



Submission to Food Standards Australia New Zealand (FSANZ)

Regarding

Labelling review recommendation 17

on behalf of the

Metabolic Dietary Disorders Association (MDDA)

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THE METABOLIC DIETARY DISORDERS ASSOCIATION

The Metabolic Dietary Disorders Association (MDDA) is a national support group created by families living with rare genetic disorders, known as Inborn Errors of Metabolism (IEM). The Association has over 650 members located throughout Australia, but estimated numbers of people living in Australia with an IEM are in excess of 2000 (some extremely rare diseases).

The MDDA fosters co-operative relationships between members, healthcare professionals, government departments, stakeholders and other interested agencies to promote the health and well-being of our members.

INTRODUCTION

Importance of accurate, clear and helpful information regarding the nutritional information panel (NIP) on manufactured food products is imperative to the adherence of a very difficult, time consuming and limited imposed diet. Removing the per serve column on the NIP will cause considerable challenges and implications for our members medically controlled diet, health and wellbeing and in turn will impact on their overall health, day to day functioning and quality of life.

If recommendation 17 were to proceed, it is our view this would be a massive step backwards for our community in being able to manage their disorders, and the effects of such a change would place this community into a high risk of non-compliance and see a number of health issues surface.

Background: IEM conditions

Inborn errors of metabolism (IEM) include inherited biochemical disorders in which a specific enzyme defect interferes with the normal metabolism of protein, fat, or carbohydrate. As a result of diminished or absent enzyme activity in these disorders, certain compounds accumulate in the body to toxic levels and the levels of others that the body normally makes may become deficient. If they are not treated, these metabolic disturbances can lead to a host of medical and developmental consequences ranging from intellectual disability to severe cognitive impairment and even death. Through early identification usually by the heel prick test at birth and initiation of treatment, many of the adverse outcomes of IEM can be mitigated or prevented. For many IEM, treatment strategies rely on the provision of specialised medical foods, dietary supplements and a strictly measured diet.

For the purpose of simplifying our submission we will refer to inborn errors of protein metabolism (IEpM) in which the body is unable to break down one of the protein building blocks from the diet. Infants diagnosed with these conditions are started on a low protein diet from birth and continued throughout life. When initiated within the first weeks of life and maintained throughout life, an appropriately designed nutritional treatment regimen can enable individuals to achieve and maintain normal development.

How do you or your organisation use per serving information in the nutrition information panel on food labels?

The per serving information on the NIP determines which products are suitable in nutrition content to consume. As many of our members find NIP already confusing to remove the per serving column would create more confusion and require more education and increase members need to refer to their metabolic dietitian.

Individuals with an IEPM are required to count in grams their daily protein intake. Under the guidance of specialised metabolic dietitians parents, children and adults are educated to interpret the NIP on commercial foods. Due to the simplicity of the per serving information individuals are able at a glance to select appropriate foods.

The aim for all children is to learn from a young age to read the NIP including the per serve column to learn about it and gradually take responsibility for counting their daily protein allowance. Many adults also continue to struggle with the NIP and require regular training.

The simplicity of the per serve column provides an accurate measurement of protein intake in an identified quantity that individuals can easily consume (ie sometimes individual wrappings, or a counted number of items in a container etc). Many struggle with the conversion using the average quantity per 100g or 100ml. A simple shopping trip to purchase suitable foods with only the average quantity per 100g listed on the NIP, would require many to perform a mathematical equation for each item to determine its suitability, and in many cases weigh the food to understand if their diet would permit them to consume an appropriate amount to make up a serve.

This is not an acceptable expectation, may lead to errors in calculations and would possibly increase the likelihood of non-compliance to diet (which is an ongoing challenge faced by these individuals). A child or adult not consuming their medically prescribed amount of protein in a day becomes highly susceptible to health issues, and can be life threatening to the young (or unborn) in the instance of a pregnant PKU women, and or cause serious brain damage or liver failure.

Are there any particular food categories or types of food packages (e.g. single serve packages) for which per serving information is particularly useful? If so, what are they? Explain why the information is useful.

The current requirements of the FSANZ which requires all food businesses to include per serving information on all products is extremely and important to our members. As individuals are calculating protein and each individual has different protein intake requirements per serving information assists with the daily dietary monitoring. Single serve packagings are useful for suitable products to be added to lunch boxes, outings, snacks, school camps, day care etc. As the diet is very restrictive it is often hard to find healthy alternatives and treats, the single serve packages provide ease of information and compliance to diet.

Also when a package contains a number of individual items (ie. chips, biscuits, cereals etc.), it is useful to have a serving amount quantified (ie. no of chips or biscuits etc) so that individual items do not need to be measured.

The Labelling Review recommendation suggests that per serving information be voluntary *unless a daily intake claim is made*.

Do you support this approach? That is, do you think declaration of per serving information in the nutrition information panel should be mandatory if a daily intake claim is made (e.g. %DI or %RDI)? Give reasons for your answer.

The declaration of per serving information should remain mandatory and also include the daily intake (%DI or %RDI). Our members struggle to comply with a specialised diet to remain healthy removing information from the NIP will add to the complexity. The percentage DI information assists with all nutrient intakes enabling them to assess their other daily nutrient intake.

If per serving information in the nutrition information panel was voluntary, do you think the inclusion of per serving information in the nutrition information panel should be mandatory when a nutrition content claim about vitamins, minerals, protein, omega-3-fatty acids or dietary fibre is made? Give reasons for your answer.

Yes – as per above it is imperative that the per serving information remain regardless for all foods.

From your perspective, what are the advantages and disadvantages of per serving information in the nutrition information panel being voluntary?

Disadvantages

Fewer companies would put the per serve on given they no longer needs. This would lead to the following clear disadvantages for any individual living with an inborn error or metabolism and managing their condition through a strict dietary intake:

- Adding confusion and further complexities to individuals to understand how to calculate amount of protein in foods consumed.
- High issues with individuals complying to diet and keeping phe levels in control– placing further pressure on already under resourced medical professionals and metabolic clinic staff.
- Greater health and wellbeing issues for patients, with increase mental health problems (incorrectly calculated daily protein leads to mental health issues, brain damage for many)
- Young children needing to learn how to manage their own daily intake – with limited numeracy skills – will be expected to calculate difficult mathematical equation prior to most meals ,making it very difficult to build independence and confidence in learning how to manage their life-long diet.
- Teenagers who just want to fit in and be considered “normal” would need to carry around scales and a calculator to weigh out most foods to ensure their self-allocated serves are permissible.
- Given the diagnosis of some conditions is not immediate, some individuals became “affected” at an early age from their disease, and only through careful dietary management now at an older age can they function cognitively. Many of these older adults struggle

already with calculating their daily and per meal allowances, and this change would set this group back drastically.

- Some patients do not speak English as their first language and have varying cultural and ethnic backgrounds. A clear and simple method for them to be able to calculate daily and per meal intake is also essential to compliance.
- The per serve column is also simplistic for caregivers, older children and adults in assisting with counting of dietary intake.

Health and quality of life is more important than Recommendation 17 which aims to reduce the regulatory burden on industry of formal cost-benefit analysis.

Conclusion

The MDDA recognises that some claims about confusion over product labelling may exist however it would like to emphasise the importance that per serve labelling has in providing essential information for people with medically diagnosed IEMs as well providing general accessible nutritional information for all consumers. The per serve labelling must be included on packaging. The MDDA hopes this will be a focus of the FSANZ and not permit this recommendation to be accepted.

References:

Australian Society for Inborn Errors of Metabolism (ASIM)

Human Genetics Society of Australasia (HGSA)