatitis herpetiformis (DH) for nearly 50 years.



We have around 80 Local Voluntary Support Groups across the UK.

We are not government funded and rely on our Members and the generosity of our fundraisers and supporters to continue our work.



We have offices in England, Scotland and Wales.

# 1968



We are a founding Member of the Association of European Coeliac Societies (AOECS).



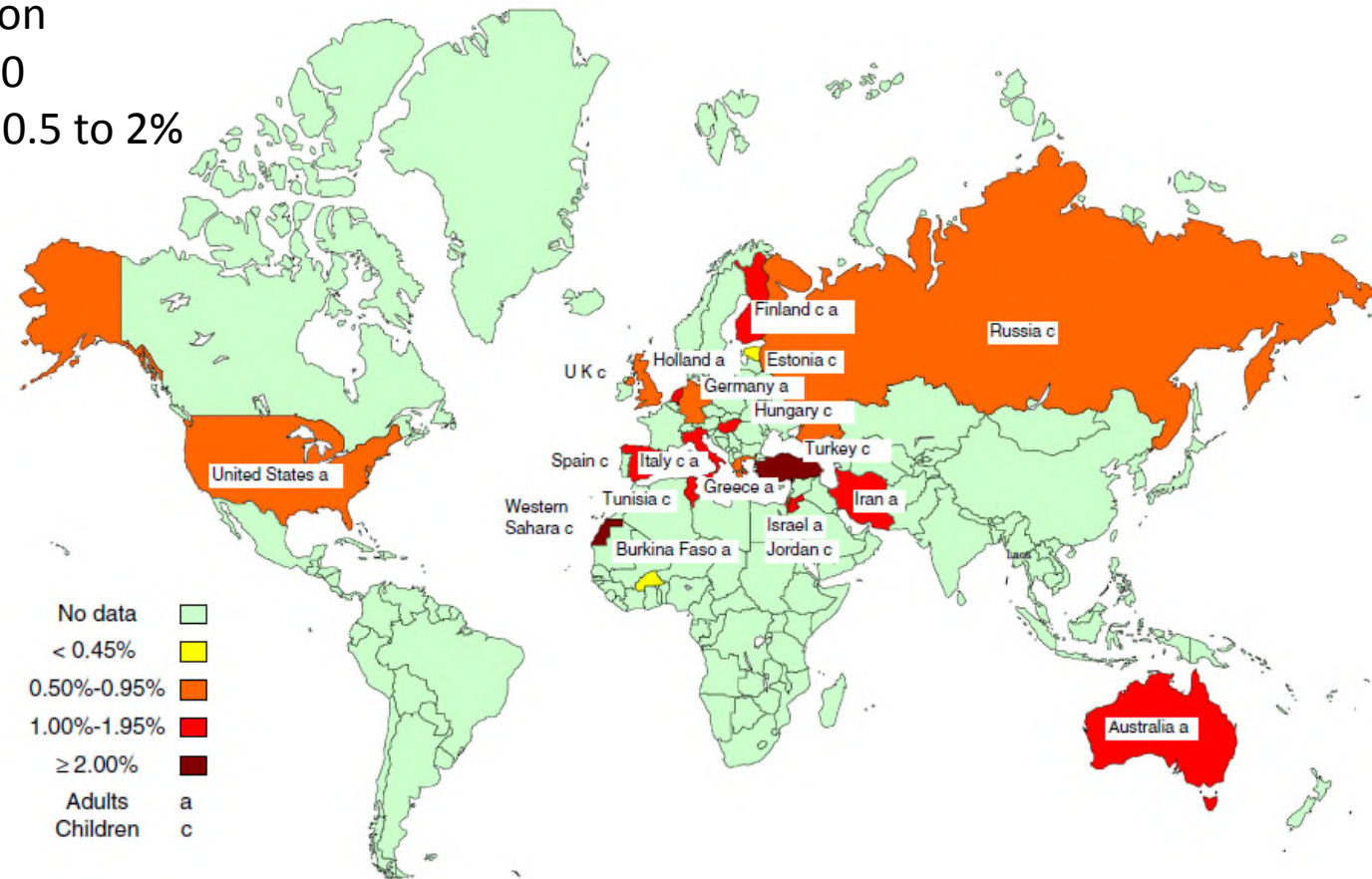
## Developing mission

- Coeliac UK founded in 1968 – primary function to provide food information
- Key developments:
  - 2005 allergen labelling legislation
  - 2008 revised Codex standard
  - 2009 law on gluten-free
  - 2014 Food Information Regulations

→ **Improved safety, improved choice**
- Today – provide support, campaign, influence, research
- Aim to remove restrictions

# Prevalence of coeliac disease

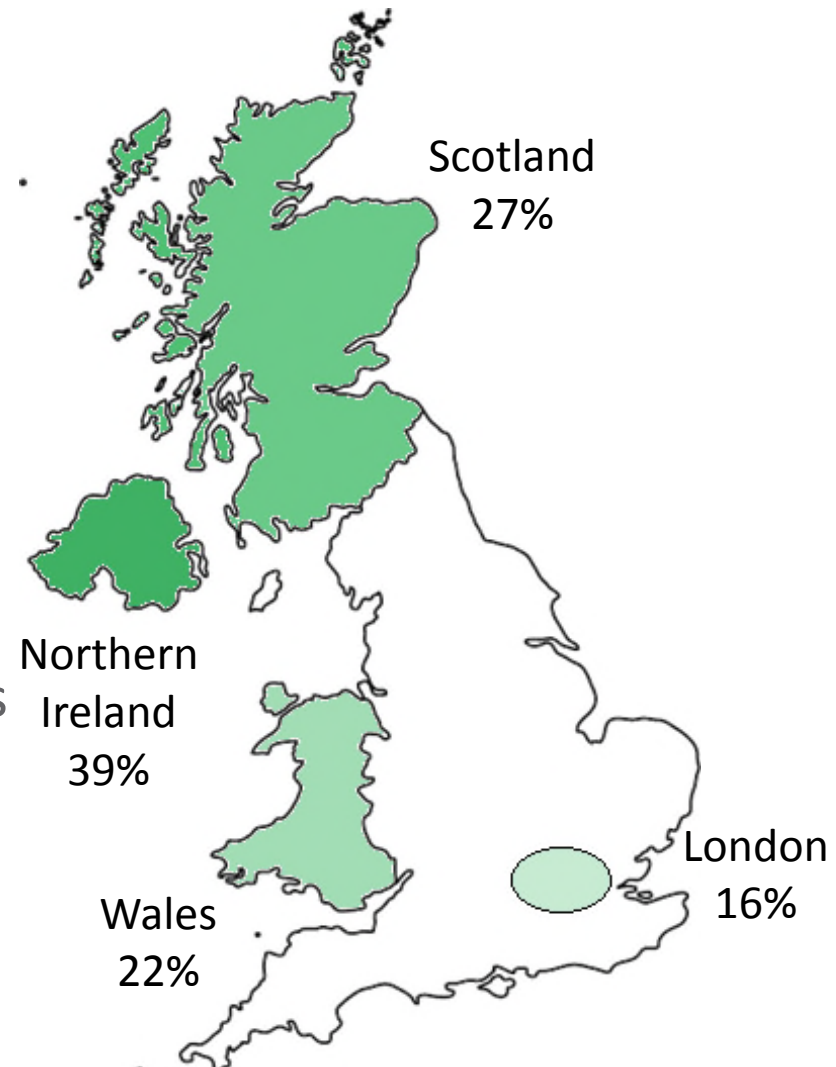
- CD is common
- UK – 1 in 100
- Varies from 0.5 to 2% in Europe



Kang et al. 2013

## Diagnosis rates

- Diagnosis rates are low but improving
- Variation in diagnosis, even within the UK
- London 16%
- Northern Ireland 39%
- Common and more awareness will lead to more people following a GF diet



West et al. 2014



## Symptoms and complications

- Osteoporosis – low bone mineral density can affect up to 75% of people at diagnosis with coeliac disease
- Secondary lactose intolerance
- Undiagnosed CD may be an underlying cause of unexplained fertility
- Intestinal malignancy
- Plus day to day symptoms affecting quality of life...



## Treatment

- Gluten-free diet is the complete treatment for coeliac disease
- Improves symptoms, quality of life
- Helps to treat complications and nutritional deficiencies
- Minimises the risk of complications including osteoporosis and malignancy – after 5 years on a gluten-free diet
- Provision of a balanced nutritional intake



## The gluten-free diet

- Wide variety of foods that can be eaten
- Naturally gluten-free foods – fruit, veg, meat, poultry, fish, pulses, rice, eggs, milk, cheese
- ‘Mainstream’ foods made from no gluten-containing ingredients
- Gluten-free staples – pasta, bread, crackers, biscuits, cakes
- Commonly made from:
  - Corn, rice, potato, soya
  - Also buckwheat, millet, sorghum, quinoa
- But it is still not easy...



## Issues affecting people with coeliac disease

- Restricted diets can be difficult to follow
- Adherence to the GF diet varies:
  - Up to 80% of people admitted to occasional or prolonged lapses
  - Studies report 42-91% for strict adherence
- Factors affecting adherence:
  - Knowledge of the GF diet
  - Cost, access, and availability
  - Taste and texture of GF foods
  - Eating out of the home



## Gluten-free diet

**What areas do our Members want to see researched? What questions do they want answered?**

- Can wheat, barley and rye be genetically modified to become GF, safe to eat?
- Why does GF food cost so much more than gluten containing?
- Can the fat content of GF bread be reduced?



## Summary

- Coeliac disease is common, 1 in 100 people affected, many more still to be diagnosed
- The GF diet is a complete treatment
- EU labelling laws have made it easier – safer environment
- People cope differently with the transition to a GF diet
- GM developments must consider safety and variety of foods for people with CD
- Clear guidance for the industry – must keep up to date with latest science
- Potential positive benefits in this area – GM modified grains
- Need for clear communication to consumers



Thank you or listening

Any questions?