



The International Dysphagia Diet Standardisation Initiative in the UK - 5 years on



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In April 2019, the UK implemented the International Dysphagia Diet Standardisation Initiative (IDDSI) to provide standardised levels for modified textured foods and drinks. But what is IDDSI and what have we learnt 5 years on? To explore the effects of IDDSI, this article details the experiences of a Mechanical Engineer and IDDSI Board Member involved in the development of the IDDSI standards, and a Speech and Language Therapist (SLT) practicing IDDSI.



Developing IDDSI standards, their impact & the future

Dr Ben Hanson, Associate Professor (part-time) in Engineering at University College London (UCL) and an IDDSI Board Member

As an engineer, previously working on biomedical devices, I became interested in dysphagia and the biomechanics of swallowing when I moved to UCL in 2005. This was the start of my understanding of texture modification and thickeners, particularly the textures of what people were eating in care homes, hospitals and amongst the elderly. This was an eye-opener and shocking because I really like my food, and it motivated me to conduct more research to improve texture modification of food and drinks. After several years, the co-Chairs of IDDSI – Peter Lam and Julie Cichero – approached me at a conference as they needed an engineer on the IDDSI Board.

IDDSI was set up a couple of years previously, when a group of passionate volunteers came together with a goal of developing new international standardised terminology and definitions to describe texture-modified foods and thickened liquids for individuals with dysphagia of all ages, in all care settings, and in all cultures, removing the existing conflicting standards from across the world. This seemed almost impossible, having to consider the different cultures, languages, priorities, professionals and resources from around the world. However, the IDDSI Board was formed, a voluntary board with a passion for dysphagia and texture modification.

For transparency, IDDSI receives sponsorship from industry which covers fees for admin, the website and webinars, for example. But the sponsors do not input into the technical content of IDDSI.

One of the first steps in developing the IDDSI Framework was the IDDSI Board’s systematic review of medical and scientific publications relating to texture modification and dysphagia. This was published in 2015 and has been cited by almost 600 papers since then.¹

In 2015, the IDDSI Board met in Vancouver, where all the different standards from around the world were presented, along with examples of texture modified foods and drinks, covering the whole range from birth to palliative care. From this meeting, the real key elements of the Framework were developed, including the pyramid, not differentiating between food and drinks, and not to specify ingredients, as food can change with age and temperature, etc. After three years of work based on evidence and global feedback, the IDDSI Framework evolved and was released in 2016 and published in 2017. Feedback from the global community led the IDDSI Board of Directors to revisit and update the Framework to the current IDDSI Framework (published 2019) which incorporates Level 7 Easy to Chew (see **Figure 1**).

Figure 1: The IDDSI Framework – www.iddsi.org

The International Dysphagia Diet Standardisation Initiative 2019 @<https://iddsi.org/framework/>
 Attribution is NOT PERMITTED for derivative works incorporating any alterations to the IDDSI Framework that extend beyond language translation. Supplementary Notice: Modification of the diagrams or descriptors within the IDDSI Framework is DISCOURAGED and NOT RECOMMENDED. Alterations to elements of the IDDSI framework may lead to confusion and errors in diet texture or drink selection for patients with dysphagia. Such errors have previously been associated with adverse events including choking and death.

IDDSI in the UK

In 2015, the UK IDDSI Expert Group was set up by NHS England. This multidisciplinary group consisted of healthcare professionals (HCP), trade associations, individual company members, a mechanical engineer, and was originally chaired and supported by Caroline Lecko, a registered nurse and former Patient Safety Lead at NHS Improvement, which changed to being co-Chaired by the Royal College of Speech and Language Therapists (RCSLT) and the British Dietetic Association (BDA).

After consulting with expert advisors, along with conducting research and audits on the IDDSI Framework, IDDSI was formally adopted in the UK by the BDA and the RCSLT in October 2017.

It was agreed by the UK IDDSI Expert Group that a 12-month phased implementation would be best to ensure manufacturers and healthcare settings were able to adjust to the IDDSI Framework before the full implementation date, with IDDSI being fully implemented in the UK by April 2019, leading to gradual adoption in different sites and across different regions of the country.

The science behind the IDDSI Framework and the levels

The Framework descriptors for each level were developed and supported by simple measurement methods (testing methods) that could be used by people with dysphagia or by caregivers, clinicians, food service professionals or industry to confirm the level a food or drink fits into.

The levels are based on physiology and the clinical need of the patient. For example, a texture level that is appropriate for somebody who doesn't have teeth, or a level for patients who have slowed movement of the tongue and reduced pressure, rather than staving viscosity. Professor Catriona Steele, a Senior Scientist and Julie Cichero, a Speech Pathologist, brought their clinical scientific experience.

Some of the previous standards being reviewed included elements of measurement of texture properties, but these were more targeted at food scientists to describe texture rather than dysphagia patients. IDDSI wanted to ensure the standards were easily relatable for the patients and caregivers and implementable in practice. The IDDSI standards are therefore practical and can be used with minimal training in every setting around the world.

The challenges of IDDSI

The main challenge was developing International Standards that are precise, easy to deliver, take minimal time and have zero cost.

Even the numbers and colours were thought out carefully to ensure they are accessible to everyone, with little ambiguity. The Framework uses as little language as possible to minimise subjectivity.

The flow test was another challenge. In 2015, we discovered that the 10 ml syringe in 10 seconds can give us a scale from zero to ten, which mapped across the range of liquids people were likely to use from water to something that is spoon or fork thick. Syringes were chosen as they are universally standard and accessible across the world. IDDSI has also developed a funnel – named a funnel so it can't be mistaken for a syringe (it has no plunger, cannot be connected to IV lines and is accepted in kitchens). However, the fundamental principle is that IDDSI is free and accessible for everyone, so there is no specific equipment needed for IDDSI.

To help with training, there are online videos, an app which works without Wi-Fi so it can be used in remote settings, as well as leaflets, booklets and posters.

IDDSI around the World

Implementation of IDDSI means different things in different countries, with some countries mandating IDDSI by incorporating it into law, and others endorsing IDDSI, like in the UK.

Some IDDSI worldwide statistics include:

- The IDDSI definitions document has been translated into 36 languages
- Official support from 31 professional institutions around the world, including the Dysphagia Research Society, European Society for Swallowing Disorders, RCSLT and BDA
- There are 57 recognised IDDSI reference groups around the world, fostering local awareness and education
- In 2023, IDDSI hosted 14 in-person or live webinar events
- There have been 275,000 views of the IDDSI YouTube videos
- There have been 500,000 IDDSI website sessions.

The positive effects of IDDSI 5 years on

One of the most positive effects of IDDSI are the IDDSI Festivals, where a diverse gathering of interested people come together to have some great debates and do some hands-on testing. There is engagement and interaction between the users, the prescribers and the producers of texture-modified foods and drinks. These are popular events which take place around the world. The next UK IDDSI Festival will take place on 19 September 2024 in London.

Raising awareness of dysphagia and high-quality food has also changed practice and encouraged manufacturers to push innovation in this area. The range of products and choice for patients with dysphagia has come on a long way.

The future of IDDSI

IDDSI is always under review but there are no plans to substantially change anything as the levels developed are being used in current research and have been widely adopted by manufacturers. IDDSI should always be used as a tool for communication, rather than being prescriptive or diagnostic. The ways people cope and compensate for their disorders varies from person to person and, therefore, it is important that the patient is reviewed by the clinician before determining the IDDSI level for the patient. The Framework can then be used as a way to communicate between chefs, caterers and suppliers of foods and drinks for patients.

That being said, there are plans to provide additional detail to make some of the Framework level measurements more precise, but the fundamental levels will not change. It is important that IDDSI is simple for users.

The final hope is that more settings use IDDSI as a labelling tool; in restaurants, cafes and even on cruise ships, which often have a large elderly population!



IDDSI 5 years on – The experiences of a Speech and Language Therapist

Sandra Robinson, Independent SLT

As an Independent SLT and Director of Speech Therapy Works Ltd.,² I assess and treat adults with acquired dysphagia arising from neurological, respiratory and gastro disorders and diseases. I train multidisciplinary teams (MDT) on dysphagia in care homes and neuro-rehab units across the country. I also provide dysphagia consultancy to businesses and charities, as well as working with the RCSLT on relevant projects.

The change from the National Descriptors to IDDSI raised awareness across the UK about the usefulness of a consistent framework and approach within and across clinical settings. This standardisation has aided colleagues and of course, the patients and their families/carers as training and practice has become more consistent, making it safer for patients with dysphagia.

The positives of IDDSI

Published research³ suggests that *'attitudes toward the implementation of IDDSI are favourable, and approval of IDDSI is widespread'* and further demonstrated that IDDSI lends itself to effective training for care home colleagues to understand IDDSI implementation and audit it within dysphagia training programmes. Their results showed significant improvement in the percentage of meal compliance audited in all texture-modified diets. This is also my experience. The Framework can only be as good, useful and safe as its implementation. With effective training, it's a helpful compensatory tool.

The challenges of IDDSI

Preparing thickened drinks to a specific thickness can be a challenge. However, there have been changes since I first trained, away from starch-based thickeners to amylase-resistant gum-based thickeners, from National Descriptors to IDDSI, from the use of luer-tip syringes to check flow rate to the new IDDSI funnels and there has always been a diverse range of opinion on the use of thickeners in dysphagia care. The Framework is a guide, not a law. It is for us SLTs to use evidence-based therapy to determine how we use IDDSI with each patient in a person-centred and holistic manner, hence I was pleased to contribute to the RCSLT position paper on this topic, which was published in January this year.⁴

The IDDSI Framework in practice for patients and HCPs

In my experience, delivering training from Speech Therapy Works or Dysphagia Kitchen along with a professional chef and registered dietitian, HCPs have enjoyed learning new things, to unlearn some practices(!) and to reignite their interest in supporting patients with dysphagia. By focusing on how much of a difference each of them makes to the safety and quality of life of an individual with dysphagia and by understanding the IDDSI Framework and its rationale, this can vastly improve care.

Many patients understandably would prefer steak and chips to an IDDSI Level 4 purée meal. It is the job of the SLT, with the support of the MDT, to work with their patients on why this might be needed and so that patients can be fully involved in their own care and rehabilitation. Oftentimes, the food may not have been made to the required standard and/or does not look appealing or appetising. By working with chefs, this barrier can be overcome, and patients are more likely to engage in taking texture-modified meals.

Advice for HCPs wanting to understand IDDSI

Get training! The IDDSI website has some great resources, but it can also be overwhelming. The content of IDDSI courses across the country varies. There are good and bad examples, online and in person. Depending on your role, keep an eye out by signing up to IDDSI eBites for the latest news, webinars and roadshows and look for a training course that meets your particular needs. There is training for carers, nurses, medics, volunteers, chefs and AHPs. For each patient and their family, the SLT is responsible for explaining the IDDSI Levels they recommend and can signpost them to further resources or educational information.

The future of IDDSI

The number of languages in which IDDSI is available is increasing significantly and this helps support UK patients and families for whom English is not their first language. IDDSI have working groups, continued research and education to build on progress so far. They are establishing an IDDSI Stamp Project so that companies who provide relevant products and services can demonstrate that they meet the IDDSI Framework Standards. I think this is a great motivation and I look forward to seeing its implementation.

To find out more about IDDSI and how you can get involved in the UK IDDSI Festival, please visit: iddsi.org.

References: **1.** Steele CM, et al. (2015). The influence of food texture and liquid consistency modification on swallowing physiology and function: a systematic review [published correction appears in *Dysphagia*.; 30(2): 272-273. **2.** Robinson S. Speech Therapy Works. Accessed online: <https://speechtherapyworks.co.uk/> (Feb 2024). **3.** Wu XS, Miles A, Braakhuis A (2022). The Effectiveness of International Dysphagia Diet Standardization Initiative-Tailored Interventions on Staff Knowledge and Texture-Modified Diet Compliance in Aged Care Facilities: A Pre-Post Study. *Curr Dev Nutr.*; 6(4): nza0032. **4.** RCSLT (2024). Position paper on the use of thickened fluids in the management of people with swallowing difficulties. Accessed online: www.rcslt.org/wp-content/uploads/2024/01/Thickened-fluids-position-paper.pdf (Feb 2024).

About the British Specialist Nutrition Association

BSNA is the trade association representing the manufacturers of products designed to meet the particular nutritional needs of individuals; these include specialist products for infants and young children (including infant formula, follow-on formula, young child formula and complementary weaning foods), medical nutrition products for diseases, disorders and medical conditions, including oral nutritional supplements, enteral tube feeding and parenteral nutrition, as well as companies who aseptically compound chemotherapy, parenteral nutrition and CIVAS.

