Thickened fluids position paper frequently asked questions

The following questions were generated by RCSLT members who attended the thickened fluids listening event on 30 November 2023. The questions have been split into the sections below.

Use of the guidance

How should we use this guidance within our own practice?
The guidance should be used in the way you feel best suits your workplace and your service. Some teams within a service may choose to come together to jointly reflect on how this guidance may impact their own service and service delivery. For others, the guidance may come as a reminder to take a step back and evaluate what they are doing; to think of the rationale of using an intervention and then consider it, whilst weighing up the risks and benefits and the use of informed consent with the speech and language therapist (SLT) expert opinion. To conclude, it is a tool to use within the way that you reflect on your own practice already.

Can we use this body of work in Ireland?
Yes, SLTs can use this to influence their work and the people they work with in Ireland. The paper mentions consent/informed consent and the processes within the UK. It is recommended that a clinician would need to look at these within the context of the Irish legal system. Everything within this paper is focused on the principles of evidence-based practice and person-centred care and, no matter where you work in the world, those principles are still key.

How should SLTs deal with differing clinical viewpoints on the rationale of recommending thickener within the profession?
It is important to consider principles of evidence-based practice and set up CPD/reflective sessions to create a space to talk openly and with curiosity. It is helpful to be aware that thickener can be tied up in an SLTs identity so it can be challenging for some to re-evaluate their practice. It is also valuable to reflect on the discomfort of why these topics are challenging and the uncertainty on the evidence for this topic. It is essential to continue questioning and creating that safe space to do so.

Has anyone (or a team) managed to go thickener-free in their practice? Do you think that is the direction of travel?
RCSLT are not advocating for thickener free services, what we are advocating for is person centred care where the use of thickener is still considered within the toolkit alongside the potential the risk and burdens associated with it. There are still some service users where using thickened fluids is the most appropriate intervention. It is vital to recognise the autonomy service users have in their decisions to use thickener.

Education

Are universities who offer SLT discussing the evidence base for thickener with their students?
The pre-registration eating, drinking and swallowing (EDS) competencies have recently been released and most Higher Education Institutions (HEIs) have started to teach against these. The RCSLT haven't directly specified this within the competency framework, but part of the framework is to have an awareness of the interventions around EDS, of which thickened fluids is an intervention. As part of this project consultation, the RCSLT have had representation from HEIs and researchers. The RCSLT also regularly update CREST, who will have full access to this paper once it is published.

Is dysphagia training adequate for SLTs to be questioning more about aspiration pneumonia diagnosis?
We are undergoing a period of change for pre and post dysphagia training and we hope this change will improve dysphagia training. Our training is currently inadequate, and our undergraduate training does not prepare us for understanding respiratory physiology/disease and how the lungs react to aspiration and all the complications associated with aspiration pneumonia diagnosis itself. There are many possible reasons for pneumonia that are unrelated to oropharyngeal dysphagia, and we need to understand that to understand the impact of our treatments and whether we have a role at all. A multidisciplinary team (MDT) approach is needed that involves influencing HEIs and reinforcing that NQPs need to have a better understanding of chest physiology and disease. There are many possible reasons for pneumonia. Ventilator Associated Pneumonia, Non-Dysphagia Related Aspiration Pneumonia and DAP have overlapping risk factors, pathophysiology and signs and symptoms. Knowledge of pulmonary physiology and diseases is not covered well enough in training, but we must embrace it to assess the risk that dysphagia poses to service users.

Dissemination

What key pieces of evidence would you use to help disseminate change of thickener practice to a clinical team?
This position paper can be used to disseminate to teams. Hansen et al (2022) and Werden-Abrams et al (2023) are two systematic reviews that can be used to consider for all clinical populations. It is also useful to consider pieces of evidence that are relevant to your own clinical population area, take time to read it and scrutinise it using your own clinical judgement through an evidence-based practice perspective.

Dissemination strategies - is there a plan or recommended approach to disseminate this information locally?
We all need to share changes in evidence and practice at the local level. It is useful to make a list of stakeholders and key members in the MDT (including adult social care) and map out how you might disseminate information. Each service will need to do this individually as there will be different variables/context to consider.

Please could the panel talk through the process of reducing reliance of thickened fluids in their services and what alternatives they now offer instead of thickened fluids.
It is important that service users have a swallow assessment before thickened fluids is recommended. Sometimes other professionals may have introduced thickened fluids without a swallow assessment with the hope that it will prevent aspiration pneumonia. There may not always be a need to offer an alternative intervention. It is suggested that clinicians reflect on their own practice using a person-centred approach following a swallow assessment.

MDT

How is the RCSLT planning to share this information with GPs and other HCPs?
This position paper will be open access. The RCSLT are also publishing a podcast, an easy read

information leaflet and a non-SLT summary; all of which are open access to the public so information can be accessible in different ways. External service user organisations and external professional organisations were invited to be involved in this project. These organisations will be able to access all resources which can then be shared with their members/service users. The position paper aims to get people reflecting on thickened fluids and the potential risks and benefits of using these.

How can we support doctors in getting the correct diagnosis for aspiration pneumonia?
It is not specifically the SLTs role to do this. However, given that we need to understand the complexity of aspiration pneumonia, it is always useful to share knowledge of that complexity because it is very hard to accurately diagnose given the lack of standard definition, agreement and sufficient information. SLTs have a crucial role in delving into the medical history, looking at the circumstances surrounding the possible aspiration event that led to a person's hospitalisation/diagnosis. It is useful to highlight this in notes – e.g. that it isn't likely a pneumonia but rather a pneumonitis because of a reflux event or regurgitation event rather than an aspiration pneumonia caused by oropharyngeal dysphagia. There are many factors that increase risk of pneumonia that are unrelated to dysphagia, fluid texture is only one element in a range of characteristics that influence swallow physiology and there is a possibility for a misdiagnosis about the reasons for pneumonia. It is important to share the information to come to a joint decision on the most likely reason for the aspiration pneumonia to have taken place.

Should care homes / GPs / SLTs still be advising thickener without a clinical dysphagia assessment and if not, how do we undo that from current practice / service delivery models?
RCSLT is trying to influence the major conditions strategy and how we can get dysphagia assessments happening sooner and reduce waiting lists (e.g. having SLTs as first contact practitioners in GP surgeries). SLTs are currently not on the recognised payable list of first contact practitioners, and we are lobbying against this. GP surgeries often put service users on thickened fluids to mitigate the risk of long waiting times for swallowing assessments. The RCSLT are trying to get CQC involved with educating GP surgeries that putting service users on thickened fluids might not be mitigating risk. What is needed is better investment in speech and language services and different more rapid response models.

Specific populations

What about using thickened fluids in an acute setting with stroke survivors?
The scope of this position paper does not allow for coverage of different clinical populations and settings. Instead, it is important that the clinician goes back and considers their own setting in line with key principles such as:

- Is the service user involved in the informed consent process?
- Look at your clinical rationale on an individual, service user basis around the potential harms and benefits of using thickened fluids.
- Is there an ability to review and monitor the use of thickened fluids?

SLTs may wish to consider referring to research by Maggie Lee Huckabee and Arlene Mccurtain within stroke service users.

Non evidence based / anecdotally offered symptom and quality of life management in end-of-life care - what's the position?
There may be a role in end-of-life care, but clinicians need to consider situations on an individual basis and look at the evidence in that area. Clinicians may need to consider what their main aim is i.e. is it to keep someone medically stable, is it to increase their hydration or is it to consider their social, cultural, spiritual aspects at end of life. Clinicians may also wish to consider carer perceptions during this process also.

What impact will guidance have for children/early years?
The guidance is the same as for any population but individualised to the child and their family. We know that there is limited evidence in the paediatric population, and that children are not just small adults, they are very different. As SLTs we extrapolate evidence from available research and apply it to the populations we work with, acknowledging what evidence is appropriate to apply and what other considerations need to be made. One very important point about the paediatric population is that they are developing and changing. This must be considered when recommending thickener, monitoring its impact (positive or negative) and weaning off, as well as considering impact of aspiration on the developing lungs. We know that in the paediatric population the trigger for a swallow assessment is often not aspiration pneumonia, but potentially lung changes or persistent / recurring respiratory symptoms. It is vital that considerations of the risks and benefits should be done in collaboration with the MDT (including the respiratory team and the paediatrician). These decisions are made as a team and not in isolation.

Relevance to the paediatric and neonatal population?
The scope of this position paper does not allow coverage of different clinical populations and settings. It's important to consider that thickened fluids are not used as much with the neonatal population. This paper would not necessarily change views but more reinforces what we already know within the neonatal population.

I completely support person centred approach and involving families / caregivers etc. but I would welcome ideas on how this works in practice in extremely busy acute settings?
Acute care is a different environment where decisions must be made very quickly. An informed decision must be made, that includes the advantages, disadvantages, what the treatment entails, what are the alternatives and what would happen if the service user decided not to engage with treatment. If the service user is unable to give informed consent, then you need to follow the path of the best interest decision. When working in a busy environment, and where it is not possible to present this information, then there is still opportunity to reflect on the treatment. This can include what the biological plausibility of the treatment in this setting is, what is the cost vs benefit ratio, and what is the risk vs benefit ratio. It is not an all or nothing approach. If a service user in an acute setting is placed on thickened fluids, this does not mean they will be on thickened fluids forever. Acute therapists are unable to see a service user over several visits and so it is vital for SLTs work together across different clinical environments with the MDT.

In terms of monitoring service users on thickened fluids - do you feel those who are on thickener in the community should be automatically reviewed and monitored by acute services should they be admitted to hospital - even if they are not showing signs of deterioration?
Acute services can only see service users if it is related to their admission reason or if there is a deterioration or change to their swallow. If a service user is on long term intervention, they

should be routinely reviewed by the team they are under in the community. If a service user is readmitted into acute care, the SLT needs to investigate the reasons for this and if it is related to the burden of the use of thickened fluids. If a community service is not commissioned or set up to monitor service users on long term use of thickener, then they need to consider the risks this may pose and highlight this to commissioners and senior management teams. We recognise the current climate of staff shortages and underfunded services within the NHS, however discharge criteria should consider the potential risks and potential benefits of long term thickened fluid use.

The lead authors mentioned people being put on thickener in nursing homes pending assessment - how do others deal with this as an approach given that it may not be beneficial for the individuals? We are thinking to recommend small sips of water with good positioning and alertness until SLT can assess. Is this a suitable approach?
Anyone who has prescribing rights is an autonomous practitioner and it is their responsibility to be up to date and understand the benefits and potential burdens of what they are prescribing. More questions need to be asked during clinical triage e.g. how distressing is the coughing, how frequent is it, are they drinking fewer fluids, is it affecting them from a social perspective, etc. Having more information at a triage stage helps to prioritise patients. There is a risk of using a blanket approach for all nursing homes, the advice would not be individualised to each service user. It is worth considering the benefits of educating the nursing home staff on what to look out for so that they can monitor a service users' symptoms and return if they have any concerns.

Is thickener helpful for paediatrics who show overt signs of aspiration on thin fluids but who haven't had VF to establish whether aspiration is occurring (where chest health appears stable and environmental adaptations have already been trialled)? Is there a need for VF prior to using thickener as intervention in such cases (in the context of very long wait times for VF)?
It is important to consider why the child is on your caseload. If there are no chest health concerns and environmental changes help with their coughing, then you need to consider why they ended up on your caseload. You would also need to consider why you are assessing their swallow, what is the impact on them and what is their health and their quality of life? It is also important to recognise that when used alone, no clinical indicator is a useful sole indicator for aspiration pneumonia. There are risks and benefits of instrumental assessments too.

Rationale

Do you think thickener is justified for people who struggle to register or hold thin liquid in their mouth?
It may have a role to play, as may positioning, sensory modification, dispensing devices, and the environment. Our rationale is ultimately going to be based on what the clinical benefit is for that individual service user. Is it providing comfort, or hydration, or improved socialisation? It is difficult because we are dealing with a treatment that has not yet been comprehensively evaluated by clinical trials. There are three factors we must consider, the first of which is the biological plausibility of that treatment and how can we confidently reason that there is a cause-and-effect relationship between thickened fluids and clinical benefit? Secondly, what is the risk versus benefit profile, including the direct risk to the service user? Finally, what is the cost versus benefit profile? This includes the investment for both the service user and the clinician to apply a

therapy.

Could you discuss the rationale for grouping naturally thickened fluids with commercially thickened fluids?
A consensus agreement was achieved within the working group to include both naturally thickened and commercially thickened fluids. When thinking about naturally thickened fluids and commercially thickened fluids, the main difference to consider is their palatability. Palatability is only one factor of the many that interact here. Naturally thickened fluids are far more likely to be acceptable than commercially thickened fluids and being more acceptable will help to improve oral consumption and hydration. Another factor to consider includes feelings of satiety. Increasing satiety reduces the amount of fluids that we consume when we compare it to thin fluids and this can be impacted when using both naturally and commercially thickened fluids. Oral hygiene is important to consider for both naturally and commercially thickened fluids. The bioavailability of medication is impacted by semi liquid or semi solid foods (this includes both naturally thickened and commercially thickened fluids). There are studies also that report on the effect of the electrical charge created by the interaction between commercially thickened products and certain base fluids.

Do the lead authors have a view on recommending thickened fluids from a bedside swallow assessment vs instrumental assessment within the scope of this paper?
Instrumental assessments such as Videofluoroscopies (VFs) are a useful tool but provide a snapshot in time of someone's swallowing. They are not able to solely predict aspiration pneumonia risk in the future and the impact of what you see on the VF in terms of risk of aspiration pneumonia survival. It is a useful adjunct to bedside assessment for some people e.g. to understand the swallow physiology and what interventions may be appropriate. As with all ways to assess swallowing the results of a VF need to be interpreted within the context of the individual. We are also aware of the limitations that SLTs have in terms of access to and resource allocation for instrumental assessments. We are aware that there are large parts of the UK who have no or reduced access to instrumental assessments. We would encourage members to advocate for the use of instrumental assessments (where clinically appropriate) to support better decision making.

How do you recommend community SLTs navigate the lack of available instrumental assessment to support decision making?
Instrumental assessment is a snapshot and may not predict the rate of aspiration pneumonia survival. Information gathering is important and will give a lot of answers to the decisions you need to make. Access to instrumental assessment is not limited to the area of thickened fluids. There are huge variations between client groups and regions in terms of access and waiting times for instrumental assessment. Auditing and benchmarking your service can prove useful in reducing these waiting times.

Alternatives

What do they see the role of the Frazier free Water Protocol as, at this time of possible transition?
This position paper is only looking at thickened fluids but several of the referenced studies in the position paper reference the use of the Frazier free Water Protocol with service users on

thickened fluids to improve oral intake. The Frazier free Water Protocol already has a role as part of the speech and language therapy toolkit. Like any treatment, the evidence has a risk of bias, and we must reflect on what is the risk to the service user of using a Free Water Protocol relative to thickened fluids, sensory modification, and any of the other treatments that you might use in your clinical practice.

Can you comment on the need to be ambulatory if on Frazier free Water Protocol- this is important aspect and not suitable for all acutely unwell service users?
It is one aspect of the Frazier free water protocol. Some organisations have looked at an internally modified free water protocol to try to use the evidence base within a non-ambulatory population, but it is an important factor that needs to be considered on an individual basis. Not being ambulatory has an impact on chest health if the service user is on thickened fluids.

If found not to recommend thickener, should we get people off thickener if they have been on it long term and try new strategies?
It depends on the clinical situation and whether a speech and language therapist feels that there is evidence to perhaps review that intervention. It may be useful to consider the clinical rationale as to why that person was put on thickened fluids in the first place and the impact this has on their quality of life. It is also key to consider whether the person has been placed on thickened fluids following a robust swallow assessment?

What is our duty of care to children who are on prescribed thickener?
We should not discharge children on thickener because then we would be unable to monitor the use, the impact, and the outcomes relative to the aims for that child. Children are consistently developing and changing. Thought therefore needs to go into the practicality of what is the right time to assess weaning the child off thickener. It is also important to regularly review if the child still needs thickener.

Resources

More practical guidance for clinicians would be helpful.
Along with the position paper, additional resources such as a podcast, easy read version, a non SLT summary and practice-based learning scenarios will also be available. There is so much variation across the UK in terms of service models and individual practices with the use of thickened fluids it is impossible to be prescriptive about its use. The RCSLT encourage services and individuals to go back and reflect on their own practice and to consider what they think is best for their service users.

As clinicians how might we support carers, family members and others involved in a service user to monitor use of thickener?
It will depend on the setting, the input you are providing, the rationale for the thickener trial and your access to support from the MDT. General principles will apply e.g. the use of food and fluid charts to monitor hydration, and patient leaflets about the potential harms and benefits of using thickener. Thorough and detailed education as part of the informed consent process will mean that service users and their carers can then advocate for any changes or concerns. It is key that the service user and their carers or family members know that they have a choice in the use of thickened fluids. Involve the service user, carers and family members in decision making, making

sure they understand risks and benefits, what to monitor, and when and who to contact at any given time. It is key to help service users and their families understand they are not alone in the process and that the SLTs have an important role in working and monitoring with them the use of thickened fluids.

I often encounter service users who weren't aware they had a choice to say no to thickened fluids as intervention. Do you have any recommendations for standardised consent gaining procedures or tools to use in daily practice - or more regional/national approaches?
Locally clinicians need to consider how to gain and log informed consent, considering the HCPC and the Mental Capacity Act. It is recommended to refer to informed decision-making documents and consider how these can be audited in practice to ensure that consent giving is happening. In Scotland, clinicians can refer to the Adults with Incapacity Scotland Act. It is important that service users can express their wishes and are informed about the benefits/risks of using thickened fluids. Information sharing with service users should be seen more as a teaching opportunity that can also help the wider MDT understand that we should not just assume that a service user is unable to make an informed decision about this. The RCSLT website has further information around consent and having difficult conversations.

Evidence

What are going to be the challenges of addressing some of these gaps in the evidence base?
As part of the RCSLT research priority setting work, the use of thickened fluids within dysphagia, eating, drinking and swallowing was identified as an area of priority. The National Insitute for Health and Care Research (NIHR) approached the RCSLT to produce some research questions for them to consider. A small working group are helping to address and prioritise research questions around thickened fluids that are going to be the most clinically meaningful. There will be a minimum of two research questions, one paediatric and one adult. Organisations will then be able to put bids in for the money to answer these questions.

Which evidence specifically references the effects of taking medications with thickened fluids. We have consulted with our pharmacy team about this, and their review concluded that there was no evidence of a clinical impact of this in service users (apparently a big mismatch between the in vitro studies and studies in humans). I am just interested to read the papers you were describing.
The papers referenced in the position paper that are useful to consider are Cichero (2013) and Marique et al. (2014, 2016). We know that there is an impact on some medication absorption in patients who have gastroparesis. Some medications also need to be taken on an empty stomach to enable fast absorption. If you are giving that medication with a thickened fluid, it stands to reason that that is going to slow down absorption of the medication. It is the viscous substance itself and not necessarily the commercial chemical properties of a thicker that's delaying that, if a medication needs to be taken with a fluid.

Other

Is a similar process is planned for texture modified foods?
At present, no. If members would like to propose a project that they feel should be occurring at the RCSLT please contact info@rcslt.org to let us know.

If thickener is thought not to be overall beneficial as it decreases hydration, education is given regarding best positioning / good oral care but someone is coughing on fluids, are they drinking with acknowledged risk even if evidence is not there for oropharyngeal aspirated chest infections?
It is important to consider the following questions: What is the risk? How have we evaluated the cough? Have you spent time looking at the service user's baseline cough? What are the possible rationales for why we would recommend an intervention for someone who is coughing? Is an intervention needed at all? These all influence the impact on the service user and their coughing when eating and drinking.

What resource could be used for measuring distressing cough - for patients unable to comment themselves often others will say cough is distressing even if not verified by the service user?
It may be useful to monitor the quality of the drinking episode. Consider the service users receptiveness towards fluids. Do they refuse fluids or food after a coughing episode? What is their physical state like after a coughing episode? It is key, when thinking about a holistic approach, the need to communicate with the service user and their families about how much distress they feel with coughing and if it is impacting on their quality of life.

Should people on thickener remain on the community caseload for review even if no concerns and are stable?
For an adult population, if you have completed the assessment, carried out education and you are confident that the service user can advocate and recontact if there has been a change then that may be ok. It will likely depend on your service model. It's key for the SLT to reinforce that the service user has a choice to use or discontinue using thickened fluids. If the SLT highlights openly the uncertainty of this treatment option, the limited evidence base, the benefits and risks to using thickened fluids then that may be ok. This does link back to having strong triage systems in place, so when a service user does come back to an SLT service you can identify if a person may be having difficulties on the thickened fluids and may benefit from a different approach.
For a paediatric population, the thickeners that are generally available are less stable and more difficult to use. The SLT may therefore need to consider the frequency of reviews based on each individual child.

Can you please share the link to the podcast by John Ashford and James Coyle?
https://swallowyourpridepodcast.com/ and https://dysphagiacafe.com/

Additional useful resources:
DisDat resources - https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/distress-and-discomfort-assessment-tool-disdat/