

TEN THOUSAND **MORE** VOICES

# Your experience of Living with a Swallowing Difficulty

- The lived experience of people with swallowing difficulties living in Northern Ireland, their relatives & carers

March 2020



Share your story, shape our service



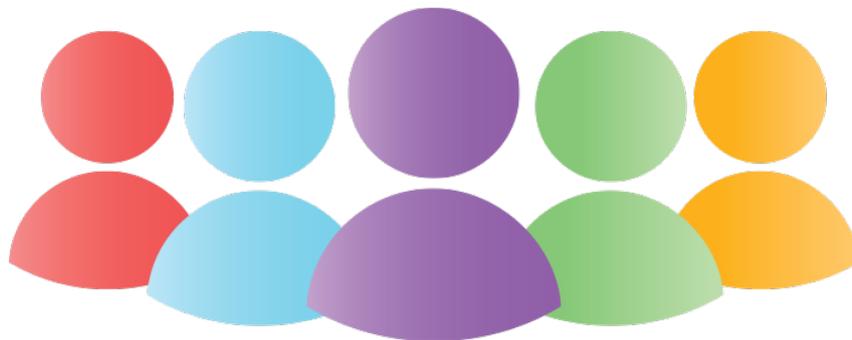
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# ACKNOWLEDGEMENTS

The 10,000 More Voices team would like to express their heartfelt thanks to the patients, clients, relatives and carers who shared openly their experiences of living with a swallowing difficulty. It is recognised many patients, relatives and carers gave of their time to share the stories to support the development of services and have openly shared their experiences. The engagement of people using services is essential for health and social care services in Northern Ireland to recognise what is working and also where changes are required.

The Public Health Agency and Patient Client Experience leads would also like to sincerely thank the people who co-designed the survey – Quality Improvement lead, Jocelyn Harpur and a group of 15 service users who supported the team to identify the core concepts. Our thanks and appreciation to the many staff who supported this survey – in particular the Dysphagia NI partnership, HSCB, PHA, Speech and Language Therapy managers and speech and language therapy staff. It is important to acknowledge the work of the Trust Patient Client Experience Facilitators, their energy and support enabled the collection of this experience in the short timeframe available (Appendix 1).

**“ I really worry about the choking. I had an experience of it myself, it was horrible, it frightened the life out of me. I’m sure when it happens it scares her too...”**



# CONTEXT

Data collection commenced in 1st February 2020 and ended 31st March 2020.  
In total **82** stories were collected across the region.



## Trust

(n=82)

- **18** from Belfast Health and Social Care Trust
- **34** from Northern Health and Social Care Trust
- **16** from South Eastern Health and Social Care Trust
- **4** from Southern Health and Social Care Trust
- **9** from Western Health and Social Care Trust
- **1** Other



## How Long Before You Sought Help?

(n=82)

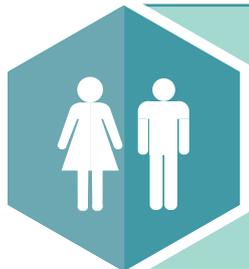
- **4** - Managed from birth
- **38** - Immediately
- **14** - After 1 month
- **11** - After 6 months
- **2** - After 1 year
- **13** - After more than 1 year



## Age Represented

(n=82)

- **4** - 0-18 yrs
- **5** - 19-29 yrs
- **6** - 30-39 yrs
- **4** - 40-49 yrs
- **8** - 50-59 yrs
- **19** - 60-69 yrs
- **16** - 70-79 yrs
- **18** - 80+ yrs
- **2** - No comment



## Who Responded

(n=82)

- **7** x I am a carer
- **52** x I am a person who has a swallowing difficulty
- **21** x I am a relative
- **2** x Other



## Rating

(n=82)

- **31** x Very positive
- **31** x Positive
- **15** x Neutral
- **4** x Negative
- **1** x Very negative



## Where Did You Seek Help From?

(n=82)

- **32** - Hospital/Specialist services
- **22** - GP
- **8** - Day Centre
- **6** - Self referral to Speech & Language Therapy
- **5** - Nursing/Residential Care Home
- **3** - Community Nursing Team
- **2** - Social Worker
- **1** - Dietitian
- **1** - Occupational Therapy
- **2** - Can't remember/no answer

# ANALYSIS OF SURVEYS

Key messages and areas for reflection highlighted in this report have been identified using a range of analysis tools, these provide rich insight and understanding into the experience of the children, parents and guardians engaging with services.



# RESULTS

Summary of the main findings in relation to the key concepts analysed through Sensemaker®.

## 1 PCE Standards

76% reflected that they were treated with privacy, respect and compassion.

## 3 Information

59% of responses indicating the information received was timely, easily understood and answered questions related to swallowing difficulties.

## 5 Enjoyment of food

Swallow assessment had a minor impact on the emotional experience of respondents relating to eating food: 68% before assessment; 62% after assessment reflected they enjoyed their food.

## 7 Eating with friends & family

52% felt it was easy to eat with friends and family at home; however 29% noted they found eating with friends and family difficult.

## 9 Participating in sport activity

Further study required to gain insight into this area. 12 respondents reflected a negative tone in relation to how their swallowing difficulty affected participation in sports.

## 11 Embarrassment

43% had felt varying degrees of embarrassment due to their swallowing difficulty.

## 13 Experience of people staring

Over 50% responded with a high concern related to people staring in public.

## 2 Engagement

62% reflected positively on meaningful engagement as they had the opportunity to ask questions, to be part of decisions around care and were believed and listened to.

## 4 Service or care received

70% felt confidence in the service provided, and that they received individualised treatment where professionals had worked in collaboration.

## 6 I followed my management plan

59% of respondents indicated they almost always followed the management plan.

## 8 Eating in public

44% stated they found it extremely difficult to eat in public.

## 10 Anxiety around choking

85% of responses indicated anxiety in varying degrees towards choking.

## 12 Concern regarding my weight

28% indicated some concern about weight management within their experience.

# KEY MESSAGES

The following is a summary of the findings from the regional data. Each Trust can also review local Trust data to inform further service improvement.

- The provision of clear, concise information regarding a person's management plan is crucial to support them, their carers and others to implement the plan. This includes communicating and consulting with families and carers regarding assessments and changes to the plan.
- To support confidence in the delivery of the management plan it is recognised that training and support is required for informal and formal carers. Such training should support them to develop a practical knowledge base and to deliver safe and compassionate care.
- Awareness training on swallowing difficulties is essential across the whole system as many patients or clients have complex needs with a wide range of healthcare professional engagements.
- Increased awareness in our communities is essential to support the health & wellbeing of someone with swallowing difficulties. Strategies engaging with restaurants and caterers support someone to socialise safely and easily.
- Management plans need to be individualised in partnership with the person and their carer- it should explore the whole person, including personal preference and tackling wider issues such as concerns regarding choking, impact on weight and socialising.
- Management plans need to be readily available for all healthcare professionals as management of a swallowing difficulty extends beyond Speech and Language therapy and often requires input from others such as dentists, physiotherapists, dietitians.
- There is a need to develop a framework or risk assessment to support the complex debate between patient safety versus patient choice in the case of a person who does not comply with the management plan. This is particularly important for carers such as domiciliary care and care home assistants.

## Next steps:

The Dysphagia NI partnership will include this insight from the voices of patients, relatives & carers to influence the current strategic work.

# 1.0 INTRODUCTION

The 10,000 More Voices Initiative has been commissioned and funded by the Health and Social Care Board (HSCB) and the Public Health Agency (PHA) to provide a person centred approach to improving and influencing experience of health and social care services. Embracing the principles of Co-Production, Patient Client Experience (PCE) is both a driving force for service improvement and also a quality indicator for service improvement. The methodology for 10,000 More Voices engages service users at the point of survey design, and on completion of the project presents the findings to service users to validate or challenge the findings. Projects are undertaken in partnership with HSC Trust nominated service leads and the Trust PCE facilitators for 10,000 More Voices (detailed in Appendix 1).

The project entitled “The Experience of Living with a Swallowing Difficulty” was part of the work plan 2019/2020, reflecting the strategic developments in relation to dysphagia being identified as a public health issue in Northern Ireland. In 2018 an interprofessional review team undertook the Regional Choking Review, exploring the themes from Serious Adverse Incidents across the region. Eight key themes were identified:

1. Factors causing high risk of choking
2. Behaviours increasing risk of choking
3. Signs & Symptoms of a Swallowing Difficulty
4. Communication & Understanding of recommendations
5. Individual Care Plans
6. Physical Environment & impact of changes
7. Meal time & snacks
8. Dysphagia training & Awareness

The Regional Dysphagia NI partnership, a transformation project was formed in 2018 to address the issues outlined in the Regional Choking Review (2018). The aim of the regional group is to develop collaborative whole systems solutions to support outcomes for adults with dysphagia to include:

1. Improve awareness of dysphagia
2. Standardise identification & management of people with learning disabilities
3. Improve access to specialist interventions
4. Adopt a co-production approach across all action

This report has been co-produced alongside Dysphagia NI and the findings will inform the future direction of the regional learning. These elements inform the analysis, reflection and learning identified in the 10,000 More Voices Project.

## 2.0 PROJECT OUTLINE

### 2.1 Aim

The aim of the study was to explore the experience of living with a swallowing difficulty, to identify key features of positive experiences and to learn where further developments are required.

### 2.2 Objectives

1. To capture and learn from the narrative of people who live with swallowing difficulties through a bespoke survey and support them to engage with a platform to share freely their experience.
2. To explore the experience of engaging with services to support living with swallowing difficulties.
3. To consider areas for reflection and improvement and to inform new ways of working to support people living with swallowing difficulties.

### 2.3 Target Group

This project embraced the experience of anyone living with a swallowing difficulty, including those under 18 years old, with the exception of people who were acutely unwell and with a new diagnosis of a problem with their swallow, for example, following a stroke. Relatives and carers could also share the experience from their perspective.

## 3.0 METHODOLOGY

### 3.1 Survey Design

In keeping with the core principles of 10,000 More Voices the survey was co-designed and piloted with people who have experience of swallowing difficulties. Stories shared, as part of face to face interviews, identified the core concepts to be explored using Sensemaker® Analyst software. This software gathers the experiences of real people and supports the visualisation of patterns in the narrative, as explained in Section 3.3.

### 3.2 Engagement

The project was launched in February 2020 with a focus to share learning on Swallow Awareness day, however due to the COVID-19 pandemic the collection of stories was discontinued in March 2020. In total 82 stories were collected prior to the project ceasing. Surveys were completed in collaboration with the Trust PCE facilitators. Additional support was required for the completion of some surveys to support communication by the patient/carer. In this context surveys were completed as part of semi-structured interviews and the responses recorded on the survey by the PCE facilitator.



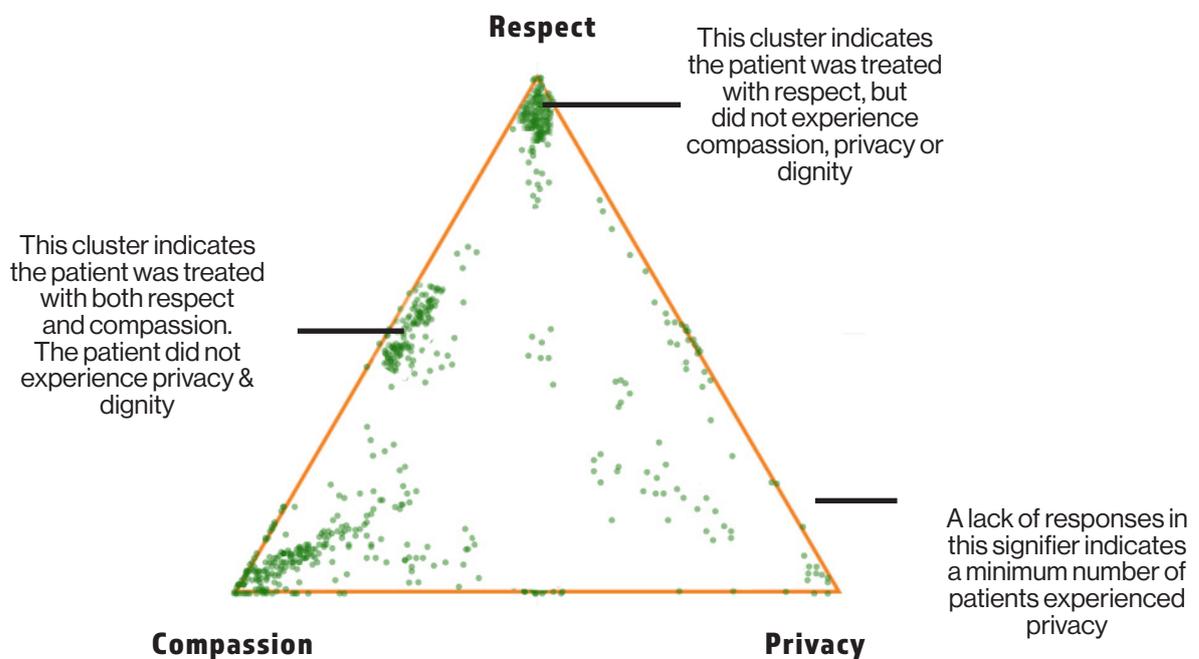
### 3.3 Data Analysis - Using Sensemaker®

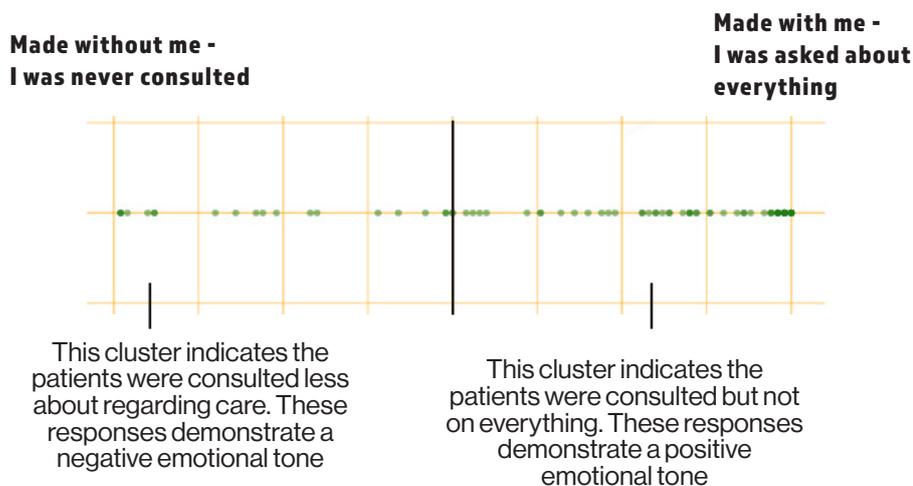
When completing the survey respondents were first asked to describe the experience of engaging with services regarding their swallowing difficulty. The second section contained a number of statements to support the respondent to “self-index” or analyse their experience.

Section 4.0 of this report displays a series of triangles (known as triads) which contain clusters of response to the statements. In relation to triads, respondents were asked to mark in each triangle the position which best describes their experience in relation to three pre-specified responses (known as signifiers). If none of the responses applied the respondent could tick “this does not apply to me”. The closer the marker is to any one statement, the stronger this relates to the experience. Each dot within the triad represents an individual experience of a patient, client or stakeholder. A high concentration of dots in a specific area identifies an emerging pattern in relation to the signifier. This illustrated in Figure 1. The same principles apply for dyads, which demonstrate two extreme responses to a statement/question, moving from negative emotional tone to a positive emotional tone, as illustrated in Figure 2.

**Figure 1. Example of a Triad**

**Responses to statement: In my experience I was treated with...**



**Figure 2. An example of a Dyad.****Responses to statement: Decisions regarding my care were...**

### 3.5 Limitations

- Project was only promoted for 4 weeks and closed early in response to the pandemic. It is recognised the opportunity to complete the surveys were limited and a wider reach would have supported additional benefits for robust analysis.
- An easy read version of the survey was requested but not developed within the timescale therefore reducing the opportunity for people with cognitive impairment who did not have access to a PCE facilitator.
- The survey focused upon people with experience of swallowing difficulties. It did not support collection of the experience of people newly diagnosed with a swallowing difficulty.

The following section presents the regional findings from the stories (inclusive of the pilot) and informs the areas for learning and reflection (Section 5.0). Appendix 2 includes an overview of the context questions included in the survey. Further briefing papers can be explored under each of the context questions for example - trust specific briefing reports.

# 4.0 FINDINGS & ANALYSIS

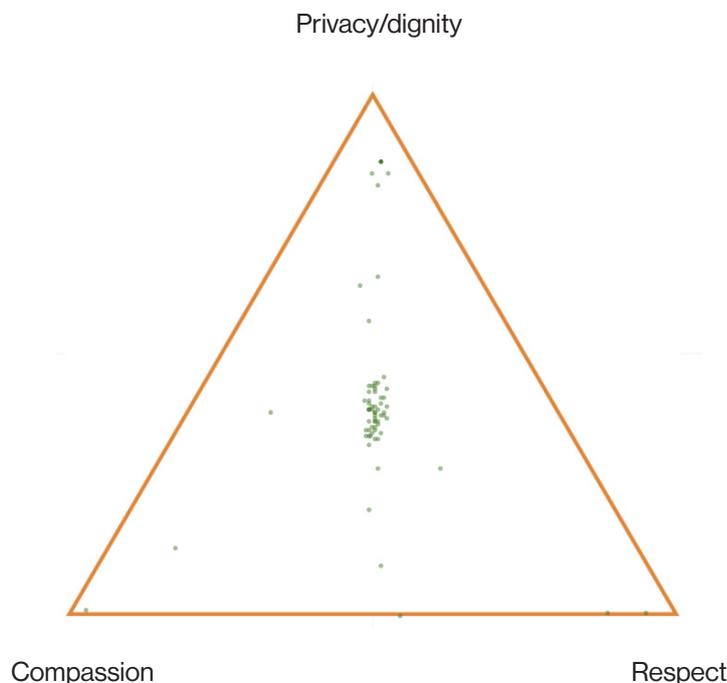
## Presenting the voice of the service user

The following section presents the responses in relation to 9 statements/core concepts, presented as Triads and Dyads. The main messages are highlighted as clusters and indicate the majority of responses however it is also important to take cognisance of the smaller patterns emerging which can indicate areas for further reflection and development. Each pattern formation is analysed using the narrative shared and the results further demonstrated using some of the anonymised quotes from the database. The first 4 statements reflect upon the services relating to a swallowing difficulty and are presented as Triads. **The narrative includes stories of people having deviated from their professional Speech and Language Therapy Eating, Drinking, and Swallowing Recommendations, at their own risk. Health and social care professionals strongly advise that people with eating, drinking and swallowing difficulties and their carers adhere to Speech and Language Therapy Eating, Drinking and Swallowing Recommendations**

### 4.1 Patient Client Standards

Statement 1 addresses the key elements in the Patient Client Experience Standards. These standards present that health and social care staff should at all times treat patients/carers with respect; have a positive and compassionate attitude; have professional and considerate behaviour; be sensitive in their communication manner; and uphold privacy & dignity. Responses are shown below in Figure 3.

**Figure 3. (n=67) Statement 1: In telling your story were you treated with ....**



The central cluster of 76% (n=62) reflects upon being treated with privacy, respect and compassion. Within the narrative patients and carers reflect upon being listened to about preferences and being engaged during assessment or care. This extends outside of HSC services to others such as staff in restaurants or private carers. In relation to the standards respondents highlighted the importance of respecting personal choice and empowerment through education and information.

**“...The Speech Therapist is a good girl she knows what I like, she let me have a piece of bread and jam. It has to be cut up but I enjoy it.... If we go out we take thickener with us for the tea. We would ask the staff to cut the sandwiches up small and cut the crusts off. They do it no problem...”**

**“...We had education sessions with SLT to show us how to feed my daughter. They were very attentive and provided us with written information...”**

**“...The Speech Therapist has been amazing, she is so caring when she speaks to him she shows him respect. I have been given a lot of information and places to contact for advice and information...”**

Outlying minor pattern formations still reflect upon a positive experience, however in a small number of stories where respect was not included respondents reflected upon the lack of choice in relation to their plan of care.

**“... I didn’t know I had a problem and all of a sudden I am told I cannot eat the things I love. I do not like it – they tell me I must thicken my coffee, but this is not how I like my coffee...”**

The key messages in this concept were the importance of understanding the perspective of the patient or client and exploring choice in relation to a plan of care.

#### 4.2. Meaningful Engagement

Statement 2 explores elements of meaningful engagement – the opportunity to ask questions, to be part of decisions around care and to be believed and listened to. This is illustrated in Figure 4.

**Figure 4. (n=69) Statement 2: In your experience were you....**



Central cluster of 62% (n=51) reflects positively on meaningful engagement. Again in the narrative respondents shared on the importance of exploring their choice and preference and responding to questions. Also included is the complex debate on how to ensure patient safety versus offering patient choice.

**“... She [Day Care Support] always talks to me and lets me ask questions... I know to eat slowly and not talk. I am told to cut up food. I get a personal place mat PPM with my picture on it and it has all the instructions about my diet on it. It shows food I can eat, the level of supervision and all good information...”**

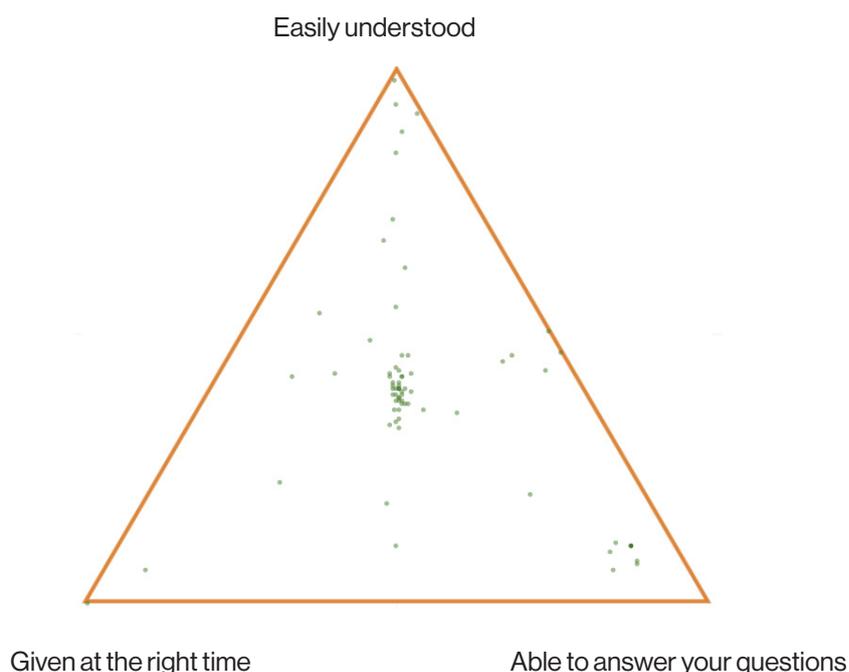
**“...They just give you advice (SLT) about what you should and shouldn't be doing for eating and drinking. It was up to me; 'my discretion to make the decision- as long as you understand what might happen. It was helpful to make my own decision...”**

There are a number of responses which are varied across the triad, which although do not form a pattern, they do focus on the bottom half of the triad reflecting upon the experience of being believed & listened to and being involved in decisions. Partnership working with the patient or carer is an important element of meaningful engagement - to support understanding of the risks and empower the patient or carer to follow an agreed plan. This is further discussed in Section 4.4.

### 4.3 Effectiveness of Information given

Statement 3 focuses about important elements for information sharing – that the information is easily understood, timely and answered the respondents questions. This is demonstrated in Figure 5.

**Figure 5. (n=70 )Statement 3: The information given was...**



Central cluster represents 59% (n=48) of responses indicating the information received was timely, easily understood and answered questions related to swallowing difficulties. In particular carers reflected upon the importance of the information shared.

**“...She [daughter] was put on a thickened fluids and soft diet so she could adapt and her care plan was clearly set out and this was explained to us a family in a way that we could understand....”**

10% (n=8) of respondents did not feel this was part of their experience. In these cases there was a lack of information shared or the information was not accessible at the right time. Examples include lack of information on how to use thickener, conflicting information between health professionals and lack of engagement with carers, in particular in the case of a resident in a Care Home.

**"...I got different pieces of information from staff in hospital and what the therapist told me. This can be confusing..."**

**"...I have been prescribed thickener for my drink, left with little information, how long to take, how to order any follow up..."**

**"... they changed all his [brother] regime. I didn't know until I arrived at the home and found something stuck on his wardrobe door – when I asked staff they weren't sure and said it was something to do with guidelines; I am still his next of kin... I love him... I need to know when things change..."**

The key message relating to the provision of information is the importance of information which is consistent across the region. It is also important to ensure key people who support care such as next of kin and carers are aware of changes and this information is shared in a timely manner.

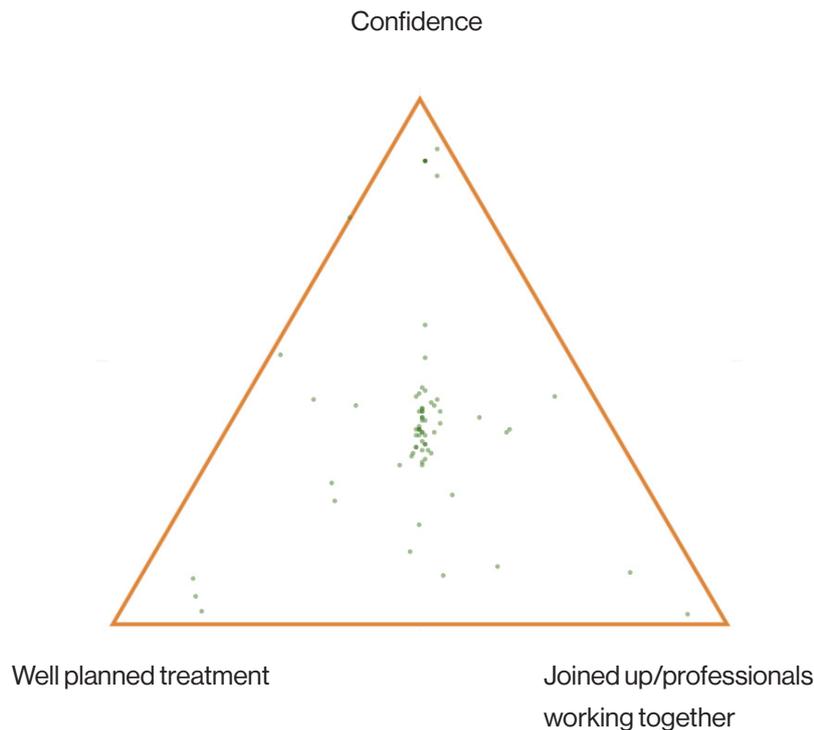
#### **4.4. Outcome of Engaging Services**

Statement 4 considers the outcome of engaging services – considering elements of confidence in the service provided, individualised treatment and collaborative working with others. Figure 6 demonstrates a central cluster of 70% (n=57) whereby all these elements were part of the experience. The narrative within the central cluster reflects upon examples of collaborative working between Speech and Language therapy and carers or other allied health professionals, supporting confidence and well planned treatment.

**"....If I have any problems I would link with the senior carer who would contact the speech therapist. She is very very good/ fantastic. They keep close connections with her community nurse and speech therapist..."**

**"...If I have an issue or if they notice something that doesn't seem right they will contact me. We discuss it and the Speech Therapist is contacted straight away and followed up..."**

**"...I have a neck brace that helps to support my head up for eating, the Speech Therapist spoke to the Occupational Therapist and they got me this..."**

**Figure 6. (n=68) Statement 4: The service or care you received provided...**

There is a diverse range of responses to the bottom third of the triad, reflecting how the experience did not instil confidence. Identified in the narrative is a lack of confidence in the knowledge base of other healthcare professionals - two contributing factors were a lack of skill in managing a swallowing difficulty and lack of knowledge on the individual's care due to agency work/lack of consistency in domiciliary care. The challenge is to identify the training needs to support someone with a swallowing difficulty and also how to communicate an individual's care needs for consistency in care. This is a key theme identified in the Regional Choking Review (2018) which identified the need for consistent, accessible training. This need extends beyond HSC workforce and into the independent sector – care homes, agency workers and domiciliary care.

**“...My mother is in a care home. The awareness of swallowing difficulties is very poor and the management even worse – My mother had a near miss choking episode...”**

**“...Agency night staff have often given her solid meds with a real risk if her choking or spitting them out and not getting them...”**

**“...I look after him [brother] every day; I know him and I know his needs but twice a week someone comes to let me get out and have a breather. I don't really blame them for not knowing him as we would be lucky if it is the same girl each week. I wish we could get someone regular – someone who wants to know my brother and learn what he wants. Most of the girls don't really care – they come, they go ... he might have eaten nothing but they sign the book and leave. There is only one I have faith in...”**

There are also external stakeholders which make a significant impact upon someone living with a swallowing difficulty. One of the stories entitled “Everyone needs to know the right information” outline concerns in relation to unscheduled care (often in a crisis or period of acute illness) and lack of knowledge and support from the staff or service.

**“...There have been times when in A&E they don't have any of the powder for thickening fluids and I have to bring down some from home. Another thing is that he has had a stroke 2 years ago and did not always get the assistance he needed do ended up spilling food over himself. He can manage when he has a feeder cup but sometimes they are not available either. I feel when he moves departments information isn't shared properly and the patient gets lost in the middle. Sometimes I feel guilty when I can't get down to feed him. On occasions he has been given the wrong diet. Once when I challenged this, the doctor told me to go to the shop and buy a couple of yoghurts...”**

Another key professional is dentistry. Dental care significantly impacts upon the ability to eat.

**“...I went to get my dentures tightened up but they said there was nothing they could do but I know my dentures are not right. I wish they would listen to me...”**

Other reflections which demonstrate a lack of confidence in the system are delays in communication or management. A story entitled “Lost in the system” expresses concern their condition is serious but the system is not responding in a timely manner causing anxiety.

**“...Consultant felt my problem was quite serious and wondered how I had managed with my symptoms. I was given a copy of my test that day. He wished for me to have a barium swallow test they were very nice doing the test and I got an appointment very quickly-however I was a little baffled when they said I would get my results when I see my Consultant next .I advised I do not have another appointment that I am aware of to the best of my knowledge they have not arranged another appointment neither have the offered to send me my results? I questioned this as I do not want lost in the system...”**

The key messages highlight the importance of collaborative working when supporting someone who lives with swallowing difficulties. The support required extends beyond Speech and Language therapy with a multidisciplinary approach required. The main challenges is ensuring there is effective communication for continuity of care between the various disciplines; also where necessary a joint eating, drinking and swallowing management plan to support the individual as a whole. There is also a challenge to ensure the wider understanding of how to support someone with a swallowing difficulty across the system, in particular within nursing profession.

The following statements consider the personal reflections of a respondent living with a swallowing difficulty – the deeper emotional responses and challenges faced on a daily basis by the person or their carer.

#### **4.5 Relationship with food**

Statement 5 is divided into the relationship with food before and after the specialist dysphagia swallow assessment performed by Speech and Language Therapists. It considers the impact on enjoying food. These are demonstrated as dyads in Figure 7 and 8.

**Figure 7. (n= 71) Statement 5a – ENJOYMENT OF FOOD: Before assessment****Figure 8. (n= 69) Statement 5b – ENJOYMENT OF FOOD: After assessment**

Before assessment the majority of responses (68%/n=56) had a positive emotional experience relating to eating food. There is also minimal change in the impact of the assessment with 62% (n=51) of respondents reflecting they enjoyed food. Therefore the process of Specialist Dysphagia Assessment for the majority of respondents does not impact significantly on the enjoyment of eating. In the narrative individuals did reflect upon how the assessment made them feel safer and more in control.

**“...I’m not coughing or choking I’m much happier about this now. Although I do not enjoy coffee the way I used to, it’s not the same with thickener...”**

**“...The speech therapist told me to eat slowly and to make sure my food is moist. Before I began liquidising my food at home I had an awful fear it would stick in my throat...”**

**“...I love my food but my food doesn’t love me Sometimes I have a mouthful of saliva, I just can’t swallow or control it and it just lets go and I have to spit it out...”**

**“...now a pureed diet which he has tolerated without complaining. He was allowed jaffa cakes but he is not allowed anymore, he misses this. We try and subsidise this with trifles. As a learning disability he is not in a position to disagree but we act as advocates to him. He is so compliant. What helps our patients is when the food looks appealing..”**

A small number highlighted the use of pureed meals was less appealing to them and impacted upon their enjoyment of food. Dissatisfaction with the taste, consistency and lack of visual presentation of pureed textured meals was highlighted.

**“...I never thought I had any problems, it came out of the blue. I loved my food and ate everything. Now I have to eat thick meals, they are rotten, I don’t think much of them. There’s a lump of stuff on the plate you wouldn’t know what it was. I can eat the puree peas and carrots. There is no taste to them. The custard and yogurt are alright. I asked for a boiled egg, a salad and a piece of bread but they wouldn’t give it to me. I can’t really understand it but I have to abide by it...”**

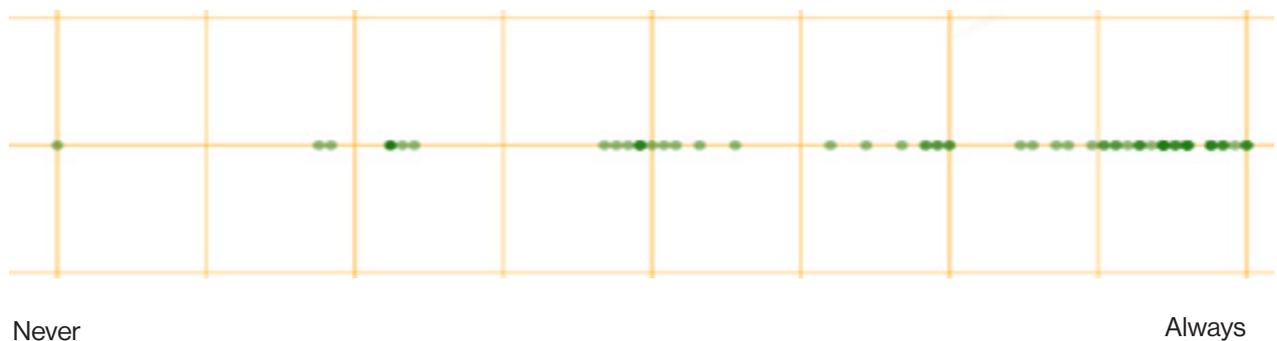
**“...At the beginning I found the change in meals hard to adapt to. I would love to just have normal meals but I know if it keeps me safe that is the most important thing...”**

**“...I have to put in 2 spoonfuls in all of my drinks, except tea. It’s unpleasant in tea although it is tasteless, it’s like wall paper paste..”**

**“...When I was in hospital I had to eat the pureed meals they were awful, it sickens me now even thinking about them. When I came to XXXXX [name removed] I got potatoes and mince mashed up and it was lovely. When I started to liquidise my own food at home, I felt more comfortable eating not as afraid of choking, but I always like to have a glass of water beside me just in case...”**

The final statement regarding the relationship with food was to explore how closely individuals follow the management plan. As demonstrated in Figure 7 59% (n=48) of respondents indicated they almost always followed the management plan. **The narrative includes stories of people having deviated from their professional Speech and Language Therapy Eating, Drinking, and Swallowing Recommendations, at their own risk. Health and social care professionals strongly advise that people with eating, drinking and swallowing difficulties and their carers adhere to Speech and Language Therapy Eating, Drinking and Swallowing Recommendations.**

**Figure 9. (n=66) Statement 5c – I followed my management plan...**



In the narrative where respondents indicated they did not always follow the management plan a number of factors were identified.

1. Individual's favourite foods were not part of the management plan
2. Challenge to modify behaviours
3. Carers decision to change the recommendations as influenced by the individual with swallowing difficulties
4. Conflict by carer in adhering to recommendations and pleasing the individual with swallowing difficulties
5. Accessing the correct resources (for example recommended thickener)

**"...Although she sticks to her diet here [day centre] I cook normal meals for her at home and I cut her food up into small pieces. I understand the Centre's position they have to do what is right as it is a big responsibility to feed her. I am responsible for what I do at home and I am happy for her to have cut up meals.."**

**"...He loves his food and when we go out he likes to get chips. Although the chips aren't recommended we cut them up into small pieces and feed him slowly..."**

**"...When I am at the Day Centre I think I could eat normal food but I don't get a choice, I have to eat pureed meals. I feel like they don't listen to me. At home or if I go out to a restaurant I can eat what I want. I enjoy normal food much more. My wife is very alert to it she would cut up my food into small pieces. She keeps me right – It's a hard job I normally eat quite quickly and swallow quickly..."**

**"...I asked for a boiled egg, a salad and a piece of bread but they wouldn't give it to me. I can't really understand it but I have to abide by it..."**

**"...The food didn't look like ordinary food at all as it put on plate it looked a lot which put my mother off eating. She didn't like the thickener in the fluids. I myself was quite concerned of how I was going to cope when she came home from hospital. I would have been more afraid and more aware of what could happen more so than my mother. It does change the life of a family eating together because of my mother looking to have the same food as you..."**

**"...My son has severe swallowing difficulties with fluids but he is OK with mashed foods. He takes nutilis clear and I think this can cause extra secretions. I really don't like giving it to him but it is the only safe way I can give him fluids. Before I had thick n easy which I believed caused stomach problems. I believe thickener can add to my son having more problems. The SLT team located a thickener that suited my son but we can't access it..."**

**"...Sometimes temptation rears its ugly head and I eat certain foods which are not blended - but generally I am sticking to the plan..."**

The narrative also demonstrates a challenge for day care centres/care homes/domiciliary workers whereby they seek to keep the person safe by adhering to the management plan, but in some cases against the person's choice. This conflict of interest is a challenge for all healthcare professionals when seeking a balance between patient choice and patient safety.

**“...Need a more detailed risk assessment to protect staff and allow them to take calculated risks to go outside of level 4 diet occasionally so that more treats would be possible...”**

**“...You really need to know her when your feeding her, she sometimes turns her head away, like she is refusing her food but she’s not it’s just what she does. I go to the other side and feed her if she turns her head away, but the staff think she is refusing the food and stop trying as they don’t want to force her. She really needs to eat...”**

It is evident from the narrative that the relationship with food is complex, in particular when seeking a balance between the safety of the individual versus their desires and choice around food. These decisions should be made in partnership with the individual and/or their carer and in the case of a Care Home or Day Centre the relevant staff need to be involved to ensure informed decision making.

## 4.6 Challenges living with a Swallowing difficulty

The following dyads demonstrate responses to possible scenarios whereby living with a swallowing difficulty may be a challenge. These challenges were identified by the service users who supported the design of the survey.

### 4.6.1 Eating with others

Figure 10 explores the concept of eating with friends and family – often those closest to us. There is a diverse spread of responses - main cluster of 52% (n=43) find it easy to eat with friends and family at home; however a cluster of 29% (n=24) in negative emotional tone indicated they found eating with friends and family difficult. Contributing factors are the length of time taken to eat a meal and adding to family worries/concerns.

**Figure 10. (n= 65) Statement 6: Eating with friends & family**



**“...I don’t like to go out or eat in front of people I just like to eat on my own”.**

**“...I have to eat slowly and by the time I come to the end of my dinner my food is usually cold. I’m always way behind the family a lot slower than they are...”**

**“...It does change the life of a family eating together because of my mother looking to have the same food as us...”**

**“...At the start I couldn’t understand I found it strange but now it’s a part of life. It effects the whole family and their lives...”**

The next statement, illustrated in Figure 11 explores the experience of eating in public. The dyad shows a shift in responses with more stating it was extremely difficult to eat in public (44%/n=36).

**Figure 11. (n= 59) Statement 7: Eating in Public**

Main cluster of 44% (n=36) found eating in public (for example at work or in a restaurant) to be difficult. On balance 41% (n=34) responded with a positive emotional tone indicating they did not find eating in public a challenge. A contributing factor for this positive shift is access to a restaurant which facilitates modified meals.

**"If we are going out for something to eat, I would phone the restaurant before we go and ask to speak to the chef. If they can accommodate a meal for my son then we go and if not we go somewhere else. On most occasions people are very accommodating. We have been on holiday to XXXXX [country name removed] with my son, even in XXXXX [name removed] I ask to speak to the Chef. It is a courtesy to the Chef to ask and most places accommodate."**

**"...frightening how much it can change your life can change so much even though it's a silly thing or seems to be a silly thing. - I don't go out for meals anymore.-I have my tea before I go out for a meal.-It's inconvenient to say one thing. More embarrassing on the other hand..."**

**"...If I'm going out for something to eat I am conscious about what I order, it has to be moist and easy to eat. I always feel conscious that I am a lot slower at eating than my family. Not that it makes any difference to them but I'm still conscious of it..."**

**"...If we go out we take thickener with us for the tea. We would ask the staff to cut the sandwiches up small and cut the crusts off. They do it no problem..."**

**"...If we are going out for something to eat, I would phone the restaurant before we go and ask to speak to the chef. If they can accommodate a meal for my son then we go and if not we go somewhere else..."**

The key messages reflect upon the importance of understanding the needs of the individual when eating in front of friends & family and in public. Factors which support the individual include meals which can be adapted to meet their needs, ability to ask for support and an understanding of the time required to eat safely. This applies to eating in front of anyone however there is a challenge in restaurants, coffee shops etc. to help them understand their role in supporting someone who lives with a swallowing difficulty.

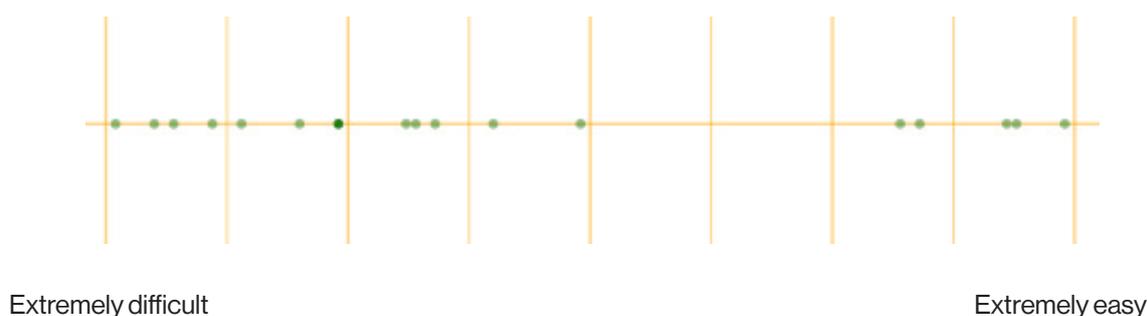
#### 4.6.2 Engaging with sports

This question refers to any sporting activity which may be affected by a swallowing difficulty. As part of the pilot a respondent shared her fear of swimming – a sport which she used to undertake daily. This impacted upon her health & wellbeing as she couldn't overcome the fear she might drown when swimming. The following two dyads explore how people engage with sports.

Figure 12 demonstrated that only 10% of respondents (n=8) regularly participated in sports. The sports regularly engaged with are walking, swimming, jogging, day-care activities and circuit training.

**Figure 12. (n= 23) Statement 8a: I participate in sports activities...**

Only 17 respondents completed Statement 8b exploring if a swallowing difficulty impacted upon sports as illustrated in Figure 13. Although no one expanded upon this in the narrative it is important to note that 12 responses had a negative emotional tone stating the swallowing difficulty impacted negatively on the sports.

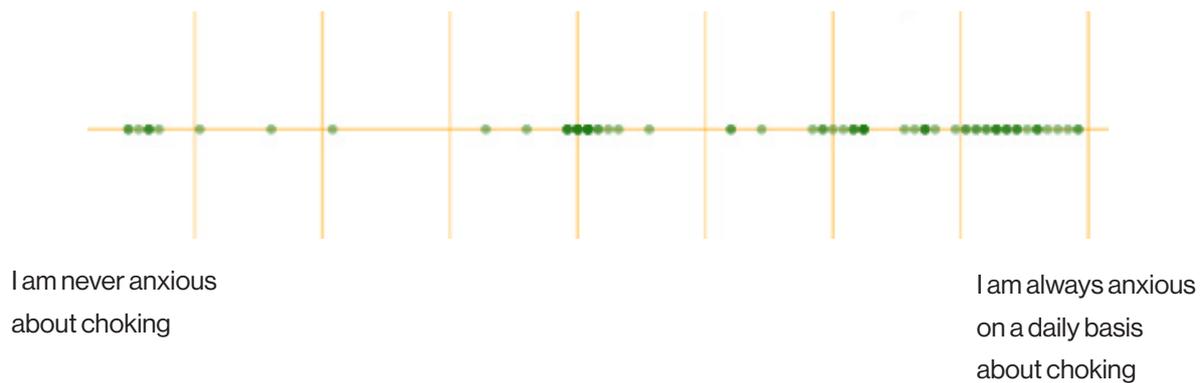
**Figure 13. (n= 17) Statement 8b: I find my swallowing difficulty means sports is...**

This reinforces, as part of the swallow assessment, the importance of looking at the person as a whole and where appropriate include detail around sporting activity. Due to the lack of narrative on this matter in the project it is proposed that this area requires a further deep dive into the experience.

#### 4.6.3 Choking

The next statement explored anxiety around choking, as demonstrated in Figure 14. 85% (n=70) of responses indicated anxiety in varying degrees towards choking. A number of elements contributed to this fear, as demonstrated in the narrative.

1. Previous episode of choking
2. Lack of confidence in others to assist
3. Embarrassment in relation to choking

**Figure 14. (n= 82) Statement 9a: Anxiety around choking**

**“...One time I did choke I felt like someone was putting their hands around my throat and wouldn’t let go, it scared the life out of me...”**

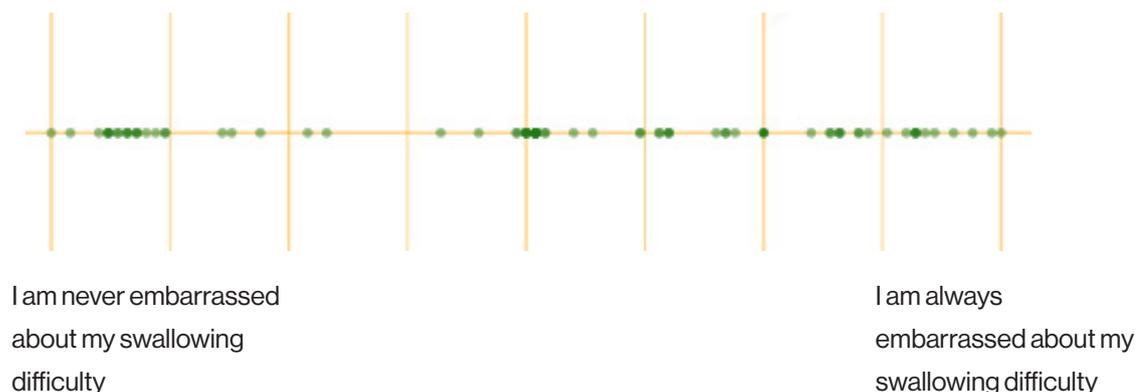
**“...My fear that my experiences from significant choking events make me believe that when a 'major' choking event occurs my family will be unable to respond effectively to help and save me as they have not been trained in choking response and do not have access to choking release equipment...”**

**“...I nearly choked on carrots a year ago, my son had to save me, and it scared me. I didn’t eat for days after...”**

A key message in the responses is the recognition of the trauma caused by a choking episode – for the individual or the carer involved. There is a need to provide training and information to empower key people to respond appropriately. Also, in a case where someone has choked, it is important to support the person as whole – not only considering the cause of the incident, but recognising an emotional response which can challenge their confidence and general wellbeing.

#### 4.6.4 Embarrassment

Embarrassment was an element highlighted in the event of choking, however the experience of embarrassment was also linked to requiring a modified meal, excessive secretions or people staring. Figure 15 demonstrates a diverse range of responses regarding embarrassment. 29% (n=24) stated they did not experience embarrassment due to their swallowing difficulty; however 43% (n=35) stated varying degrees of embarrassment in their experience.

**Figure 15. (n= 82) Statement 9b: Embarrassment**

**“... I don’t take him out often. I know it sounds awful – he doesn’t know to be embarrassed but I feel it especially as he drools and requires a bib. He’s a grown man...”**

**“...I kind of knew I wasn’t well I had a choking episode on holiday last year it was frightening I choked on a bit of steak. It was my birthday few weeks ago and I wouldn’t go out for dinner with the wife and sons in case I choked. I also have stopped going out as often with my mates for a pint. It’s the fear and embarrassment of choking in public....”**

The responses in this dyad reinforce some of the difficulties faced by someone living with a swallowing difficulty. It is important in the assessment and management plan that these factors are recognised and included to provide a holistic approach to care.

#### 4.6.5 Weight management

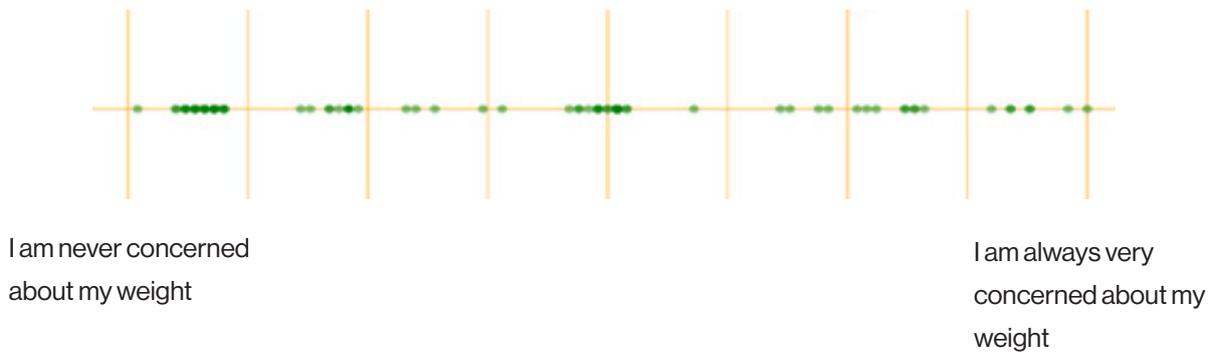
The responses in this dyad reinforce some of the difficulties faced by someone living with a swallowing difficulty. It is important in the assessment and management plan that these factors are recognised and included to provide a holistic approach to care.

**“... he is finally starting to gain weight now we have his swallow sorted...”**

**“...before all this he lost so much weight it scared me...”**

However a diverse range of answers towards high levels of concern – a cluster of 28% (n=23) in the middle indicates they experience some concern about weight management.

**Figure 16. (n= 82) Statement 9c: Concern regarding my weight**



A small number of responses indicated high levels of concern regarding weight. In the narrative of these stories the concern related to weight loss referenced the importance of the role of the dietitian and use of supplements.

**“...She had a swallowing assessment done, they started her on liquidised meals and her fluids were thickened with thick and easy. I became unwell myself and she had to go into respite care, she was there for 7 weeks then for 4 weeks... They let me out to visit her one day and I noticed that she had lost a lot of weight, I saw it in her arms, and her watch was spinning round her wrist. When she went in she was 6and a half stone when she came out she was 4 stone... we are dealing with it... she is now on supplements”**

**“...I am now having meals blended or pureed which I find agrees with me more. I am also on high protein drinks and a powder in a sachet to help with absorption of food. I have made some adjustments to my diet & eating habits with the help of Speech & Language Therapists & Dietitians. Sometimes it can be difficult socially to lead a normal life but slowly I am gaining weight and remain positive that all will be well...”**

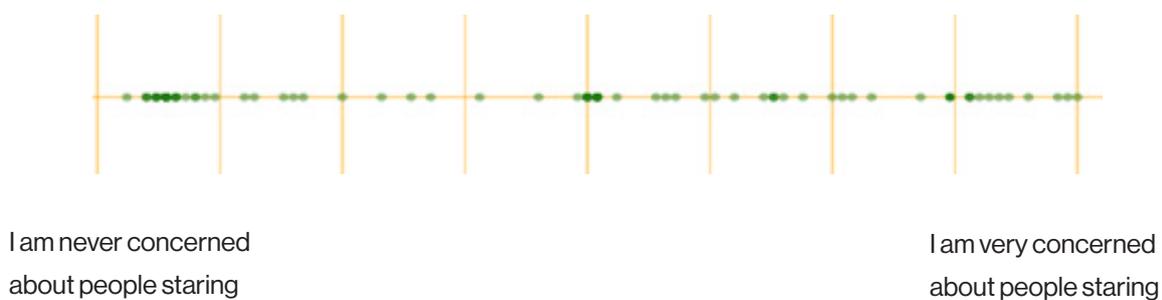
**“...I miss my proper food and am losing weight but the food they make me is nice...”**

It is evident in the responses of this dyad that weight management is an indicator for the patient or the carer of how effective the management plan is. Input is required from a various disciplines such as Speech & Language Therapy, Dietetics and Nursing – once again reinforcing the importance of a multidisciplinary approach to supporting someone living with a swallowing difficulty.

#### 4.6.6 Staring

The final statement explored the possibility of being stared at because of their swallowing difficulty. Figure 17 demonstrated 39% (n=32) experienced little or no concern in relation to people staring.

**Figure 17. (n= 82) Statement 9d. Experience of people staring**



Over 50% of the responses were plotted towards high concern relating to people staring. The narrative reflects upon people staring in public. This highlights the importance of improving awareness around dysphagia and increasing public understanding to support people with swallowing difficulties to engage socially.

**“...I don't go out very often but when I do I notice that people stare, it makes me feel embarrassed...”**

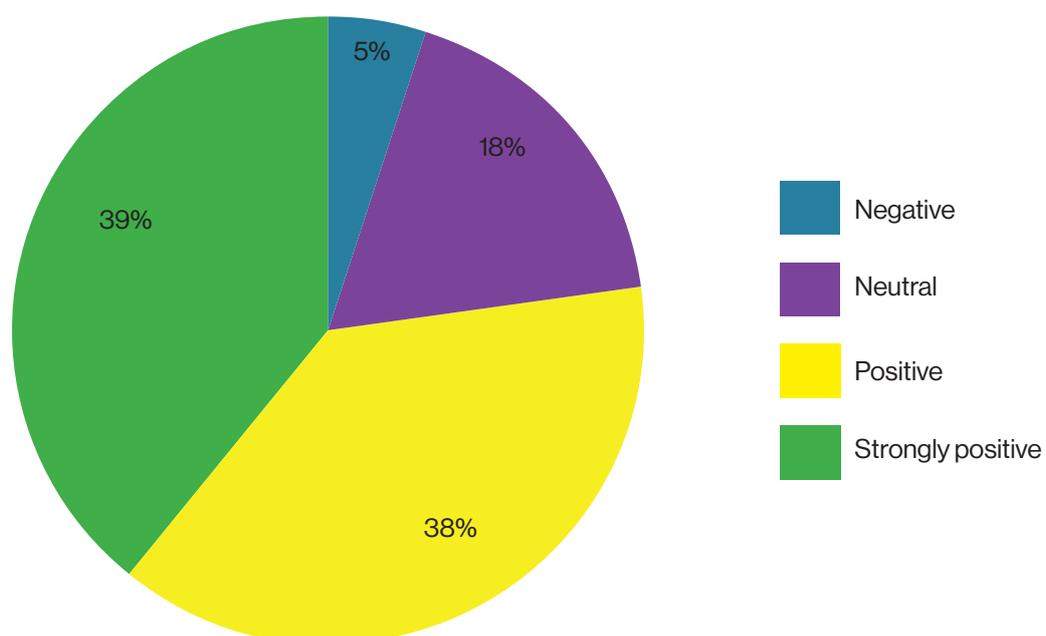
**“...Sometimes I feel embarrassed when people stare, it doesn't feel nice. I don't like to give out about it but my friend would tell them...”**

Through exploring the day to day concerns when living with a swallowing difficulty (choking, embarrassment, weight change, sports and eating with others) it is important these concerns inform the assessment and individualised management plan. Through addressing concerns and anxieties in these areas the person can be supported in their daily lives. Individual Care planning is a key theme identified in the Regional Choking Review (2018).

## 4.7 Overall Experience

Respondents were asked to rate their overall experience of managing their swallowing difficulty. It is largely positive with a smaller number rating neutral or negative; there were no stories rated strongly negative. This is illustrated in Figure 18.

**Figure 18. (n= 82) How would you rate your overall experience?**



It is encouraging to learn from the positive experience of respondents, who reflect upon the importance of effective information, partnership working, individualised care and meaningful engagement. It is also important to learn from the issues raised in the neutral and negative stories. All these elements and the key messages in Section 4.0 are summarised in the following Section 5.0 Areas for Reflection & Learning.

# 5.0 AREAS FOR REFLECTION AND LEARNING

## 5.1 Key Messages

The following summarises the key messages outlined in Section 4.0, embracing the voices of patients, clients, relative and carers into areas of learning and to influence future work in these experiences.

- The provision of clear, concise information regarding a person's management plan is crucial to support them, their carers and others to implement the plan. This includes communicating and consulting with families and carers regarding assessments and changes to the plan.
- To support confidence in the delivery of the management plan it is recognised that training and support is required for informal and formal carers. Such training should support them to develop a practical knowledge base and to deliver safe and compassionate care.
- Awareness training on swallowing difficulties is essential across the whole system as many patients or clients have complex needs with a wide range of healthcare professional engagements.
- Increased awareness in our communities is essential to support the health & wellbeing of someone with swallowing difficulties. Strategies engaging with restaurants and caterers support someone to socialise safely and easily.
- Management plans need to be individualised in partnership with the person and their carer- it should explore the whole person, including personal preference and tackling wider issues such as concerns regarding choking, impact on weight and socialising.
- Management plans need to be readily available for all healthcare professionals as management of a swallowing difficulty extends beyond Speech and Language therapy and often requires input from others such as dentists, physiotherapists, dietitians.
- There is a need to develop a framework or risk assessment to support the complex debate between patient safety versus patient choice in the case of a person who does not comply with the management plan. This is particularly important for carers such as domiciliary care and care home assistants.

## 5.2 Next Steps

This project is supported by the Dysphagia NI partnership to champion the voices of patients, relatives & carers to influence the current strategic work. In particular, consideration should be given to the areas of reflection and learning and defined actions to ensure the messages have been heard. This includes identifying the key messages in work undertaken since the project closed.

It is recognised this report presents the wider regional learning; however the database remains open and available for further briefing papers through Trust PCE facilitators (Appendix 1). This would support learning at a local level. It is also important to identify other lenses through which the narrative can be analysed, for example, according to age or services engaged.

Moving forward it is important this report supports our continuous conversation across related forums to ensure the voice of the patient, relatives and carers is central to the work by HSCNI to support people living with swallowing difficulties.

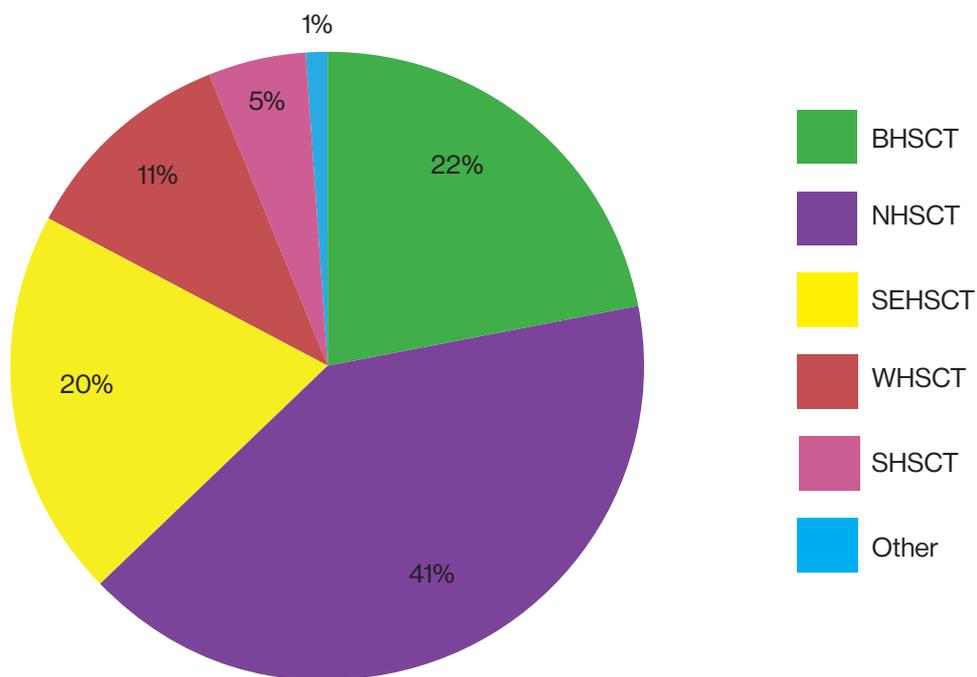
# 6.0 APPENDICES

## Appendix 1 – 10,000 More Voices Team

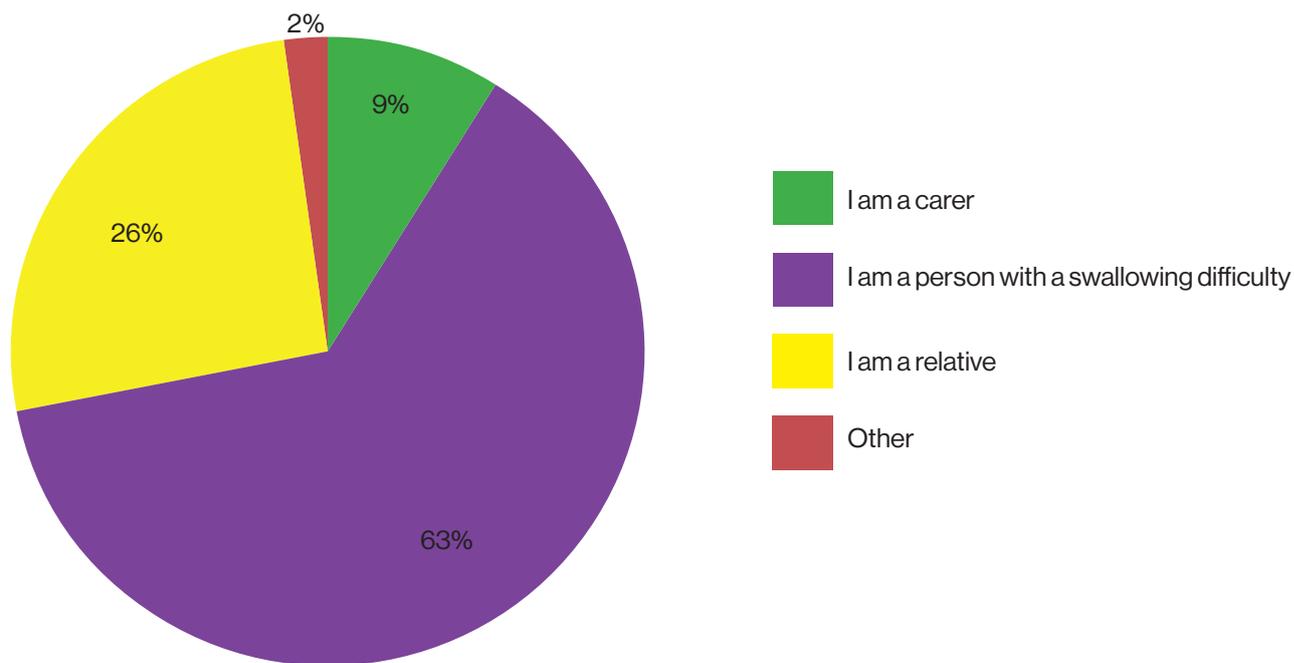
Organisation	Patient Client Experience Representative	Role	Contact Details
PHA	Michelle Tennyson	AD for AHP/PPI/PCE	michelle.tennyson@hscni.net
	Linda Craig	Regional Lead for PCE	linda.craig3@hscni.net
	Dalrene Masson	PCE Facilitator	dalrene.masson2@hscni.net
	David Todd	Project Support	david.todd@hscni.net
BHSCT	Barry Murtagh	PCE Facilitator	barry.murtagh@belfasttrust.hscni.net
NHSCT	Sarah Arthur	PCE Facilitator	sarah.arthur@northerntrust.hscni.net
SEHSCT	Emma Campbell	PCE Facilitator	emma.campbell@setrust.hscni.net
SHSCT	Mairead Casey	PCE Facilitator	mairead.casey@southerntrust.hscni.net
WHSCT	Vi Gray	PCE Facilitator	vi.gray@westerntrust.hscni.net

## 6.2 Appendix 2. Context of returns

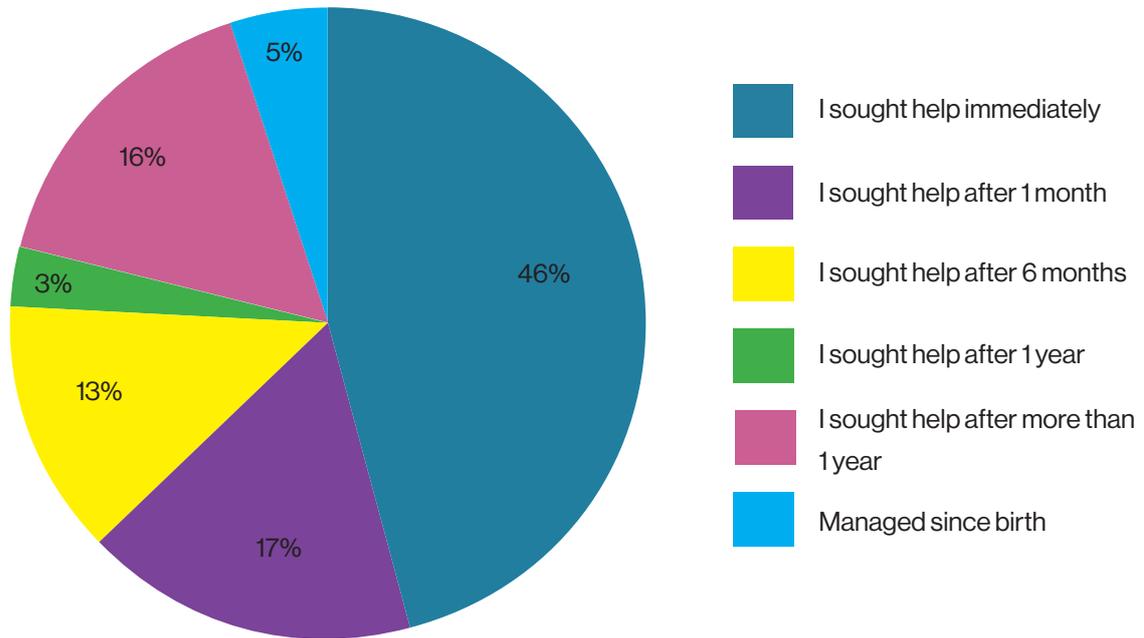
(a) Trust Returns (n=82)



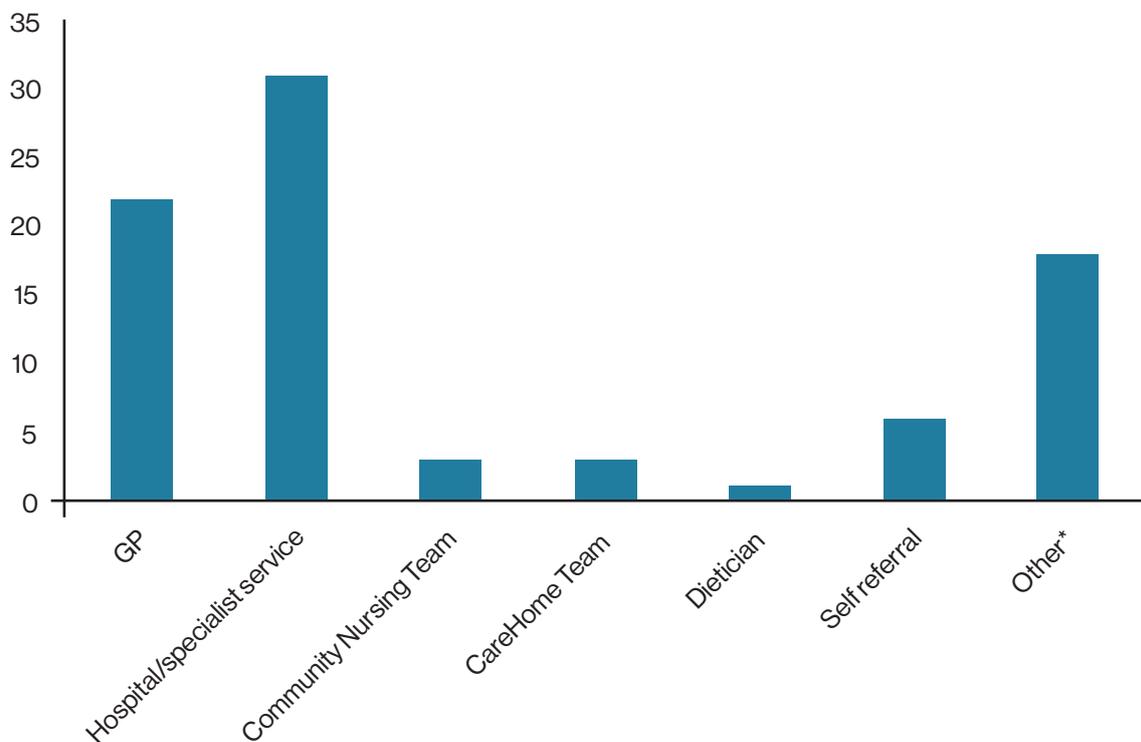
(b) Who responded? (n=82)



(c) When did the person seek help for their swallowing difficulty? (n=82)



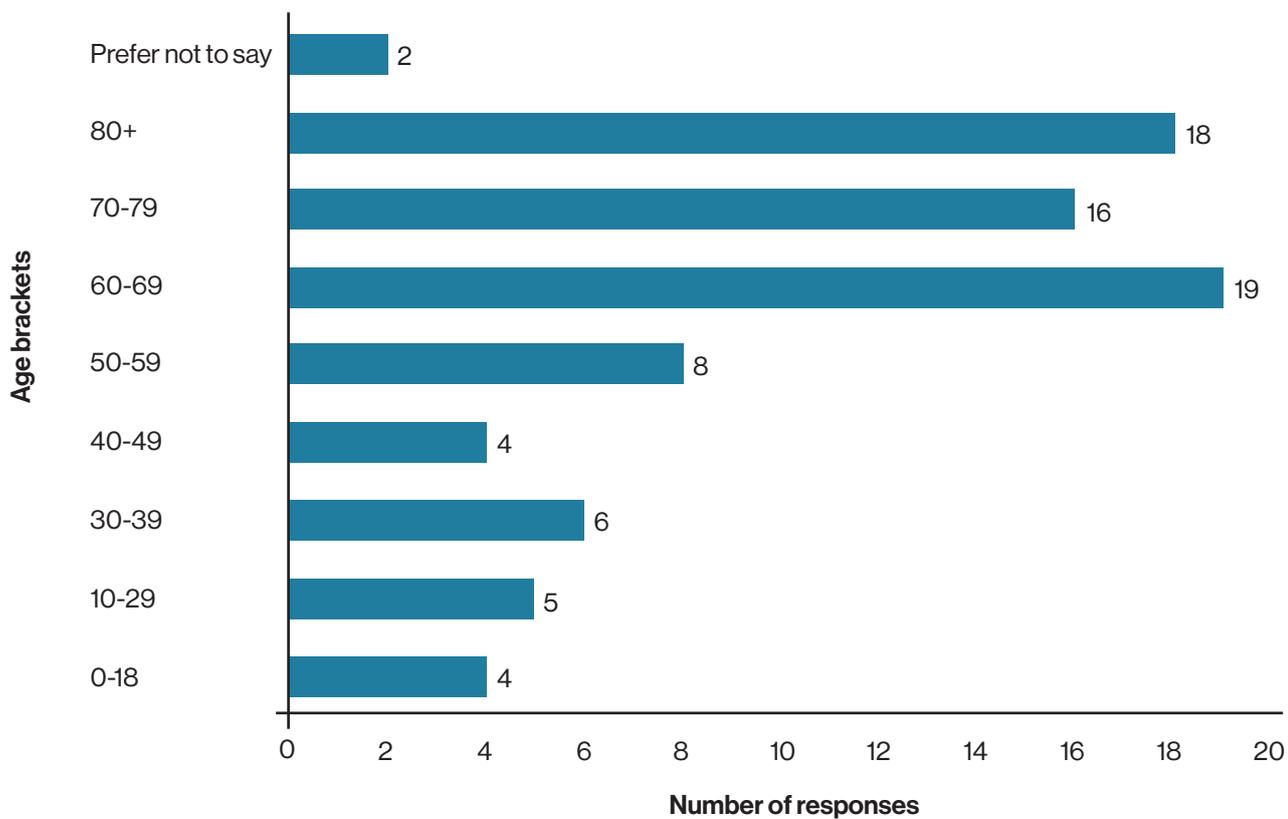
(d) Where did you first seek help? (n=82)



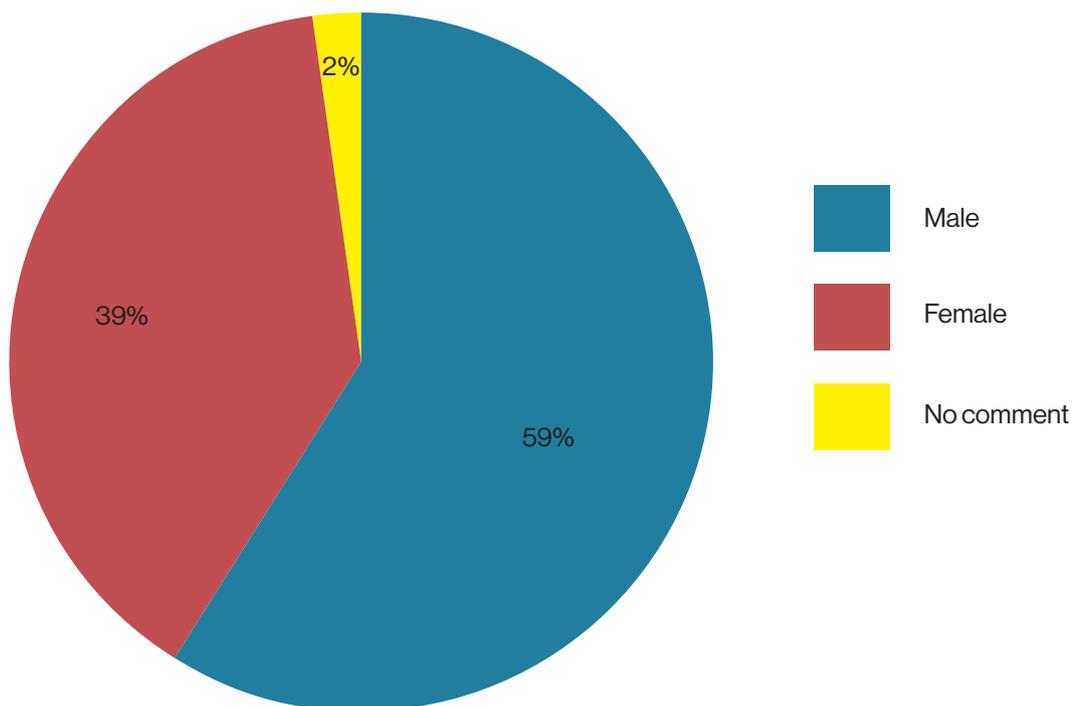
(\*other includes Occupational Therapy, Day Care Centre, Social Work)

### Appendix 3. Demographics

(a) Age of person with swallowing difficulties (n=82)



(b) Gender (n=82)



## (c) Country of Birth (n=82)

Northern Ireland	75
England	5
Republic of Ireland	1
Elsewhere	1

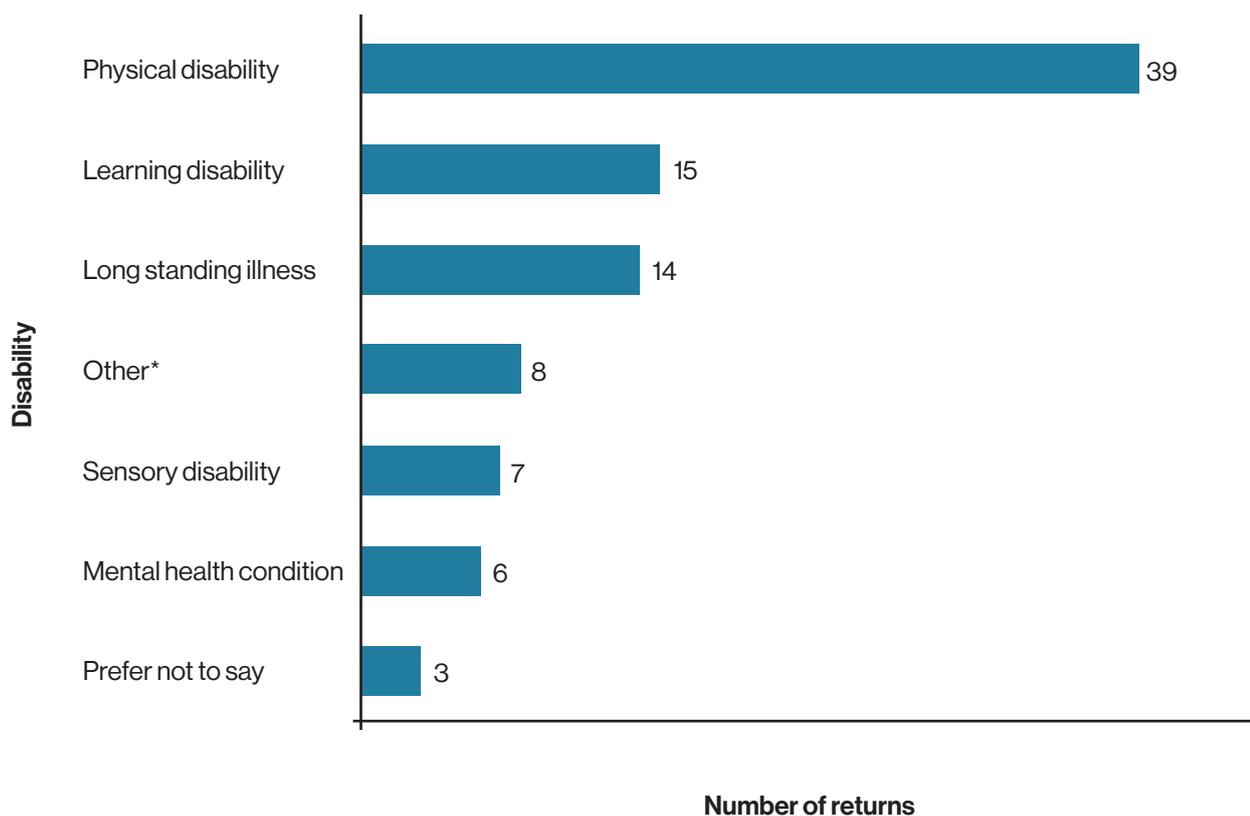
## (d) Sexuality (n=82)

Heterosexual	75
Homosexual	0
Other	1
No comment	6

## (e) Do you have a disability according to the stated definition (n=82)

Yes	55
No	21
Prefer not to say	6

## (f) Which of the following do you identify with? (respondents can select more than one)



\*heart attack, kidney failure, Motor Neurone Disease, Stroke, Neurological, Dementia



**The Regional Team for 10,000 More Voices can be contacted by:**

Email: [10000morevoices@hscni.net](mailto:10000morevoices@hscni.net)

Telephone: 028 95362868 (Monday-Friday 9am-5pm)



<http://10000morevoices.hscni.net>