

**Dietetic Update for
Coeliac UK Local Group
11.10.16**

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Prescriptions

Current situation

- Coeliac UK and the British Dietetic Association recommends provision of gluten free foods on prescription
- Historically, this has been provided on the NHS
- Since NHS finances have hit the black, many CCGs have reduced or stopped gluten free food on prescription
- Cornwall has just stopped
- South Devon & Torbay have stopped prescription for adults, (reduced amounts and limited choice for children)
- Eastern (& ? Northern) are going out to consultation on whether prescriptions continue

Why are GF products available on prescription?

- Gluten containing foods are a staple in the UK diet (removing them has much more of an effect than milk, egg, soya or other 'allergens')
- Historically GF items were not available to buy over the counter
- More recently, they have become widely available in large supermarkets
- GF items where available were/are much more expensive
- Some ranges only available on prescription e.g. Juvela

Prescriptions

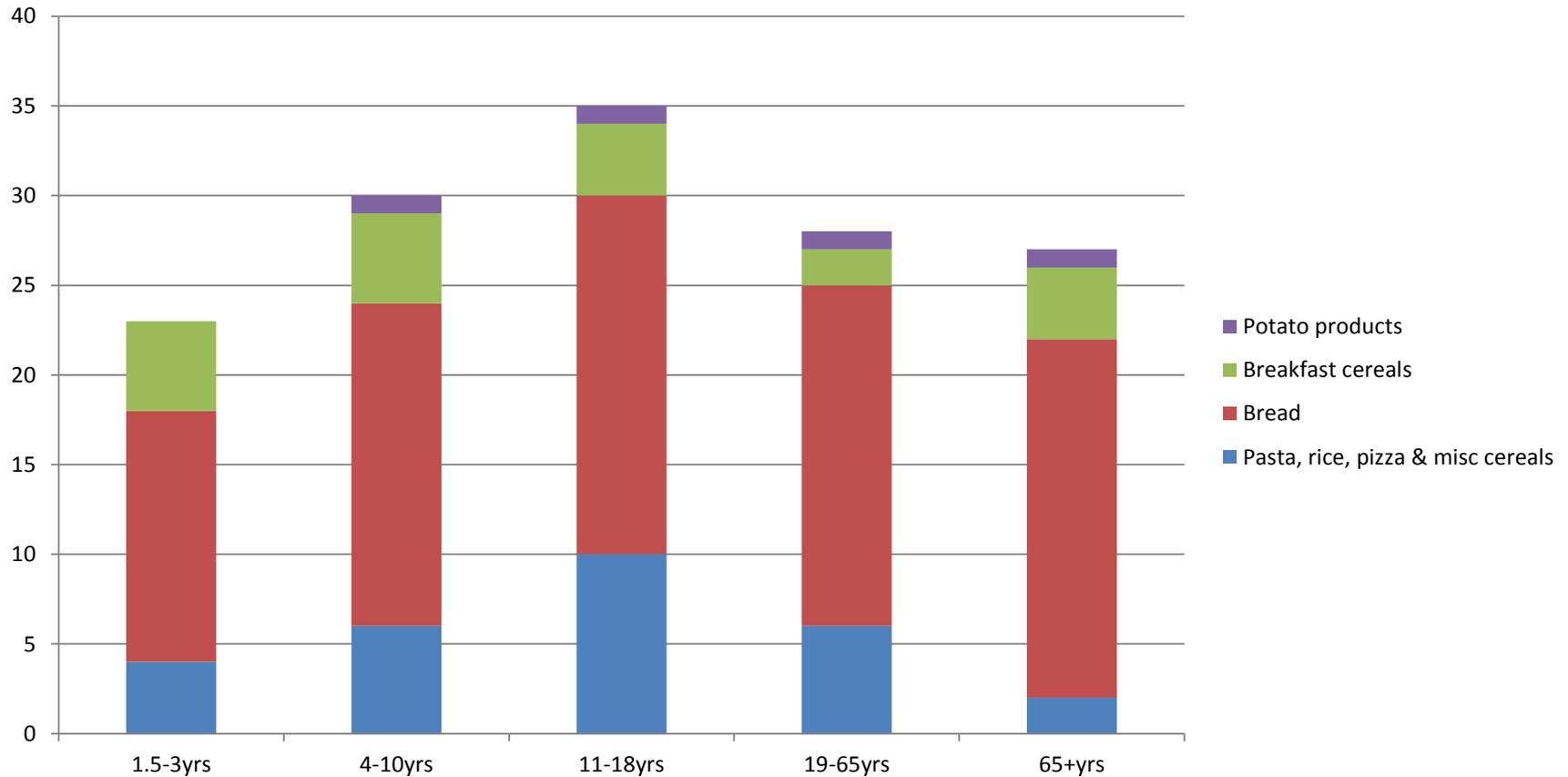
- What contribution to carbohydrate-containing foods make to the UK diet?
- Do gluten free foods cost more?
- What contribution do gluten free foods make to the diets of people with coeliac disease?
- Are current GF food provisions excessive?
- How much gluten free prescription food do coeliacs consume?

Why are carbohydrates important?

- The National Diet & Nutrition Survey
- The NDNS programme began in 1992 and comprised a series of cross-sectional surveys, each covering a different age group:
 - pre-school children (aged 1.5 to 4.5 years) - data collection 1992-1993
 - young people (aged 4 to 18 years) – data collection 1997
 - adults (aged 19 to 64 years) – data collection 2000-2001
 - older adults (aged 65 years and over) – data collection 1994-1995
 - AND Low Income Diet and Nutrition Survey 4+ years – data collection 2003-2005
- Since 2008 the NDNS has been a rolling programme for people aged 1.5 years and over. So far, collated data from 2008- 2014 has been published in years 1-6
- From the NDNS, we know how much people are eating, and what those foods provide nutritionally
- **THESE ARE PEOPLE WITHOUT COELIAC DISEASE**

Calcium

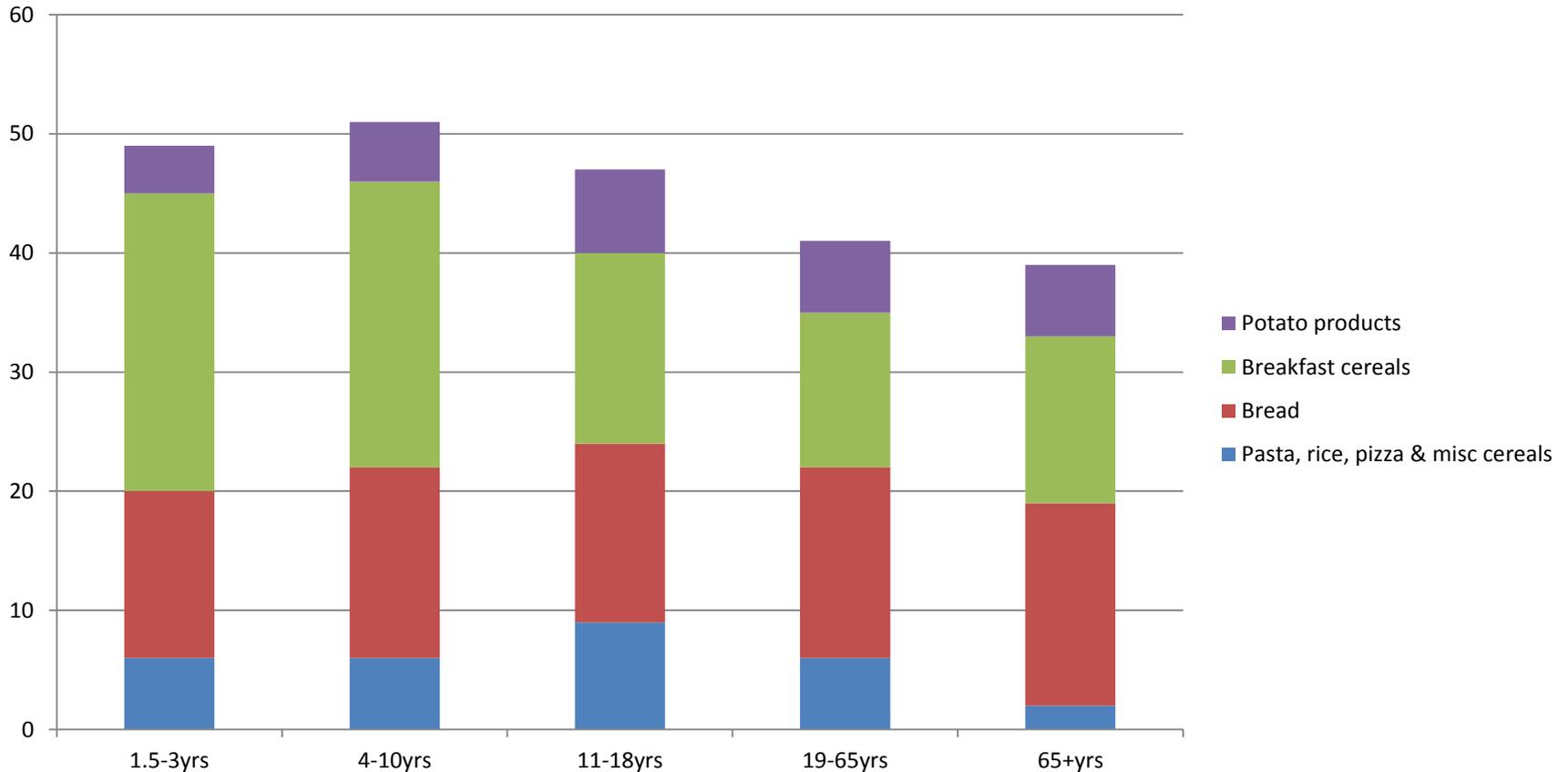
% contribution of food groups to average calcium intake



Bread is a significant contributor to calcium intakes in the UK – reducing intake of bread would impact on calcium intake and thus bone health. Ideally, GF bread needs to be fortified with calcium

Iron

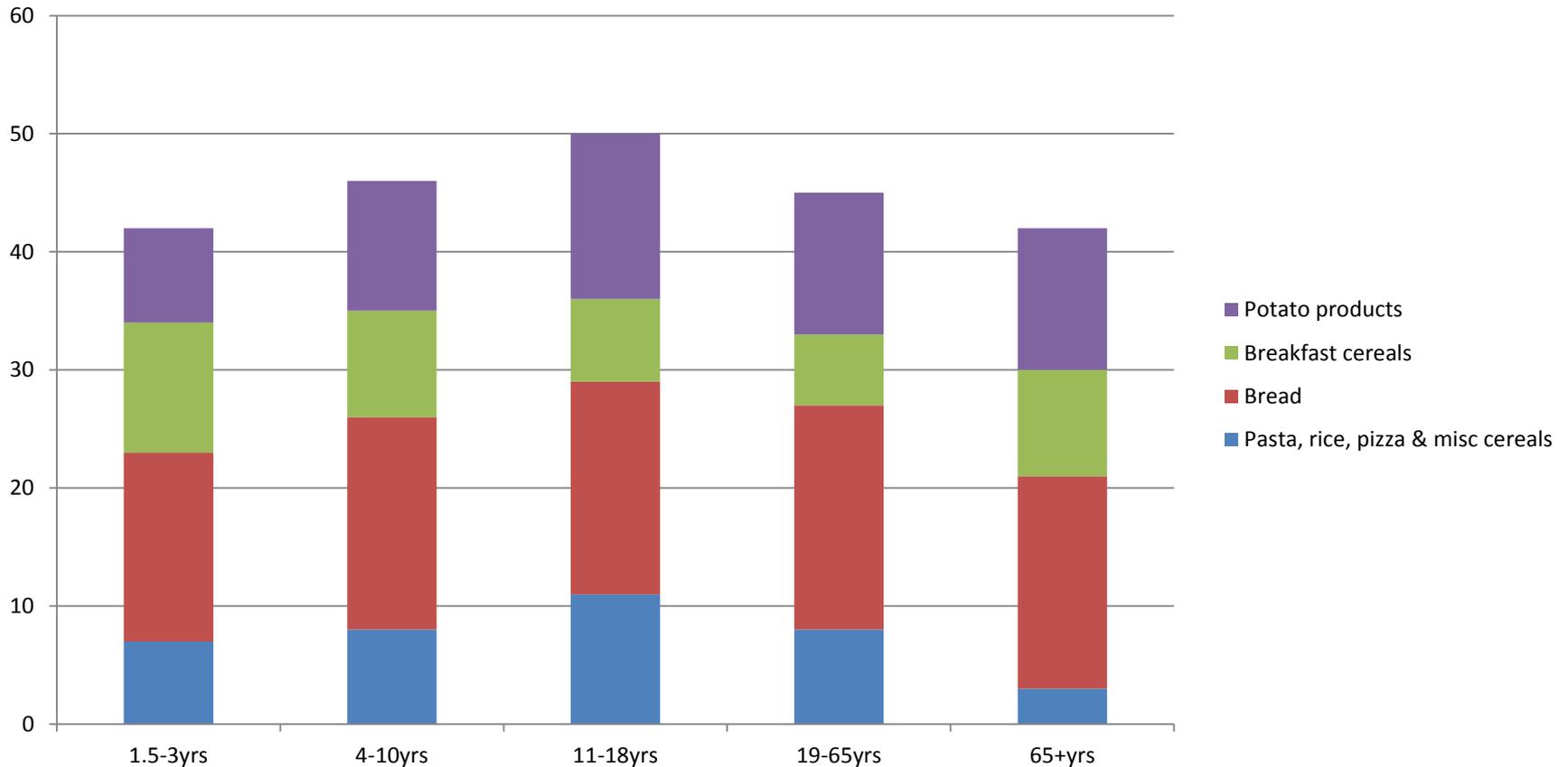
% contribution of food groups to average iron intake



Breakfast cereals are a significant contributor to iron intakes in the UK. Choosing free from (usually organic and unfortified) cereals impacts on iron intake considerably

Fibre

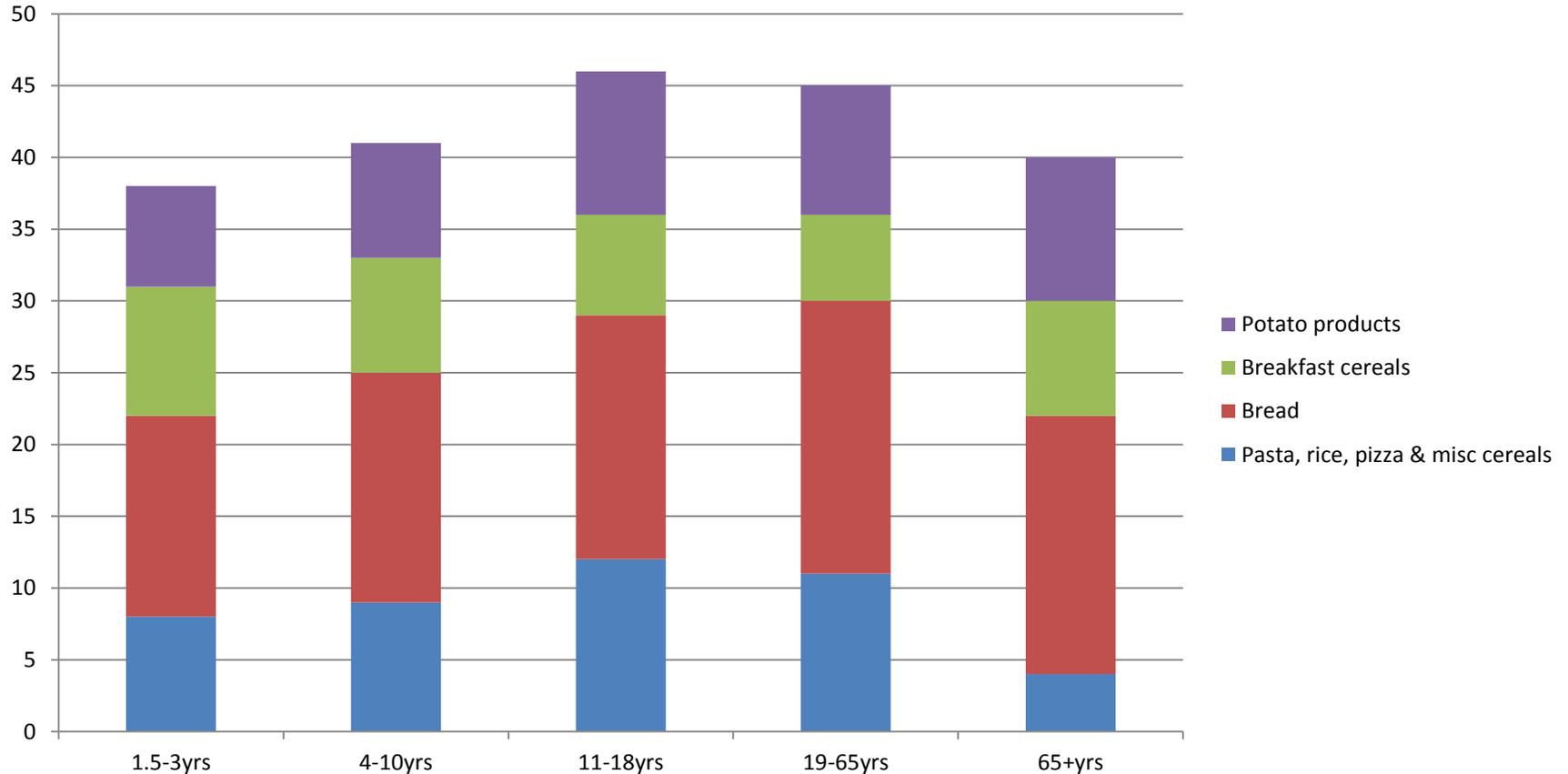
% contribution of food groups to average fibre intake



Bread is a significant contributor to fibre intakes in the UK. Limiting bread intake, particularly higher fibre versions impacts on fibre intake, and thus risk of lifestyle diseases

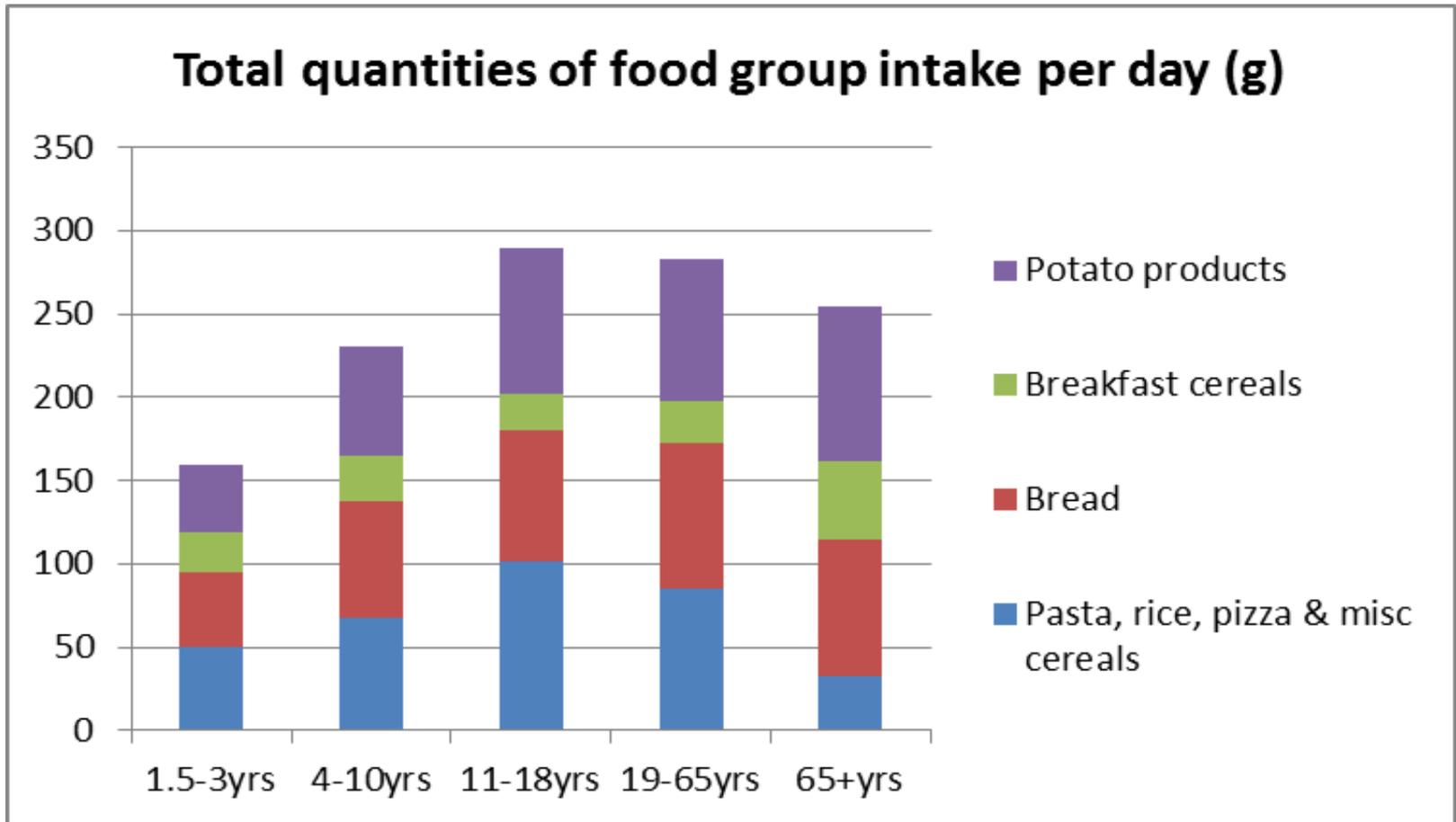
Carbohydrates

% contribution of food groups to average carbohydrate intake



Based on average intake of UK citizens, asking GF patients to rely on eating rice and potatoes as carbohydrate would significantly impact on carbohydrate intake

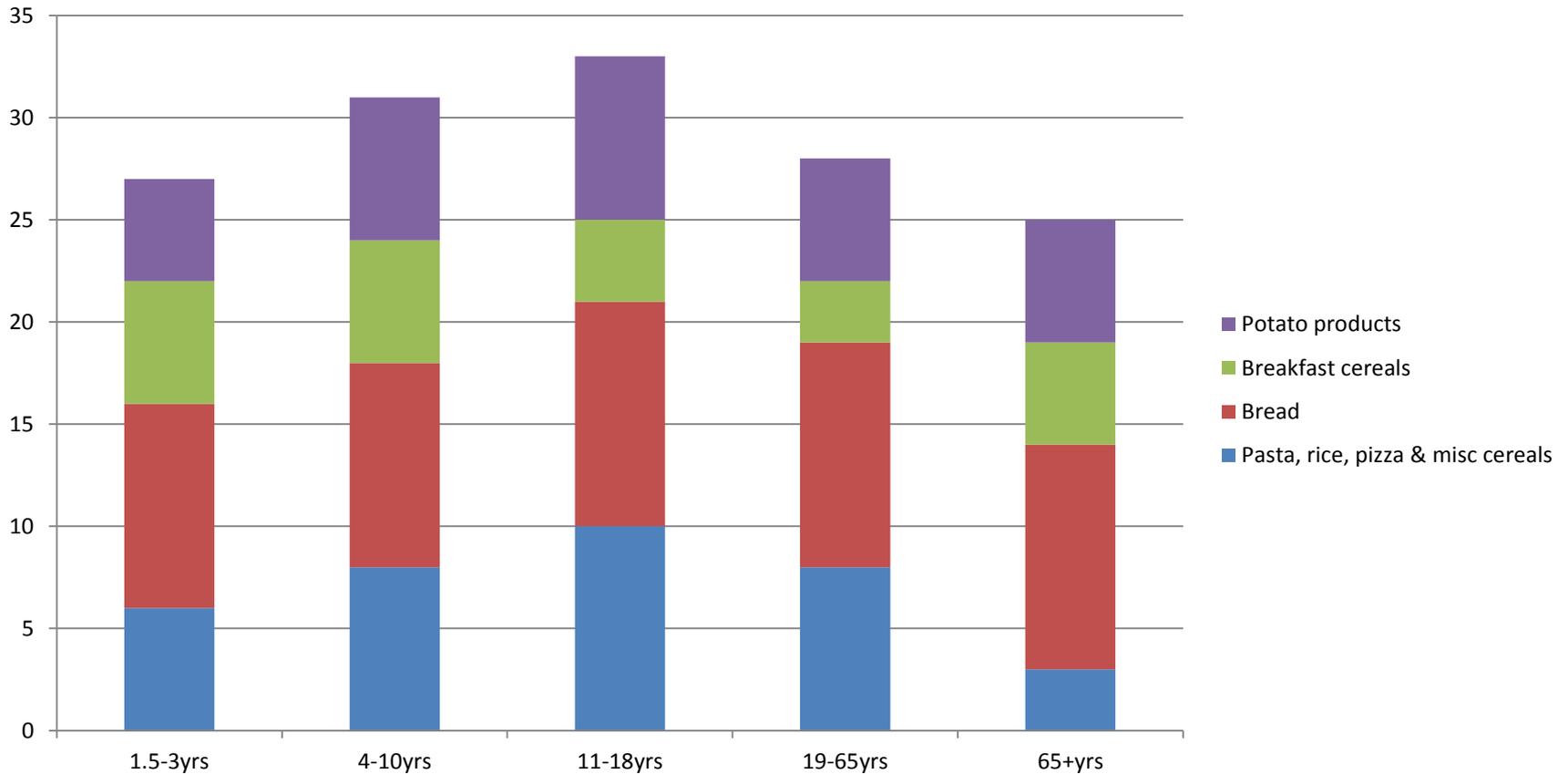
Total Food Intake



Elderly patients are less likely to eat pasta/rice/pizza, and more likely to eat potatoes and breakfast cereals. A uniform restriction of GF products will not take into account the dietary preferences of different ages

Total Energy Intake

% contribution of food groups to average energy intake

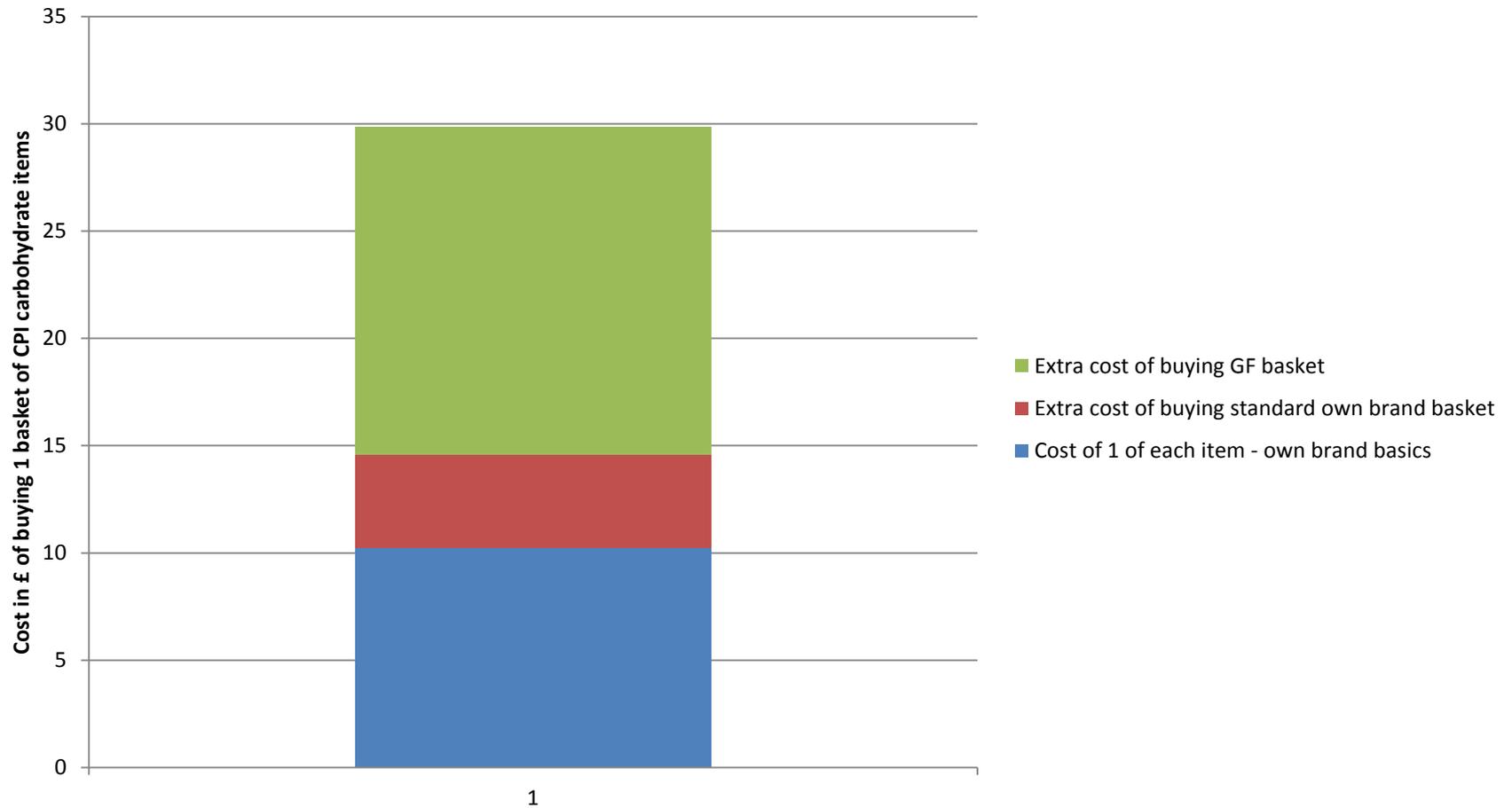


If patients unable to afford GF bread and cereals, energy intake likely to be significantly reduced.

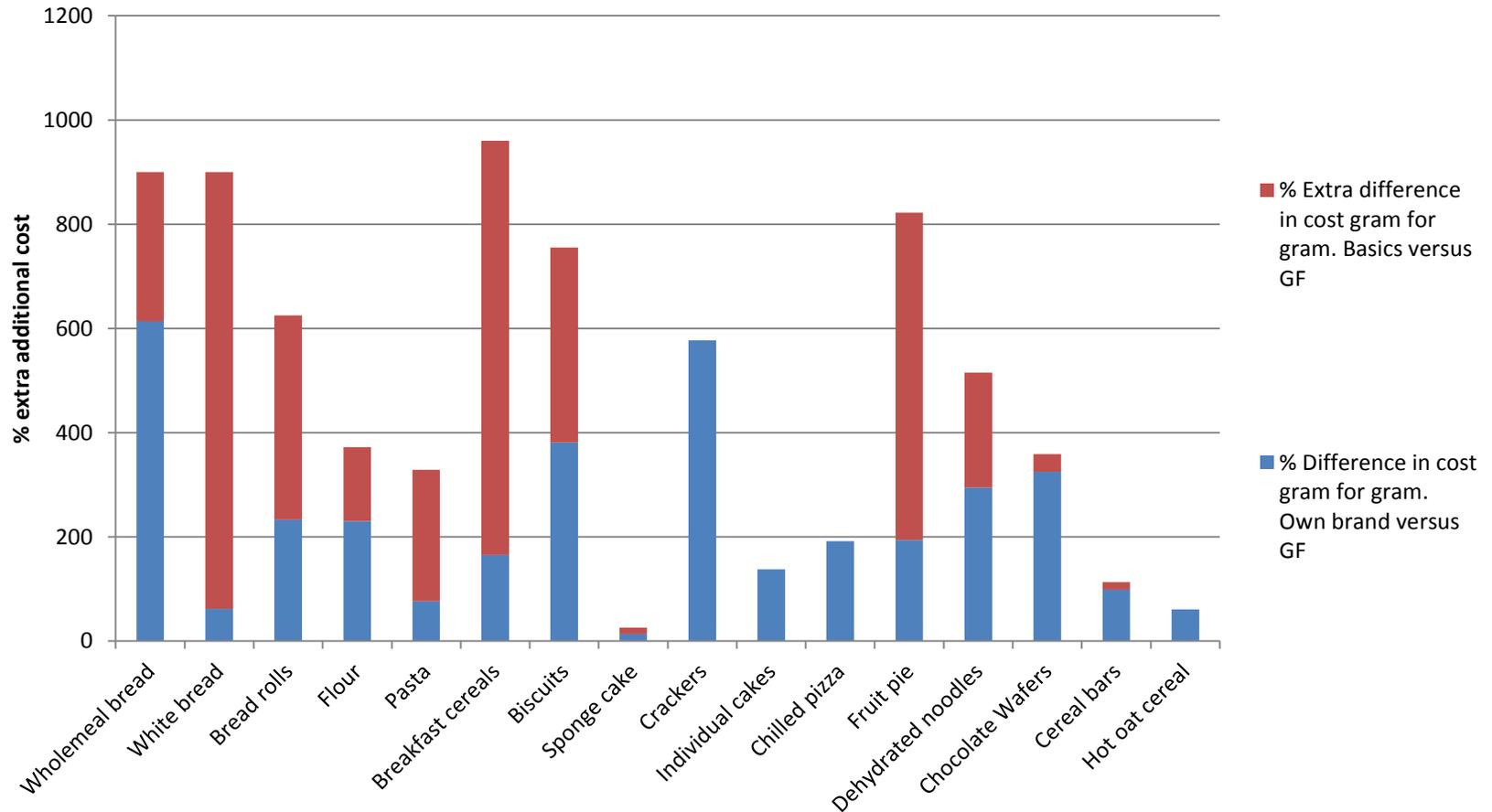
What is the Consumer Price Index?

- imagine a very large 'shopping basket' full of goods and services on which people typically spend their money - from food, to bikes, to holidays.
- The content of the basket is fixed for a period of 12 months, however, as the prices of individual products vary, so does the total cost of the basket. The CPI measures price changes.
- In 2015, the 'food' part of the CPI includes the following carbohydrate options
 - Bread, rolls, flour, pasta, breakfast cereals, biscuits, sponge cake, crackers, individual cakes, chilled pizza, fruit pie, dehydrated noodles, chocolate wafers, cereal bars, hot oat cereals, doughnuts, corn based snacks, rice and garlic bread
- I imagined a basket containing one of each of these items, and compared the price of buying one of each of the items from:
 - a standard supermarket own brand
 - a supermarket basics range
 - a supermarket own brand gluten free range (where available, if not cheapest branded item was used)
 - Doughnuts and garlic bread were excluded as these are not routinely available gluten free
 - Corn based snacks and rice were excluded as they are naturally gluten free

Cost of buying 1 basket of CPI carbohydrate items



CPI Basket Sainsburys Online August 2015



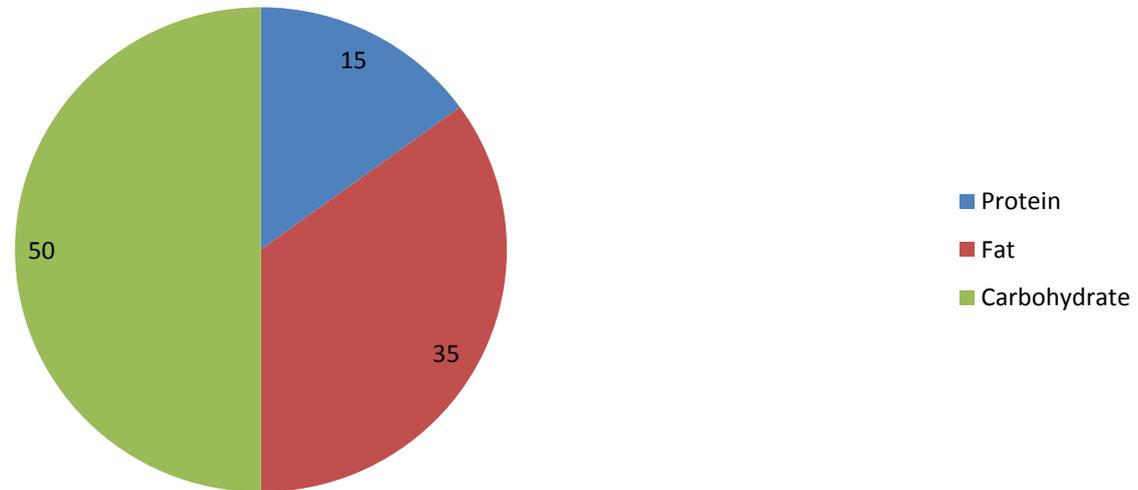
On average – basket of gluten free items was 228.4% more expensive , and 477.7% more expensive than buying basic items

What do current guidelines provide?

- Prescriptions limited to basic carbohydrate items (nothing sweet)
- Amounts limited for age and activity (10-18 units per month)
- Prescriptions for everyday foods e.g. stock cubes are not provided
- Not free unless you qualify for free prescriptions in general. £104 for 12 month pre-pay certificate
- Designed to provide just 15% of total energy intake, with the expectation that the remaining 35% of energy from starchy carbohydrates comes from rice, potatoes and other naturally GF grains like maize.

Is the national guidance of 15% of total energy intake to be provided by prescription food excessive?

Ideal proportion of energy derived from each dietary component in a healthy diet



National Department of Health guidance recommends that 50% of total energy intake should be provided by starchy carbohydrates in healthy UK diets

**WHAT DOES THE SCIENTIFIC
LITERATURE TELL US?**

Singh, J, et al. (2011) Limited availability and higher cost of gluten-free foods. JHND, 24:479-486

- Out of 20 GF foods, 90% were available in supermarkets, 49% in health food shops, 48% in quality supermarkets, 9% in budget supermarkets and 9% in corner shops.
- Many categories were 2-3 x more expensive (76-518% more expensive).
- For all wheat-based foods, every GF version was statistically significantly more expensive than its standard counterpart.
- Some, but not all, GF versions of everyday foods were also significantly more expensive than standard counter-parts (2-124% more expensive).

Whitaker, J, et al (2009) Patient perceptions of the burden of coeliac disease and its treatment in the UK. Aliment Pharmacol Ther, 29:1131-1136

- '46% [of coeliacs] believed their food cost them more than people without dietary restrictions, and perceived this to be about £10 per week
- Of those reporting greater cost of food, 31% said this was a problem for them.'

Abernethy, G, et al. (2011) Comparison of the cost, choice and availability of a healthy balanced gluten-free diet (GFD) with a standard diet that meet nutrient and food based guidance. Proc Nutr Soc, 70:E188

- the cost of a nutritionally balanced GF basket was significantly more expensive (£7.50) than the standard basket and also more than the average weekly spend on food.
- There was less choice and availability of GFP compared with standard foods, particularly in rural areas.
- Across all supermarkets, foods high in fats/sugars were more readily available compared with other food groups.'

Kinsey, L, et al (2008) A dietary survey to determine if patients with coeliac disease are meeting current healthy eating guidelines and how their diet compares to that of the British general population. EJCN, 62:1333-1342

- ‘GFP are a very important source of [fibre], calcium, iron, CHO and energy...patients get a major percentage of these nutrients from ... prescription GFP.
- This highlights the clinical importance of these prescription GFPs and the need for health professionals to ensure that these are utilised.’
- ‘These products are more likely to be fortified with calcium, iron and [fibre] than those commercially available.
- It is also important that health professionals support the availability of these of GFP on prescription’

Kinsey, L, et al (2008) A dietary survey to determine if patients with coeliac disease are meeting current healthy eating guidelines and how their diet compares to that of the British general population. EJCN, 62:1333-1342

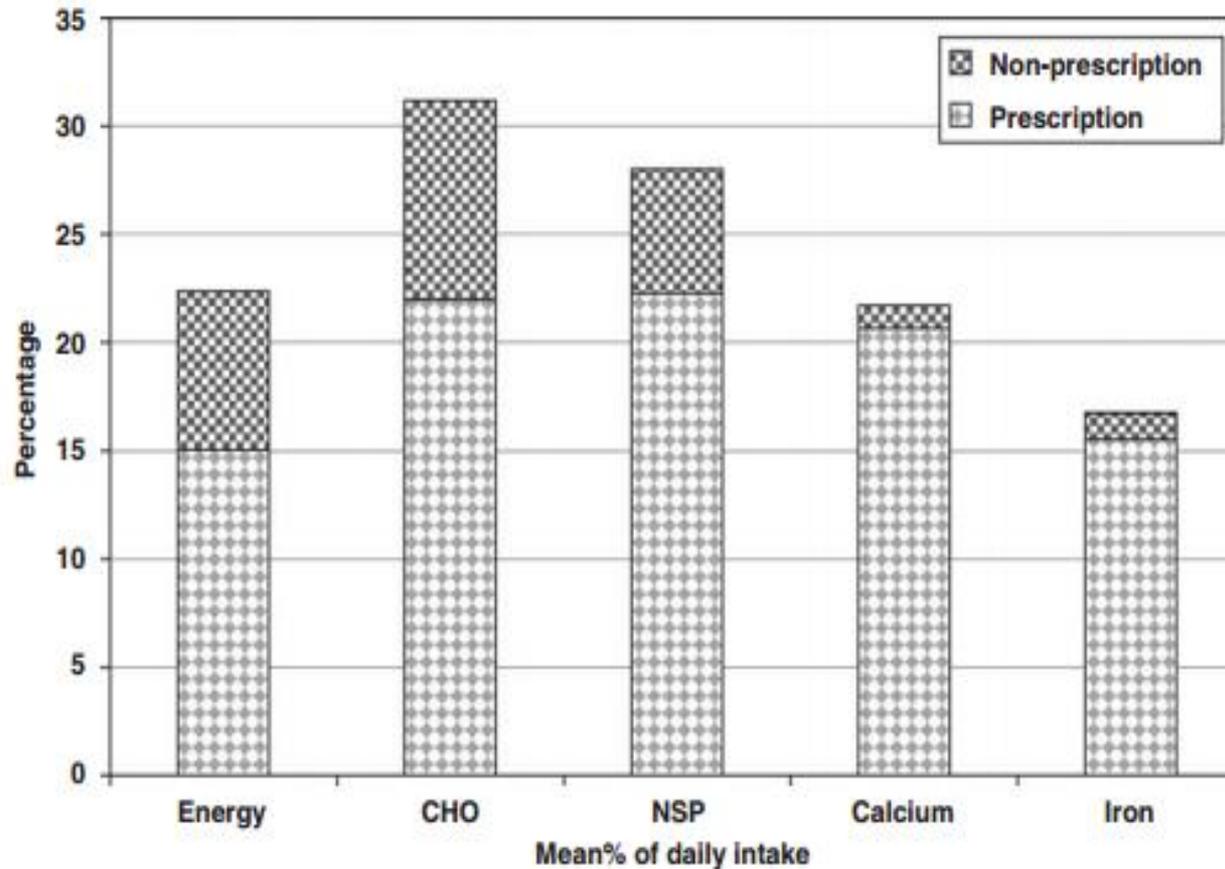


Figure 1 Percentage of energy, CHO, NSP, calcium and iron that prescription and commercial gluten-free products provide to the mean daily intake in patients with coeliac disease. CHO, carbohydrate; NSP, non-starch polysaccharide.

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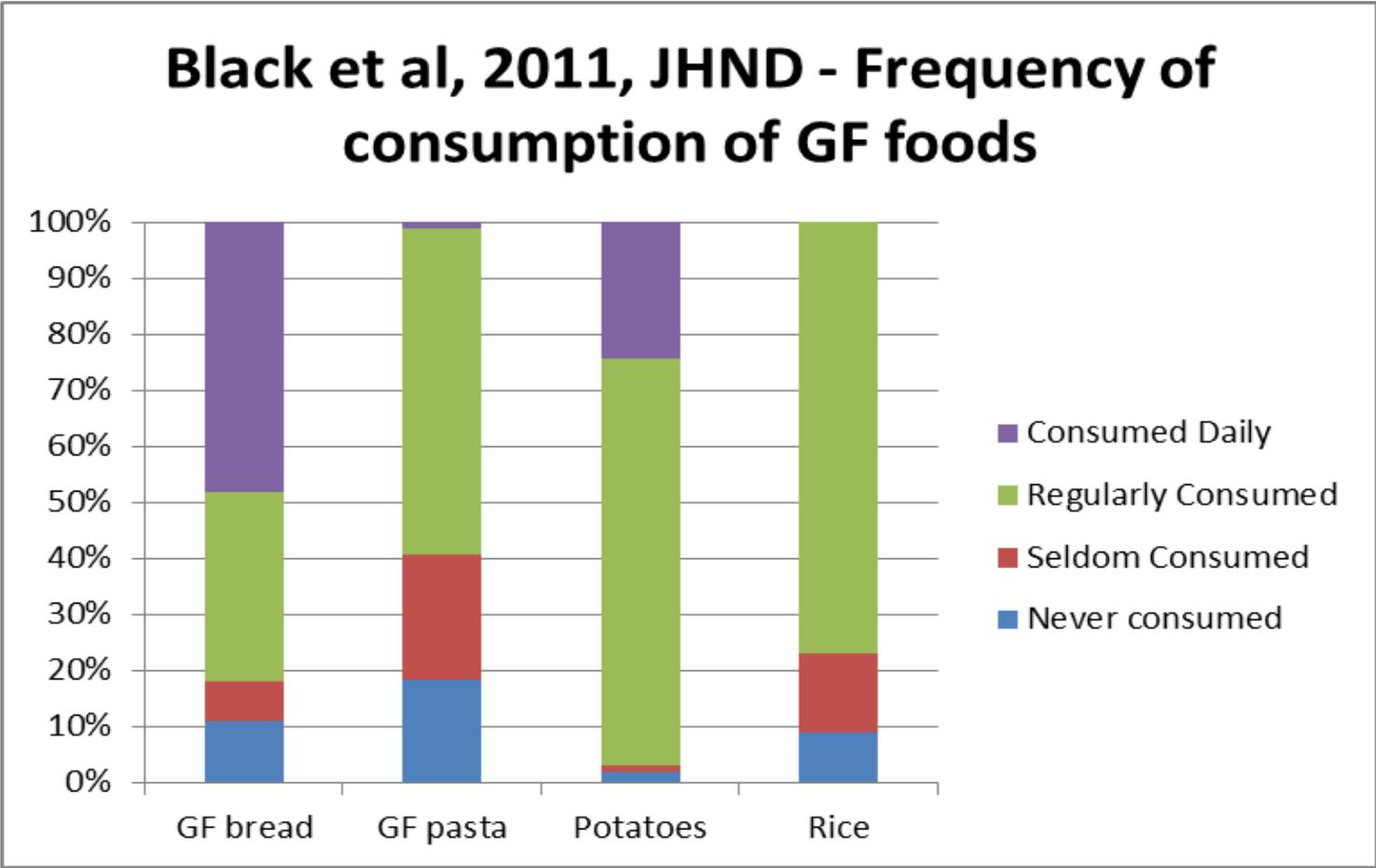
In addition, for following nutrients, significant numbers were consuming less than the recommended amount:

- Energy (98%)
- Vitamin D (100%)
- Fibre (98 %)
- Calcium (95%)

Rose, C et al (2014) Living with coeliac disease: a grounded theory study. JHND: 27, 30-40

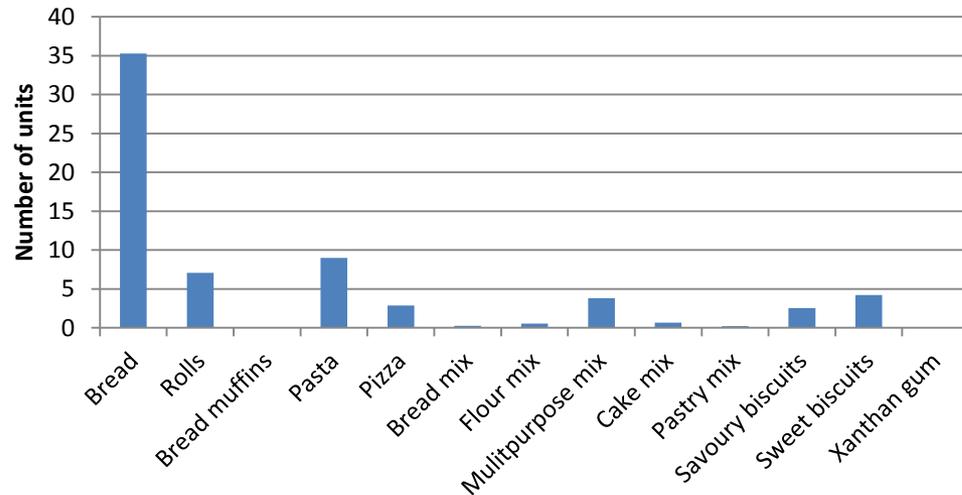
- ‘the most difficult part of the coeliac regime is the limited range of suitable food products stocked in the supermarkets’
- ‘the Free From sections in supermarkets are disappointing, focussing mainly on biscuits and cakes etc, the proper meal choices hardly exist, particularly for a vegetarian’
- ‘the most difficult part of the coeliac regime is the limited range of food products stocked by the supermarkets’
- ‘the GF food is not as nice or tasty as proper food’
- ‘I can buy GF scones and even jam doughnuts now from supermarkets but they still aren’t very palatable. They look odd and are very dry and crumbly’
- ‘the food has come on such a long way and is improving all the time now’

Black, J.L and Orfila, C. Impact of coeliac disease on dietary habits and quality of life. JHND, 2011,24:582-587)

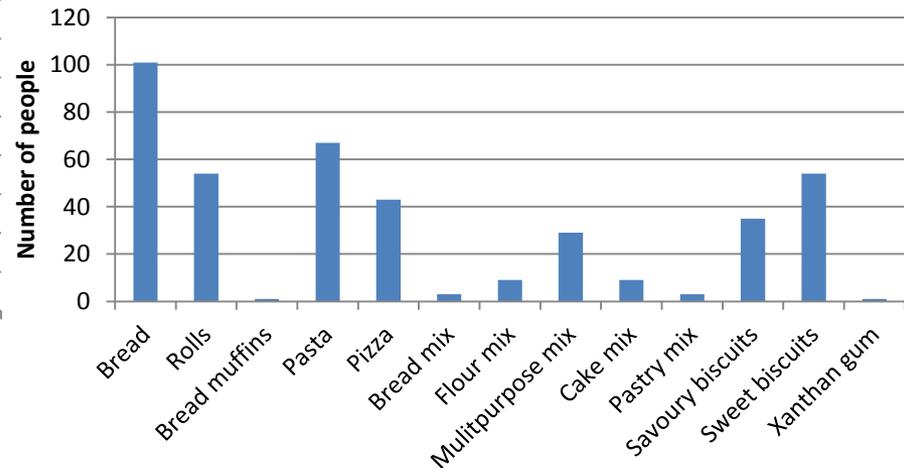


Martin, U and Mercer, S,W. A comparison of general practitioners prescribing of gluten-free foods for the treatment of coeliac disease with national prescribing guidelines. JHND, 2013, 27:96-104

Total provision of different prescription items



Number of people receiving different items on prescription



‘the perception from many medicines management teams throughout the UK is that prescribing is above recommended levels’

‘Within 1 area of Scotland:

- >1/3 of those with coeliac disease do not receive any GF foods on prescription
- Of those who do receive , 82% receive less than the recommended guidance
- Only 6.6% of people with coeliac disease received more than the recommended allowance’

Violato, M et al. Resource Use and Costs Associated with Coeliac Disease before and after Diagnosis in 3,646 Cases: Results of a UK Primary Care Database Analysis. PLoS ONE, 2012 7(7):e41308

- After diagnosis, average healthcare costs per patient per year rose by 91%
- This stabilises about 6 years after diagnosis, but remains at a much higher level than previously
- Prescriptions under 'Nutrition & Blood' categories rises by 25 fold after diagnosis (from £10 - £246 per year), 89% of this cost is associated with GF prescriptions

What don't we know?

The impact of stopping GF prescriptions

- Do people eat less and lose weight?
- Do they stop following a gluten free diet and suffer more complications of coeliac disease
- Does prescribing on treatments for diarrhoea/constipation, anaemia and osteoporosis go up?
- Do they develop nutritional deficiencies?
- Do they spend more money on food and become poorer?
- Or is it all okay – will people go and buy the food they need, follow their diet and manage?

In Devon, are there places where people CANNOT buy gluten free foods at all and have to rely on prescriptions?

In Devon, how many coeliacs do not take advantage of GF foods on prescription, and get all their GF foods from shops?

If gluten free prescriptions go...

- Who am I worried about
 - People who are house bound with no internet connection (no internet shopping!)
 - People who have no transport and who can only shop in local shops
 - People who shop in budget supermarkets
 - People who have specific sensory needs
 - People who choose prescription products based on nutritional content
 - People who are struggling financially
 - People who struggle to read labels accurately

Is this my future as a dietitian?

THE CELIAC DIET, SERIES #8

Carol Rees Parrish, R.D., M.S., Series Editor

The Gluten-free Diet: Can Your Patient Afford It?



Pam Cureton

Currently, the only treatment for celiac disease (CD) is a strict gluten-free diet (GFD) for life. This means the elimination of products containing wheat, rye and barley. Following a GFD presents significant challenges and many barriers to compliance. One of the most significant challenges patients face is the cost of certain components of the diet. Great tasting gluten-free alternatives are essential to help patients comply with the diet, but come at a much higher cost than their gluten containing counterparts. Helping patients manage the cost of the diet is as important as understanding the basic concepts of the GFD.