

**WE DO HAVE A VOICE: USING A PERSONAL CONSTRUCT PSYCHOLOGY  
TECHNIQUE TO EXPLORE HOW CHILDREN AND YOUNG PEOPLE WITH  
SELECTIVE MUTISM CONSTRUCT THEIR CURRENT AND 'IDEAL' SELVES**

**By**

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## **ABSTRACT**

Within published Selective Mutism (SM) research, few studies have gained the views of children and young people (CYP) with SM themselves, meaning their unique experiences are largely missing from the literature. Whilst contextual non-speaking may restrict traditional 'pupil voice' interview approaches, alternative non-verbal methods should be sought to enable CYP with SM to be involved in decision-making and person-centred planning regarding their future.

In this study, five CYP with SM were interviewed, using an adaptation of the Personal Construct Psychology technique 'Drawing the Ideal Self' (Moran, 2001), to explore how they constructed their current and 'ideal' selves, their 'movement' over time, and their goals for the future. This was done without the need for verbal communication. Common themes were identified regarding CYP's 'non-speaking' selves, their desire to change, factors which had contributed to their SM, factors which had helped and hindered progress over time, and their action plans for the future, which addressed the research questions. Conclusions advocate that educational psychologists are well placed to support CYP with SM using this novel technique and implications for future research and practice in this area are considered.

## **DEDICATION**

To the five children and young people who participated in the interviews and therefore made this research possible, thank you so much. I feel privileged to have had the opportunity to work with you and hope I enabled your 'voices' to be heard. I learnt so much from you all, you are the real experts of Selective Mutism.

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## CONTENTS

<b>CHAPTER 1: INTRODUCTION .....</b>	<b>1</b>
1.1 Chapter overview .....	1
1.2 Purpose of the study .....	1
1.3 Interest in Selective Mutism.....	2
1.4 Context and rationale for the research .....	4
1.5 Research aims .....	6
1.6 Philosophical position .....	6
1.7 Structure of the research.....	7
<b>CHAPTER 2: LITERATURE REVIEW - SELECTIVE MUTISM.....</b>	<b>8</b>
2.1 Chapter overview .....	8
2.2 Current conceptualisation of SM .....	8
2.3 Historical terminology and understanding of SM .....	9
2.3.1 Inclusion of SM in the DSM .....	11
2.3.2 Categorisation of types of mutism.....	12
2.3.3 Further developments in the understanding of SM.....	14
2.4 Current thinking regarding aetiology.....	15
2.5 Rethinking the link between SM and social anxiety.....	17
2.6 Other comorbidities .....	18
2.7 Prevalence .....	20
2.8 Assessment and diagnosis of SM .....	23
2.9 Intervention and management of SM .....	24

2.9.1 Psychosocial interventions .....	27
2.9.2 Psychodynamic interventions .....	29
2.9.3 Psychopharmacological interventions.....	29
2.10 Chapter summary .....	30
<b>CHAPTER 3: LITERATURE REVIEW - PUPIL VOICE .....</b>	<b>31</b>
3.1 Chapter overview .....	31
3.2 History of pupil voice .....	31
3.3 The EP as an advocate for CYP.....	32
3.4 Barriers to accessing CYP's views and how EPs have overcome these .....	34
3.5 Accessing the views of anxious CYP .....	35
3.6 Lived experiences of SM within the literature .....	36
3.6.1 Literature search strategy .....	38
3.6.2 Overview and critique of papers .....	39
3.6.3 Summary of key themes from a lived experience perspective .....	47
3.6.3.1 Onset and origins.....	47
3.6.3.2 Context.....	48
3.6.3.3 Psychological and physiological impact .....	49
3.6.3.4 Maintaining and hindering factors .....	50
3.6.3.5 Facilitating factors .....	51
3.6.3.6 Desire to change.....	52
3.6.4 Lived experiences of SM: gaps in the literature .....	53
3.7 Chapter summary.....	54

<b>CHAPTER 4: METHODOLOGY .....</b>	<b>55</b>
4.1 Chapter overview .....	55
4.2 Research aims and research questions .....	55
4.3 Ontological and epistemological approach .....	55
4.4 Researcher positionality .....	57
4.5 Case study design .....	58
4.5.1 Strengths and weaknesses of case studies and issues of trustworthiness .....	58
4.6 Research methodology.....	61
4.6.1 Personal Construct Psychology (PCP) .....	61
4.6.2 The dichotomy and choice corollaries.....	63
4.6.3 Relevance to the current study .....	64
4.6.4 PCP methods to elicit personal views.....	65
4.6.5 PCP techniques based on the dichotomy and choice corollaries .....	67
4.7 Research method and interview design .....	71
4.8 Ethical considerations.....	75
4.9 Pilot study.....	81
4.10 Recruitment.....	82
4.11 Responses received and excluded participants .....	83
4.12 Participants.....	85
4.13 Parental role in the interviews .....	87
4.14 Procedure.....	87
4.15 Data analysis.....	89
4.15.1 Increasing trustworthiness - external review of the data .....	91



4.16 Chapter summary .....	92
<b>CHAPTER 5: RESULTS AND DISCUSSION .....</b>	<b>93</b>
5.1 Chapter overview .....	93
5.2 RQ1: How do CYP with SM construct their current and 'ideal' selves? .....	95
5.2.1 Theme 1: Acknowledgement of their 'non-speaking' selves .....	95
5.2.2 Theme 2: Desire to change .....	100
5.2.3 Theme 3: Flexibility and willingness to compromise regarding their 'ideal' self .....	103
5.2.4 Summary of RQ1 .....	106
5.3 RQ2: What factors do CYP attribute to the causes of their SM? .....	106
5.3.1 Theme 1: Negative treatment from peers .....	107
5.3.2 Theme 2: Uncertainty about the trigger .....	108
5.3.3 Summary of RQ2 .....	110
5.4 RQ3: How do CYP with SM construct their 'movement' over time? .....	110
5.4.1 Theme 1: Factors that facilitated progress .....	110
5.4.2 Theme 2: Factors that hindered progress .....	114
5.4.3 Summary of RQ3 .....	118
5.5 RQ4: What action plans do CYP with SM create for their future? .....	119
5.5.1 Theme 1: Actions for self .....	119
5.5.2 Theme 2: Actions for others .....	121
5.5.3 Theme 3: Uncertainty .....	123
5.5.4 Summary of RQ4 .....	125
5.6 Chapter summary .....	125

<b>CHAPTER 6: CONCLUSIONS .....</b>	<b>126</b>
6.1 Chapter overview .....	126
6.2 Summary of findings.....	126
6.3 Strengths .....	127
6.3.1 Contributions to knowledge of SM from a lived experience perspective .....	127
6.3.2 Contributions to PCP .....	131
6.3.3 Positive feedback.....	132
6.4 Limitations .....	135
6.5 Further research suggestions.....	138
6.6 Implications for EP practice .....	140
6.7 Final comments .....	144
<b>REFERENCES.....</b>	<b>145</b>
<b>APPENDICES.....</b>	<b>162</b>

## LIST OF BOXES

<b>Box 1:</b> Essential characteristics of Selective Mutism acknowledged in the DSM-V (APA, 2013), taken from Johnson and Wintgens (2016, p.30).....	8
<b>Box 2:</b> Four categories of Elective Mutism as identified by Hayden (1980, p.118) .....	12
<b>Box 3:</b> Key principles from the Children and Families Act (2014) which underpin the SEND Code of Practice (DfE and DoH, 2015, taken from p.19) .....	32
<b>Box 4:</b> Instructions for part C of the interviews .....	73
<b>Box 5:</b> P1's part C responses highlighting reasons for his close association with the 'non-speaking' person .....	96
<b>Box 6:</b> P5's part C responses highlighting her 'now' rating midway between the 'non-speaking' and 'speaking' person .....	97
<b>Box 7:</b> Introverted/negative traits used by participants to describe themselves in part C and the 'non-speaking' person in part A.....	98
<b>Box 8:</b> Responses which suggested speech anxiety .....	99
<b>Box 9:</b> P2's responses in part C illustrating her desire to change.....	101
<b>Box 10:</b> Responses showing P1, P2 and P5's desired jobs in the future.....	102
<b>Box 11:</b> P1's part C responses illustrating his willingness to compromise regarding his 'ideal' self.....	104
<b>Box 12:</b> P4's part C responses showing little willingness to compromise regarding his 'ideal' self.....	105
<b>Box 13:</b> Part C responses highlighting the role of peers in the cause of SM .....	107
<b>Box 14:</b> P3 and P4's part C responses indicating uncertainty about the trigger	

of their SM.....	109
<b>Box 15:</b> Data extracted from P1’s part C response indicating factors he attributed to his progress with speaking between Reception and Year 6 .....	111
<b>Box 16:</b> Data extracted from P1’s part C response indicating factors he perceived had hindered his progress with speaking between Year 2 and Year 6.....	114
<b>Box 17:</b> P2’s part C data illustrating her explanations regarding why certain individuals would rate her lower on the scale than she currently rated herself .....	118
<b>Box 18:</b> Data from P1, P2 and P5’s action plans (part C) reflecting actions for themselves to facilitate ‘movement’ towards their ‘ideal’ self.....	119
<b>Box 19:</b> Data from P1, P2 and P5’s action plans (part C) reflecting actions for others to facilitate ‘movement’ towards their ‘ideal’ self.....	121
<b>Box 20:</b> Data from P1, P3, P4 and P5’s action plans (part C) highlighting uncertainty about actions for self and actions for others .....	123
<b>Box 21:</b> Additional comments from two of the parents on the parent evaluation form .....	134
<b>Box 22:</b> Feedback from SLTs following my presentation of the research findings.....	135

## LIST OF FIGURES

<b>Figure 1:</b> The history of Selective Mutism .....	15
<b>Figure 2:</b> The contribution of genetic and environmental factors in the development of SM (Johnson and Wintgens, 2016, p.37) .....	17
<b>Figure 3:</b> Multidisciplinary care pathway for SM (Johnson and Wintgens, 2016, p.43) .....	25
<b>Figure 4:</b> A visual representation and instruction of the three stages of the Drawing the Ideal Self technique (Moran, 2001) .....	69
<b>Figure 5:</b> A visual representation of the three stages of the new technique to elicit the subjective experiences of CYP with SM .....	74
<b>Figure 6:</b> An overview of the research procedure .....	88
<b>Figure 7:</b> Process of thematic analysis as recommended by Braun and Clarke (2006) .....	92
<b>Figure 8:</b> A thematic map representing data gathered during part C of the interviews .....	94
<b>Figure 9:</b> Bar chart showing average ratings from the CYP's evaluation form.....	132
<b>Figure 10:</b> Bar chart showing average ratings from the parent evaluation form ..	133
<b>Figure 11:</b> Proposed multidisciplinary care pathway for SM which I hope to further develop in my placement LA .....	141

## LIST OF TABLES

<b>Table 1:</b> Categorisation of biological and psychological mutism as identified by Kolvin and Fundudis (1981).....	13
<b>Table 2:</b> Stages of confident talking (Johnson and Wintgens, 2016, p.74) .....	26
<b>Table 3:</b> Inclusion and exclusion criteria for the literature review regarding lived experiences of SM.....	39
<b>Table 4:</b> Overview of the nine studies included in the literature review regarding lived experiences of SM .....	40
<b>Table 5:</b> Measures which investigate the quality and trustworthiness of qualitative data (as identified by Guba and Lincoln, no date, cited in Treharne and Riggs, 2014) and how these were addressed in the current research.....	60
<b>Table 6:</b> Adaptations made to parts A and B of the Drawing the Ideal Self technique (Moran, 2001) to explore the ‘non-speaking’ and ‘speaking’ poles of SM.....	72
<b>Table 7:</b> Key ethical issues relating to the research and how these were addressed.....	77
<b>Table 8:</b> Inclusion and exclusion criteria for involvement in the research study...	82
<b>Table 9:</b> Participant characteristics and details of each interview .....	86
<b>Table 10:</b> Possible areas for future research .....	138

## LIST OF APPENDICES

<b>Appendix 1:</b> Crib sheet and instructions for the Drawing the Ideal Self method (Moran, 2001) taken from the prompt sheet (Moran, 2012b).....	162
<b>Appendix 2:</b> Crib sheet and instructions for the research interview technique adapted from Moran’s Drawing the Ideal Self method (2001) .....	165
<b>Appendix 3a:</b> Written prompt cards for parts A and B of the interviews .....	168
<b>Appendix 3b:</b> Visual prompt cards that were developed for some of the part A and B areas following the pilot study to account for younger participants / poorer readers .....	170
<b>Appendix 3c:</b> Prompt cards for part C of the interviews .....	171
<b>Appendix 4:</b> Table representing the prompts available for each of the nine areas in parts A and B of the interviews, and the literature which informed these..	172
<b>Appendix 5:</b> Application for ethical review form completed prior to conducting the research .....	175
<b>Appendix 6:</b> Email confirming ethical approval for the research study.....	190
<b>Appendix 7:</b> Recruitment letter sent to SLTs.....	192
<b>Appendix 8:</b> Cover letter sent to potential participants by SLTs.....	195
<b>Appendix 9:</b> Child and Young Person Information Sheet sent to potential participants by SLTs.....	196
<b>Appendix 10:</b> Parent Information Sheet sent to the parents of potential participants by SLTs.....	198
<b>Appendix 11a:</b> Child and Young Person consent form completed by participants before the research interviews .....	203

<b>Appendix 11b:</b> Child and Young Person consent form including visuals which was adapted following the pilot study to account for younger participants .....	204
<b>Appendix 12:</b> Parental consent form completed by parents prior to their child participating in the research .....	205
<b>Appendix 13:</b> Form used to gather demographic and background information from parents about their child before the interviews .....	206
<b>Appendix 14:</b> Eligibility checklist used with parents prior to the interviews to ensure their child met the DSM-V criteria for SM (APA, 2013) .....	207
<b>Appendix 15:</b> Visual system used with participants during the interviews.....	208
<b>Appendix 16a:</b> Child and Young Person evaluation form completed by participants after the research interviews .....	209
<b>Appendix 16b:</b> Child and Young Person evaluation form including visuals which was adapted following the pilot study to account for younger participants .....	211
<b>Appendix 17a:</b> P1’s part A response.....	214
<b>Appendix 17b:</b> P1’s part B response .....	215
<b>Appendix 17c:</b> P1’s part C response .....	216
<b>Appendix 18a:</b> P2’s part A response.....	217
<b>Appendix 18b:</b> P2’s part B response .....	218
<b>Appendix 18c:</b> P2’s part C response .....	219
<b>Appendix 19a:</b> P3’s part A response.....	220
<b>Appendix 19b:</b> P3’s part B response .....	221
<b>Appendix 19c:</b> P3’s part C response .....	222
<b>Appendix 20a:</b> P4’s part A response.....	223
<b>Appendix 20b:</b> P4’s part B response .....	224



<b>Appendix 20c:</b> P4’s part C response .....	225
<b>Appendix 21a:</b> P5’s part A response.....	226
<b>Appendix 21b:</b> P5’s part B response .....	227
<b>Appendix 21c:</b> P5’s part C response .....	228
<b>Appendix 22:</b> Lone Working Policy used by my placement local authority .....	229
<b>Appendix 23:</b> Notes from the external review of my data with a TEP colleague...230	
<b>Appendix 24:</b> Certificate given to participants after completion of the interviews .....	238
<b>Appendix 25:</b> Example written summary letter sent (to P1) after the interview ...	239
<b>Appendix 26:</b> PowerPoint presentation delivered to SLTs to feedback research findings.....	241
<b>Appendix 27:</b> Evaluation form completed by parents after their child had participated in the research interviews .....	244
<b>Appendix 28:</b> Letter sent to E1 giving her the opportunity to express her views and experiences of SM without participating in the interviews.....	246
<b>Appendix 29:</b> Pen portraits of the five participants.....	251
<b>Appendix 30:</b> Coding process for data gathered in parts A, B and C of the interviews .....	253
<b>Appendix 31:</b> A thematic map representing data gathered from part A of the interviews .....	260
<b>Appendix 32:</b> A thematic map representing data gathered from part B of the interviews .....	261

## LIST OF ABBREVIATIONS

<b>ASC</b>	Autistic Spectrum Condition
<b>CAMHS</b>	Child and Adolescent Mental Health Service
<b>CBT</b>	Cognitive Behavioural Therapy
<b>CYP</b>	Children and Young People
<b>DSM-V</b>	Diagnostic and Statistical Manual of Mental Disorders-fifth edition
<b>EM</b>	Elective Mutism
<b>EP</b>	Educational Psychologist
<b>EPS</b>	Educational Psychology Service
<b>LA</b>	Local Authority
<b>PCP</b>	Personal Construct Psychology
<b>RQ</b>	Research Question
<b>SALTS</b>	Speech and Language Therapy Service
<b>SEMH</b>	Social Emotional and Mental Health
<b>SEND</b>	Special Educational Needs and Disabilities
<b>SLT</b>	Speech and Language Therapist
<b>SM</b>	Selective Mutism
<b>SMIRA</b>	Selective Mutism Information and Research Association
<b>SSRIs</b>	Selective Serotonin Reuptake Inhibitors
<b>TA</b>	Teaching Assistant
<b>TEP</b>	Trainee Educational Psychologist

## **CHAPTER 1: INTRODUCTION**

### **1.1 Chapter overview**

This chapter introduces volume one of a two-part doctoral thesis in Applied Educational and Child Psychology, completed at the University of Birmingham. It provides an overview of the purpose, context, rationale and aims of the study, my interest in Selective Mutism (SM) and positionality as a researcher which influenced the research methodology, before introducing the following chapters.

### **1.2 Purpose of the study**

The purpose of the research was to gain the views of children and young people (CYP) with SM to increase understanding of the condition from a lived experience perspective and to add to the limited evidence base in this area. SM is defined by the Diagnostic and Statistical Manual of Mental Disorders-fifth edition (DSM-V; American Psychological Association [APA], 2013) as an anxiety disorder whereby an individual presents a consistent speaking pattern in some situations but fails to speak in others. It has been further conceptualised as an expressive speech phobia in certain social situations such as school (Johnson and Wintgens, 2016).

Literature searches identified few studies exploring personal accounts of SM due to difficulty engaging with this group using traditional interview techniques.

Consequently, existing knowledge is largely based on “observer interpretations rather than experiential accounts” (Walker and Tobbell, 2015, p.457) which raises concerns that “methodologies which fail to take into account the perspectives of those with SM

may be presenting a misleading or partial representation of SM by reporting only how it appears to outsiders” (p.456). This quote provides the rationale for the study, emphasising the need for further research with individuals with SM to capture their views and the importance of disseminating these to key figures supporting the child.

### **1.3 Interest in Selective Mutism**

My interest in SM stemmed from experience prior to commencing my doctoral Educational Psychologist (EP) training, when I worked as a teaching assistant (TA) in a pupil referral unit for pupils with social, emotional and mental health (SEMH) needs. During this role, I ran a choir which was attended by numerous pupils, including a girl with SM. Whilst she did not talk to staff, interacted minimally with her peers and presented as highly anxious in school, her engagement and confidence in choir gradually increased, resulting in her participating in an assembly performance to the whole school. The pupil also began acknowledging me around school and whispering to me when no one else was present. Consequently, I was asked to support her in a meeting with her social worker, during which she wrote down her views for me to share. This experience made me reflect on the importance of those with SM having a trusting relationship with a key adult, and their role in minimising the child’s anxiety by creating a relaxed environment and removing the expectation to speak.

Additionally, in my second year as a trainee educational psychologist (TEP), I supported a Year 6 pupil with SM, conducting weekly home visits and delivering a cognitive behavioural therapy (CBT) intervention which reduced his anxiety and

facilitated progress towards his goal of speaking to his teacher and headteacher in school. Whilst this pupil had been discharged from the Child and Adolescent Mental Health Service (CAMHS), due to non-engagement as a result of non-speaking, I reflected on the necessity for non-verbal therapeutic methods to enable individuals with SM to express their wishes and feelings. Consequently, I adopted a flexible and creative approach and promoted alternative ways for the pupil to communicate with me, including writing and drawing, recording his voice, and using rating scales and card sorting activities to elicit his views. The most prominent factors I identified in the pupil's success were his willingness to engage in the intervention and his motivation to change, both of which aided positive progress towards him speaking to staff. This made me further reflect on the need to understand SM from individuals' own perspectives to ascertain whether talking is an important goal for them and whether they are ready for support in this area.

Finally, my own values, beliefs and experiences resulted in a personal interest in studying SM further. As a quiet person myself I have reflected how, as a child, my shyness around some teachers and peers in school and, as an adult, my preference to listen and internally reflect when in group situations, rather than expressing my views verbally, have meant that at times my thoughts and ideas may go unnoticed. For this reason, and being mindful that speaking is a persistent difficulty which has a significant impact on social communication for those with SM, I was motivated to develop a tool which 'championed' the voices of this population and enabled such individuals to share their views and experiences non-verbally.

#### **1.4 Context and rationale for the research**

The current study was conducted during a two-year TEP placement with an Educational Psychology Service (EPS) in a large rural local authority (LA). During this time, I had the opportunity to collaborate with a speech and language therapist (SLT) specialising in SM, as well as parents and school staff, to devise an intervention plan for the pupil discussed above. This coordinated approach proved effective in facilitating the pupil's progress, increasing his key adults' understanding of SM, and reducing his speech anxiety by sensitively addressing current maintaining factors to his non-speaking patterns.

I also attended a termly SM clinical excellence network which furthered my interest in SM and identified the focus for my research. Historically, in this LA, EPs were not involved in SM casework and individuals with SM were referred to the Speech and Language Therapy Service (SALTS) due to their overarching remit of addressing speech, language and communication difficulties. Discussions with SLTs indicated that they predominately liaised with key figures supporting the pupil (parents and school staff) and completed observations rather than working directly with the individual and, whilst the literature promotes environmental adjustments and systemic management of SM (Johnson and Wintgens, 2016) as discussed in Chapter 2, this approach fails to elicit CYP's thoughts about necessary support.

As removing barriers to learning, promoting emotional wellbeing and advocating for CYP are fundamental to the EP role, gaining pupil views using age and ability-appropriate methods form much of their work (Hardy and Hobbs, 2017). Additionally,

the Special Educational Needs and Disability (SEND) Code of Practice (Department for Education and Department of Health [DfE and DoH], 2015) further emphasises professionals' statutory duty in gaining the views of CYP with SEND and involving them in decision-making regarding necessary support. Consequently, I became interested in how EPs could elicit the lived experiences of those with SM, and how their views could inform a person-centred approach to subsequent intervention at an individual, school and family level.

A further rationale for addressing this gap was due to anticipated changes to the SM pathway in the LA. Due to limited capacity within the SALTS for ongoing involvement, it was proposed that, following an initial assessment, individuals with SM would be referred onto CAMHS for support in managing their anxiety. However, research has acknowledged the growing strain on mental health services (Ford, Goodman and Meltzer, 2003) with a 26% increase in CAMHS referrals over the last five years (Crenna-Jennings and Hutchinson, 2018), whereby 23% are rejected for not reaching diagnostic thresholds (Frith, 2016) and those accepted waiting up to 267 days for assessment and 345 days for treatment (Crenna-Jennings and Hutchinson, 2018). These statistics, as well as knowledge that CAMHS had discharged the Year 6 pupil I was involved with as he could not engage in a traditional CBT intervention, raised concerns about the efficacy of the proposed pathway.

During clinical excellence network meetings, it also transpired that SLTs were not fully aware of the breadth of the EP role, including their primary focus on promoting psychological wellbeing, their systemic and ecological approach to practice and value

as a “key therapeutic resource” (Mackay, 2007, p.7) for schools. Furthermore, with SEMH needs now recognised as a discrete category of SEND (DfE and DoH, 2015), and SM being attributed to anxiety rather than a specific language difficulty, this presented a robust argument for EPs being well placed to support this group.

Johnson and Wintgens (2016) acknowledge the importance of early assessment and intervention for SM in which I believe CYP’s views should be at the centre to ensure planning is person-centred, relevant and meaningful. This background context led to a strong research interest in this area.

### **1.5 Research aims**

The research utilised a creative non-verbal method based on Personal Construct Psychology (PCP) (Kelly, 1955) to explore personal experiences of SM and address the following research questions:

**RQ1:** How do CYP with SM construct their current and ‘ideal’ selves?

**RQ2:** What factors do CYP attribute to the causes of their SM?

**RQ3:** How do CYP with SM construct their ‘movement’ over time?

**RQ4:** What action plans do CYP with SM create for their future?

### **1.6 Philosophical position**

My research adopts an interpretivist epistemology in which I accept that knowledge, thoughts and attitudes about the world are situated in people (Thomas, 2013) and are constructed subjectively depending on the meaning individuals ascribe to their personal experience. This viewpoint connects with my professional values and



approach to practice regarding facilitating pupil voice and promoting person-centred planning. This stance also informed my chosen methodology as PCP techniques align well with qualitative research to “provide in-depth insight into personal experience” (Burr, King and Butt, 2014, p.341), hence enabling exploration of lived accounts of SM.

### **1.7 Structure of the research**

The subsequent chapters outline literature relevant to the research, followed by the methodology, results, and conclusions of the study. Chapter 2 reviews existing literature relating to the history, aetiology, prevalence, diagnosis and management of SM to provide an understanding of the phenomenon. Chapter 3 discusses literature regarding the importance of pupil voice in research, as well as the few studies that have explored lived experiences of SM. Chapter 4 details the chosen methodology, including the research aims, ethical implications, participant information, and data collection and analysis methods used. Chapter 5 discusses the research findings in relation to previous literature in this area. Finally, Chapter 6 provides an overall conclusion, considering the strengths and limitations of the research and implications for EP practice.

## CHAPTER 2: LITERATURE REVIEW - SELECTIVE MUTISM

### 2.1 Chapter overview

This chapter introduces the broad context for the research by presenting published literature regarding SM to increase understanding of the phenomenon.

### 2.2 Current conceptualisation of SM

The term 'Selective Mutism' characterises a condition whereby individuals present a consistent pattern of speaking in some situations, such as home, but persistently fail to speak in others where speech is typically expected, such as in school or other social situations (Muris and Ollendick, 2015). Whilst SM is now widely accepted as an anxiety disorder (APA, 2013) and, more specifically, a learned phobia of speech in particular social contexts (Omdal and Galloway, 2008; Johnson and Wintgens, 2016), historically there has been much misunderstanding and disagreement about the nature of the condition. However, current conceptualisation in the DSM-V (APA, 2013) states that SM is characterised by the four defining features shown in Box 1.

*Box 1: Essential characteristics of Selective Mutism acknowledged in the DSM-V (APA, 2013), taken from Johnson and Wintgens (2016, p.30)*

1. Individuals present a consistent pattern of speaking in some situations where speech is expected but not in others
2. The failure to speak is persistent, lasting more than one month, but not including the first month in a new environment such as school
3. The failure to speak has a significant impact on educational or occupational achievement or social communication
4. Lack of knowledge or comfort with the required spoken language, or a disorder of communication or a condition like social anxiety disorder, may also be present, but is not the cause and does not explain the mutism

### **2.3 Historical terminology and understanding of SM**

SM was initially coined “aphasia voluntaria” by the German physician, Kussmaul (1877, cited in Browne, Wilson and Laybourne, 1963, p.605), and later became known as “elective mutism” (EM) (Tramer, 1934, cited in Hayden, 1980, p.118). Both terms were used to describe children who, despite possessing average intelligence and the ability to speak, elected not to in certain environments for unknown reasons. Early knowledge developed from several case studies of EM children (Gutzmann, 1893; Trüper, 1897; Liebmann, 1898; Stern, 1910, all cited in Pustrom and Speers, 1964) and primary explanations centered around the individual’s personality and psychopathology in relation to the psychosexual stages of development. At this time, some attributed EM to regression to the preverbal and presocialisation ‘oral’ stage (Weber, 1950, cited in Pustrom and Speers, 1964; Silverman and Powers, 1970), where difficulties with object relationships and subsequent perception of danger led to speech avoidance. Conversely, others argued that its roots were in the ‘anal’ stage (Browne, Wilson and Laybourne, 1963; Pustrom and Speers, 1964), due to conflict with authority figures and a consequent resistance to comply with expectations to speak.

Further research generated interest into the role of the family in EM, with Brown, Wilson and Laybourne proposing that “the symptom can be understood only by studying the entire family constellation” (1963, p.617). For example, Salfeld (1950) described the home environment of one case as “insecure and partly hostile-rejecting” (p.1031), in addition to the child having a shy and sensitive personality. Similarly, Adams and Glasner (1954) identified that most of their cases came from

“severely disturbed home situations” (cited in Silverman and Powers, 1970, p.182), where children lacked trust in their caregivers. Furthermore, von Misch (1952, cited in Browne, Wilson and Laybourne, 1963) acknowledged the contribution of environmental, genetic and psychological factors within this subgroup, including “excessive ties” (p.606) and separation anxiety from the mother when beginning school, and the influence of a traumatic event during the critical phase of speech development. Pustrom and Speers (1964) also described a “pathological mother-child dependency relationship” (p.297) amongst three EM children, suggesting that the threat of total abandonment by the mother, if the child divulged intimate family details, led to selective communication patterns.

Two large-scale American studies elicited additional early insight into EM. Parker, Olsen and Throckmorton (1960) reviewed 27 social work cases over a 15-year period, involving children in Tacoma schools who did not speak, noting that the onset of the condition appeared to be a reaction to environmental or cultural stressors. These included family bereavement, hospitalisation resulting in separation from the mother, and family relocation from rural to urban communities, as well as “neurotic factors within the family structure” (p.65) such as family patterns of non-speaking and parental anxiety and overprotection. Other triggers related to a mouth injury or trauma including a dental procedure, during which a mother was not permitted to be in the room with her child, and the use of physical punishment, whereby a mother slapped her child around the mouth whenever she made disapproving comments. In these cases, it was hypothesised that the child then associated the mouth with pain and anxiety and, consequently, restricted their speech due to the trauma

experienced. Other observations noted that the children were highly anxious and depended excessively on their mother, with speech avoidance felt to be a functional way of controlling their environment.

Similarly, Wright (1968) studied 24 children with EM, identifying commonalities regarding intellectual ability, dependent yet controlling behaviours towards the mother, excessive shyness outside of the home and a family history of speech phobia in school.

Whilst these two studies provided a greater understanding of EM and hypothesised typical origins in maternal over-protection, trauma, shyness and dysfunctional speaking patterns within the family, knowledge about the condition remained limited due to the rarity of cases and paucity of substantial research.

### **2.3.1 Inclusion of SM in the DSM**

EM was first referenced in the DSM-III under *Other Disorders of Infancy, Childhood and Adolescence* as:

“a continuous refusal to speak in almost all social situations, including school, despite an ability to comprehend spoken language and to speak” (cited in Spitzer and Cantwell, 1980, p.365).

At this time, emphasis was on the individual’s refusal to talk, conceptualising non-speaking as wilful, controlling and manipulative, and an intentional decision of the child. No reference was made to anxiety or social phobia at this stage.

### 2.3.2 Categorisation of types of mutism

Further research into the aetiology and characteristics of the condition was conducted by Hayden (1980) who identified four distinct categories of EM based on observations, video and audio-recordings, written reports, questionnaires and information from key figures in the child's life, shown in Box 2.

*Box 2: Four categories of Elective Mutism as identified by Hayden (1980, p.118).*

1. **sybiotic mutism**, characterised by a symbiotic relationship with a caretaker and a submissive but manipulative relationship with others;
2. **speech phobic mutism**, characterised by fear of hearing one's own voice and use of ritualistic behaviours;
3. **reactive mutism**, characterised by withdrawal and depression which apparently resulted from trauma and
4. **passive-aggressive mutism**, characterised by hostile use of silence as a weapon.

The first group represented children who purposely withheld speech as a form of control around dominant adults, whilst the second group characterised those to whom speech induced high levels of anxiety due to a fear of disclosing private family details. Many of these children also displayed repetitive behaviours to induce or minimise the effects of speech. Mutism within the third group was attributed to traumatic experiences - such as rape, physical violence and mouth or throat injuries - which resulted in fear and withdrawal from social interactions, whilst the fourth group displayed a strong-willed nature and defiant refusal to speak. Hayden (1980) argued that classification and understanding aetiological differences was important due to the implications for identifying appropriate intervention. Hayden also noted the prevalence of physical and sexual abuse amongst the four groups which provided further evidence regarding the role of trauma in the manifestation of EM.

A paper by Kolvin and Fundudis (1981) identified numerous flaws in Hayden’s research (1980) concerning the diagnostic criteria, apparent total mutism in some cases, lack of specificity regarding contextual speaking patterns and omission of a control group, thus questioning the rigour of her findings. In an attempt to address these issues, they studied 24 cases and proposed two distinct categories of mutism - those with a biological basis, where speech was always absent, and those with a psychological basis, where speech was affected by social and emotional factors - with the latter offering a new perspective regarding trauma. Table 1 illustrates the main differences between these two categories.

*Table 1: Categorisation of biological and psychological mutism as identified by Kolvin and Fundudis (1981)*

<b><i>Mutism with a <u>biological</u> basis:</i></b>	<b><i>Mutism with a <u>psychological</u> basis:</i></b>
<ul style="list-style-type: none"> <li>• Physical disability e.g. profound deafness, aphasia</li> <li>• Severe learning difficulties</li> <li>• Autism</li> </ul>	<ul style="list-style-type: none"> <li>• ‘Traumatic mutism’ – occurs immediately following a psychological or physical shock</li> <li>• ‘Elective mutism’ – talking is confined to a familiar situation and a small group of intimates</li> </ul>

Kolvin and Fundudis (1981) acknowledged organic causes of mutism, such as physical disability, severe learning difficulty or autism, and reconceptualised Hayden’s ‘speech phobics’ within this category due to their features of autism. Additionally, they proposed two types of psychological mutism - ‘traumatic mutism’ and ‘elective mutism’ - being the first in the field to view trauma-based and context-based mutism as separate entities. ‘Traumatic mutism’ was used to represent the sudden reaction to a psychological or physical shock, resulting in restricted speech

and withdrawal from *all* situations, despite displaying typical communication skills before the event. Meanwhile, 'elective mutism' described those who consistently limited speech and displayed excessive shyness in only *certain* contexts. The researchers reclassified Hayden's 'reactive mutism' as 'traumatic mutism', due to the onset being triggered by an identifiable trauma, with such labels still used to describe a symptom of post-traumatic stress disorder (PTSD) (APA, 2013). Based on their research, Kolvin and Fundudis (1981) argued that the term 'elective mutism' should be reserved for children whose restricted speaking patterns persisted over time, rather than to describe those who fail to speak when first starting school. They defined the initial speaking patterns of the latter group as an expected "transient adaptation reaction" (p.230) due to increased anxiety in an unfamiliar environment, noting that the speech of over 90% Brown and Lloyd's (1975) sample improved spontaneously within their first year at school and therefore did not fit the profile of EM.

### **2.3.3 Further developments in the understanding of SM**

Following Hayden (1980) and Kolvin and Fundudis' (1981) research, the condition continued to attract wider attention until, in 1991, the Foundation for Elective Mutism Inc. was founded by two parents of children with the condition. The disorder was later renamed 'Selective Mutism' for the DSM-IV (APA, 1994), with the phrase 'continuous refusal to speak' replaced with 'consistent failure to speak' in the new definition. This rewording reflected a shift in thinking, challenging the existing assumption that SM resulted from defiance and intentional withholding of speech in favour of anxiety and social phobia inhibiting speech in certain contexts (Rapoport

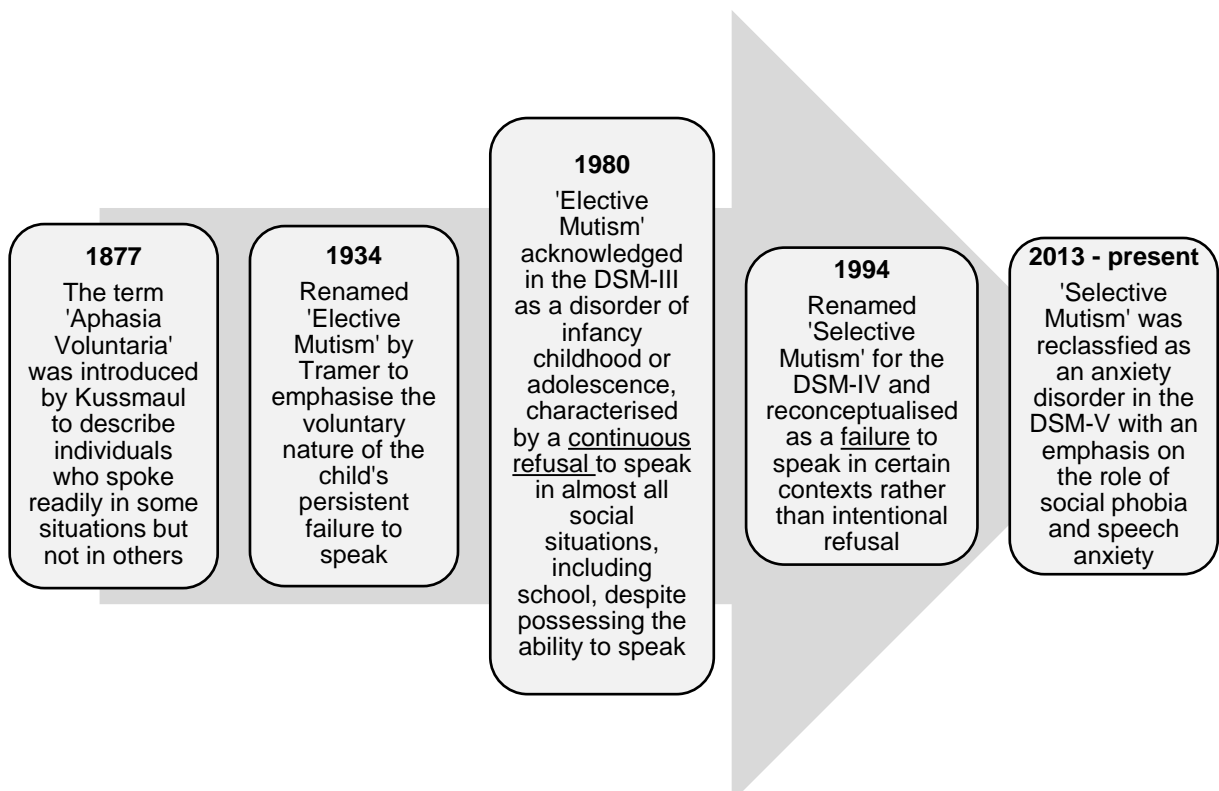


and Ismond, 1996). The prevalence of social anxiety and social phobia in SM was further emphasised in later studies by Black and Uhde (1995), Dummit *et al.* (1997) and Kristensen (2002).

## 2.4 Current thinking regarding aetiology

In 2013, SM was reclassified in the DSM-V (APA, 2013) from a disorder of infancy, childhood and adolescence to an anxiety disorder, to emphasise the role of anxiety and account for the possible trajectory into adulthood. Figure 1 illustrates developments in understanding and terminology from 1877 to the present day.

*Figure 1: The history of Selective Mutism*

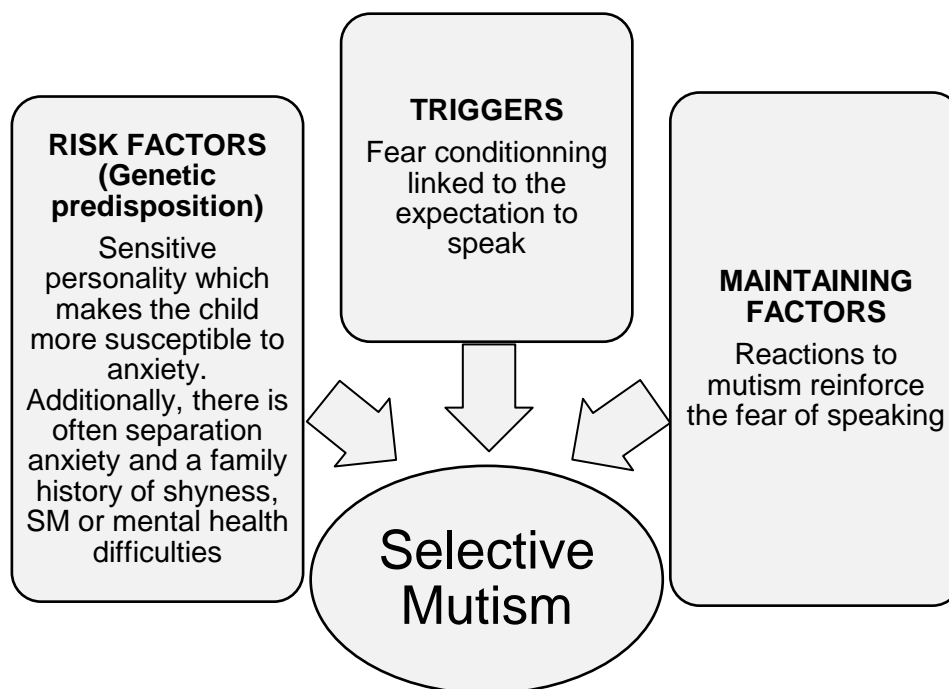


In addition to typical SM, the DSM-V also introduced the term 'low profile' SM to describe individuals who respond minimally to others but do not initiate or engage freely in conversations. Johnson and Wintgens (2016) hypothesised that speech compliance within this group was due to being "anxious about upsetting authority figures or looking foolish in front of their peers" (p.31), despite speech remaining a considerable source of anxiety.

As various later studies found little evidence to support a causal relationship between psychological or physical trauma and SM (Black and Uhde, 1995; Dummit *et al.*, 1997), the phenomenon is currently conceptualised as a specific phobia whereby the child develops an irrational conditioned fear of speech (Omdal and Galloway, 2008) and, consequently, avoids talking to those outside of their comfort zone in order to minimise associated anxiety (Johnson and Wintgens, 2015; 2016). Physiological responses such as "shock", "paralysed" and "freeze response" (Johnson and Wintgens, 2016, p.33) further highlight the role of anxiety in SM. Whilst Johnson and Wintgens (2016) acknowledge that an event which the child perceives as 'traumatic' - such as getting lost, being left with strangers or being teased about poor pronunciation - may trigger and maintain SM in *particular* contexts, this differs from 'traumatic mutism' or PTSD (APA, 2013) whereby a physical or psychological trauma results in flashbacks, nightmares and speech withdrawal across *all* environments. Therefore, Johnson and Wintgens (2016) propose that in SM, it is the child's reaction to the situation that is extreme, rather than the experience of an actual trauma, thus demonstrating the role of cognition in reinforcing the fear and repeated avoidance of speech.

Based on previous research, Johnson and Wintgens (2016) proposed that SM has a multifactorial aetiology due to the interaction between the genetic risk factors, triggers and maintaining factors shown in Figure 2 (page 17).

Figure 2: The contribution of genetic and environmental factors in the development of SM (Johnson and Wintgens, 2016, p.37)



## 2.5 Rethinking the link between SM and social anxiety

Johnson and Wintgens (2016) offered an alternative view regarding the role of social anxiety in SM, proposing that CYP's limited interactions are better explained by their fear of speech rather than not wanting to participate. This theory was also documented by Bruce (1996) who identified that not all children with social anxiety developed SM, and Omdal and Galloway (2008) who argued that social anxiety is secondary to SM as an expressive speech phobia gradually isolates them from others and may therefore lead to social anxiety. Additionally, Cunningham, McHolm

and Boyle (2006) found that children with SM had weaker verbal and non-verbal social skills than controls, likely due to their socially inhibited behaviour, however the DSM-V acknowledged that those with SM may be “willing or eager to perform/engage in social encounters when speech is not required” (cited in Johnson and Wintgens, 2016, p.35). This shows how social anxiety may not always be present and limit interactions. Furthermore, Laptook (2012) suggested that in some cases SM becomes a learned behaviour, due to the amount of time non-speaking has been maintained, and then may no longer be attributed to anxiety.

## **2.6 Other comorbidities**

As well as social anxiety, Johnson and Wintgens (2016) identified that CYP with SM may experience comorbid internalising difficulties such as separation anxiety, generalised anxiety and other phobias. This was also documented by Kristensen (2000) who found that 74.1% of a sample of 54 children with SM met DSM-IV criteria for an anxiety disorder; Cunningham, McHolm and Boyle (2006) who found higher levels of anxiety, separation anxiety, OCD and depressive symptoms amongst SM participants compared to a control group; and Steinhausen *et al.* (2006) who found higher rates of phobic disorder in SM adults than controls. Consequently, personality traits such as shyness, passivity, fearfulness and self-consciousness have been identified within this subgroup (Cline and Baldwin, 2004).

However, evidence regarding comorbid externalising difficulties is less definitive.

Whilst some studies noted how a small number of CYP with SM also exhibited attention deficit hyperactivity disorder (Arie *et al.*, 2006) and oppositional, aggressive

and delinquent behaviours (Manassis *et al.*, 2007; Alyanak *et al.*, 2013; Diliberto and Kearney, 2016), opposing results suggested externalising behaviours were low (Ford *et al.*, 1998; Vecchio and Kearney, 2005; Cunningham, McHolm and Boyle, 2006). Therefore, current thinking continues to conceptualise SM as the result of anxiety, as reflected in the DSM-V criteria (APA, 2013).

Another area attracting interest is the relationship between SM and autistic spectrum conditions (ASCs). Whilst early studies noted how Asperger syndrome was evident in just 7.4% (Kristensen, 2000) and 8.1% (Andersson and Thomsen, 1998) of SM cases, more recently Steffenberg *et al.* (2018) referenced that 63% of participants met the criteria for an ASC. Additionally, research by Carroll (2018) found that of 364 UK respondents, 34% reported both an SM and ASC diagnosis, whilst 53% with an SM-only diagnosis were also undergoing assessments for an additional diagnosis, further highlighting a possible link. However, the accuracy of these findings is questionable due to the reliance on retrospective analysis of patient records and self/parental reports regarding diagnosis, as opposed to concrete evidence of a clinical diagnosis. Despite this, Carroll (2019) endeavoured to explain the comorbidity, proposing that some individuals with an ASC experience social anxiety as a result of their condition, which then leads to contextual SM. Valaparla, Sahoo and Padhy (2018) noted that “when SM and ASD co-occur, the condition becomes more difficult to treat and requires intensive non-pharmacological therapies” (p.39), whilst McKenna *et al.* (2017) developed an assessment protocol for diagnosing ASC when SM is also present.

Additionally, other research has noted the prevalence of speech, language and communication problems in SM, specifically expressive language and articulation difficulties (Steinhausen *et al.*, 2006), phonological discrimination deficits (Kristensen, 2000; Manassis *et al.*, 2003) and auditory processing difficulties (Arie *et al.*, 2006; Muchnik *et al.*, 2013), suggesting a possible neurodevelopmental delay. Johnson and Wintgens (2016) also acknowledge how self-awareness of a speech impairment may exacerbate SM due to fear and embarrassment of getting things wrong or being misunderstood. Whilst Cunningham *et al.* (2004) questioned whether SM has a negative impact on academic performance, the study found no difference between reading and maths attainments in SM and control participants. This was further supported by Nowakowski *et al.* (2009) where those with SM had average academic abilities and receptive vocabulary scores for their age. These findings mirror historical views that such CYP tend to have “average or above average intelligence” (Browne, Wilson and Laybourne, 1963, p.605). However, Jefferies and Dolan (1994) acknowledged how talking is “an essential tool for learning in every area of the curriculum” (p.117), showing how SM may limit the opportunity to practice and further develop verbal communication skills.

## **2.7 Prevalence**

SM is considered to be a low incidence phenomenon, with Imich (1998) suggesting that an EP will only encounter a pupil with SM every five years. However, estimated prevalence rates are based on small population studies and vary according to the country of origin, sample size, age range and diagnostic criteria used by researchers (Viana, Beidel and Rabian, 2009). For example, in a study of Birmingham primary

schools, Brown and Lloyd (1975) proposed that 7.2 per 1000 children under five (0.72%) had EM, however Kolvin and Fundudis (1981) questioned the specificity of their definition as 12 months later just 0.33 to 0.66 per 1000 (0.033 to 0.066%) remained affected. When narrowing the definition to non-speaking that persisted beyond age seven, Fundudis, Kolvin and Garside (1979) estimated that 0.8 per 1000 (0.08%) children in Newcastle upon Tyne were affected; however Kolvin and Fundudis (1981) also questioned the accuracy of these figures due to the reliance on parental reports.

A more current review of literature conducted in a number of countries (Viana, Beidel and Rabian, 2009) estimated prevalence rates of 0.47% amongst native families and 2.2% amongst immigrant families. The higher incidence amongst immigrant children who have limited second language proficiency has been acknowledged for a number of years (Bradley and Sloman, 1975; Lesser-Katz, 1986; Steinhausen and Juzi, 1996). However, Toppelberg *et al.* (2005) recognised that there is a typical “silent period” (p.592) in second language development and therefore argued that a SM diagnosis should only be given when “mutism is prolonged, disproportionate to second language knowledge and exposure, present in both languages, and/or concurrent with shy/anxious or inhibited behaviour” (p.594). Elizur and Perednik (2003) proposed a Diathesis Stress Model to explain why immigrant children may be more susceptible to SM than native children, suggesting that a sensitive and anxious disposition, coupled with the stress of migration and beginning a new school with different language demands, can result in speech anxiety.

More recent figures which account for DSM-V criteria suggest that SM affects approximately 1/140 children under the age of eight (0.71%) and 1/550 older children (0.18%) (Johnson and Wintgens, 2016, p.36), acknowledging that it is more common in younger children. Research indicates that SM typically develops between the ages of two and four (Ford *et al.*, 1998; Elizur and Perednick, 2003), however Johnson and Wintgens (2016) argue that it becomes more apparent when the child starts school. Twice as many girls are thought to be affected (Bergman *et al.*, 2008; Steffenburg *et al.*, 2018), which may reflect that anxiety disorders are more prevalent in girls than boys due to a combination of genetic, social and cultural factors (Bell, Foster and Mash, 2005).

Whilst Johnson and Wintgens (2001) argue that an increase in expertise has resulted in better identification of SM, Campasano (2011) claims that recent figures may be an underrepresentation due to a tendency to mislabel non-speaking as “excessive shyness” (p.46) which the child will outgrow. For example, 77% of parents in Black and Uhde’s study (1995) described their children as ‘moderately or extremely shy’, whilst Schwartz, Freedy and Sheridan (2006) found that amongst a sample of 33 children who met the criteria for SM, 70% had not received a diagnosis from a physician. Additionally, Kopp and Gillberg (1997) noted that many parents do not seek help until concerns are raised by teachers, meaning the literature may not represent an accurate account of the phenomenon. This is a concern as such issues restrict early intervention and can result in mental health and social communication and interaction difficulties that persist into adulthood (Shipon-Blum, 2007; Johnson and Wintgens, 2016).



## **2.8 Assessment and diagnosis of SM**

In 2008, Keen, Fonseca and Wintgens noted that “the condition is not the remit of any one professional group” (p.838), which can delay diagnosis and intervention and increase the likelihood of additional difficulties such as school refusal, self-harm and social anxiety disorder (Johnson and Wintgens, 2016). Consequently, in collaboration with educational and clinical professionals, the researchers developed a consensus-based care pathway for the management of SM. This proposed the need for a multi-professional approach to enable early identification, and a named service in each LA to diagnose SM and offer further advice to schools. Whilst Keen, Fonseca and Wintgens (2008) faced disagreement about whether SLTs or EPs were best suited to this role - which reflects current thinking in my placement LA - it was acknowledged that both services required further training to increase inter-professional understanding of the phenomenon. The pathway also specified the need to assess for coexisting difficulties, as well as social and family issues, and the importance of early intervention to address these areas of concern. Additionally, emphasis was placed on professionals working collaboratively with parents and staff, regularly reviewing social functioning and considering pharmacological treatment, in addition to psychological therapy, if progress was hindered by severe anxiety.

However, Johnson and Wintgens (2016) argued that the pathway needed further clarification, emphasising the importance of a holistic assessment of SM to identify individual, experiential and environmental factors and to inform the professionals necessary for intervention. They acknowledged how SLTs’ “skills in communication assessment and small-steps treatment planning” and EPs’ “skills in contingency

management, graded exposure and cognitive reframing are particularly relevant” (p.43), advocating a coordinated approach to eliminate any underlying language or communication disorders, which could be causing the absence of speech, and to plan how to address the speech anxiety (Johnson and Wintgens, 2015). Building on Keen, Fonseca and Wintgens’ (2008) work, Johnson and Wintgens (2016) proposed that LAs should have a multidisciplinary SM care pathway focusing on prevention and awareness raising in educational settings, an agreed assessment and referral route based on DSM-V criteria (APA, 2013), and delivery of intervention programmes, represented in Figure 3 (page 25).

## **2.9 Intervention and management of SM**

As acknowledged by Hesselman (1983), there is no standard treatment for SM and instead programmes should be individualised based on the client’s needs. Current literature documents various psychosocial, psychodynamic and psychopharmacological interventions for SM, which commonly take a multimodal approach to address the speech phobia at an individual level, as well as maintaining factors at a systemic level (Johnson and Wintgens, 2015). This holistic approach is favoured as much research has attributed success to both collaborative working with key adults and direct work with the child (Watson, 1995; Jackson *et al.*, 2005; Ponzurick, 2012; Lawrence, 2017). Johnson and Wintgens (2016) state that interventions should aim to develop confident talking, as defined below, and outline eight stages towards ‘recovery’, as shown in Table 2 (pages 26-27).

“the ability to talk freely with a range of people in a range of places, both one to one and in a larger group, to meet all conversational needs without undue fear of negative judgement” (p.46).

Figure 3: Multidisciplinary care pathway for SM (Johnson and Wintgens, 2016, p.43)

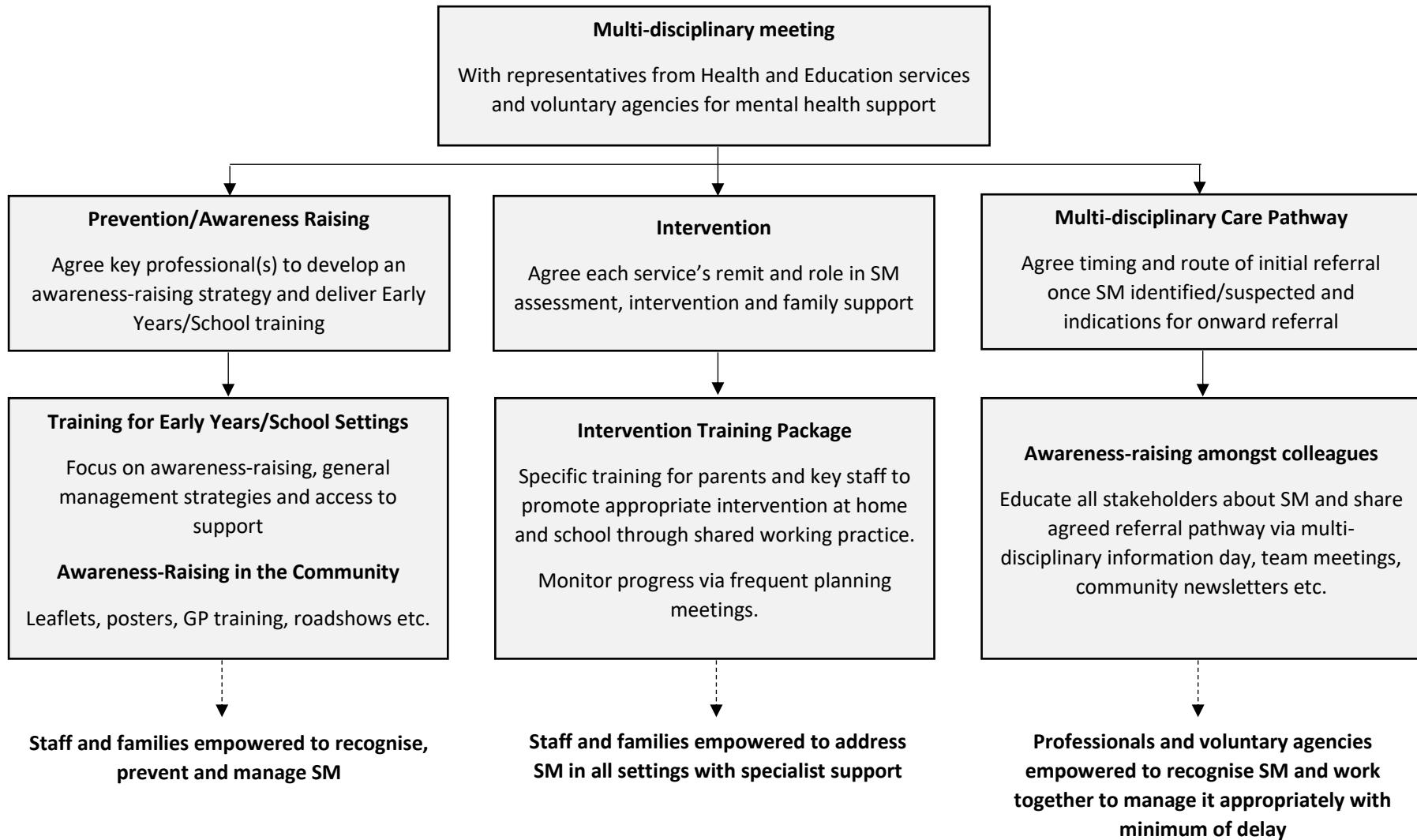


Table 2: Stages of confident talking (Johnson and Wintgens, 2016, p.74)

<b>Stage</b>	<b>Child's presentation</b>	<b>Example of behaviour</b>
<b>0</b>	<i>Absent</i>	<i>Child or young person stays in the bedroom, hides behind a chair or observes activity from a distance.</i>
<b>1</b>	<i>Frozen</i>	<i>Child sits passively or accepts help without moving (e.g. does not take a ball that is offered; stands motionless while coat is buttoned up).</i>
<b>2</b>	<i>Participates without communication</i>	<i>Child participates silently in activities such as board games or jigsaw puzzles; takes items that are offered (e.g. a biscuit or crayons); and complies with requests which do not require an answer (e.g. deals out cards or draws a picture).</i>
<b>3</b>	<i>Uses non-verbal and written communication</i>	<i>Child responds to questions and may even initiate contact through: pointing; nodding or shaking head; tapping; gesture; drawing or writing. Child is relaxed and responds to the adult with a variety of facial expressions.</i>
<b>Talking bridge</b>	<i>Tolerates voice being heard by a bystander</i>	<i>Child talks to or laughs with parent without hiding their mouth in a visitor's or the therapist's presence; talks to other children in the same room as their teacher; talks to family member using a telephone in a public area. Voice may be quiet but is audible rather than whispered.</i>
<b>4</b>	<i>Talks through another person</i>	<i>Child answers when the parent repeats the therapist's question; asks the parent if a person present can play a game with them; talks in a structured activity with an adult but looks at their friend or parent when they speak. Voice may be quiet but is audible rather than whispered.</i>
<b>5</b>	<i>Uses voice</i>	<i>Child vocalises an audible rather than a whispered sound to express emotion, accompany shared play, participate in an activity or directly communicate (e.g. laughter, humming, sound of police siren, animal noises, letter sounds, 'mmm' for 'yes'). Child reads familiar material aloud on request (reading is a vocal exercise for proficient readers, rather than communication).</i>
<b>6</b>	<i>Communicates using single words</i>	<i>Child says a single word in response to questions or choices or in structured activities such as games. Voice may be very quiet but is audible rather than whispered.</i>

<b>7</b>	<i>Communicates with sentences</i>	<p><i>Child uses sentences in response to questions or in structured activities such as games or play readings. Child may:</i></p> <ul style="list-style-type: none"> <li>• <i>Occasionally offer a spontaneous comment</i></li> <li>• <i>Only ask questions during structured activities</i></li> </ul> <p><i>Voice may be very quiet but is audible rather than whispered.</i></p>
<b>8</b>	<i>Conversation</i>	<p><i>Child has an adult-led, two-way conversation, provided no one else is perceived to be listening. Child:</i></p> <ul style="list-style-type: none"> <li>• <i>Volunteers spontaneous comments but questions may be limited</i></li> <li>• <i>May not initiate contact or seek help outside planned sessions</i></li> </ul>
<b>Note</b>	<p><i>Whispering is not included in this progression because it is an avoidance of using voice. For the purposes of keeping records, whispering can be regarded as stage 3+.</i></p> <p><i>When the child is completely comfortable, 8+ may be observed, for example: unplanned conversation on most topics; child-initiated questions and requests; social language and conversation-fillers (words and phrases that add no meaning but feature in relaxed, uninhibited conversation)</i></p>	

### 2.9.1 Psychosocial interventions

As SM is conceptualised as a specific phobia of expressive speech (Omdal and Galloway, 2008; Johnson and Wintgens, 2016), psychosocial approaches involving anxiety-reduction and exposure-based techniques are most commonly used. For example, a literature review conducted by Cohan, Chavira and Stein (2006) identified how 17/23 studies involved behavioural or cognitive-behavioural methods - such as shaping (gradually increasing the use of speech in certain contexts), systematic desensitisation (imagining speaking in a currently feared situation), stimulus fading or 'sliding-in' (another person gradually joining in when a child is speaking comfortably with a trusted other), and contingency management (positive reinforcement of verbal behaviour) - all of which resulted in increased speaking patterns and some

maintained progress at follow-up.

Additionally, a review by Muris and Ollendick (2015) identified a further 14 psychosocial interventions for SM, highlighting the effectiveness of group and online cognitive-behavioural programmes (Sharkey *et al.*, 2008; Ooi *et al.*, 2012), combined child-focused exposure therapy and parent-focused contingency management (Vecchio and Kearney, 2009) and integrated behavioural therapy involving the child, parent and teacher (Bergman *et al.*, 2013). More recently, Oerbeck *et al.* (2018) offered additional evidence for the long-term effectiveness of CBT for SM.

Furthermore, studies with greatest outcomes emphasise the importance of parent/staff psychoeducation and skills training (Sharkey *et al.*, 2008; Oerbeck *et al.*, 2012; Lang *et al.*, 2016; Skedgell, Fornander and Kearney, 2017), consultation-based problem-solving with teachers and parents (Jackson *et al.*, 2005; Howe and Barnett, 2013; Mitchell and Kratochwill, 2013) and home-school communication (Sanetti and Luiselli, 2009), in addition to child-focused work, showing the value of environmental adjustments and systemic management of SM. Other psychosocial methods have adopted augmented self-modelling, whereby clips are edited to show the child speaking successfully in situations where they are usually mute (Kehle *et al.*, 1990; 1998; 2012), as well as structured social skills training (Fung *et al.*, 2002; Reuther *et al.*, 2011; Conn and Coyne, 2014).

### **2.9.2 Psychodynamic interventions**

Psychodynamic interventions aim to explore the origins of SM by accessing the child's unconscious mind and addressing internal conflict (Zakszeski and DuPaul (2017). Whilst various research proposes the benefits of play therapy (Rossouw and Lubbe, 1994; Valner and Nemiroff, 1995; Fernandez and Sugay, 2016), parent-child psychoanalysis (Bonovitz, 2003), music therapy (Amir, 2005; Jones, 2012) and family therapy (Monzo, Micotti and Rashid, 2015) for SM, findings are based on single case studies where "outcomes are often unclear due to lack of systematic assessment" (Cohan, Chavira and Stein, 2006, p.1093) and no follow-up data is provided. Additionally, Camposano (2011) acknowledged how psychodynamic approaches may be overwhelming due to their focus on accessing the child's thoughts and feelings which disregards their associated anxiety.

### **2.9.3 Psychopharmacological interventions**

Psychopharmacological approaches for SM combine selective serotonin reuptake inhibitors (SSRIs) with other forms of treatment, in cases where psychosocial intervention alone has proved ineffective in reducing anxiety. A literature review conducted by Manassis, Oerbeck and Overgaard (2016) identified just ten studies in this area, noting how fluoxetine was most commonly used and facilitated improved social speech and lower anxiety symptoms (Black and Uhde, 1994; Dummit *et al.*, 1996; Moreno and Pedreira, 1998; Manassis and Tannock, 2008). Furthermore, Eke (2002; cited in Østergaard, 2018) and Ooi *et al.* (2012) concluded how medication and CBT was more effective in reducing SM than medication alone, highlighting the benefits of combined treatment methods. However, many of the studies did not

involve an unmedicated control group and used small sample sizes, meaning knowledge regarding the impact of SSRIs remains inconclusive. Moreover, many CYP with SM have maintained treatment progress without medication (Oerbeck *et al.*, 2012; Bergman *et al.*, 2013; Lang *et al.*, 2016), showing how psychosocial approaches should be the primary intervention choice. Johnson and Wintgens (2016) reiterate the importance of a holistic management programme involving the child and key adults within the family and school systems.

## **2.10 Chapter summary**

This chapter has presented a range of literature relating to the historical and current conceptualisation of SM, including its aetiology, prevalence, diagnosis and intervention approaches. Whilst knowledge about SM has increased considerably since it was first recognised in 1877, understanding continues to be largely based on small population or single case studies which rely on observational data and the 'outsider views' of professionals, teachers and parents. Consequently, there is little knowledge about the subjective and lived experiences of SM from the 'experts' - those affected themselves - which forms the rationale for this study. Chapter 3 discusses the importance of pupil voice in research and presents the nine studies that have gained the views of those with SM to date.



## **CHAPTER 3: LITERATURE REVIEW - PUPIL VOICE**

### **3.1 Chapter overview**

This chapter discusses the importance of gaining CYP's views in research and everyday practice, and the fundamental role of EPs in this area. It also presents the nine papers which have elicited lived experiences of SM, considering their strengths and weaknesses and discussing key themes that have emerged about the phenomenon from the 'experts' themselves. Finally, it identifies the gaps in the literature which informed the rationale for this study.

### **3.2 History of pupil voice**

Christensen and James (2000) noted how, historically, "children's lives have solely been explored through the views and understandings of their adult caretakers" (p.2), which fails to elicit personal, or accurate, insight into their lives. However, the Convention on the Rights of the Child (United Nations, 1989) stated that "every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously" (UNICEF, no date).

Consequently, there has been increasing interest and commitment towards gaining the views of CYP, both in research and government legislation.

For example, Christensen and James (2000) identified a paradigm shift in the culture of research, whereby children have been repositioned as the 'subjects' rather than the 'objects' of study, which enables greater accuracy and validity for understanding the individual's world via innovative methodologies. Additionally, many studies have

highlighted the benefits of exploring CYP's 'expert' viewpoints (Bergström, Jonsson, & Shanahan, 2010) in terms of promoting self-worth and confidence (Kellock, 2011), empowering them to "reflect on and have autonomy over issues in their lives" (Mengwasser and Walton, 2013, p.4) and informing appropriate support based on insight into their skills and abilities (Harding and Atkinson, 2009). Furthermore, child-focused research promotes active engagement and democratic participation (Lewis, Florian and Porter, 2007) and ensures that knowledge is constructed *with* CYP rather than *for* them (Fox, 2013). These person-centred themes are also reflected in the Children and Families Act (2014) and the SEND Code of Practice (DfE and DoH, 2015) - as shown in Box 3 - emphasising professionals' statutory responsibilities in consulting with CYP and including them in decision-making about their future.

*Box 3: Key principles from the Children and Families Act (2014) which underpin the SEND Code of Practice (DfE and DoH, 2015, taken from p.19)*

LAs must have regard to:

Principle 1 – the **views, wishes and feelings** of the child or young person, and the child's parents

Principle 2 – the importance of the child or young person, and the child's parents **participating as fully as possible in decisions**

Principle 3 – the importance of **providing information and support** necessary to enable the child, young person and the child's parents **to participate in those decisions**

Principle 4 - the need to **support** the child or young person, and the child's parents in order to facilitate the development of the child or young person and to help them **achieve the best** possible educational and other **outcomes, preparing them effectively for adulthood**

### 3.3 The EP as an advocate for CYP

EPs have been acknowledged as key advocates for CYP for a number of years

(Raymond, 1987; Gersch, Holgate and Sigston, 1993; Hardy and Hobbs, 2017).

Initial interest in this area stemmed from Kelly's PCP theory (1955) which proposed that, in order to understand people, we must directly explore their unique constructs about themselves and the world. Consequently, Ravenette (1977; 1988; 1999) and other researchers developed various methods to explore CYP's attitudes and core constructs (Fransella and Bannister, 1977; Tschudi, 1977; Salmon, 1988; Butler, 2001), generating further interest into how EPs could facilitate pupil voice.

Furthermore, in a paper titled 'Listen to the child: a time for change', Davie (1993) argued that the perspectives of CYP should be given due weight in all areas of psychological involvement, whilst Roller (1998) and Todd (2003) noted how this was particularly important for those with SEND to facilitate personal motivation, independence and responsibility for change. However, research by Noble (2003) raised concerns that the views of pupils with SEND are largely ignored during the assessment process, which can result in them being passive recipients of specialist support (MacConville, 2006).

Advocacy for pupil voice has since been reflected in statutory legislation which informs EP practice (Children and Families Act, 2014; DfE and DoH, 2015), emphasising the importance of person-centred approaches to ensure CYP are at the centre of service delivery and decision-making. Person-centred thinking incorporates the work of Rogers (1957) who attributed successful intervention with clients to the core conditions of empathy, genuineness, confidentiality and unconditional positive regard, hence reiterating the importance of close collaboration with the 'experts'.

More recently Gersch, Lipscomb and Potton (2017) recognised how interviewing CYP and reporting their views to parents and staff has become a fundamental aspect of EP assessments. However, they also noted how practice and evidence-based pupil voice research is still scarcely represented in the literature. Despite this, a book by Hardy and Hobbs (2017) illustrated a range of methodologies adopted by EPs to ascertain the voices of CYP, showing how the profession is well-placed and well-skilled at conducting qualitative research to increase understanding of lived experiences.

### **3.4 Barriers to accessing CYP's views and how EPs have overcome these**

Despite literature and legislation advocating for CYP's views to be reflected in research and everyday practice, Rose and Shelvin (2004) acknowledged how the experiences of marginalised groups, such as pupils with SEND, remain largely invisible. This indicates how certain subgroups may be systematically excluded from pupil voice studies due to their age or communication skills (Breakwell, 2000), social exclusion (Vromen and Collin, 2010), issues of adult gatekeeping and restricted consent (Fox, 2013), and conflicting views of key influencers such as parents or teachers (Hill *et al.*, 2017). Additionally, Fox (2013, p.995) noted how the "formal" and "discursive" nature of traditional interview approaches present as fundamental barriers to accessing CYP's views and argued that alternative methods should be sought to facilitate meaningful participation. Similarly, Duckett and Pratt (2001) highlighted the importance of "getting people out of the woodwork" (p.825) in order to elicit hidden and underrepresented views.

The literature documents how EPs have addressed these issues by adopting creative techniques which account for CYP's age, ability and preferred methods of communication. For example, Soni (2017) combined observations, child conferencing, photography and child-led tours to explore children's experiences of early years provision. Additionally, Harding (2017) identified how sign language, high-technology communication aids, Talking Mats (Murphy, 1998), the Mosaic approach (Clark and Moss, 2006) and the 'In My Shoes' method (Calam *et al.*, 2000) were used successfully to access the views of CYP with profound and multiple learning disabilities. Furthermore, Hill *et al.* (2017) illustrated how ethnographic techniques, structured observations and communication checklists elicited detailed insight into the experiences of pre-verbal pupils and those with complex needs. Moreover, Gersch, Lipscomb and Potton (2017) noted how EPs have used computer technology (Barrow and Hannah, 2012), drawing techniques (Williams and Hanke, 2007) photo elicitation (Hill, 2014) and activity-orientated interviews (Winstone *et al.*, 2014), over traditional interview techniques, to listen to children with ASCs.

### **3.5 Accessing the views of anxious CYP**

As noted by Curtis *et al.* (2003) "disabled young people are not the only ones who may find conventional qualitative research processes inaccessible" (p.168), acknowledging that those who struggle to communicate, possibly for emotional reasons, may also be disadvantaged. Subsequently, several studies have sought ways to elicit the views of individuals presenting with anxiety. Such research, as detailed below, is particularly relevant to this study as anxiety is widely accepted as a prevalent feature of SM (APA, 2013).

Nilsson, Buchholz and Thunberg (2012) noted how distress may compromise “cognitive and communicative competence” (p.1) and developed a modified Talking Mats method to support anxious children to complete a shortened version of the State-Trait Anxiety Inventory (Spielberger, 1973). In this study 42 participants, aged three to nine, used pictures to rate the frequency they experienced four emotions - tenseness, fear, calmness and happiness - with the researchers concluding how this had been an effective non-verbal self-report method for seven-to-nine-year-olds. Whilst the study was conducted by health professionals, the Talking Mats method has also been used by EPs to gain the views of CYP with SEND (Atkiss and Gomez, 2015), thus illustrating its applicability for those displaying anxiety.

Additionally, Reichardt (2017) used the Free Association Narrative Interview technique (Holloway and Jefferson, 2000) with young people displaying self-injurious behaviours, to explore their experiences of school, coping, bullying and associated self-harm. Furthermore, Baker (2017) conducted semi-structured interviews with CYP who had experienced extended non-attendance, to elicit their perceptions of how key adults understood their disengagement from school, of which anxiety and depression were key themes. The latter three studies demonstrate how EPs are key advocates for CYP and have adopted a range of flexible and innovative methods to ensure anxious individuals can express their views in a non-threatening way.

### **3.6 Lived experiences of SM within the literature**

Cline and Baldwin (2004) highlight how the ‘voices’ of individuals with SM are largely missing in follow-up studies, and the SM literature as a whole. As discussed in

sections 1.2 and 2.10, existing knowledge of SM is dominated by “observer interpretations rather than experiential accounts” (Walker and Tobbell, 2015, p.457) which, concerningly “may be presenting a misleading or partial representation of SM by reporting only how it appears to outsiders” (p.456). In a paper regarding pupil voice, Ellingsen, Thorsen and Størksen (2014) argued that CYP should be viewed as “competent actors in their lives” (p.2) and, consequently, should be key contributors to our understanding of their experiences. This is of crucial importance for the SM literature to ensure knowledge is accurately co-constructed and represented.

Literature searches conducted between September 2017 and April 2019 identified nine studies which explored personal accounts of SM. This paucity of research is likely as contextual non-speaking presents a barrier to engaging in traditional verbal interview techniques. Consequently, there continues to be little understanding of SM from the ‘experts’ themselves, which questions the credibility of how the phenomenon is conceptualised. However, the following quote emphasises how ‘listening’ should not be restricted to talking and how professionals should adopt alternative methods to ensure all CYP are able to share their views, which particularly resonates for those with SM:

“it is important to understand listening to be a process that is not limited to the spoken word. The phrase ‘voice of the child’ may suggest the transmission of ideas only through words, but listening to young children...needs to be a process which is open to the many creative ways young children use to express their views and experiences” (Clark and Moss, 2006, p.5).

### **3.6.1 Literature search strategy**

To explore existing research regarding personal accounts of SM, I searched four electronic databases - Web of Science, PROQUEST, EBSCO and PsychINFO.

Multiple search strategies were used involving synonyms and truncations for selective mutism (selective mut\*/elective mut\*) and experience (view\*/voice\*/stor\*/perspective\*/interview\*).

Based on the inclusion and exclusion criteria shown in Table 3 (page 39), these searches identified seven papers for discussion in this section of the literature review (Omdal, 2007; Omdal and Galloway, 2007; Manassis, 2015; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Patterson, 2016; Vogel *et al.*, 2019). Additionally, a paper published by Roe (2011) and a paper awaiting publication by Hill (2019) were sourced from the authors following my attendance at the Selective Mutism Information and Research Association (SMIRA) conferences in April 2018 and March 2019. This totalled nine papers for review.



*Table 3: Inclusion and exclusion criteria for the literature review regarding lived experiences of SM*

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• Peer reviewed journal articles or unpublished theses sourced from Web of Science, PROQUEST, EBSCO or PsychINFO</li> <li>• Published articles (or awaiting publication) sourced at the SMIRA conference, Leicester (21 April 2018 and 30 March 2019)</li> </ul>	<ul style="list-style-type: none"> <li>• Newspaper articles, books or book chapters which may have made reference to personal accounts of SM</li> </ul>
<ul style="list-style-type: none"> <li>• Research which focused on individuals' previous or current lived experiences of SM (children, young people, or adults)</li> </ul>	<ul style="list-style-type: none"> <li>• Literature focusing solely on the views of parents, teachers and other professionals regarding SM</li> </ul>
<ul style="list-style-type: none"> <li>• Literature adopting qualitative or quantitative methods to access the views of those with SM</li> </ul>	
<ul style="list-style-type: none"> <li>• Research conducted either in the UK or internationally</li> </ul>	
<ul style="list-style-type: none"> <li>• Literature up to April 2019, with no prescribed start date</li> </ul>	

### **3.6.2 Overview and critique of papers**

Table 4 (pages 40-42) provides an overview of the nine studies. The focus population and methodology of each paper is then outlined and critiqued, before identifying common themes regarding participants' subjective experiences.

Table 4: Overview of the nine studies included in the literature review regarding lived experiences of SM

Study	Type of paper	Country of study	Focus Population	Circumstances	Method of data collection used to elicit personal accounts of SM	Key themes
<b>Albrigtsen, Eskeland and Mæhle (2016)</b>	Peer reviewed journal article	Norway	Male twins (aged 14)	Research conducted two years after recovery from SM	Retrospective, semi-structured, face-to-face interviews to elicit the twins' views on the triggers, challenges and treatment of SM	<u>Triggers</u> – school move and bullying about accent <u>Impact</u> – family conflict, helplessness, feeling invisible <u>Maintenance</u> – mutual reinforcement, reactions from others <u>Recovery</u> – medication, staff's approach in hospital unit, friends, change of school
<b>Hill (2019)</b>	Awaiting publication in SEN magazine	UK	30 teenagers (genders or ages not given)	Six participants had recovered from SM and 24 remained partially/fully affected by SM	Semi-structured, face-to-face interviews with YP to gather information about age of onset, current speaking patterns and advice they would give to teachers about SM	<u>Onset</u> – most commonly between aged 2-3 years <u>Facilitating factors</u> – staff's understanding, recognition of anxiety, trusted adult, alternative communication methods, access arrangements for exams, friendships
<b>Manassis (2015)</b>	Peer reviewed journal article	Norway	28 CYP (aged 8-14; 10 males, 18 females)	Research conducted four to six years after treatment for SM – 8/28 were still affected	Completion of Likert scales and the Inventory of Life Quality in Children and Adolescents	20/28 rated 'good' quality of life four to six years after treatment. 14/28 rated it was now 'very easy' or 'rather easy' to speak in school/elsewhere
<b>Omdal (2007)</b>	Peer reviewed journal article	Norway	Six female adults (aged 31-60)	Research conducted following recovery from SM	Retrospective, semi-structured, face-to-face interviews to explore participants' experiences of childhood and adolescence with SM	<u>Triggers</u> – social withdrawal, traumatic events <u>Maintenance</u> – defined social role, conscious determination not to speak, expectations of others

						<p><u>Psychological impact</u> - determination, social anxiety, loneliness</p> <p><u>Recovery</u> – conscious decision to change, new environment, no expectations</p> <p><u>Current psychosocial adjustment</u> – continued emotional difficulties/social anxiety</p>
<b>Omdal and Galloway (2007)</b>	Peer reviewed journal article	Norway	Three children (aged 9-13; 1 male, 2 females)	Research conducted with participants currently experiencing SM	Face-to-face interviews with children using Raven's Controlled Projection for Children (1951) using drawing and story writing	Stories reflected themes of school refusal, sexual abuse, drug and alcohol abuse, anxiety about parents' health and death, problems making friends, lies, testing authority, which were also apparent in the children's own lives
<b>Patterson (2016)</b>	Unpublished thesis	UK	Six female YP (aged 13-19)	Research conducted with participants currently experiencing SM	Online data collection using Personal Construct methodology, the repertory grid (Kelly, 1955) and experience cycle questionnaire (Oades and Viney, 2000), and the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)	<p><u>Psychological impact</u> - prevalence of negative constructs linked to anxiety and non-speaking</p> <p><u>Maintenance</u> – fears of socialising, predicting interactions, being heard by others</p> <p><u>Desire to change</u> – ideal self involved speaking</p>
<b>Roe (2011)</b>	Published paper (British Education Index)	UK	30 YP (aged 10-18; 7 males, 23 females)	Three participants had fully recovered and 27 remained partially or severely affected by SM	Postal questionnaires involving Likert scales and closed and open-ended questions about their experiences of SM	<p><u>Onset/Triggers</u> – 3-5 years, starting/moving nursery or school, moving home, bullying</p> <p><u>Facilitating factors</u> – behavioural interventions, family, friends, alternative communication methods</p>

						<p><u>Maintenance</u> – behaviours/ expectations of staff/others who did not understand</p> <p><u>Impact</u> – school, public, visiting friends/family</p> <p><u>Psychological impact</u> – mostly positive attributes, some negative attributes</p> <p><u>Desire to change</u> – desire to talk</p>
<b>Vogel et al. (2019)</b>	Peer reviewed journal article	Germany	65 CYP (aged 8-18; 25 males, 45 males)	Research conducted with participants currently experiencing SM	Online survey involving an open-ended question concerning their fears about speaking, and a questionnaire about their fear-related cognitions	<p><u>Maintenance/Psychological impact</u> – fears relating to social interactions, making mistakes, language and use of voice</p>
<b>Walker and Tobbell (2015)</b>	Peer reviewed journal article	UK	Four adults (aged 21-30; 2 males, 2 females)	Research conducted with participants currently experiencing SM	Online semi-structured interviews using Interpretative Phenomenological methodology to explore participants' historical/current experience and impact of SM	<p><u>Impact</u> – restricted social opportunities and everyday activities</p> <p><u>Psychological impact</u> – dissociation between 'true' and 'silent' identity, negative emotions, social exclusion/ isolation</p> <p><u>Maintenance</u> – conformed to 'silent' role</p> <p><u>Desire to change</u> but feelings of failure/frustration when not achieved</p>

Omdal (2007) was the first to elicit personal accounts of SM by conducting face-to-face interviews with six recovered adults. By exploring their experiences of SM in childhood, adolescence and adulthood, five themes were identified relating to their origins, maintenance, psychological impact, recovery and current psychosocial adjustment. Whilst this research offered new insight into SM and addressed a gap in the literature, methodological weaknesses include sampling bias due to self-recruitment, and the inclusion of participants without a formal diagnosis of SM. Whilst the author confirmed that they met DSM-IV criteria (APA, 1994), this was questionable in one case, where non-speaking may have reflected speech and language delay or traumatic mutism rather than SM, which introduces potential researcher bias. Additionally, Omdal's reliance on retrospective reports may be prone to memory or selective recall bias, thus questioning the accuracy and validity of the findings.

Omdal and Galloway (2007) were the first to interview children with SM, using Raven's Controlled Projection for Children (Raven, 1951). During the research, three children made up a story, following which fictional themes of school refusal, sexual abuse, drug and alcohol abuse, anxiety about parents' health and death, difficulties making friends, lies, and testing authority, were related to the participants' own lives. However, projections were based on fictional accounts and were influenced by the authors' prior knowledge of participants. Additionally, none referred to SM in their stories, so it is questionable why the deeper themes were attributed to SM. Whilst the research presented a novel way of communicating with this group, the children's 'expert' views were largely overridden by the 'outsider' perspectives of teachers and

parents, which reflects concerns in the wider literature. Furthermore, the psychodynamic methodology did not reflect the existing conceptualisation of SM, involving the role of anxiety and an expressive speech phobia.

In 2011, Roe gathered the views of 30 CYP with SM via postal or email questionnaire involving Likert scales and closed and open-ended questions. Whilst Roe acknowledged limitations due to the small sample size and purposive recruitment method, the study provided greater understanding of the triggers, facilitating and hindering factors, CYP's self-perception and the impact of SM, from a much larger sample than had previously been accessed. Additionally, this was the first piece of UK-based research regarding lived experiences of SM.

In another study, Manassis (2015) used Likert scales and the Inventory of Life Quality in Children and Adolescents (Jozefiak, Matzejat and Remschmidt, 2012) to assess how children perceived their quality of life and speaking behaviour four-to-six years after treatment for SM. Whilst most participants indicated a 'good' quality of life, with 50% reporting that it was now 'very easy' or 'rather easy' to speak in school/elsewhere, the researchers did not incorporate qualitative measures to explore the reasons for change, meaning progress cannot be solely attributed to treatment. Additionally, consulting with the children was just one part of a larger follow-up study involving parents and teachers, meaning their views were not the main focus of interest.

Furthermore, Walker and Tobbell (2015) used online instant messaging software to interview four adults about their current experiences of SM and, following interpretative phenomenological analysis, gained insight into the maintaining factors and psychological impact of SM. However, as one of the authors also participated in the study, his 'insider' knowledge may have influenced the results and therefore affected the confirmability of the findings. There is also possible sampling bias due to the self-selection of subjects, as Roe (2011) acknowledged how those who volunteer for research may be more "motivated, articulate and computer literate" (p.9). Despite these limitations, the paper contributed to the UK-based literature in this area and increased understanding of the long-term consequences of SM if left untreated.

In 2016, Albrigtsen, Eskeland and Mæhle conducted an in-depth interview with a set of twins two years after recovery (able to communicate freely) from SM. This research elicited further insight into the origins, maintenance, psychological impact and treatment of SM from a lived perspective, however the interviews relied on speech, which would be inaccessible for much of the SM population. Additionally, the study was based on retrospective accounts, which were triangulated with parents', and it was conducted in Norway, so may not reflect UK experiences of SM due to possible cultural differences.

Additionally, Patterson (2016) explored the personal experiences of adolescents with SM using PCP techniques, the repertory grid (Kelly, 1955) and experience cycle questionnaire (Oades and Viney, 2000), and the Hospital and Anxiety Depression

Scale (Zigmond and Snaith, 1983). Findings emphasised the prevalence of anxiety amongst participants and identified a range of fears which had maintained their SM. Whilst data was gathered online, this proved an effective way of accessing current experiences of SM and further added to the limited UK literature in this area.

Furthermore, Hill (2019) conducted face-to-face interviews with 30 teenagers who were currently or previously affected by SM. This research generated valuable information about the age of onset, current speaking patterns and advice participants would give to teachers about helping CYP with SM, thus further increasing phenomenological knowledge of SM in the UK and providing clear implications for practice.

Finally, Vogel *et al.* (2019) used an online survey to explore the psychological and physiological impact of SM amongst 65 CYP currently experiencing the condition. Participants answered an open-ended question about fears that might restrict speech in certain situations and completed a questionnaire involving their fear-related cognitions in speech-demanding situations, which identified several maintaining factors relating to anxiety. Whilst this research accessed the largest number of participants of any of the previous studies, identification of SM was based on a parental rating scale rather than a formal diagnosis. This may have resulted in potential experimenter-expectancy effects or “prestige bias” (Thomas, 2013, p.208) - where participants answer in the way they believe is expected - which could have affected the reliability of the sample. Additionally, the research was conducted outside of the UK and used online rather than face-to-face measures to communicate



with CYP.

### **3.6.3 Summary of key themes from a lived experience perspective**

On review of the nine papers, six themes were identified relating to participants' views of the onset and origins, context, psychological and physiological impact of SM, maintaining and hindering factors, facilitating factors, and their desire to change, which are discussed below.

#### **3.6.3.1 Onset and origins**

Several studies identified that the most common age to develop SM was two-to-five years (Omdal, 2007; Omdal and Galloway, 2007), with Hill (2019) noting how 77% of her sample were first affected in this age range, and Roe (2011) indicating how 89% of participants displayed SM before age five, which supports previous literature findings (Ford *et al.*, 1998; Elizur and Perednick, 2003). However, several studies involved those with late onset SM - including Walker and Tobbell (2015) where three participants were aged eight, 12 and 17; Patterson (2016) where SM was not identified until 11-16 years in 83% of cases; and Hill (2019) where onset between 11-12 years represented 23% of the sample - showing the age variations of SM.

Regarding the origins of SM, many participants identified specific social and environmental triggers including first starting nursery or school (Roe, 2011) or moving house and educational setting (Omdal, 2007; Roe, 2011) which, in Albrigtsen, Eskeland and Mæhle's (2016) study, resulted in bullying due to subjects being teased about their accent. Additionally, Omdal (2007) noted how all participants

gradually withdrew from social interactions as they feared talking and consequently adopted a 'silent role' in certain contexts. Furthermore, all referred to traumatic incidents during their childhood, with three directly attributing their SM to events such as maternal depression during the war, sexual abuse, change of kindergarten, school absence due to illness, bullying, the birth of twin siblings, and separation from parents, which challenges the current view that SM does not result from trauma (Black and Uhde, 1995; Dummit *et al.*, 1997). These findings highlight the importance of consulting directly with those with SM to explore their perceived triggers, as such understanding has implications for future support and intervention.

### **3.6.3.2 Context**

Many studies elicited valuable insight into the contextual nature of SM. Omdal (2007) reported how participants were most affected in school, but also around strangers and some family members, with one describing her silence as a way of "protecting herself against a chaotic world" (p.243). Similarly, the twins in Albrigtsen, Eskeland and Mæhle's (2016) study shared how their non-speaking outside of the home meant they were unable to ask for help in public or indicate their needs in school such as being hungry or needing the toilet, which resulted in frequent frustration and family conflict. Likewise, Roe (2011) found that SM had affected 80% of participants in school - mainly speaking to staff, asking for help with learning and making friends - and 70% outside of school when visiting friends or relatives or going to restaurants or leisure centres, whilst Walker and Tobbell (2015) noted how SM affected school, employment, family life and general participation in society. In line with the DSM-V criteria (APA, 2013), this emphasises the significant impact SM has

on everyday functioning, and how talking to people outside of the home presents the greatest difficulties.

### **3.6.3.3 Psychological and physiological impact**

Some of the studies deepened understanding of the psychological and physiological impact of SM, of which anxiety played a key role. Omdal (2007) identified how all participants were 'determined' not to speak as they feared change, two experienced social anxiety, and five felt lonely and isolated, with five still experiencing social anxiety in adulthood. Additionally, the twins in Albrigtsen, Eskeland and Mæhle's (2016) study recalled feeling "uncomfortable", "helpless", "ignored" and "humiliated" (p.314-315) and identified physiological symptoms of anxiety such as stomach ache and headaches.

Similarly, Patterson's (2016) participants described themselves using negative attributes such as "whispering, withdrawn, not talkative, silent and shy" as opposed to "talkative, outgoing, loud and noisy" and "terrified, uptight, uncomfortable, tense and anxious" as opposed to "relaxed, calm, composed and content" (p.168). Likewise, Walker and Tobbell's (2015) participants described SM as "distressing, uncomfortable, and separate from their sense of self" (p.462), highlighting a perceived discrepancy between their 'true' and 'silent' identities which caused frustration, disappointment and social isolation, and a sense of regret and hopelessness due to an "unfulfilled and meaningless life" (p.462).

Finally, whilst some CYP in Roe's (2011) research reported negative characteristics such as shy, quiet, anxious, unhappy and frustrated, these were far outweighed by positive attributes such as sensitive, helpful, friendly, happy and fun, which challenged general perceptions in the literature (Cline and Baldwin, 2004) and showed how SM had not defined their personality.

#### **3.6.3.4 Maintaining and hindering factors**

Another theme related to perceived maintaining and hindering factors in which, in many cases, the environment had sustained SM. Omdal (2007) noted how SM had become a well-defined social role amongst all subjects, as peers and staff did not expect them to speak and, in one case, how silence was maintained to avoid repeated embarrassment of being punished for talking in class.

Similarly, those in Walker and Tobbell's (2015) study discussed conforming to a 'silent role' and stopping attempts to communicate after consistent exclusion from social interactions in school, whilst the twins in Albrigtsen, Eskeland and Mæhle's (2016) study recalled being ignored by the teacher when they had their hand up which made them feel "invisible" (p.315). Additionally, 53% of Roe's (2011) sample identified that a lack of understanding amongst staff and peers - such as being pressured into talking and making hurtful comments about their non-speaking - was unhelpful and had maintained their SM, whilst 75% of CYP in Hill's (2019) study identified that the expectation to communicate non-verbally was equally as stressful, especially being singled out, put on the spot, cajoled or punished for not responding.

Furthermore, Vogel *et al.* (2019) highlighted the role of cognition in the maintenance of SM - identifying participants' fears of social interactions, making mistakes, language and the use of voice - which mirrors Patterson's (2016) findings regarding fears of invalidation and unpredictability in social situations, and reflects the views of one of Omdal's (2007) participants who was afraid of being laughed at for her abilities. These findings suggest that environmental and cognition-related factors may both play a role in the maintenance of SM.

### **3.6.3.5 Facilitating factors**

Several studies gained insight into factors which facilitated progress or recovery of SM. Omdal (2007) noted how participants made a conscious decision to speak when joining a new club, starting a new school or moving to a different country, where there were no prior expectations of their speaking patterns. Additionally, the twins in Albrigtsen, Eskeland and Mæhle's (2016) research identified how staff's approach in an in-patient hospital unit had helped them to feel more understood and accepted. They also identified how medication, making friends in the hospital school and changing schools following discharge also supported their recovery, noting how their new setting accepted the condition as "a state of anxiety rather than an oppositional disorder" (p.317).

Similarly, all of Hill's (2019) participants felt the best way for staff to support SM was to recognise it as a manifestation of anxiety and to make environmental adjustments such as removing the pressure to speak, using alternative communication methods, checking their understanding of tasks, supporting social interactions and having a

continuous relationship with a trusted adult. Likewise, Roe (2011) identified how behavioural strategies were the most commonly and successfully used method in 56% of cases, with CYP also valuing support from family and friends who understood them and facilitated their gradual progress. Manassis' (2015) results also suggested that a combination of defocused communication, psychoeducation for parents and staff, and the sliding-in technique had contributed to positive quality of life ratings, supporting Johnson and Wintgens' (2015; 2016) advocacy of a holistic, multimodal approach to intervention.

#### **3.6.3.6 Desire to change**

Finally, several studies reflected individuals' desire to change, with Omdal (2007) emphasising their "conscious determination" (p.245) to speak and Patterson (2016) reporting how five participants construed the speaking person as their 'ideal' self. Additionally, Roe (2011) identified how 23% of CYP wanted to talk but would find this incredibly difficult to achieve and 7% acknowledged how once they had overcome SM, life would be better, whilst those in Walker and Tobbell's (2015) research referred to a "determination and desire" to speak (p.462) which resulted in a sense of failure and frustration when their wishes were not achieved.

The nine studies discussed have offered novel insight into the subjective experiences of SM. Key themes have highlighted the importance of consulting directly with those with SM to explore their perceived triggers, the contextual, psychological and physiological impact of SM, maintaining and facilitating factors and their wishes for the future, to ensure future support is person-centred, meaningful and relevant.

### **3.6.4 Lived experiences of SM: gaps in the literature**

Following review of the nine papers, the following gaps were identified which formed the rationale for this study:

- None of the existing research was conducted by an EP or TEP so this study will add a unique psychological perspective to the literature and help to inform the role of EPs in assessment and intervention for SM
- Three of the studies focused on retrospective accounts of SM (Omdall and Galloway, 2007; Manassis, 2015; Albrigtsen, Eskeland and Mæhle, 2016), highlighting the need for more research into current experiences
- Just four of the nine studies were conducted in the UK (Roe, 2011; Walker and Tobbell, 2015; Patterson, 2016; Hill, 2019) and only three of these accessed the views of CYP regarding their current experiences of SM (Roe, 2011, Patterson, 2016; Hill, 2019), identifying the need for more UK-based research with CYP
- Two of the UK studies relied on online and postal data collection methods to access the views of CYP (Roe, 2011; Patterson, 2016), meaning only one UK study has involved face-to-face contact with CYP (Hill, 2019)
- Only one of the nine studies used PCP to elicit the views of CYP with SM (Patterson, 2016), however this did not involve an adaptation of Moran's Drawing the Ideal Self (2001) method. As this technique has previously been used to elicit the views of those with communication difficulties (Moran, 2001; 2005; 2006; Williams and Hanke, 2007), I felt it may be an appropriate tool for individuals with SM and would offer a new approach to research in this area

My research therefore aimed to address these gaps in the literature and to add to the limited evidence base in this area.

### **3.7 Chapter summary**

This chapter has presented literature relevant to the area of pupil voice and highlighted how EPs are key advocates due to their flexible and creative approach. It also discussed the nine papers representing lived experiences of SM, considering their strengths and weaknesses and identifying key themes. This further highlighted the gap regarding pupil voice in this area, which formed the rationale for my study. Chapter 4 details the methodology of my research.



## CHAPTER 4: METHODOLOGY

### 4.1 Chapter overview

This chapter details the research methodology, outlining the aims and research questions and my philosophical stance which informed the choice of PCP (Kelly, 1955) to elicit CYP's views. It explains how I adapted Moran's Drawing the Ideal Self technique (2001) to understand the 'speaking' and 'non-speaking' constructs of CYP with SM, provides details of ethical considerations, the recruitment process and participant information, and discusses the method of data analysis.

### 4.2 Research aims and research questions

The aim of the research was to elicit the subjective experiences and contrast poles of CYP with SM using a non-verbal technique based on PCP. The research questions were as follows:

**RQ1:** How do CYP with SM construct their current and 'ideal' selves?

**RQ2:** What factors do CYP attribute to the causes of their SM?

**RQ3:** How do CYP with SM construct their 'movement' over time?

**RQ4:** What action plans do CYP with SM create for their future?

### 4.3 Ontological and epistemological approach

Rojon and Saunders define research as "systematically obtaining and analysing data to increase our knowledge about a topic in which we are interested" (2012, p.55), and emphasise how research questions are essential in order to further explore a

particular issue. However, Cohen, Manion and Morrison (2017) note how philosophical assumptions about the social world influence the choice of research questions, design frame, and data collection and analysis methods. Theories about how knowledge is acquired lie on a continuum from positivism - which assumes the social world is external to individuals and can be studied objectively using scientific methods - to interpretivism, which believes knowledge is situated within people and is socially constructed depending on the meaning individuals ascribe to their experiences (Thomas, 2013). Thomas states that researchers must acknowledge their ontological and epistemological position as this informs what will be studied, how knowledge will be sought, and the associated research paradigm.

As the focus of the current study was to elicit personal accounts of SM, my research adopts a relativist ontology and interpretivist epistemology (Burrell and Morgan, 1979). Therefore, I accept that learning in the social world is an active and subjective process (Cohen, Manion and Morrison, 2017) and that there are “multiple realities” (Thomas, 2013, p.111) which can be accessed using idiographic methodology (Burrell and Morgan, 1979). Consequently, I believe that SM can only be accurately understood by consulting directly with those affected, to explore how they construct themselves and their experiences. This view informed my choice of qualitative interviews using a PCP method. An interpretivist stance also underpins my core values and professional practice as I adopt a person-centred approach, appreciating CYP as the ‘experts’ in their lives.

#### **4.4 Researcher positionality**

Given that subjective views were central to my research, an interpretive methodological approach was crucial. However, I was aware that by adopting this positionality I had played an active role in the research as, based on my previous encounters of SM and reviewing of the literature, I had developed certain assumptions or “situated knowledge” (Thomas, 2013, p.144) about the phenomenon. As my values and beliefs may have differed to the axiology of participants, this could have influenced my interpretation of their accounts (Cohen, Manion and Morrison, 2017), however, by acknowledging this conflict and discussing my positionality as a researcher explicitly, I attempt to minimise these issues.

Prior to conducting the research, I had supported two children with SM, as discussed in Chapter 1. This, along with experiencing shyness around some teachers and peers in school myself, resulted in a personal interest in studying SM further. However, I was conscious that my own views and experiences of the phenomenon did not always align with the wider literature and, consequently, questioned the trustworthiness of such ‘outsider’ knowledge. For example, whilst research found little evidence of a causal relationship between trauma and SM (Black and Uhde, 1995; Dummit *et al.*, 1997), I hypothesised whether traumatic incidents during early childhood had contributed to the restricted speaking patterns of the two children concerned. This ambiguity further highlighted the subjective nature of knowledge acquisition and emphasised the need for a phenomenological understanding of SM. Therefore, during the interviews, I adopted a neutral stance to minimise the influence of my own axiology and incorporated ‘member checking’ (Birt *et al.*, 2016) to ensure

participants' lived experiences were accurately represented.

#### **4.5 Case study design**

The research reflected a multiple case study design, as five CYP were interviewed.

Creswell (2008) defines a case study as an “in-depth exploration of a bounded system (e.g. an activity, event, process, or individuals) based on extensive data collection” (p.476). Thomas (2013) notes how case studies involve two essential elements - the “subject” and the “object” (p.151), with the subject denoting the sample and the object being the analytical frame explored by the subject. Therefore, in the current study, the ‘subjects’ were CYP with SM which gave access to the ‘object’ of lived experiences of SM. The research represented a “sequential snapshot” design (Thomas, 2013, p.153) as the interviews were conducted consecutively over a three-month period.

##### **4.5.1 Strengths and weaknesses of case studies and issues of trustworthiness**

Whilst case studies elicit rich and detailed understanding of a phenomenon (Cohen, Manion and Morrison, 2017), Hammersley (1992) acknowledged that this is a ‘trade-off’ as it is not possible to generalise findings from a small number of participants to a broader population. However, focus is on detail and description rather than wider representation (Thomas, 2013), although Yin (2009) argued that knowledge from multiple case studies can contribute to greater analytic generalisability. Similarly, Verschuren (2003) acknowledged how “complex issues in general have a much lower variability than separate variables” (p.137), meaning transferability is possible from a small number of case studies. This was evident when reviewing the nine

studies in Chapter 3 as common themes emerged regarding lived experiences of SM.

Additionally, Shaughnessy, Zechmeister and Zechmeister (2003) recognised how the case study design is prone to bias due to the researcher's interpretivist position and the influence of their prior knowledge, as well as selective memory or self-reporting bias of participants. There are also questions of validity and reliability due to the notion of multiple realities (Cohen, Manion and Morrison, 2017) however, from an interpretivist perspective, all information provided by participants is valid (Omdal and Galloway, 2007). Despite this, I am mindful that results gathered using a 'snapshot' approach (Thomas, 2013) may only reflect participants' views on the day of the interview and could vary over time. To minimise bias in my research, it was important to adopt a reflexive approach and incorporate an external review of my data to enhance the trustworthiness of results.

Guba and Lincoln (no date, cited in Treharne and Riggs, 2014) advocate that qualitative research is quality-assessed in terms of credibility, transferability, dependability, confirmability and authenticity. Table 5 (pages 60-61) shows the measures I took to enhance the trustworthiness of data in the present study.

*Table 5: Measures which investigate the quality and trustworthiness of qualitative data (as identified by Guba and Lincoln, no date, cited in Treharne and Riggs, 2014) and how these were addressed in the current research*

<b>Concept</b>	<b>Definition/ Recommendations</b>	<b>Considerations during the research</b>
<i>Credibility</i>	Do participants feel the findings represent their experiences? Member checking and peer debriefing with other researchers can be used to investigate credibility.	An initial meeting was offered to all participants prior to the interviews with the aim of building a rapport with the researcher and to increase their comfort and willingness to share their experiences during the research. Throughout the interviews, I ensured I checked my interpretations of their responses (member checking) at regular intervals and clarified any ambiguities to ensure their subjective accounts were accurately represented. Additionally, responses to a question on the evaluation form confirmed that the CYP felt the technique had enabled them to express their views and experiences of SM. Finally, I asked a TEP colleague to review the themes I had identified to reduce researcher bias and increase the trustworthiness of the data.
<i>Transferability</i>	Are the findings applicable in other contexts? How likely is it that the findings relate to other individuals with SM? Providing a rich description of participants' responses (and the researcher's interpretations) makes transferability easier to evaluate.	Whilst case studies adopting qualitative methodology do not aim to generalise, participants' views and experiences connected with those in several of the other lived experience studies regarding SM, thus offering tentative transferability. This supported Verschuren's (2003) argument that "complex issues in general have much lower variability than separate variables" (p.137).
<i>Dependability</i>	Would similar findings be produced if someone else undertook the research? Triangulation across researchers can be used to investigate dependability. Auditing can also be carried out to allow another researcher to follow the audit trail (ideally) generated by the original researcher.	As I developed a novel technique for the purpose of the research, further use or triangulation with other researchers has not yet been possible. However, it is hoped that the technique can be further developed for publication and then used by other professionals working with CYP with SM, which will elicit valuable feedback about the dependability of the tool.
<i>Confirmability</i>	Are the findings a product of participants' responses and not the researcher's "biases, motivations, interests, or	I acknowledged my interpretivist positionality, "situated knowledge" (Thomas, 2013, p.144) and active role as a researcher explicitly in section 4.4. Consequently, during the interviews, I was

	<p>perspectives” (Lincoln and Guba, 1985, p.290)? Auditing can be used to evaluate the confirmability of findings. A more transparent report of the findings (with signposted reflexivity) makes confirmability easier to evaluate.</p>	<p>mindful of adopting a neutral perspective and clarifying any ambiguities with participants to ensure their lived experiences were accurately represented and to minimise the influence of my own axiology. Furthermore, key themes relating to each research question (see Chapter 5) were derived solely from the CYP’s responses which reflected an inductive and data-driven approach. Finally, I kept a reflective diary and engaged in regular supervision throughout the research process to capture my thoughts and address any issues which may introduce researcher bias.</p>
<p><i>Authenticity</i></p>	<p>Does the research represent a range of differing viewpoints on the topic? Do the findings have transformative potential? Is there community consensus that the findings are “useful and [have] meaning (especially meaning for action and further steps)” (Lincoln, Lynham and Guba, 2011, p.116)? Member checking can be used to inquire about apparent authenticity with participants or other members of the community in question. These individuals might include practitioners who would potentially change their practice based on the findings.</p>	<p>Whilst just five CYP were interviewed for the research, their responses varied, which reflected differing views and experiences of SM. Additionally, feedback from the participants supported the authenticity of the technique, particularly in terms of them feeling the action plans would help them in the future. Furthermore, positive feedback was received from two parents regarding the greater insight they had gained about their child’s SM, as well as the SLTs who were interested in the PCP approach and the potential for future collaboration between the EPs and SALTS to create a multidisciplinary SM pathway within the LA.</p>

## 4.6 Research methodology

My interpretivist stance informed my choice of PCP methodology as this approach enables “in-depth insight into personal experience” (Burr, King and Butt, 2014, p.341) which in turn facilitated exploration of lived accounts of SM. The sections below further detail the rationale for using PCP.

### 4.6.1 Personal Construct Psychology (PCP)

In his *Psychology of Personal Constructs: Volume 1*, Kelly (1955) introduced a new

branch of interpretivism, underpinned by a constructive alternativist philosophy. The theory is based on a 'fundamental postulate' which states that "a person's processes are psychologically channelized by the ways in which he anticipates events" (p.46), thus highlighting the subjective nature of interpretation. Kelly introduced the metaphor "man-the-scientist" (1955, p.4), arguing that there are no 'facts' in science and instead viewing humans as scientists who constantly generate hypotheses about the world and conduct experiments to explore whether their predictions are correct (Dalton and Dunnett, 1992). Whilst Kelly accepted the universe's true existence, he proposed that it is open to continual revision as there are multiple ways of perceiving reality, denoting this as the 'individuality corollary'. Additionally, Kelly suggested that humans seek to identify similarities and differences in their experiences of people, objects and events, and develop "transparent patterns or templets" (1955, pp.8-9), i.e. personal constructs, which enable them to make informed predictions about the world. He termed this the 'construction corollary', to explain how events are anticipated by construing replications.

PCP assumes that when predictions are validated the construct system is elaborated, whereas invalidation causes the scientist to reconstrue the situation and modify the construct. By adopting a subjective realist position, Kelly conceptualised man as an active, interpretative construer who has cognitive capacity for enhancement and change (Blowers and O'Connor, 1995). On this basis, PCP offers a useful approach to explore the meaning CYP with SM ascribe to their lived experiences.



#### **4.6.2 The dichotomy and choice corollaries**

Kelly's fundamental postulate is underpinned by 11 corollaries (clarifying statements), of which the 'dichotomy' and 'choice' corollaries are particularly relevant to my study. Firstly, the 'dichotomy corollary' proposes that "a person's construction system is composed of a finite number of dichotomous constructs" (Kelly, 1955, p.59), such as happy-sad, tall-short, intelligent-stupid, with such oppositional construing enabling discriminations to be made about the world (Blowers and O'Connor, 1995). For example, Kelly would argue that an individual who perceives themselves as 'skilled' at mathematics does so because they judge they are different to the contrast or implicit pole e.g. 'novice'.

Rychlak (1981) used the term 'demonstrative reasoning' to describe this decision-making process, noting how construing, abstracting and predicting are all dependent on personal perception. Subsequently, Fransella (1995) acknowledged that in order to understand a person's view of the world, both the emergent (preferred) and implicit (contrast) poles must be explored, with Blowers and O'Connor (1995) further noting that these inform subjective discriminations and anticipatory predictions. Additionally, PCP proposes that higher order or 'core' constructs develop due to frequent validation and serve to maintain identity by influencing construing and subsequent behaviour (Beaver, 2011).

Secondly, Kelly's 'choice corollary' denotes that "a person chooses for himself that alternative in a dichotomized construct through which he anticipates the greater possibility for extension and definition of his system" (1955, p.64). This corollary

assumes that, when faced with a decision, individuals will select the pole of the construct that is most meaningful to them and enables the construct to be further elaborated. Furthermore, it emphasises the active nature of dichotomous construing, incorporating the concepts of motivation and logic (Fransella, 1995) and explaining how choice-making leads to the maintenance of certain behaviour patterns which are functional to the individual due to “a seeking of self-protection” (Kelly, 1955, p.67). For example, Fransella noted how a stutter may persist over time as this behaviour allows greater anticipatory prediction of events over the opposite of being fluent. In other words fluency for a stutterer is relatively meaningless, with Fransella acknowledging that “all ways of behaving that a person has adopted over many years becomes a part of their ‘self’ construing” (2005, p.99).

#### **4.6.3 Relevance to the current study**

The ‘dichotomy’ and ‘choice’ corollaries have been discussed as they can both be applied to the understanding of SM. For example, the different speaking patterns observed in SM appear to reflect a bipolar system, with ‘speaking’ and ‘non-speaking’ representing opposite ends of the same construct. This mirrors Kelly’s ‘dichotomy corollary’, illustrating how ‘speaking’ is the emergent pole in some situations, such as home, whereas the contrast pole of ‘non-speaking’ is favoured in other contexts, such as in school or public.

This discrepancy in SM also supports the ‘choice corollary’ as the literature proposes that, in certain environments, non-speaking is a functional way of managing an expressive speech phobia (Omdal and Galloway, 2008; Johnson and Wintgens,

2016). Thus, from a Kellyan perspective, when individuals with SM are faced with a speech-demanding situation outside of their comfort zone, 'non-speaking' becomes their elaborative choice as it is a meaningful way of anticipating the event and reducing their anxiety. However, in other contexts, the opposite pole of 'speaking' may be adopted as this behaviour offers greater prediction and supports construct extension. These corollaries demonstrate the role of cognition, subjective interpretation and an individual's personal construct system in the maintenance of SM, in addition to environmental factors (Johnson and Wintgens, 2016).

#### **4.6.4. PCP methods to elicit personal views**

Beaver (2011) noted how communication is an attempt to share one person's version of reality with another and emphasised the importance of accessing personal constructs in order to understand how people make sense of their experiences. Various PCP techniques - including the repertory grid, triadic elicitation and self-characterisation (Kelly, 1955), laddering (Fransella and Bannister, 1977), the ABC model (Tschudi, 1977), salmon lines (Salmon, 1988) and the self-image profile (Butler, 2001) - have been developed to explore individuals' mental representations of the world, all of which adopt a semi-structured interview approach.

Whilst Kelly (1955) acknowledged that understanding is most commonly communicated through words, Humphreys and Leitner (2007) noted how not all individuals are able to verbalise their experiences due to emotional reasons, which is particularly pertinent to SM. They recognised how "many of our most important meanings lie outside the realm of language" (p.129) and proposed drawing as a non-

verbal means of exploring core constructs. Whilst several PCP methods incorporate drawing - including the Kinetic Family Drawing (Burns and Kaufman, 1970), a drawing and its opposite (Ravenette, 1999) and the portrait gallery (Beaver, 2011) - constructs are derived during further discussions, which are likely to be inaccessible for those with SM. Therefore, in the present study, it was important to develop a technique which enabled CYP to share their experiences and personal constructs without the need for speech.

Burr, King and Butt (2014) highlighted several advantages of using PCP techniques over other methods, including their engaging and dynamic participant-led nature, close collaboration with the researcher and effectiveness for exploring sensitive issues. Furthermore, they acknowledged how PCP approaches rely less on verbal fluency and argued that they are “particularly effective in researching experiences that are hard for participants to articulate” (p.343). This emphasises the flexible nature of PCP and its applicability to access the views of the SM population.

However, Burr, King and Butt also noted potential weaknesses of PCP tools including their ‘game-like’ nature which may be perceived as failing to take participants’ responses seriously, as well as the researcher’s dilemma in deciding how much to intervene in the process of generating data.

The following section details several studies which used PCP drawing and talking techniques to access CYP’s ‘dichotomy’ and ‘choice’ corollaries. As I was interested in the ‘non-speaking’ and ‘speaking’ experiences of SM, these were particularly relevant and were adapted to create a novel, non-verbal PCP tool for this population.

#### 4.6.5 PCP techniques based on the dichotomy and choice corollaries

Several researchers have developed PCP techniques to explore individuals' dichotomous constructs and elaborative choices (Moran, 2001; Williams and Hanke, 2007; Green, 2014; Morgan-Rose, 2015). These derived from Ravenette's method 'a drawing and its opposite' (1999), whereby individuals were asked to draw a pertinent issue (e.g. anger) and then another picture which represented the opposite, with a further development involving elaborating a line to produce an image of people important to the client, followed by an opposite drawing. Beaver (2011) noted how such techniques offered a "non-verbal vehicle for tapping into a richness of verbal metaphor" (p.127) and how exploring similarities and differences enabled EPs to understand the child's unique perspective of the world.

Based on the concept of dichotomy, Moran (2001) developed the Drawing the Ideal Self technique to help CYP explore their views of their 'non-ideal' and 'ideal' selves, which ordinarily they may find difficult to put into words. This is a collaborative, enquiry-based process whereby the practitioner guides the child through three stages of a drawing and talking task and, most importantly, appreciates them as the 'expert' in their own life.

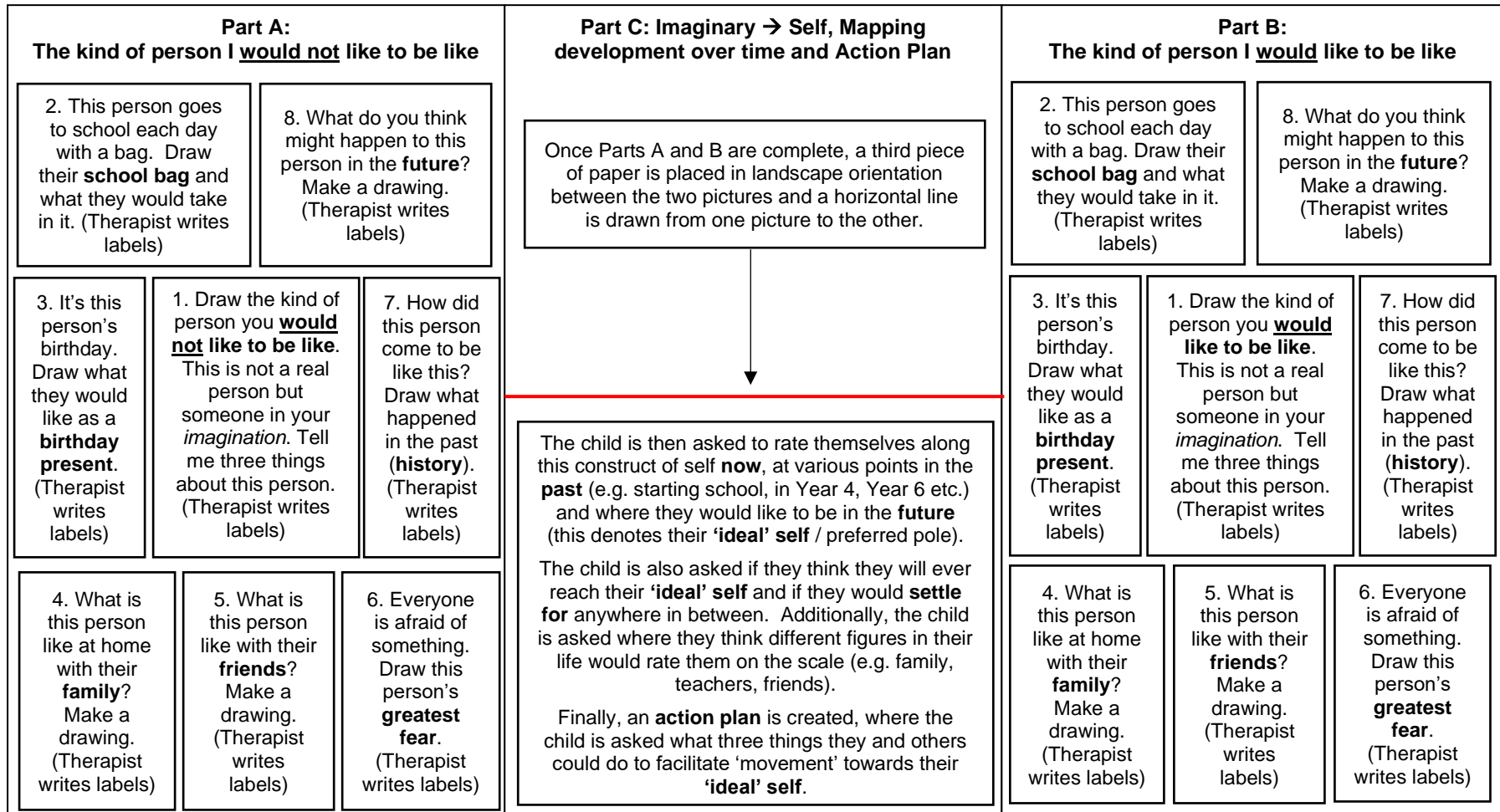
The child is first asked to consider the kind of person they *would not like to be like* (part A), followed by the kind of person they *would like to be like* (part B), completing drawings for each about eight key areas - the *person*, their *school bag*, a *birthday present*, interactions with *family* and *friends*, *greatest fear*, *history* and *future* - to create detailed pictures of the two characters. The practitioner emphasises to the

child that these are not real people but those in their *imagination*, with Moran (2001) arguing that this makes it less threatening and avoids asking direct questions about the self which the client may find difficult, until later in the process. However, she explains that the imaginary characters reflect extremes ends of the child's construct and enable later exploration of how they feel in comparison to their desired pole.

The final stage (part C) moves from the child's imagination to their real-life experience, where they are asked to rate themselves along this construct of the self *now*, in the *past* and in the *future*. This elicits their preferred pole of the construct and how closely they currently associate to this, as well as exploring their development over time and beliefs about how others perceive them. The final stage is acknowledged as the most valuable, as this elicits the child's 'ideal' self and incorporates an action plan to identify how they and others could facilitate future progress towards their preferred pole of the construct. The action plan can then be shared with key figures in the child's life and be used to inform and review subsequent intervention.

Moran (2001) recommends that the therapist labels the child's drawings throughout the process, to reduce literacy demands, but emphasises that their words must be recorded precisely to ensure their constructs are accurately represented. By learning the client's language, the therapist can then understand how the individual makes sense of their world in a respectful, curious and exploratory manner. Figure 4 (page 69) provides a visual representation and brief instructions of the technique whilst Appendix 1 shows the full crib sheet.

Figure 4: A visual representation and instructions of the three stages of the Drawing the Ideal Self technique (Moran, 2001), see Appendix 1 for full crib sheet



Moran demonstrated the efficacy of this technique with CYP displaying anxiety (2001), anger (2005) and those with an ASC and learning difficulty (2006), showing its flexibility for different types of SEND. Additionally, Howarth (2014) illustrated its success in understanding the needs and experiences of three primary-aged children - one who was reluctant to engage in lessons and aggressive towards peers, one who had poor school attendance and one who avoided verbal communication with staff and peers, with the latter appearing to reflect SM. Howarth highlighted how there was no pressure for the third child to speak, however noted that his anxiety reduced throughout the session. This enabled him to describe his drawings using single words and phrases, and identified confidence and friendships as key areas for his future development. Howarth's case studies illustrate the creative and adaptable nature of Drawing the Ideal Self (Moran, 2001) for different client groups, such as adjusting communication methods to account for speech phobia and using images instead of written headings to accommodate poor readers.

Furthermore, this tool has been adapted by several researchers to explore how CYP with ASC constructed the 'non-ideal' and 'ideal' school (Williams and Hanke, 2007), how a pupil with complex learning needs and speech and language difficulties constructed the 'non-ideal' and 'ideal' learner (Green, 2014), and how CYP attending a nurture group constructed the 'non-ideal' and 'ideal' classroom (Morgan-Rose, 2015). These studies build on Moran's work (2001; 2005; 2006) and exemplify how CYP's personal constructs and 'dichotomy' and 'choice' corollaries can be elicited creatively. However, limitations were noted including vagueness of responses and the method's reliance on a level of conceptual and language ability (Green, 2014).



#### 4.7 Research method and interview design

As discussed above, the Drawing the Ideal Self (Moran, 2001) technique has been adapted by numerous researchers to explore personal dichotomous constructs. Consequently, for the current study, I was interested in adapting it further to create a novel way of accessing the subjective experiences of CYP with SM. Whilst the original format focuses on the 'non-ideal' and 'ideal' self dichotomy, my method sought to explore the 'non-speaking' and 'speaking' behaviours in SM as, similarly, these represent contrast poles of the same construct.

Using a similar structure, the interviews followed three stages, firstly asking the CYP to consider the kind of person who *does not speak* (part A) followed by the kind of person who *does speak* (part B), before rating themselves along this construct of the self *now*, in the *past* and in the *future* to identify their preferred pole, or 'ideal' self, and 'movement' over time (part C). As advised by Moran (2001), emphasis was on 'imaginary' characters in parts A and B to avoid direct questioning about the self - which initially may have been difficult given participants' likely anxiety around an unfamiliar other - until part C. However, as Moran also suggested, these characters represented the CYP's contrast poles of their construct around speaking and acted as a vehicle to elicit their lived experiences in the final stage.

The eight areas Moran (2001) explored in parts A and B (shown in Figure 4) were adapted so that the technique was more specific to the SM population. Whilst I still incorporated the *person*, their *greatest fear*, *history* and *future*, I introduced five new areas which literature in Chapters 2 and 3 identified as particularly pertinent to SM -

*situation/activity, communication style, thoughts, feelings/physiological signs and interactions.* Exploring these nine areas enabled detailed understanding of how CYP conceptualised the ‘non-speaking’ and ‘speaking’ characters before focusing on the most important aspect - their personal experiences of SM - in part C. Table 6 shows the areas explored and questions asked in parts A and B of the interviews, Box 4 (page 73) details the instructions in part C and Figure 5 (page 74) provides a visual representation of the adapted process. Additionally, Appendix 2 shows the crib sheet used during the interviews.

*Table 6: Adaptations made to parts A and B of the Drawing the Ideal Self technique (Moran, 2001) to explore the ‘non-speaking’ and ‘speaking’ poles of SM. The five new areas are denoted with \*. See Appendix 2 for full crib sheet.*

<b>Construct</b>	<b>Questions used to investigate the construct</b>
<b>Person</b>	Think about the kind of person who <i>does not/does speak</i> . This is not a real person but someone in your <i>imagination</i> (NB: ‘character’ and ‘person’ were used interchangeably as adopted by Moran, 2012a). Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• How would you describe this person?</li> <li>• Three things about what they are like?</li> </ul>
<b>Situation/Activity *</b>	Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• Where is this person?</li> <li>• What are they doing?</li> <li>• Are they like this in other situations too?</li> </ul>
<b>Communication Style *</b>	Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• How does this person communicate?</li> </ul>
<b>Thoughts *</b>	Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• What is this person thinking?</li> </ul>
<b>Feelings/ Physiological signs *</b>	Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• How is this person feeling?</li> <li>• What physiological signs do they feel in their body?</li> </ul>
<b>Interactions *</b>	Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• Who is this person with?</li> <li>• What would they say about this person?</li> </ul>
<b>Greatest Fear</b>	Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• What is this person’s greatest fear in life?</li> </ul>

<b>History</b>	Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• How did this person come to be like this?</li> <li>• Were they always like this or did something happen?</li> </ul>
<b>Future</b>	Draw, write or use the prompt cards (Appendices 3a, 3b) to tell me: <ul style="list-style-type: none"> <li>• What will this person's future be like?</li> <li>• What do they want to happen?</li> </ul>

*Box 4: Instructions for part C of the interviews*

When responses from part A (the kind of person who *does not speak*) and part B (the kind of person who *does speak*) are complete, these are placed side by side in front of the child. Another piece of paper is then placed between parts A and B in landscape position and a horizontal line drawn across the middle of the page to join the two pictures.

Using the relevant arrows (Appendix 3c) the CYP are then asked to rate where they are on the scale (between the kind of person who *does not speak* and the kind of person who *does speak*) **NOW** and where they would like to be in the future (their '**IDEAL**' self). They are also asked where they would **SETTLE FOR** (is 'ideal' their only option?).

When exploring their **NOW** and '**IDEAL**' ratings, the CYP are asked which aspects of the 'non-speaking' and 'speaking' characters they can currently, or want to, relate to in the future (description of the *person, situation/activity, communication style, thoughts, feelings/physiological signs, interactions, greatest fear, history and future*) by pointing, drawing, writing or using prompt cards as required.

**Mapping 'movement' over time**

Using the relevant arrows (Appendix 3c) the CYP are then asked to rate where they were on the scale (between the kind of person who *does not speak* and the kind of person who *does speak*) at various points in the past (e.g. **NURSERY, YEAR 2, 4, 6** etc.).

Differences between points in time are explored (i.e. "What helped you move up from here to here?" or "What happened that made you move down from here to here?") The CYP are invited to draw or write their responses.

**Mapping different views of the child**

Using the relevant arrows (Appendix 3c) the CYP are asked where they think other people would rate them on the scale (i.e. **MUM, DAD, SIBLINGS, FRIEND, TEACHER** etc.). Differences in views are explored e.g. why would they say that? The CYP are invited to draw or write their responses.

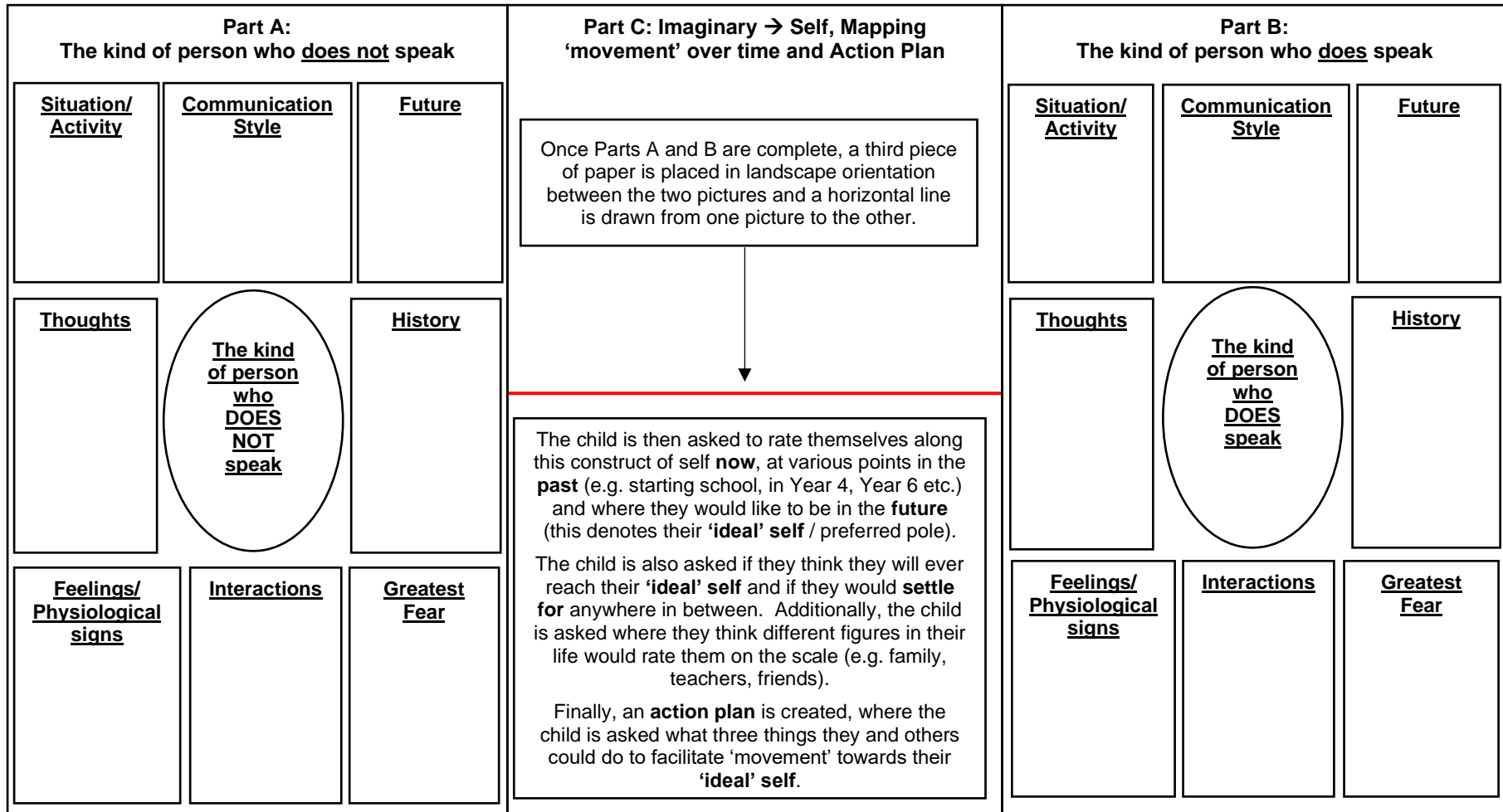
**Creating an action plan**

The CYP are then asked how they could progress towards their 'ideal' self. What three things could *they* do to help them move from where they are now to their 'ideal' rating? What three things could *others* do to help them move from where they are now to their 'ideal' rating? The CYP are invited to draw or write their responses in a table.

**Summarising responses**

The final step is for the researcher to summarise their interpretations of the CYP's responses from the three stages of the interview. This is important to check their views have been accurately understood. Once copied for data analysis purposes part A, B and C responses are sent to the CYP by post along with a personalised written summary.

Figure 5: A visual representation of the three stages of the new technique to elicit the subjective experiences of CYP with SM. Questions asked in each of the nine areas of parts A and B are shown in Table 6 (pages 72-73). See Appendix 2 for full crib sheet



Whilst Moran's (2001) method was developed assuming that CYP would be able to engage by drawing and talking, with the therapist acting as scribe, I had to make significant amendments to account for participants' likely non-speaking during the interviews. These are discussed below in respect of key ethical implications.

#### **4.8 Ethical considerations**

During the planning stages of the research, several ethical issues were identified regarding participants' anticipated non-speaking due to their SM. The Ethical Guidelines for Educational Research (BERA, 2011) and the Code of Human Research Ethics (BPS, 2014) state that researchers must adopt age and ability-appropriate methods which enable CYP to express their views. However, being mindful of participants' likely speech anxiety (Omdal and Galloway, 2008; Johnson and Wintgens, 2016), I firstly had to consider how to gain informed consent and how they could express their right to withdraw non-verbally (see Table 7, pages 77-80).

Additionally, and in line with advice from CYP in Hill's study (2019), it was important that there was no pressure to speak during the interviews and that the CYP were able to participate solely using non-verbal methods. Consequently, participants were able to respond to questions in the three stages in the way they felt most comfortable, by drawing, writing or selecting a written or visual prompt card (see Appendices 3a-3c). Whilst I was mindful that prompt cards could introduce potential researcher bias, Johnson and Wintgens (2016) advocate how, in addition to writing and drawing, sorting activities and being given choices are effective alternative forms of communication for CYP with SM. To further minimise the risk of bias, I ensured

prompt cards were informed by previous literature findings (see Appendix 4) and that participants had to indicate themselves when a prompt card was required. I only suggested use of a prompt card if participants took a long pause and seemed unsure, thus I felt support at this point was appropriate to minimise possible anxiety. There was also an 'I don't know' card (Appendix 3a) which CYP could point to if they were unsure or did not want to answer a particular question.

To increase the trustworthiness of data, Moran (2001) suggested that "the validity of the end products can be checked directly with clients by asking whether the results seem to be a reasonable representation of their views" (p.603). Consequently, I ensured I summarised my interpretations from parts A, B and C with participants both during and after the interviews ('member checking', Birt *et al.*, 2016), with all agreeing that these were accurate. Additionally, to reduce potential bias during the data analysis stage, I arranged for an external reviewer to quality assess my themes. I considered that these quality-assurance measures, along with those outlined in Table 5 (pages 60-61), were sufficient to enhance the trustworthiness of the data.

In line with the University of Birmingham's ethical procedures, I was required to complete an application for ethical review form prior to conducting the research to outline how the above issues, along with others, would be addressed (Appendix 5). Confirmation of ethical approval was received on March 23, 2018 (Appendix 6), after which I was permitted to commence recruitment and data collection. Table 7 (pages 77-80) summarises the key ethical considerations that were addressed during the research.

Table 7: Key ethical issues relating to the research and how these were addressed

Ethical issue	How this was addressed in the current study
<b>Identifying, accessing and recruiting participants</b>	The Speech and Language Therapy Service (SALTS) in my placement LA was used as the third-party recruiter to identify potential participants from their current/previous caseloads. This approach was considered to be more ethical than cold-calling due to Speech and Language Therapists' (SLTs) existing familiarity and rapport with clients, and to ensure I did not have access to any confidential personal details until CYP had agreed to participate in the research. Firstly, I sent the SLTs a recruitment letter (Appendix 7), outlining details of the research and eligibility criteria (Table 8, page 82) for potential participants. Once SLTs had identified cases who met eligibility criteria, they were asked to disseminate an information pack, developed by myself, containing a cover letter (Appendix 8), Child and Young Person Information Sheet (Appendix 9) and Parent Information Sheet (Appendix 10) which provided detailed information about the study, to the relevant families. After discussing the study with their child, parents were invited to complete an initial 'opt in' consent form and return it to myself if their child was willing to participate.
<b>Gaining voluntary informed consent</b> <i>(point 4, BPS Code of Human Research Ethics, 2014, p.15)</i>	When initial consent forms were received back, I contacted parents to introduce myself and to arrange an initial visit to meet with them and their child at a convenient time and location. At this meeting I explained the nature and purpose of the research in more detail, during which CYP and their parents had the opportunity to ask any questions or discuss any concerns they had (paper was provided so CYP could write these down if required rather than speaking). The CYP were then asked to complete a written consent form (Appendix 11a/11b) to indicate whether or not they were willing to participate. I emphasised that there was no pressure to take part and that their decision regarding whether or not to participate would be fully respected. Parents were also asked to complete a separate consent form (Appendix 12) to ensure they too gave consent for their child to take part.
<b>Deception</b> <i>(point 7, BPS Code of Human Research Ethics, 2014, p.24)</i>	The nature and purpose of the research was fully explained to the CYP and their parents both in the information sheets (Appendices 9 and 10) and verbally before the interviews. Before completing the consent forms (Appendices 11a/11b, 12), they had the opportunity to ask any questions to ensure any uncertainties were addressed and that they felt fully informed.
<b>Ensuring participants met the criteria for SM</b>	When liaising with the SLTs during the recruitment phase, they were sent a recruitment letter (Appendix 7) which listed the four essential characteristics of SM acknowledged in the DSM-V (APA, 2013). I considered it important to remind SLTs of these to ensure that cases being identified for the research met recognised criteria for an SM diagnosis. Additionally, before the interviews, I went through a background information form (Appendix 13) and eligibility checklist (Appendix 14) with parents to further clarify that their child met the DSM-V criteria. I considered this selection method and two stage checking was much more robust than relying on self-recruitment, with no professional evidence. This reduced potential sampling bias, and ensured greater credibility, transferability and authenticity of the results.
<b>Ensuring participants could express their right to withdraw</b> <i>(point 15, BERA Ethical</i>	Both the Child and Young Person Information Sheet (Appendix 9) and Parent Information Sheet (Appendix 10) explicitly stated that the CYP did not have to participate in the research and that they had the right to withdraw at any point prior to, during or after the interviews. Withdrawal time after the interviews was limited to one month as I explained that after this time data analysis would have commenced so it would be difficult to remove participants' data. Furthermore, the right to withdraw was

<p><i>Guidelines, 2011, p.6)</i></p>	<p>reiterated during the initial meeting, and also formed a question on both consent forms (see Appendices 11a/11b, 12) to ensure participants were fully aware of this option.</p> <p>Given their anticipated non-speaking during the interviews, it was important to take further steps to remind CYP about their right to withdraw and to ensure they could express their views about this non-verbally. A visual system with ‘thumbs up’, ‘thumbs down’ and ‘unsure’ signs and accompanying written prompts (Appendix 15) was made available so participants could indicate if they were happy to continue, were unsure, needed a break or wanted to stop the interviews entirely. I also closely monitored their body language, suggesting a break or reminding them of their right to withdraw if I sensed anxiety. There was also the option for CYP to write down any additional comments relating to these areas.</p> <p>After the interviews, participants were also asked to complete an evaluation form (Appendix 16a/16b) to indicate if they were still happy for their data to be used and were encouraged to tell their parents if they wanted to withdraw their data at a later stage, up to one month after the interviews. During a follow-up phone call to parents a few days after the final interview, I again checked this with parents in case the CYP had changed their mind.</p>
<p><b><i>Managing possible anxiety linked to speech and engaging with an unfamiliar professional</i></b></p>	<p>Both the Child and Young Person Information Sheet (Appendix 9) and Parent Information Sheet (Appendix 10) emphasised that there would be no pressure for participants to speak at any point during the interview and that they would be able to fully participate and express their views solely using drawing, writing and card sort activities (Appendices 3a-3c).</p> <p>When making first contact with parents, an initial meeting was offered with the aim being to start to build a rapport with the CYP prior to the data collection. I was mindful that participants may feel anxious about engaging with an unfamiliar professional so it was hoped that a preliminary visit would help them to feel more comfortable and relaxed, and address any concerns they had about the research. When I met with the CYP, I emphasised that there were no right or wrong answers as I was interested in their personal views and experiences. I adopted a friendly and respectful approach and positioned the CYP as the ‘experts’ in their lives. As it happened, the five participants were happy to start the interview during the initial visit, so I felt my calm and reassuring manner had put them at ease. CYP were able to choose where they wanted the first meeting and subsequent interviews to take place and all chose home, likely as this is an environment where individuals with SM feel more relaxed (Johnson and Wintgens, 2016). Participants were also asked if they wanted their parents/carers to be present during the interview sessions.</p> <p>Additionally, whilst qualitative research interviews are typically audio or video-recorded, I did not feel this was appropriate due to the CYP’s possible anxiety relating to their SM, or consequent anxiety that such an added observation tool may provoke. However, responses were photographed (see Appendices 17a-21c) and data analysis was conducted based on the information participants shared via writing, drawings and use of prompt cards.</p>
<p><b><i>Non-speaking</i></b></p>	<p>As discussed above, there was no pressure to speak during the interviews and instead participants were able to express their views flexibly, either by drawing, writing their answers down or selecting suitable prompt cards (Appendices 3a-3c). Whilst these options were offered, participants were able to use other methods if they preferred – for example P2 said she felt comfortable to</p>



	<p>speak whilst P3 communicated through two cuddly toys, getting them to hold his pencil and write, choose the relevant prompt card for him and nodding/shaking their head in agreement/disagreement to my questions. I felt this flexible approach enabled participants to feel more relaxed and in control of the interviews.</p>
<p><b>Risk of harm - raising emotive issues with participants</b> (point 3, BPS Code of Human Research Ethics, 2014, p.13)</p>	<p>As I was aware that the interviews had the potential to evoke emotional responses relating to participants' SM, I adopted a sensitive, empathic and attuned approach, in line with the therapeutic and counselling skills training received as part of the doctoral course. I was also vigilant and sensitive to any apparent changes in body language or mood, and offered a break, parental comfort, continuing with the session at another time, or withdrawing from the research entirely if the participant appeared to be distressed. Furthermore, the CYP and their parents were provided with the contact details of both myself and my research supervisor, so they could ask any questions or seek further information prior to, during or after their participation. Finally, a few days after the final interview session, I contacted each parent to check on their child's wellbeing. If distress was evident, I planned to inform that, with consent from themselves and their child, I could liaise with their SLT or a member of staff in school to encourage them to monitor the situation and offer further support for their child where necessary, however this was not required for any of the participants. I also signposted parents/participants to the SMIRA website (<a href="http://www.selectivemutism.org.uk/">http://www.selectivemutism.org.uk/</a>) which provides information, resources and support for parents, people with Selective Mutism and professionals, and the SMIRA Facebook page (<a href="https://www.facebook.com/Smira-Selective-Mutism-Information-and-Research-Association-120663428027161/">https://www.facebook.com/Smira-Selective-Mutism-Information-and-Research-Association-120663428027161/</a>), an online forum and community where parents, children and young people can communicate with other people with Selective Mutism and gain additional support and advice.</p>
<p><b>Confidentiality</b> (point 5, BPS Code of Human Research Ethics, 2014, p.22)</p>	<p>To ensure confidentiality, I gave each participant a pseudonym (P1, P2, P3, P4, P5) and used these, rather than their real names, during the data collection, analysis and write-up stages to ensure they could not be personally identified in any way. Additionally, I ensured participant data was stored securely and was accessible only to myself and my research supervisor throughout the project. These considerations were fully explained to CYP and parents, and also formed the final question on the consent forms (Appendices 11a/11b, 12) to ensure they understood how their identities would be protected.</p> <p>Additionally, potential limits to confidentiality regarding safeguarding were acknowledged and discussed verbally with the CYP and their parents. I explained that if anything was shared which related to harm or potential harm to participants or others, I had a duty to adhere to the LA's safeguarding policy and inform the designated safeguarding lead, after informing the CYP about this. Prior to the research I attended a Level 1 safeguarding course so was aware of the key areas of concern and the relevant steps to take should a disclosure have been made.</p>
<p><b>Risks to the researcher</b></p>	<p>As interviews were conducted at participants' homes, this involved a level of risk to myself due to accessing an unknown environment and unfamiliar individuals. To minimise this risk, I ensured that at least one parent or carer was within the home for the duration of the interviews. I also asked SLTs to inform me of any known safety issues during the recruitment stage. Whilst the CYP could choose whether they wanted their parent/carers to be present or absent during the interviews, I requested that they remained in the building if not physically present in the room, in case any concerns arose. I also followed the LA's protocol for home visits which involved ringing the administrator before entering the home to provide details of the address and the expected duration, and a further phone call when the visit was complete. If an emergency was encountered, I knew to follow the relevant</p>

	<p>procedure as outlined in the LA 'Lone Working Policy' (Appendix 22). Emotional and personal risk whilst conducting the research was minimal, however, to minimise this risk, I ensured that I was self-aware and used supervision to discuss any concerns regarding my own emotional responses or wellbeing with my research supervisor.</p>
<p><b>Possible researcher bias</b></p>	<p>As I adopted an interpretivist epistemology, I was aware that I had played an active role in the research and data analysis, and may have been influenced by my prior knowledge and experience of SM. To minimise this, I made my positionality explicit and adopted a neutral and reflexive perspective, clarifying any ambiguities with participants and valuing them as the 'experts' in their lives. At the end of each interview I summarised the information the CYP had shared with me to check I interpreted their views correctly. Additionally, question 11 on the CYP evaluation form (Appendix 16a/16b) gave participants the opportunity to share anything else that had not been covered in the interviews. These quality-assurance measures increased credibility and confirmability.</p> <p>Furthermore, as I was aware that prompt cards could introduce potential researcher bias, I ensured these were informed by previous literature findings rather than my own assumptions (Appendix 4) and that the CYP had to indicate when these were needed by selecting the 'prompt card' sign (Appendix 3a). The only time I suggested use of a prompt card was if participants took a long pause and seemed unsure, thus I felt support at this point was appropriate to minimise their possible anxiety.</p> <p>To reduce potential researcher bias during the data analysis stage, I asked a TEP colleague to review my data and identified themes. The themes and corresponding data sets were presented separately, and my colleague was then asked to identify the data sets she felt corresponded with each theme (see Appendix 23 for notes from session). This external review was an important stage of the data analysis and resulted in several themes being amended accordingly, thus enhanced the trustworthiness of how the data was represented.</p> <p>Finally, I kept a reflective diary and engaged in regular supervision throughout the research process to capture my thoughts and address any issues which could introduce potential researcher bias.</p>
<p><b>Feedback to participants and stakeholders</b> (point 8, BPS Code of Human Research Ethics, 2014, p.26)</p>	<p>After each interview, participants were given a certificate (Appendix 24) to thank them for providing their views and experiences. Additionally, the CYP were sent their interview data (Appendices 17a-21c) by post once they had been copied by the researcher for data analysis purposes, along with a written summary about my interpretations of their accounts (see Appendix 25 for example). This explained how and with whom their information would be shared and how their experiences would help EPs and other professionals working with CYP with SM.</p> <p>I also presented an overview of my research, key findings and implications for practice to the SALTS in April 2019 (see Appendix 26 for slides) and my TEP colleagues in June 2019. A presentation is also planned for the Educational Psychology Service during the Autumn Term 2019.</p>

#### 4.9 Pilot study

As I had developed a novel technique to explore the experiences of CYP with SM, I conducted a pilot study with the Year 6 pupil I had previously worked with (discussed in Chapter 1). This was to ensure my explanations and consent and evaluation forms were accessible, and to trial the three stages of the interview. This also assessed how suitable the prompt cards (Appendix 3a) and visual system (Appendix 15) were in enabling CYP to express their views and right to withdraw non-verbally.

This was an important stage of the research design and highlighted that each interview would likely take two to three hours in total, which I had considerably underestimated, as well as informing some minor changes that were necessary prior to the subsequent interviews. These included developing visual prompt cards in addition to written prompt cards for three of the sections in parts A and B (descriptions of the *person, situation/activity, feelings*) (Appendix 3b), and replacing written text on the consent and evaluation forms with 'thumbs up', 'thumbs down' and 'unsure' images to account for younger participants or poorer readers (Appendices 11b and 16b). Furthermore, I developed an evaluation form for parents (Appendix 27), as I considered their views would also be valuable feedback.

Whilst I hoped to recruit five to six participants for the research, this proved difficult and, consequently, I decided to include data from the pilot study (P1) in the overall research findings. As no significant changes were made to the technique after this interview, I felt this judgment was justifiable. Additionally, whilst I was aware that I had an existing rapport and professional relationship with this participant, which could

have introduced researcher bias, I ensured my prior knowledge did not influence my interpretations by focusing solely on the information P1 shared during his interviews.

#### 4.10 Recruitment

The SALTS acted as the third-party recruiter as they were the key professional group for SM in the LA at the time of the research. Subsequently, following ethical approval, SLTs were asked to identify potential participants from their caseloads based on the inclusion and exclusion criteria shown in Table 8.

*Table 8: Inclusion and exclusion criteria for involvement in the research study*

Inclusion criteria:	Exclusion criteria
✓ CYP known to the SALTS for meeting the DSM-V diagnostic criteria for SM (see Box 1, page 8) and aware that they find it difficult to speak	☒ CYP not meeting the DSM-V diagnostic criteria for SM (see Box 1, page 8)
✓ CYP attending a mainstream setting	☒ CYP attending a specialist setting - <i>as literature suggested that CYP with SM have 'average' abilities (Nowakowski et al., 2009), it was felt that those in a specialist setting would have significant learning needs and therefore be unable to access the interview technique. Additionally, mutism in these cases could represent biological factors rather than psychologically based SM</i>
✓ CYP in Key Stage 2 and above (age 7+) able to write, draw or use written/visual prompt cards to express their views	☒ Children in Key Stage 1 or below (under 7 years) – <i>it was felt that this age may find the concept of 'imaginary' characters difficult to understand</i>
✓ CYP at or above the 'Uses non-verbal and written communication' stage of confident talking (Johnson and Wintgens, 2016) - see Table 2, pages 26-27	☒ CYP at the 'Absent' or 'Frozen' stage of confident talking (Johnson and Wintgens, 2016) - see Table 2, pages 26-27 - and unable to communicate non-verbally

The SLTs were then asked to distribute a cover letter (Appendix 8), Child and Young Person Information Sheet (Appendix 9) and Parent Information Sheet (Appendix 10) developed by myself to potential participants, which included details of the study and an initial 'opt in' consent form to return to myself if they were willing to be contacted. When responses were received, I contacted parents to discuss the research in more detail and to arrange a convenient time and location for the interview sessions. In all cases an initial meeting was offered, to meet participants and attempt to build rapport before the research, however this was only requested by two parents who were unsure whether their children would participate (see section 4.11). I reiterated that participation was voluntary and that the CYP had the right to withdraw at any time.

#### **4.11 Responses received and excluded participants**

Of 36 known cases of SM in the LA, information packs were distributed to 16 CYP and their families (44%), who met the inclusion criteria, over a two-month period. Six initial responses (17%) were received, however two children (E1 and E2) were excluded from the research prior to the interview stage. During my initial visits, both presented at the 'frozen' stage of communication (Johnson and Wintgens, 2016, see Table 2, pages 26-27) and appeared too anxious to communicate with me non-verbally, which meant the technique would have been inaccessible for them.

Whilst E1 was reluctant to complete the consent form in front of me, in respect of her likely anxiety around an unfamiliar adult, I left the room so she could do this privately. Whilst she indicated that she did want to participate, when I went back at a later date to commence the interview she presented similarly, hiding behind her mother,

avoiding eye contact and remaining frozen when asked to draw the *kind of person who does not speak*. After several minutes of adapting the task by offering different prompt cards, it became apparent that she was too anxious to participate, so I suggested that we cancel the interview entirely to prevent any further undue distress. When I contacted the mother a few days later to check on E1's wellbeing, she explained that her daughter still wanted to participate as she liked drawing but struggled to communicate with new people. This feedback reflected the role of social anxiety and expressive speech phobia documented in the literature (Kristensen, 2002; Omdal, 2007; Omdal and Galloway, 2008; Johnson and Wintgens, 2016). Consequently, I wrote to E1 and gave her the opportunity to draw or write about the 'non-speaking' and 'speaking' characters in her own time if she wished (see Appendix 28). Whilst I was aware that this data collection method was not standardised as I had adapted the technique substantially, and would also be prone to bias, I felt it was important that E1 had the chance to share her views as requested. A stamped-addressed envelope was enclosed for ease of return, however I did not receive a response, therefore E1 was not included in the research.

Similarly, when meeting E2 and her father, I sensed a high level of anxiety when introducing myself and giving an overview of the research. During my explanation she avoided eye contact, kept her head down and was unable to communicate non-verbally, either by nodding/shaking her head or writing down her responses. When I then presented her with the consent form she started to cry, which further indicated likely anxiety. At this stage, I deemed it inappropriate and insensitive to continue, so it was agreed that we would end the session and E2 would not participate in the

research. I contacted her father a few days later to check on her wellbeing and to thank them for attending the meeting. Afterwards I reflected that, if time had allowed, several rapport building sessions may have been beneficial for E2 , as previous research emphasises the importance of support, sensitivity and understanding from a trusted adult (Roe, 2011; Manassis, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Hill, 2019). Additionally, I questioned whether the meeting location had been suitable (her father requested it was held in a free room at the SLT clinic, rather than at home), as Roe (2011) highlighted how communicating outside of the home presents the greatest difficulties for those with SM.

#### **4.12 Participants**

After E1 and E2 were eliminated, this left five CYP aged 8-14 who participated in the study (including P1 from the pilot study), representing 14% of the known SM cases in the LA. The sample consisted of three males and two females and was purposive and opportunistic, based on those who returned the consent forms and were willing to participate. When making initial contact with the parents, I used an eligibility checklist (Appendix 14) to confirm that their child met the DSM-V criteria of SM (APA, 2013) and were subsequently able to participate.

A pen portrait of each participant is provided in Appendix 29 whilst Table 9 (page 86) illustrates participant characteristics and further details of the interviews. Four participants (P1, P3, P4, P5) communicated with me non-verbally, whilst one (P2) was happy to talk, in addition to using drawings, writing and prompt cards to share her views.

Table 9: Participant characteristics and details of each interview

Participants (P) and excluded participants (E)	Gender	Age	Ethnicity	Interview location	Sessions	Parent present?	Stage of Confident Talking	Communication style during interviews
P1	Male	11	White British	Home	3	Yes	Stage 3 – Uses non-verbal communication and written communication	Drawing, writing, pointing, nodding/shaking head, use of prompt cards
P2	Female	14	White British	Home	3	Yes	Stage 7/8 – Communicates with sentences/conversation	Talking, drawing, writing, use of prompt cards
P3	Male	8	White British	Home	4	Yes	Stage 3 - Uses non-verbal communication and written communication	Communicated through toy goat via drawing, writing, pointing, nodding/shaking head, use of prompt cards
P4	Male	10	White British	Home	3	No	Stage 3 – Uses non-verbal communication and written communication	Drawing, writing, pointing, nodding/shaking head, use of prompt cards
P5	Female	9	White British	Home	3	Yes	Stage 3 – Uses non-verbal communication and written communication	Drawing, writing, nodding/shaking head, use of prompt cards
E1 *	Female	7	White British	Home	2	Yes	Stage 1 - Frozen	Hid behind parent and would not participate non-verbally during initial meeting and first visit so it was agreed that the interview would be cancelled. She was given the opportunity to share her views by letter (Appendix 21) but no response was received
E2 *	Female	9	White British	SLT Clinic	1	Yes	Stage 1 - Frozen	Consent not given at initial meeting so interview did not take place

\* These two children did not participate in the research as they presented at the 'frozen' stage of communication (see section 4.11). As they were unable to communicate with me non-verbally, it was felt that they would be unable to access the technique.



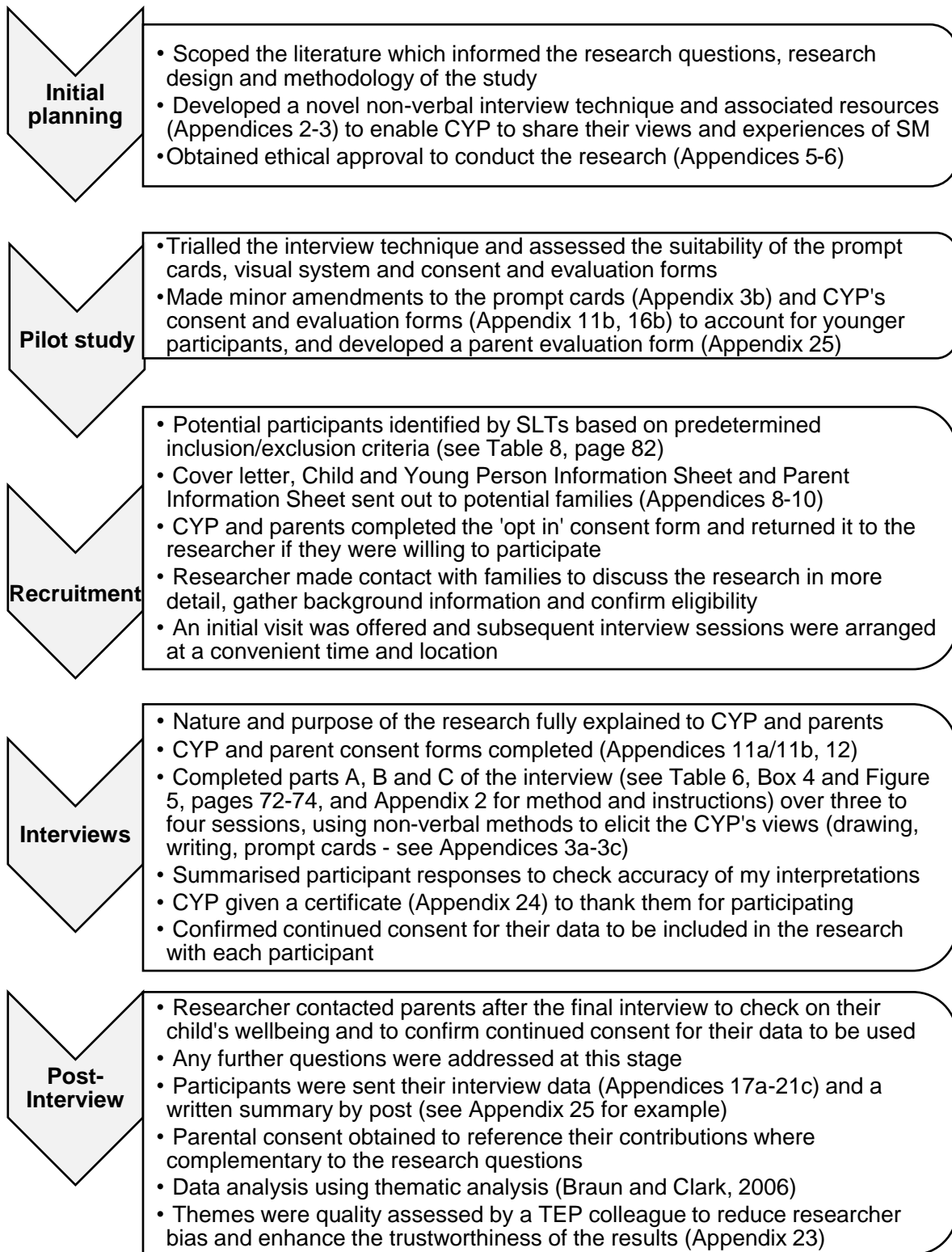
#### **4.13 Parental role in the interviews**

Participants were asked if they wanted a parent to be present during the interviews. Four (P1, P2, P3, P5) selected this option, whilst one (P4) did not, which was respected by his mother who left the room for the duration. The CYP agreed that their parents could contribute to the interviews if they wished, and consequently some offered their views. Whilst I emphasised that the research focus was on the CYP's lived experiences, following the interviews verbal informed consent was gained from the parents to reference their contributions where complementary to the research questions.

#### **4.14 Procedure**

Figure 6 (page 88) outlines the research procedure from the initial planning to post-interview stages.

Figure 6: An overview of the research procedure



#### **4.15 Data analysis**

After data collection, thematic analysis (Braun and Clark, 2006) was used to interpret the “data corpus” (p.5) and identify key themes relating to CYP’s experiences of SM. Braun and Clark note how this is a flexible, accessible and useful tool which lends itself well to qualitative methodology adopting an interpretivist epistemology as it provides a “rich and detailed, yet complex account of data” (p.5).

Braun and Clark (2006) propose six stages of thematic analysis, whereby the researcher immerses themselves in the data and actively searches for themes which describe individual “data items” (p.6) and illuminate their research questions. Whilst this method is most commonly used to analyse data elicited from verbal interviews, my analysis was based on the information participants shared with me non-verbally using drawings, writing and prompt cards. However, such adaptations are supported by Braun and Clarke and, ultimately, mirrored the way verbal interview responses are analysed once they have been transcribed into written format.

As the areas explored in the three stages of the interviews (parts A, B and C) were predetermined, the analysis phase initially took a deductive theoretically-driven approach. Whilst I am aware that this limited participants’ freedom to communicate freely about their SM, I felt a structured approach was necessary to account for their likely anxiety and difficulty answering open-ended questions non-verbally. However, themes relating to each research question were solely derived from the CYP’s responses, therefore this stage reflected a more inductive and data-driven approach.

After familiarising myself with the data, I generated initial codes to capture all responses given in parts A, B and C and transferred these into a coding table (Appendix 30), followed by creating a thematic map for each (see Appendices 31 and 32 for parts A and B and Figure 8 (page 94) for part C).

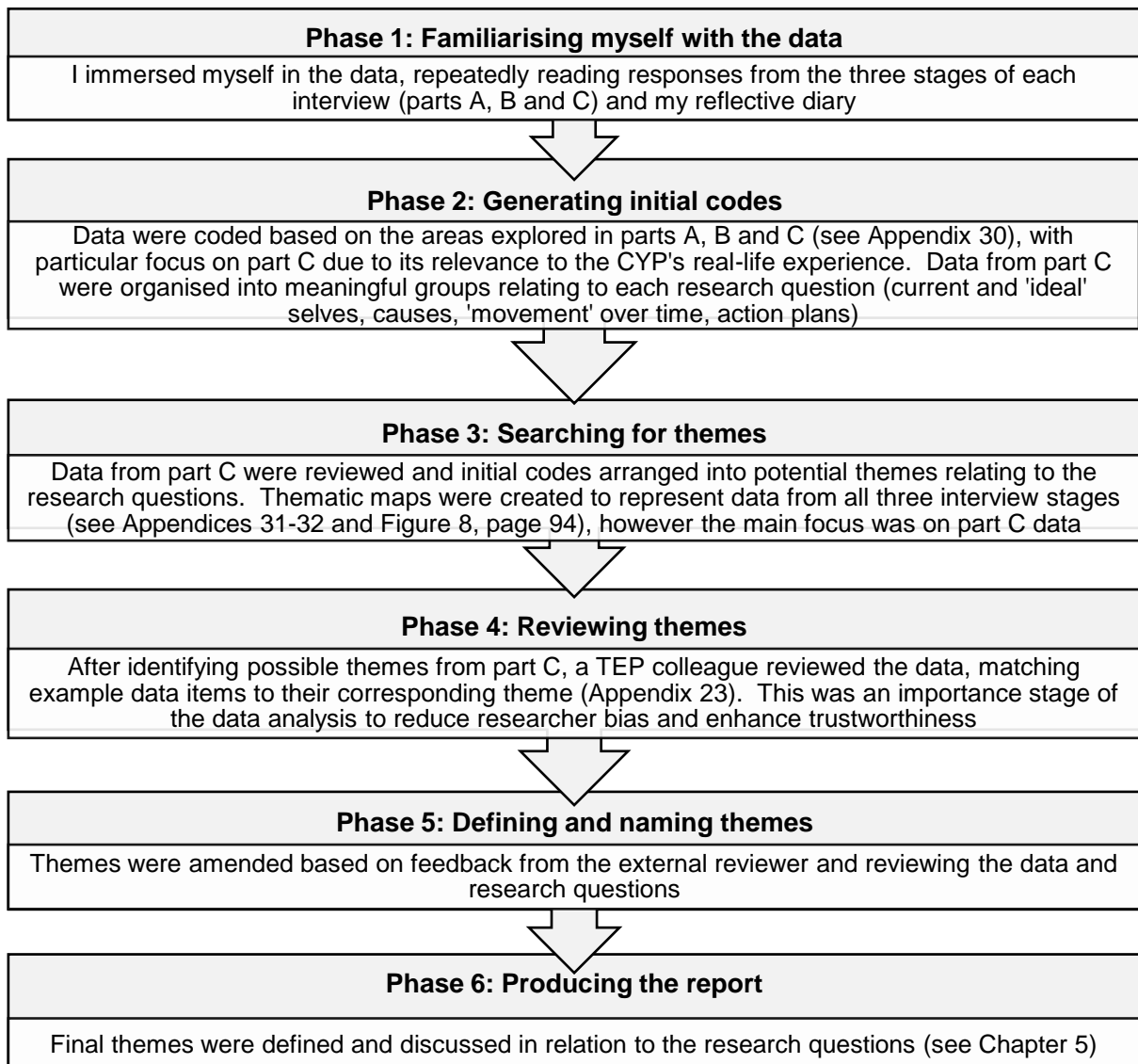
Whilst numerous themes emerged from parts A and B of the interviews - providing rich data about how the 'non-speaking' and 'speaking' person are conceptualised - these did not form the focus of the subsequent analysis. This is because, as in Moran's (2001) original format, these stages were based on 'imaginary' characters and, whilst they elaborated the individual's contrast poles regarding speaking, I judged it inappropriate to project 'fictional' responses onto participants' own experiences due to accuracy and reliability issues. Additionally, parts A and B acted as a vehicle to elicit CYP's real-life experiences in the final stage so, consequently, my interest was on "data sets" (Braun and Clark, 2006, p.5) from part C (see Appendices 17c, 18c, 19c, 20c, 21c) due to their higher trustworthiness and applicability to the self. However, data from parts A and B were referred to during the write-up stage where complementary to the research questions.

Data from part C was arranged based on the focus areas of the research questions (current and 'ideal' selves, causes, 'movement' over time, action plans), and possible themes for each were explored which would capture all data items. This was done by repeatedly reviewing the interview responses by hand and transferring and grouping individual data sets into the table shown in Appendix 30. A total of ten themes were identified which enabled the research questions to be answered.

#### **4.15.1 Increasing trustworthiness - external review of the data**

Following analysis, an external review of the data was conducted by a TEP colleague who was asked to match example data items to the themes identified and offer feedback on their suitability (see Appendix 23 for notes from session). This was an important stage of the analysis process and generated valuable discussion about the wording of some of the themes. Consequently, I made several slight amendments to reduce researcher bias and enhance the trustworthiness of the data. Once the final themes were defined, they were discussed in relation to each research question (see Chapter 5). Figure 7 (page 92) summarises the thematic analysis process.

Figure 7: Process of thematic analysis as recommended by Braun and Clark (2006)



#### 4.16 Chapter summary

This chapter has detailed the research methodology, including the case study design, rationale and process of the interviews, key ethical considerations, participant information and the method of thematic analysis. Chapter 5 discusses the findings of the study in relation to the research questions and existing SM literature.

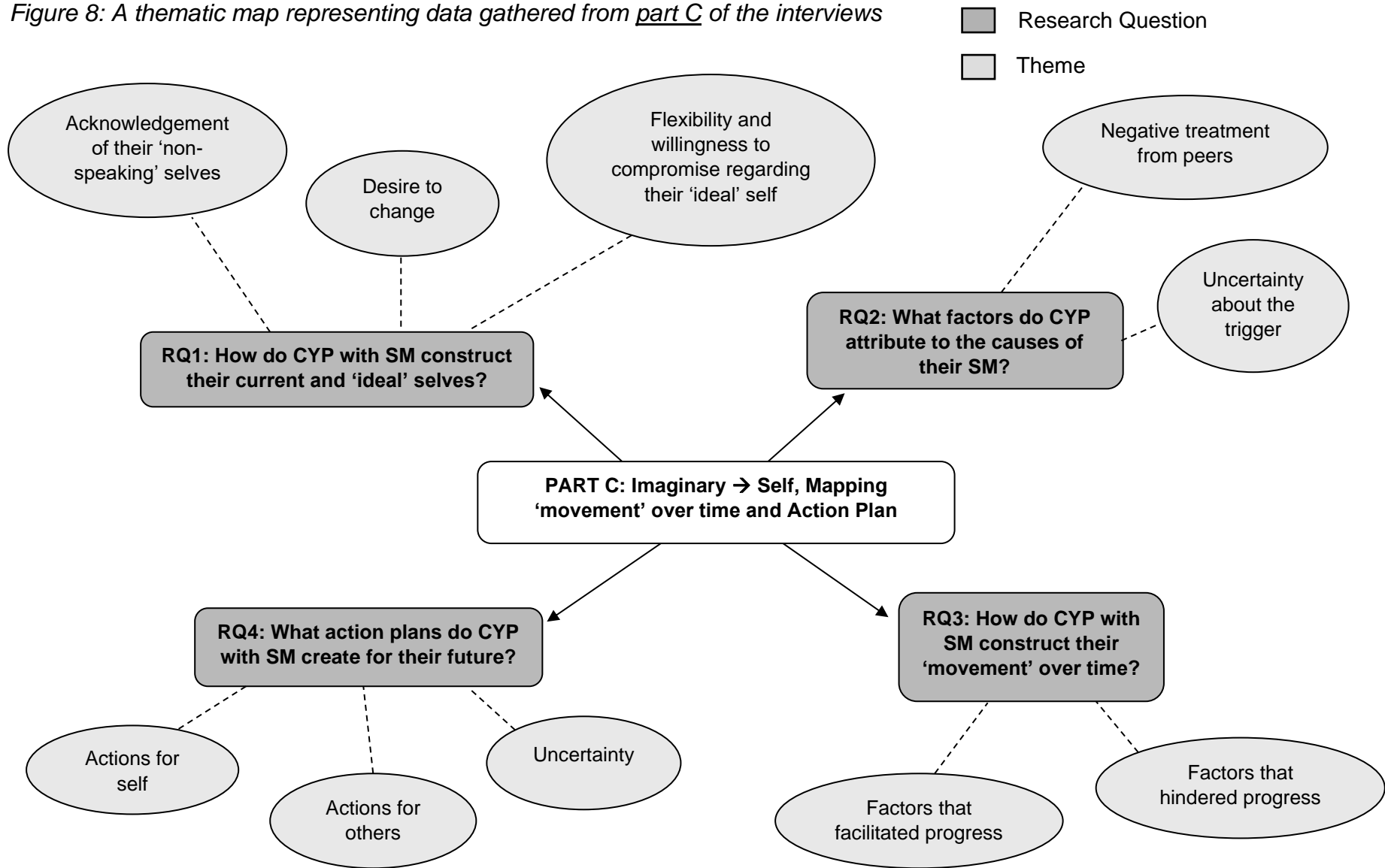
## CHAPTER 5: RESULTS AND DISCUSSION

### 5.1 Chapter overview

This chapter presents the research findings from data elicited in part C of the interviews and discusses these in relation to the existing pupil voice and wider literature about SM. As discussed in section 4.15, part C data formed the focus of analysis and discussion due to its higher trustworthiness and applicability to the self. However, I am mindful that data from parts A and B elicited participants' contrast poles regarding speaking, which would have been interesting to explore in further depth if the word count allowed.

Figure 8 (page 94) shows the thematic map created to capture part C responses. The research questions are then discussed in turn, in relation to their key themes.

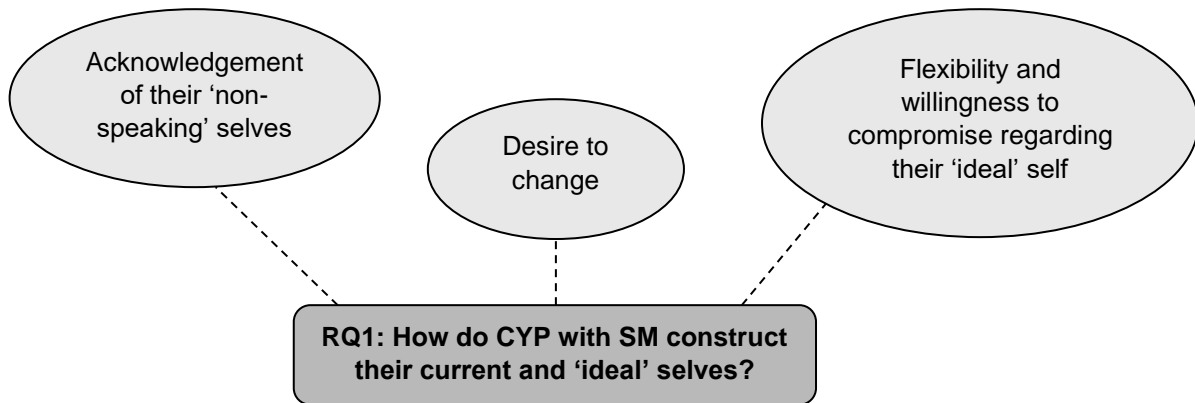
Figure 8: A thematic map representing data gathered from part C of the interviews





## 5.2 RQ1: How do CYP with SM construct their current and 'ideal' selves?

Three themes were identified relating to RQ1 - CYP's acknowledgement of their 'non-speaking' selves, their desire to change, and flexibility and willingness to compromise regarding their 'ideal self' - as shown and discussed below.



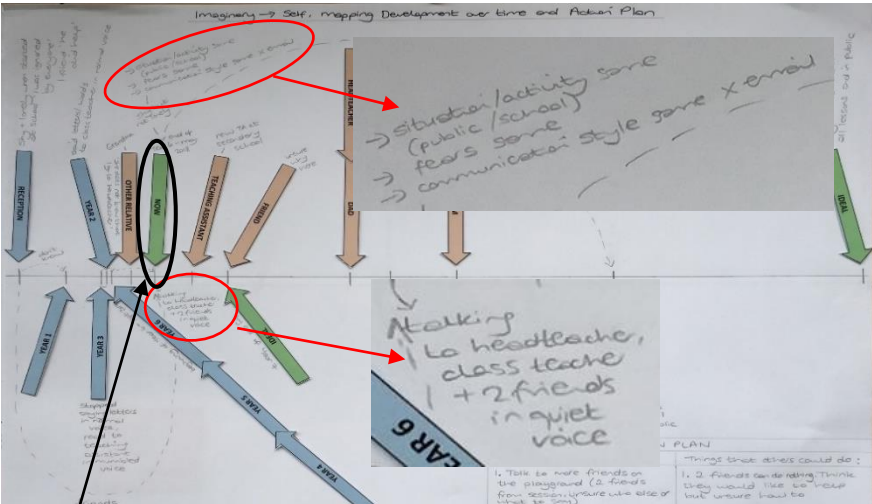
### 5.2.1 Theme 1: Acknowledgement of their 'non-speaking' selves

Four of the five participants (P1, P2, P4, P5) rated themselves as currently more like the 'non-speaking' person than the 'speaking' person, showing acknowledgement and willingness to disclose their SM in line with the previous lived experience research in this area (Omdal, 2007; Omdal and Galloway, 2007; Roe, 2011; Manassis, 2015; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Patterson, 2016; Hill, 2019; Vogel *et al.*, 2019). However, how the CYP perceived the severity and impact of their speaking habits varied which was similar in Roe (2011) and Hill's (2019) studies.

For example, as shown in Box 5 (page 96), P1 identified that he was very similar to his 'non-speaking' character as he did not speak in public, communicated predominately using non-verbal methods in school - e.g. pointing, nodding and

shaking his head, and writing his answers down - and only spoke quietly to two staff members and two friends during sliding-in sessions. His close association to the 'non-speaking' person therefore suggested that he felt greatly affected by SM at present.

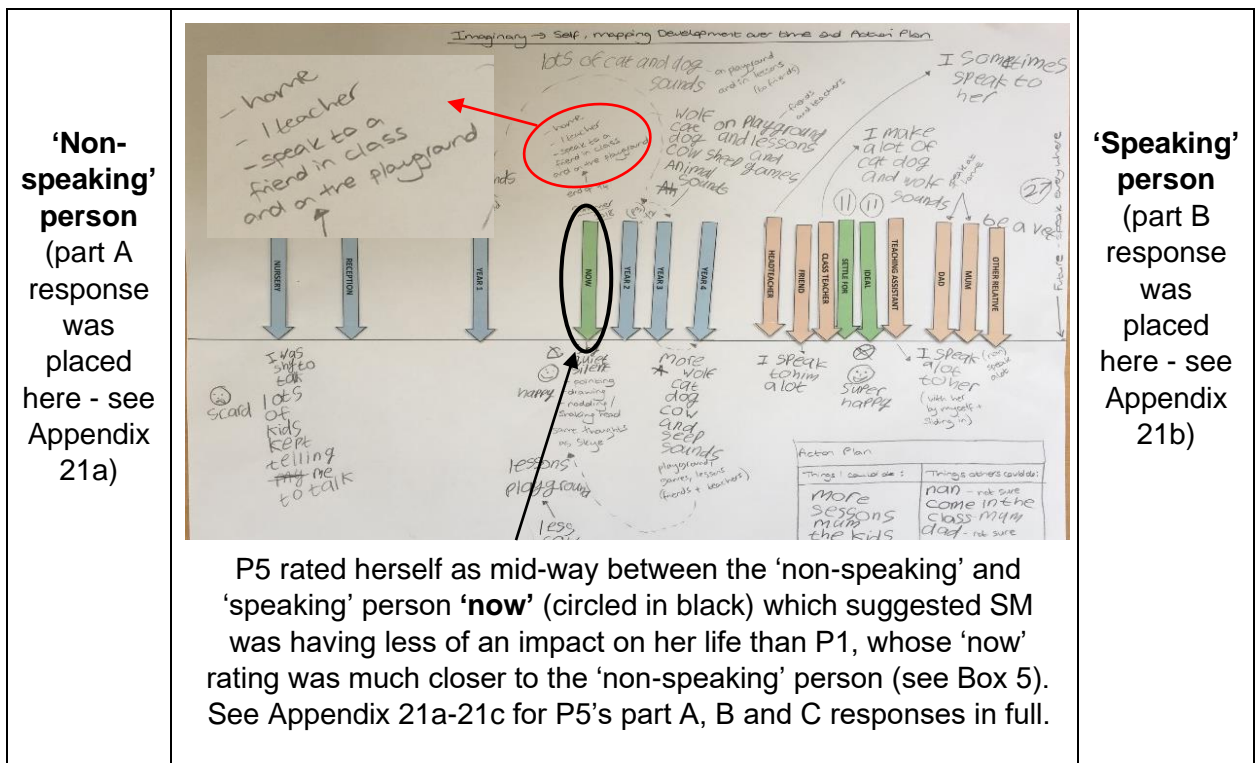
*Box 5: P1's part C responses highlighting reasons for his close association with the 'non-speaking' person*

<p><b>'Non-speaking' person</b> (part A response was placed here - see Appendix 17a)</p>	 <p>P1 identified that he was similar to the 'non-speaking' person <b>now</b> (circled in black) as the context of his speaking patterns, communication style and fears were the same as his character's in part A (circled in red) - see Appendix 17a-17c for P1's part A, B and C responses in full.</p>	<p><b>'Speaking' person</b> (part B response was placed here - see Appendix 17b)</p>
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Conversely, as shown in Box 6 (page 97), P5 rated herself as just less than half-way between the 'non-speaking' and 'speaking' characters as she spoke at home, as well as to one teacher and one friend in the classroom and playground, suggesting that she did not feel as significantly impacted by SM as P1.

P1 and P5's part C responses (Box 5, 6) are shown for illustrative purposes, whilst all part C data sets are represented in Appendices 17c, 18c, 19c, 20c and 21c.

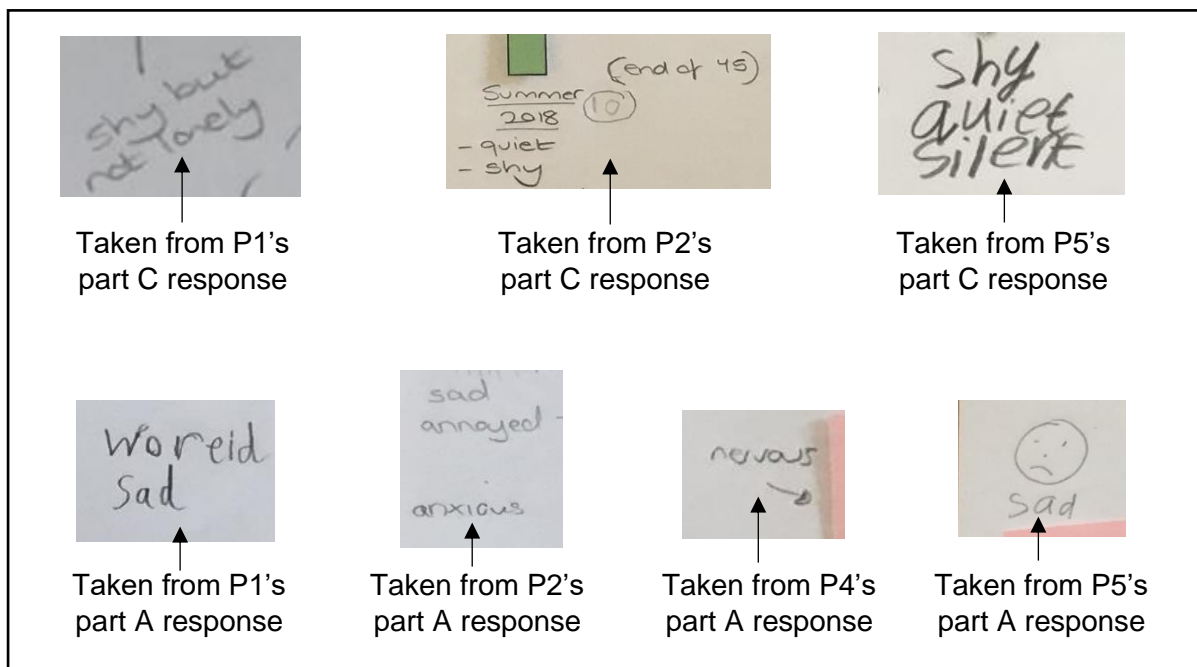
Box 6: P5's part C responses highlighting her 'now' rating midway between the 'non-speaking' and 'speaking' person



P5 rated herself as mid-way between the 'non-speaking' and 'speaking' person 'now' (circled in black) which suggested SM was having less of an impact on her life than P1, whose 'now' rating was much closer to the 'non-speaking' person (see Box 5). See Appendix 21a-21c for P5's part A, B and C responses in full.

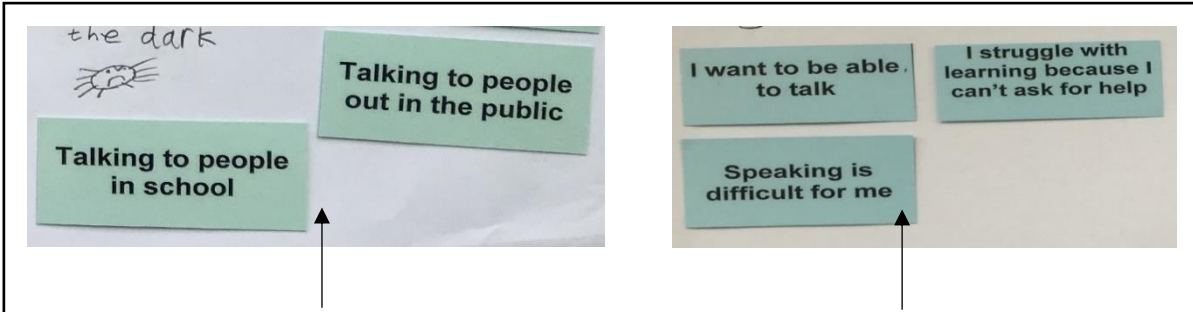
When describing their current selves, participants used adjectives such as 'shy' (P1, P4, P5), 'quiet' (P4, P5) and 'silent' (P5) which connect with assumed introverted personality traits within the general SM literature (Salfield, 1950; Wright, 1968; Black and Uhde, 1995; Cline and Baldwin, 2004; Johnson and Wintgens, 2016), as well as self-reports from participants in several of the pupil voice studies (Omdal, 2007; Roe, 2011; Walker and Tobbell, 2015; Patterson, 2016). Additionally, when describing the 'non-speaking' person in part A, feelings such as 'sad' (P1, P2, P5), 'worried' (P1), 'nervous' (P4) 'anxious' (P2) and 'annoyed' (P2) were used which were also traits identified in Roe's research (2011), showing how some CYP with SM perceive themselves negatively. Box 7 (page 98) shows where these traits were extracted from the interview data.

*Box 7: Introverted/negative traits used by participants to describe themselves in part C and the 'non-speaking' person in part A (see Appendices 17a-21c for full responses)*



However, attributes such as 'not lonely' (P1) and 'happy' (P3, P5) were also identified which mirrors CYP's more positive self-perceptions as noted by Roe (2011) and Johnson and Wintgens' (2016) claim that social anxiety may not always be present in SM, as CYP may be eager to engage in social interactions when speech is not required. This said, anxiety did appear to be a common theme amongst several participants such as P1 reporting fears of talking to people in school and in public, and P5 acknowledging that speaking was difficult for her, that she struggles with learning because she cannot ask for help and felt scared when her peers put pressure on her to speak, as shown in Box 8 (page 99).

*Box 8: Responses which suggested speech anxiety*



During part C, P1 identified that he had the same fears as his 'non-speaking' character. These are shown above, demonstrating a possible link between speaking and anxiety

During part C, P5 identified that she had the same thoughts as her 'non-speaking' character. These are shown above, again indicating a possible link between speaking and anxiety

These anxiety-based cognitions support Vogel *et al's* (2019) findings regarding the prevalence of voice-related fears and offer additional evidence that SM may be a specific phobia of expressive speech (Omdal and Galloway, 2008; Johnson and Wintgens, 2016) rather than social phobia. Furthermore, such anxieties highlight the impact of SM outside of the family home, as also reported by others with SM (Omdal, 2007; Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Hill, 2019). The occurrence of anxiety is also emphasised in the DSM-V criteria (APA, 2013) and widely accepted in the general SM literature (Kristensen, 2000; Cunningham, McHolm and Boyle, 2006; Steinhausen *et al.*, 2006).

Interestingly, P3 was the only participant to rate himself as very much like the 'speaking' person already (see Appendix 19c) and, when exploring this further, he identified that this was because he speaks at home to his family, to teachers and friends in school, and in public. This implied he felt he may have 'recovered' from SM (able to communicate freely in all situations) like the twins in Albrigtsen, Eskeland

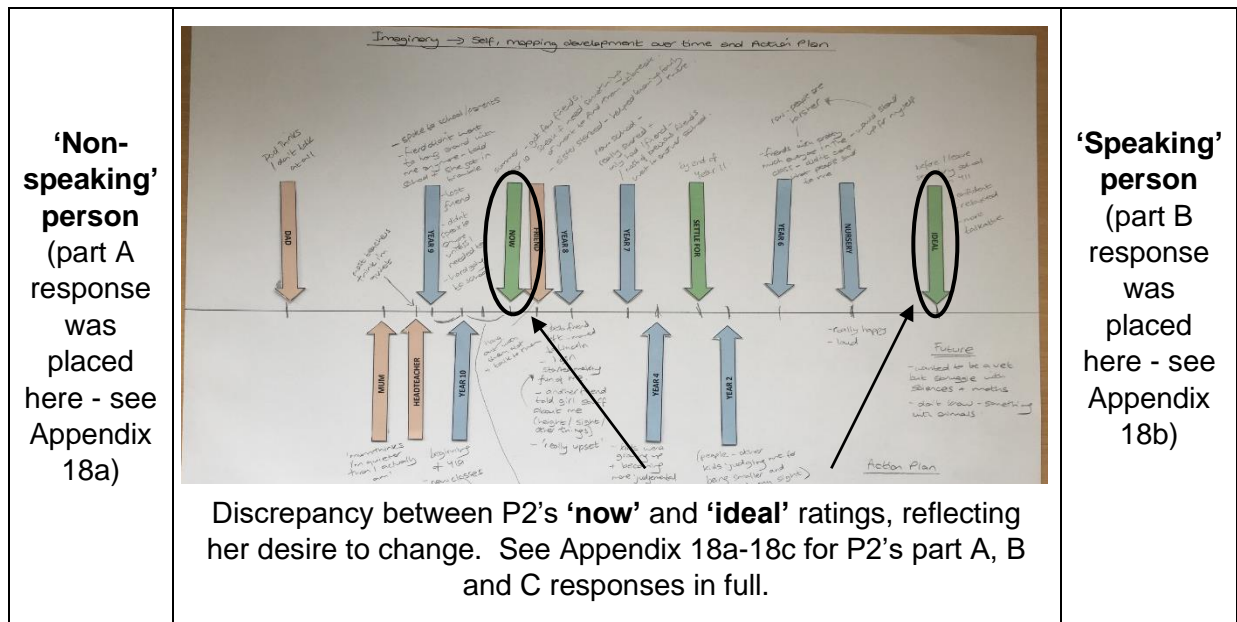
and Mæhle's (2016) research, however this was only partially supported by P3's mother. Whilst she shared that he did communicate normally at home and had made some progress with speaking in school, she explained that this was not yet done freely. It may therefore be that P3 based his current rating on the progress he had made or could reflect a perception that SM had minimal impact on his life, despite his mother's 'outsider' views. This emphasises the importance of consulting directly with those affected by SM to gain insight into how they construct their experiences.

### **5.2.2 Theme 2: Desire to change**

Another key theme was participants' desire to change, with all five identifying that their 'ideal' self was closer to the 'speaking' person than their current rating. Four (P1, P2, P4, P5) placed the 'ideal' arrow significantly higher than their 'now' ratings, indicating their hopes to make considerable progress in the future. An example of this is shown in Box 9 (page 101), whilst all responses are represented in Appendices 17c, 18c, 19c, 20c and 21c.

Additionally, whilst P3 connected closely to the 'speaking' person already, he rated his 'ideal' self as even closer to this, which also illustrated some desire to change.

Box 9: P2's responses in part C illustrating her desire to change



When exploring how their lives would be different if they made progress, CYP referred to being able to talk more in school (P1, P2, P4) and in public (P1, P4), thus conceptualising a future where SM had less impact on their life. This theme connected closely with Omdal (2007) and Patterson's (2016) findings, with participants in the first study referring to their 'determination' to speak, and the latter where five CYP construed a 'speaking' person as their 'ideal' self. P5's strong desire to change was further emphasised when she selected the prompt card 'I want to be able to talk' to represent her current self. However, she also pointed to the 'speaking is difficult for me' card, which reflected the views of 23% of Roe's (2011) participants who wanted to talk but acknowledged this would be very difficult for them.

Interestingly, all participants associated change with positive feelings such as 'happy' (P1, P3, P4, P5), 'confident' (P2) and 'relaxed' (P2) which, from a dichotomy corollary perspective (Kelly, 1955), assumes that they currently identify with the contrast pole

(i.e. 'sad', 'unconfident', 'anxious'), however are keen to alter their emergent pole.

The psychological and physiological impact of SM has also been reported by CYP in several of the other pupil voice studies, via descriptions such as 'uncomfortable', 'helpless', 'terrified', 'anxious', 'unhappy', 'distressing' and 'frustrating' (Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Patterson, 2016). 'Ideal' ratings suggest that participants associated being able to speak freely with a positive future, which connects with 7% of Roe's (2011) sample who felt once they had overcome SM, life would be better.

Additionally, as shown in Box 10, three participants referred to jobs in their 'speaking' future which, interestingly, relied heavily on speech, e.g. a doctor (P1) and a vet (P2, P5).

*Box 10: Part C responses showing P1, P2 and P5's desired jobs in the future*

The image displays three hand-drawn cards within a rectangular frame. The first card on the left is titled 'Future' and features a drawing of a person in a white coat standing at a podium, with the word 'talk' written in a bubble to the left and 'doctor' in a bubble below. A vertical note on the right side of the card reads 'being able to talk in all lessons and in public'. A green arrow points downwards from this note. Below the card is the text: 'P1 identified that he would like to be a doctor in the future'. The middle card is also titled 'Future' and contains two lines of text: '- wanted to be a vet but struggle with Sciences + maths' and '- don't know - something with animals'. Below this card is the text: 'P2 and P5 expressed that they would like to be a vet in the future'. The third card on the right has the phrase 'be a vet - speak' written across the top. Below this, there is a vertical orange bar with the text 'OTHER RELA' written vertically inside it. To the right of the bar, the words 'Future - speak' are written vertically. Arrows from the text below the middle and right cards point towards the middle and right cards respectively.



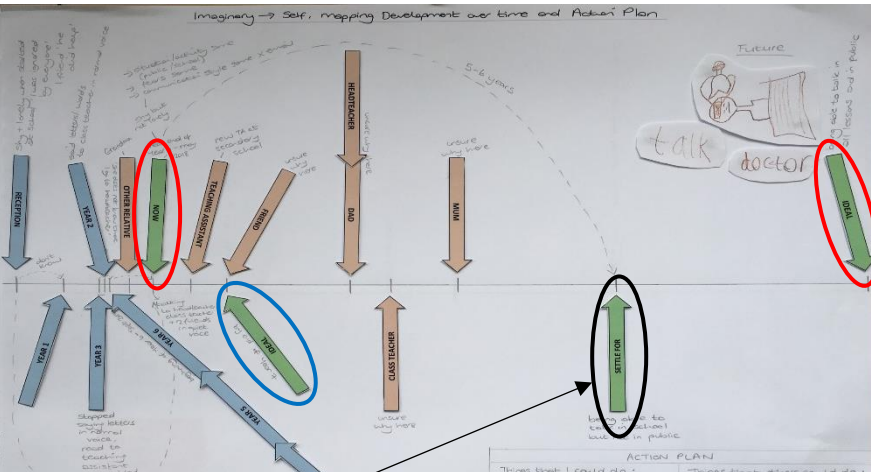
This suggests that P1, P2 and P5 believed they could recover from SM and were hopeful that it would not always affect them - optimism also apparent amongst 7% of Roe's (2011) participants. Similarly, the futures of P1, P2 and P4's 'non-speaking' characters in part A involved progress with speaking, and referenced jobs, family and friends, suggesting how SM was not conceptualised as a fixed behaviour by these individuals. This sense of connectedness expands on Patterson's (2016) findings, in which participants' constructs when speaking were dominated by relational constructs. However, these views contradict the experiences of Walker and Tobbell's (2015) participants who remained greatly affected by SM in adulthood, both in work and social situations.

### **5.2.3 Theme 3: Flexibility and willingness to compromise regarding their 'ideal' self**

Whilst all CYP expressed a strong desire to be more like the 'speaking' person, four (P1, P2, P4, P5) acknowledged that they would 'settle for' somewhere between their current and 'ideal' ratings. This illustrated flexibility regarding their preferred pole of the construct, however the degree to which they were willing to compromise varied. Moran (2012a) acknowledged how exploring flexibility was a crucial step in the Drawing the Ideal Self process "to note whether the child will settle for less than perfection in their personal development" (p.21), which has potential consequences for their self-concept.

For example, P1 and P2 placed their ‘settle for’ ratings mid-way between their ‘now’ and ‘ideal’ selves (see Box 11 for example), indicating high flexibility and likely feelings of accomplishment and acceptance if they were to make at least some progress with speaking.

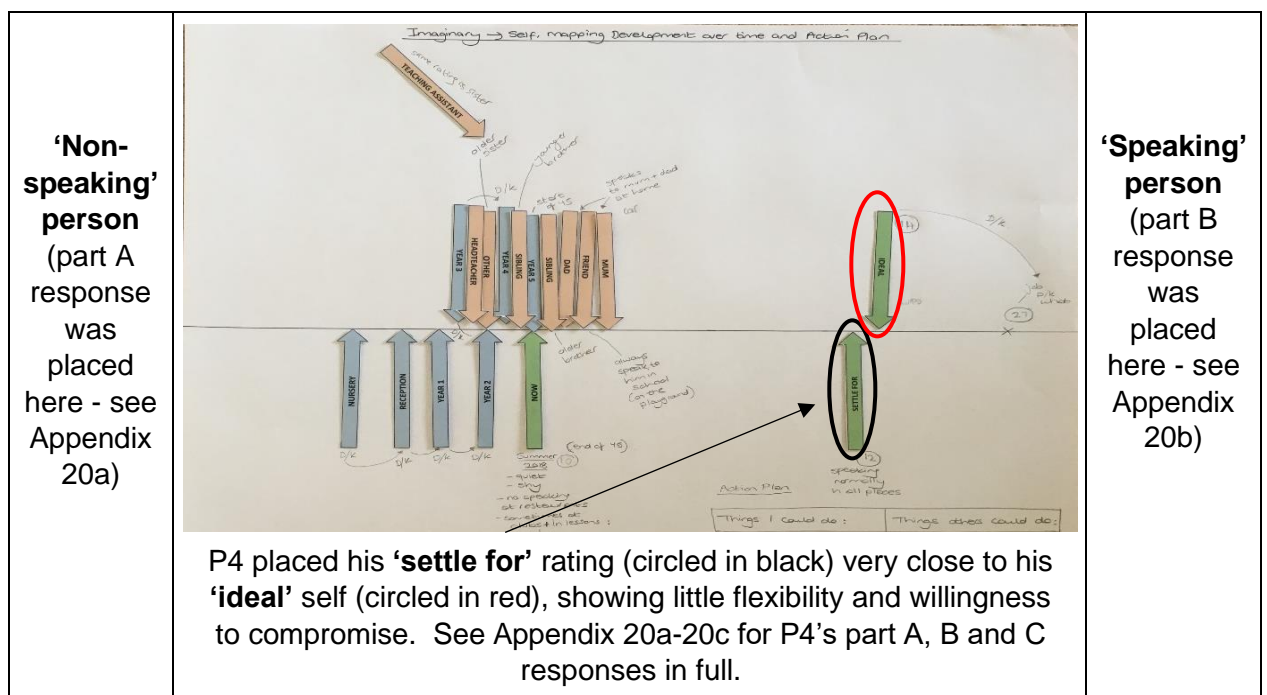
*Box 11: P1’s part C responses illustrating his willingness to compromise regarding his ‘ideal’ self*

<p><b>‘Non-speaking’ person</b> (part A response was placed here - see Appendix 17a)</p>	 <p>P1 placed his <b>‘settle for’</b> rating (circled in black) mid-way between his current and <b>‘ideal’</b> self (circled in red), showing flexibility and willingness to compromise. His <b>‘ideal’</b> rating for the end of Year 7 is also circled in blue, showing further flexibility. See Appendix 17a-17c for P1’s part A, B and C responses in full.</p>	<p><b>‘Speaking person’</b> (part B response was placed here – see Appendix 17b)</p>
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P1 and P2’s sense of compromise was further highlighted when they identified a second ‘ideal’ rating to indicate where they would like to be in a year’s time, at the end of Year 7 (P1) and Year 11 (P2). In P1’s case this was just higher than his current rating, whilst for P2 this was the same as her ‘settle for’ rating, showing how these participants were able to identify shorter, more realistic and achievable goals for the next year, which they would be happy to achieve.

In contrast, P4 and P5's 'settle for' ratings were very close to their 'ideal' (see Box 12 for example), showing more rigid and greater expectations of themselves. However, they too distinguished between their 'ideal' self in a few years' time and much further in the future, showing some degree of compromise.

Box 12: P4's part C responses showing little willingness to compromise regarding his 'ideal' self



Furthermore, P3's 'settle for' rating was the same as his 'ideal' rating, showing no flexibility or willingness to compromise. As discussed by Moran (2012a), when CYP have high expectations of themselves they are more likely to experience disappointment when they do not achieve their 'ideal' self. Consequently, it is possible that P3, P4 and P5's low flexibility could prove problematic in the future, due to the risk of invalidating desired theories about themselves which may cause distress such as anger or anxiety (Kelly, 1955; Moran, 2012a). This connects with

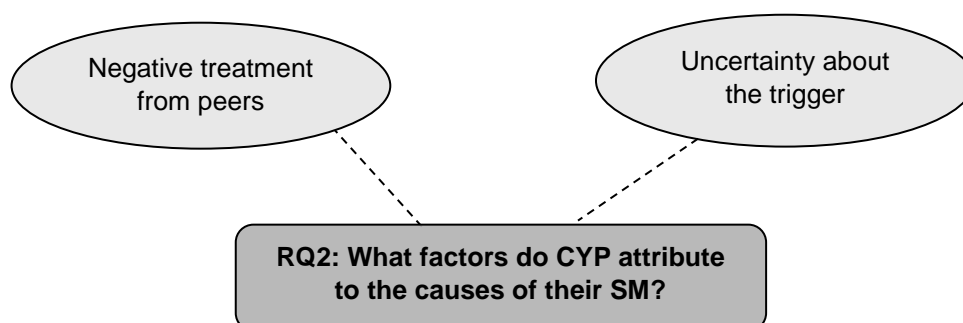
participants' views in Walker and Tobbell's (2015) study, who reported a "determination and desire" (p.462) to speak yet feelings of frustration and failure when this could not be fulfilled. It also links to Roe's (2011) findings, whereby six CYP acknowledged wanting to talk but being unable to do so, and others referred to feeling "different", "frustrated" and "wanting to be like others" (p.25), implying a lack of self-acceptance due to not being able to speak freely.

#### 5.2.4 Summary of RQ1

The aforementioned themes highlight how four of the five CYP associated closely with the 'non-speaking' pole of the construct, however all had the desire to reach their emergent pole of the 'speaking' person in the future. Additionally, four participants showed some flexibility and willingness to compromise regarding their 'ideal' self, whilst one would not 'settle for' anything less than his desired rating.

#### 5.3 RQ2: What factors do CYP attribute to the causes of their SM?

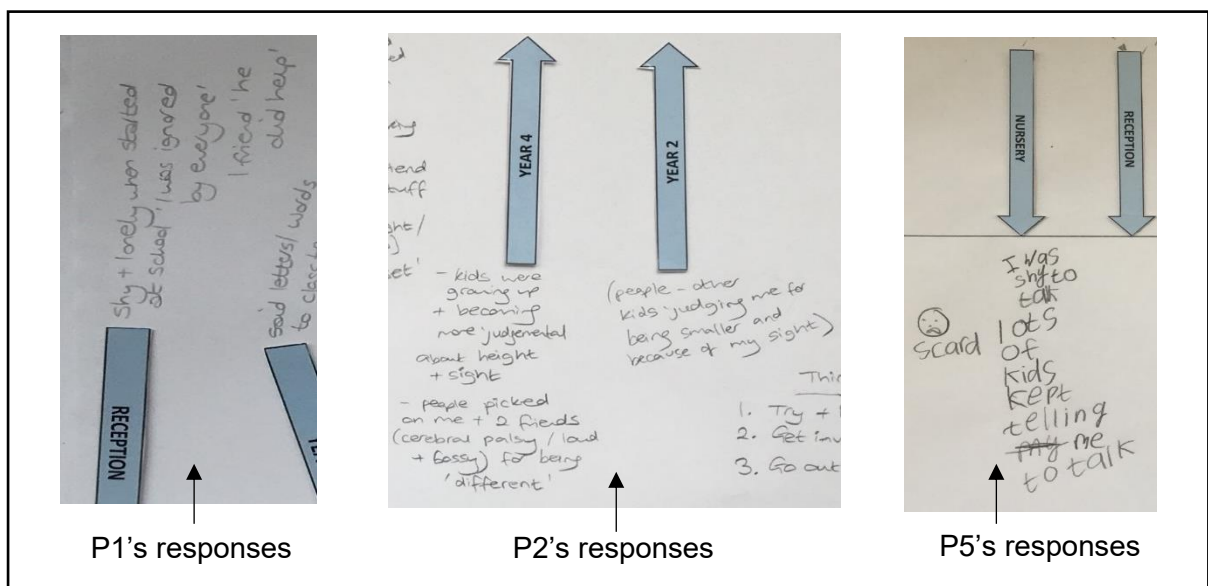
Two themes were identified relating to RQ2 - CYP's negative treatment by peers and uncertainty about the trigger - as shown and discussed below.



### 5.3.1 Theme 1: Negative treatment from peers

As shown in Box 13, three of the five CYP (P1, P2, P5) referred to the role of their peers in the development of their SM.

Box 13: Part C responses highlighting the role of peers in the cause of SM



For example, P1 wrote that he was "ignored by everyone" when he started school in Reception which made him feel "shy and lonely", whilst P2 talked about being judged and picked on by several peers about her height and sight, between Years 2 and 4, which made her lose confidence - (P2 shared that she had a growth deficiency which affected her eyesight). These views mirror the experiences of others with SM such as CYP in Roe's (2011) study who attributed their SM to factors such as starting school and bullying, as well as the twins in Albrigtsen, Eskeland and Mæhle's (2016) research, who were teased about their accent.

Additionally, P5 wrote, “I was shy/scared to talk, lots of kids kept telling me to talk”, further illustrating how the behaviour and reactions of others can be a significant factor in the development and maintenance of SM as acknowledged by Johnson and Wintgens (2016).

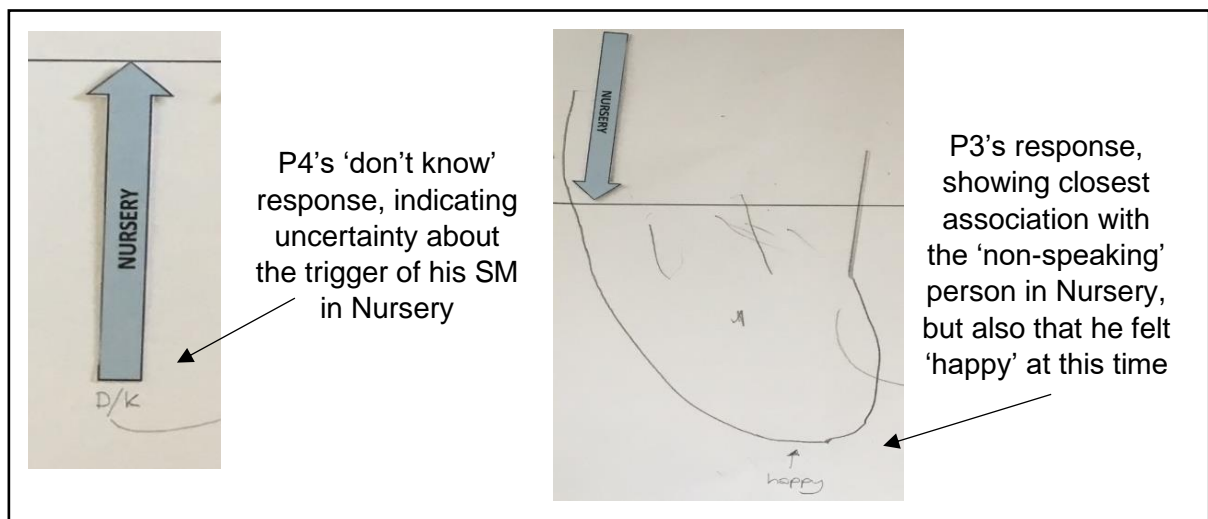
Finally, due to CYP’s reports of feeling ‘shy’ (P1), ‘lonely’ (P1) and ‘scared’ (P2, P5) when referring to treatment from their peers, I sensed that these situations had been traumatic and anxiety-provoking for them. These findings may therefore expand on Omdal’s (2007) findings whereby three participants directly attributed ‘traumatic’ incidents - such as moving school and bullying - to their SM. This theme challenges the current assumption in the literature, that there is no causal relationship between trauma and SM (Black and Uhde, 1995; Dummit *et al.*, 1997), and supports the findings of more historical studies (von Misch, 1952, cited in Browne, Wilson and Laybourne, 1963; Parker, Olsen and Throckmorton, 1960) which recognised the influence of trauma. However, P1, P2 and P5 did not meet Kolvin and Fundudis’ (1981) definition of ‘traumatic mutism’ as they were able to speak freely in some situations, which questions whether trauma should be incorporated within the general definition. This finding further emphasises the need to elicit the views of the ‘experts’ themselves to ensure SM is correctly understood by ‘outsiders’.

### **5.3.2 Theme 2: Uncertainty about the trigger**

Whilst P3 and P4 did not report any particular triggers of their SM, they both identified that they were most like the ‘non-speaking’ person in Nursery, as shown in Box 14 (page 109). When seeking to explore their explanations for this, P4 pointed

to the 'don't know' card so I did not pursue this any further. In P3's case, I was unsure if he had understood the wording of the question, however after adapting it by asking, "How did you feel in Nursery?", he drew a smiley face to indicate he was happy. As P3 drew several smiley faces during part C (Appendix 19c), these may have further reflected his positive sense of self and perceived minimal impact of SM as discussed in section 5.2.1.

*Box 14: P3 and P4's part C responses indicating uncertainty about the trigger of their SM (see Appendices 19c and 20c for full responses)*



Additionally, memory issues could explain why P3 and P4 did not report a specific trigger, which was also evident amongst Omdal's (2007) participants who were unable to recall when their SM started. This can be a weakness of studies which rely on retrospective reports due to potential memory or selective recall bias.

Consequently, P3 and P4's closest associations with the 'non-speaking' person in Nursery may have been influenced by their knowledge of typical development, i.e. that speech is less sophisticated at this point compared to later years in school, rather than attributing it to anxiety. However, I am mindful that these are my own

interpretations rather than the 'experts' so may lack validity and reliability.

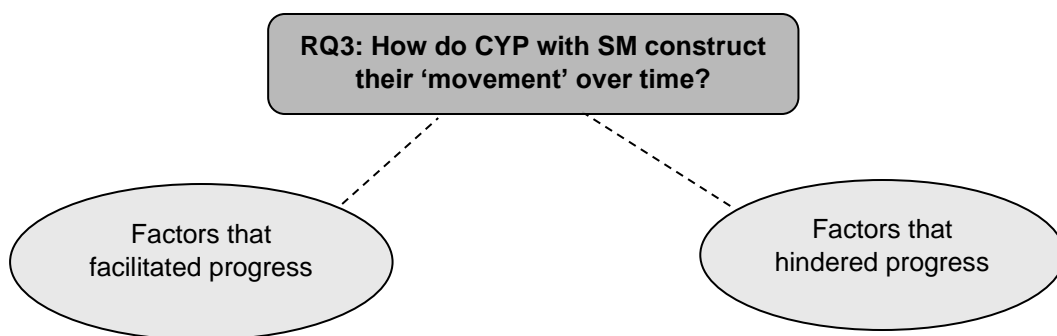
Furthermore, I cannot assume that P3 and P4 were unaware of the triggers of their SM and rather must acknowledge that the style of questioning may have limited their opportunity to share this information non-verbally.

### 5.3.3 Summary of RQ2

The above themes demonstrate how three of the CYP attributed their SM to negative treatment by peers - which appear to have been traumatic and anxiety provoking for them - whilst two participants did not identify any specific trigger.

### 5.4 RQ3: How do CYP with SM construct their 'movement' over time?

Two themes were identified relating to RQ3 - factors that facilitated progress and factors that hindered progress, as shown and discussed below.

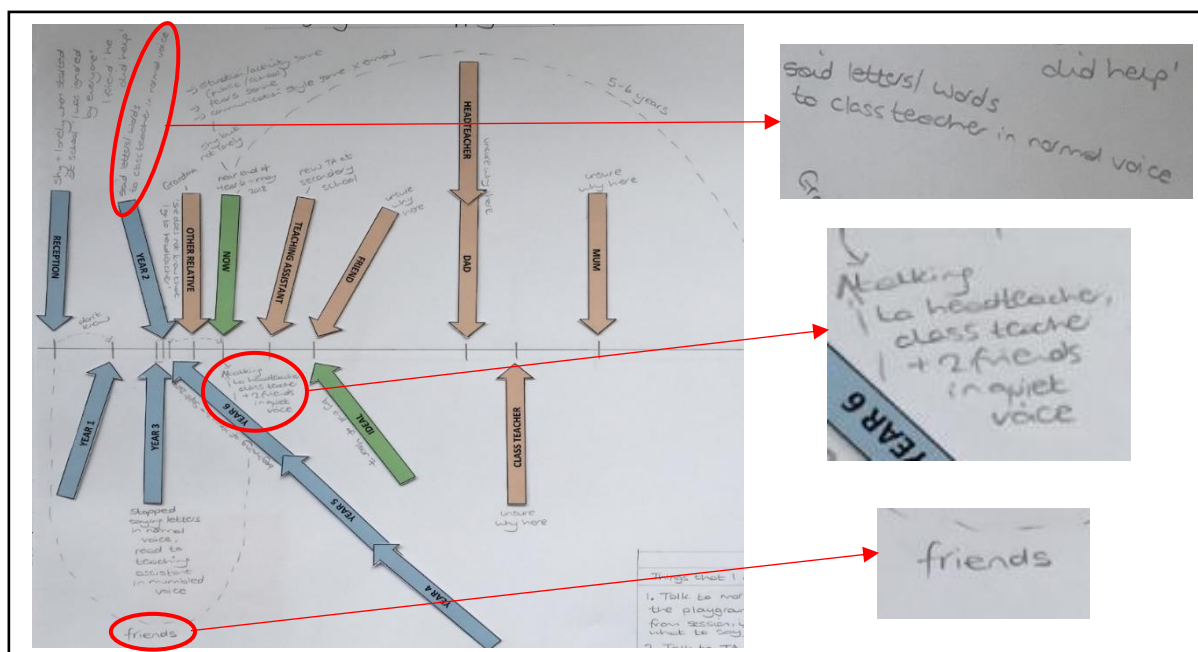


#### 5.4.1 Theme 1: Factors that facilitated progress

Four participants (P1, P2, P3, P5) were able to identify particular factors that had enabled them to make varying levels of progress with speaking over time. An example is shown in Box 15 (page 111) and all responses in Appendices 17c, 18c, 19c and 21c.



*Box 15: Data extracted from P1's part C response indicating factors he attributed to his progress with speaking between Reception and Year 6*



For example, P1 attributed his development from Reception to now (Year 6) to his friends, referring to one particular friend who had helped him to not feel lonely. He also acknowledged how one-to-one reading sessions with his class teacher in Year 2, and sliding-in sessions with his head teacher, class teacher and two peers in Year 6, had facilitated small steps of progress. P1's responses connect with the views of SM participants in other studies regarding the importance of friendships, understanding and acceptance from staff, continued support from a trusted keyworker and the effectiveness of behaviour interventions (Roe, 2011; Manassis, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Hill, 2019), as well as the wider literature which advocates for early identification and a holistic, multimodal approach to SM interventions (Johnson and Wintgens, 2015; 2016).

Similarly, P2 attributed progress between Year 4 and Year 6 to friendships, sharing that she was “friends with pretty much everyone in the class”. However, she also identified personal factors - such as standing up for herself and not caring what people said to her - as relevant, which were sharp contrasts to previous years when she was teased for being ‘different’ and did not defend herself. This reflects a “conscious decision to start talking” (p.245) as echoed amongst Omdal’s (2007) participants.

Moreover, P2 attributed slight progress between Year 9 and Year 10 to starting new GCSE classes where she “tried talking to people and made some friends”, which further emphasises a conscious choice to change in situations where there are no expectations of previous speaking patterns (Omdal, 2007). I also considered whether P1’s higher ‘ideal’ rating for Year 7 (one year on from the interview) reflected his hope for a ‘fresh start’ at secondary school, which was a facilitating factor in the recovery of the twins in Albrigtsen, Eskeland and Mæhle’s (2016) study.

Finally, P2 informed me that her younger sister joining Year 7 - when she was in Year 10 - had helped by “knowing family were there”. This mirrors Roe’s (2011) findings - in which 43% of participants valued the support they had received from their family (including siblings) - and feedback from the twins in Albrigtsen, Eskeland and Mæhle’s (2016) study who acknowledged how their younger sister had helped them to communicate in public.

P3 attributed his progress to increasing levels of happiness. For example, regarding his Nursery rating (where he was most like the 'non-speaking' person), he used his toy goat to draw a 'happy' face, whilst for his Reception and Year 1 rating (where he had moved considerably towards the 'speaking' person) he drew a 'very happy' face. Furthermore, for his Year 2 and current Year 3 rating, both his level of animation and his facial expressions indicated even greater emotion. When I asked if this meant he was 'even happier' at these points he repeatedly bounced the toy goat and nodded its head, which I interpreted as agreement. Consequently, it appeared that P3 associated his speaking progress with greater degrees of happiness, which may expand on Roe's (2011) findings regarding CYPs' positive self-ratings of themselves and Albrigtsen, Eskeland and Mæhle's (2016) reference to self-acceptance. Whilst I was unsure whether P3's reliance on happiness ratings reflected limited understanding or insight into the concept of 'movement' over time, the technique aimed to elicit how CYP constructed their experiences and therefore I accepted that "all information provided by the child is valid" (Omdal and Galloway, 2007, p.211).

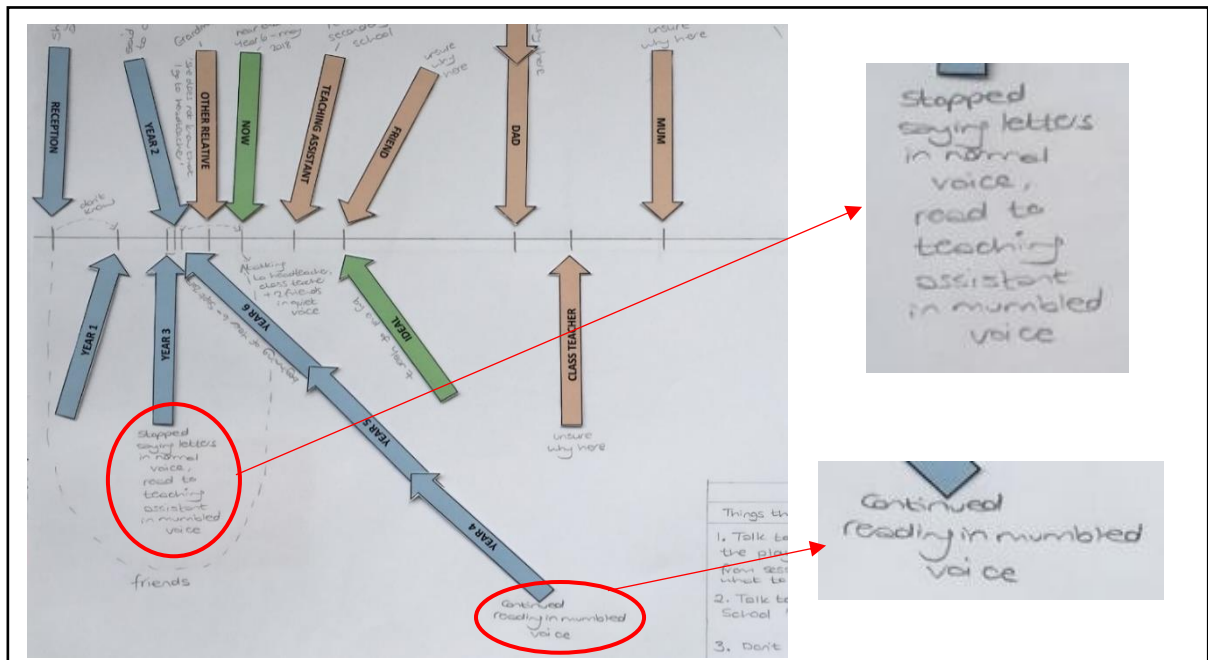
Finally, similarly to P2, P5 attributed her progress from Nursery to Year 5 to personal factors within her control, offering additional supporting evidence regarding CYP's conscious determination to change (Omdal, 2007; Albrigtsen, Eskeland and Mæhle, 2016). For example, when exploring progress from Nursery and Reception, P3 wrote that she made "dog sounds" when playing, whilst between Reception and Year 1 this increased to "dog and cat sounds". Furthermore, progress between Year 1 and Year 2 was attributed to "lots of cat and dog sounds on the playground and in lessons to friends" followed by "more wolf, cat, dog, cow and sheep sounds to friends and

teachers on the playground, in games and in lessons” in Year 3 and Year 4. It was interesting how P3’s perceived progress related to animal sounds rather than words, however such audible vocalisations are recognised at stage five of Johnson and Wintgens’ (2016) model of confident talking (‘Uses voice’, see section 2.9).

### 5.4.2 Theme 2: Factors that hindered progress

Three of the CYP (P1, P2, P5) were able to identify factors that had hindered their progress over time, whilst this did not appear to be relevant or was not reported by P3 or P4. An example is shown in Box 16 and all responses are given in Appendices 17c, 18c and 21c.

*Box 16: Data extracted from P1’s part C response indicating factors he perceived had hindered his progress with speaking between Year 2 and Year 6*



For example, P1 shared that between Year 2 and Year 3 he “stopped saying letters in a normal voice” and instead “read to the TA in a mumbled voice” which resulted in

slight regression towards the 'non-speaking' person. As he reported that he "said letters/words to the class teacher in a normal voice" in Year 2, I considered whether his progress may have been hindered by the change of staffing in Year 3.

Additionally, P1 perceived that his SM had remained the same in Years 4-6 as he "continued reading in a mumbled voice" and did not progress until his sliding-in sessions started mid-way through Year 6 (see section 5.4.1). His responses may therefore link to Roe's (2011) findings, whereby staff's limited understanding was identified as an unhelpful maintaining factors by 53% of the sample, as well as Johnson and Wintgens (2016), who acknowledged how expecting a response (i.e. via reading) or dismissing/ignoring a child's speech anxiety can also sustain SM.

Similarly, P2 attributed distinct reasons to her regression over time. Whilst she felt most like the 'speaking' person in Nursery, as she was "really happy and loud", she rated her speaking patterns in Year 2 and Year 4 as considerably lower due to her peers "becoming more judgemental about my height and sight", and consequently picking on her. Her response supports existing literature and further emphasises how the behaviours and reactions from others can maintain SM (Omdal, 2007, Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Johnson and Wintgens, 2016; Hill, 2019).

Additionally, P2 associated regression from Year 6 to Year 7 to starting at a new school where she felt "really scared" as she only had one friend, which connects with CYP in Omdal (2007), Roe (2011) and Albrigtsen, Eskeland and Mæhle's (2016) studies whose speaking patterns also worsened following a school move. However,

this also contradicts the experiences of Omdal (2007) and Albrigtsen, Eskeland and Mæhle's (2016) participants who later made a conscious decision to speak when joining a new environment, thus illustrating the unique and individual presentation and trajectory of SM.

Furthermore, P2 linked negative 'movement' from Year 7 and Year 8 to her best friend moving away and a particular peer making fun of her which made her "really upset", and her considerable regression between Year 8 and Year 9 to a difficult fall out with a friend. This resulted in P2 losing her friend, sharing that she then "didn't speak to anyone unless I had to" and found it "hard going to school". Due to these events, P2 rated herself as most like the 'non-speaking' person in Year 9. Again, this reinforces other direct experiences of SM in which peer issues acted as a maintaining factor (Omdal, 2007, Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Johnson and Wintgens, 2016; Hill, 2019). It may also reflect conformity to a 'silent role' when excluded from social interactions as acknowledged by Omdal (2007) and Walker and Tobbell's (2015) participants.

Finally, whilst P5 reported steady progress with speaking between Nursery and Year 4, she identified some regression towards the 'non-speaking' person during Year 4. When exploring the reasons for this, P5 shared that she was making "less cow and sheep sounds in lessons and on the playground" at the end of Year 4 than earlier in the year. This suggests that P5 perceived her speaking habits in terms of the frequency of animal noises, as opposed to the use of actual words. Whilst P5 appears to be at stage five of confident talking, ('Uses voice' - Johnson and

Wintgens, 2016, p.74, see section 2.9), she is not yet 'communicating using single words' (stage 6) so is not progressing towards confident talking.

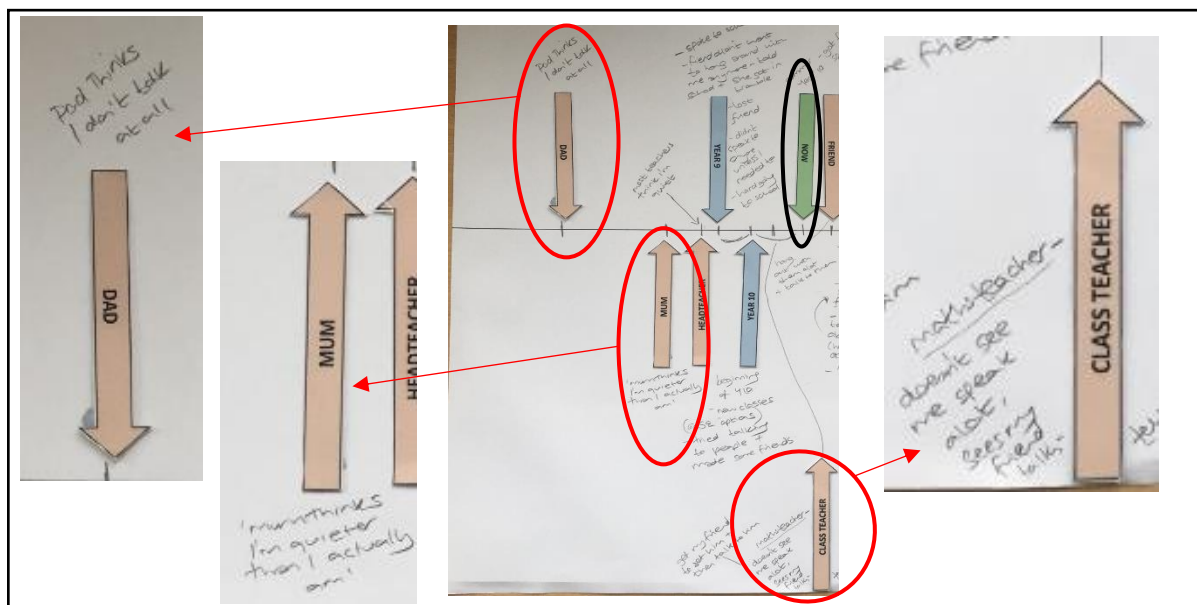
A final interpretation, which may reflect other hindering factors, came from CYP's views about how they are perceived by others. During part C, participants were asked to identify where they thought certain figures in their life (family members, friends and staff) would rate them on the scale. Interestingly, P1, P2 and P4 thought that particular individuals would rate them as more like the 'non-speaking' person than they had rated themselves.

For example, P1 believed his grandmother would rate him lower down on the scale as "she does not know that I go to the head teacher" (for sliding-in sessions), whilst P4 felt his siblings, TA and head teacher would rate him closer towards the 'non-speaking' person, although he did not give reasons for this.

Additionally, P2 felt her class teacher and head teacher would give her a lower rating on the scale, explaining that "most teachers think I'm quiet and don't see me speaking a lot", whilst her parents, especially her father, would rate her as much more like the 'non-speaking' person than she rated herself. When exploring this further, P2 commented that "mum thinks I'm quieter than I actually am" and that "dad thinks I don't talk at all".

Box 17 (page 118) gives P2's part C responses as an example, whilst Appendices 17c and 20c show P1 and P4's responses.

Box 17: P2's part C data illustrating her explanations regarding why certain individuals would rate her lower on the scale than she currently rated herself (circled in black)



The participants' perceptions made me reflect on whether, in line with previous literature, the opinions and reactions of certain individuals could also be hindering progress and maintaining factors of their SM (Johnson and Wintgens, 2016).

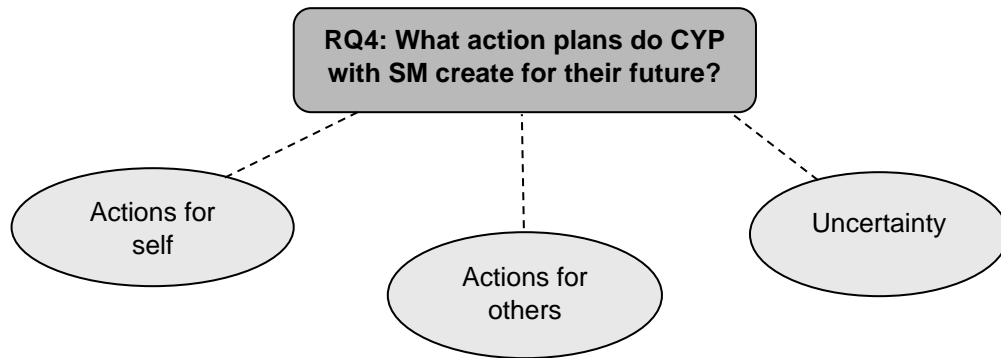
### 5.4.3 Summary of RQ3

The themes discussed above illustrate how CYP identified a range of factors which had facilitated and hindered their progress with speaking. Facilitating factors included environmental influences - such as support from peers, trusted keyworkers and siblings - and personal factors, such as making a conscious decision to change their behaviours and increasing levels of happiness. Hindering factors related to a school move, the negative reactions and behaviours of staff and peers, and a reduction in animal noises, whilst the perceived opinions of other key figures, including family members, may also be relevant.



## 5.5 RQ4: What action plans do CYP with SM create for their future?

Three themes were identified relating to RQ4 - actions for self, actions for others and uncertainty about what might facilitate progress - as shown and discussed below.



### 5.5.1 Theme 1: Actions for self

As shown in Box 18, three participants (P1, P2, P5) identified actions for themselves which they felt would facilitate 'movement' towards their 'ideal' self.

*Box 18: Data from P1, P2 and P5's action plans (part C) reflecting actions for themselves to facilitate 'movement' towards their 'ideal' self*

**P1's response:**

ACTION  
 Things that I could do :  
 1. Talk to more friends on the playground (2 friends from session, unsure who else or what to say)  
 2. Talk to TA at secondary school 'yes/no'  
 3. Don't know  
 TA to talk to mum + dad at parents evening

**P2's response:**

Action Plan  
 Things that I could do :  
 1. Try + talk to more people (girl in Art class who likes some drawings)  
 2. Get involved in more after school clubs - badminton  
 3. Go out with friends more

**P5's response:**

Action Plan  
 Things I could do :  
 more sessions  
 mum  
 the kids

For example, P1 recognised that he could speak to more friends on the playground (although he was unsure what he would say to them) and continue sliding-in sessions with his new TA at secondary school. Similarly, P2 identified that she could speak to a peer in her art class who liked the same drawings as her, join a badminton after-school club, and meet up with her friends more outside of school. These responses suggest that participants were keen to interact with others and therefore reinforced Bruce (1996) and Johnson and Wintgens' (2016) proposals that SM may not necessarily be the result of social anxiety but rather a phobia of expressive speech (Omdal and Galloway, 2008), which leads to social isolation.

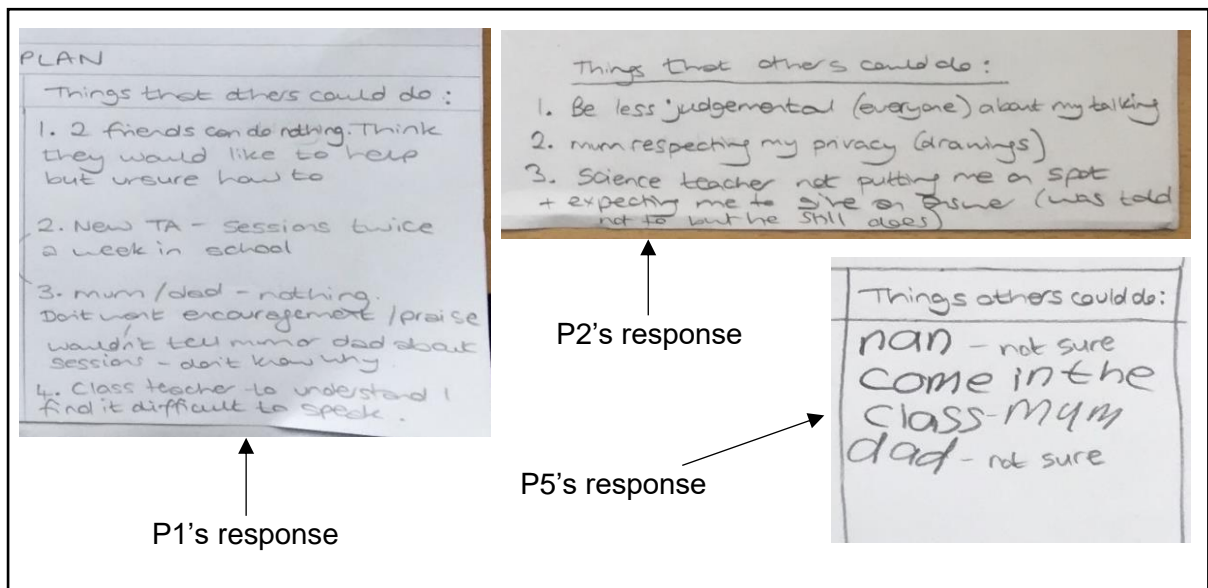
Whilst P1 and P2's actions reflected a personal ownership and determination to speak - evident amongst Omdal (2007) and Albrigtsen, Eskeland and Mæhle's (2016) participants - I felt they also illustrated naivety about how difficult achieving change would be due to speech patterns being so entrenched (Roe, 2011, Walker and Tobbell, 2015). However, these responses demonstrate their motivation and willingness to change, which has direct implications for professionals supporting the child, such as EPs, as discussed in the conclusion.

Finally, P5 felt that participating in "more sessions with mum and the kids" would aid her progress, which was in reference to the sliding-in work already in place in school. This highlights how P5 valued support from her mum and a behavioural approach to increase her speaking patterns, which connects with the findings of other studies in the literature (Cohan, Chavira and Stein, 2006; Roe, 2011; Bergman *et al.*, 2013; Manassis, 2015).

### 5.5.2 Theme 2: Actions for others

As shown in Box 19, the same three participants (P1, P2, P5) also identified actions for others that would support their progress towards the 'speaking' person.

*Box 19: Data from P1, P2 and P5's action plans (part C) reflecting actions for others to facilitate 'movement' towards their 'ideal self'*



For example, P1 felt twice-weekly sliding-in sessions with his TA at secondary school would be helpful, in addition to his new class teacher understanding his difficulty speaking. The first suggestion further supported the effectiveness of behavioural interventions for SM (Cohan, Chavira and Stein, 2006; Roe, 2011), whilst the latter connected with Hill's (2019) findings in which CYP felt the best way for staff to support SM was to recognise it as a manifestation of anxiety, rather than a deliberate silence or lack of motivation to speak. This would be an important issue to address at P1's new school to ensure staff understood potential maintaining factors.

Similarly, P2's responses in this section related to maintaining factors within her environment. For example, she shared that she wanted people to be "less judgemental" about her talking as she felt under pressure to speak, which likely reinforced her anxiety. This unhelpful expectation was also reported amongst Roe (2011) and Hill's (2019) participants. Additionally, P2 expressed that she wanted her mother to respect her privacy, especially when she was drawing, as this was her way of relaxing after school. This seemed to be a powerful stage of the interview as P2 informed her mother that she would be more likely to tell her about her day if this was on her own accord, rather than in response to direct questioning. This statement appeared to resonate with P2's mother, evidenced by her commenting that she would respect her daughter's wishes now that she was aware.

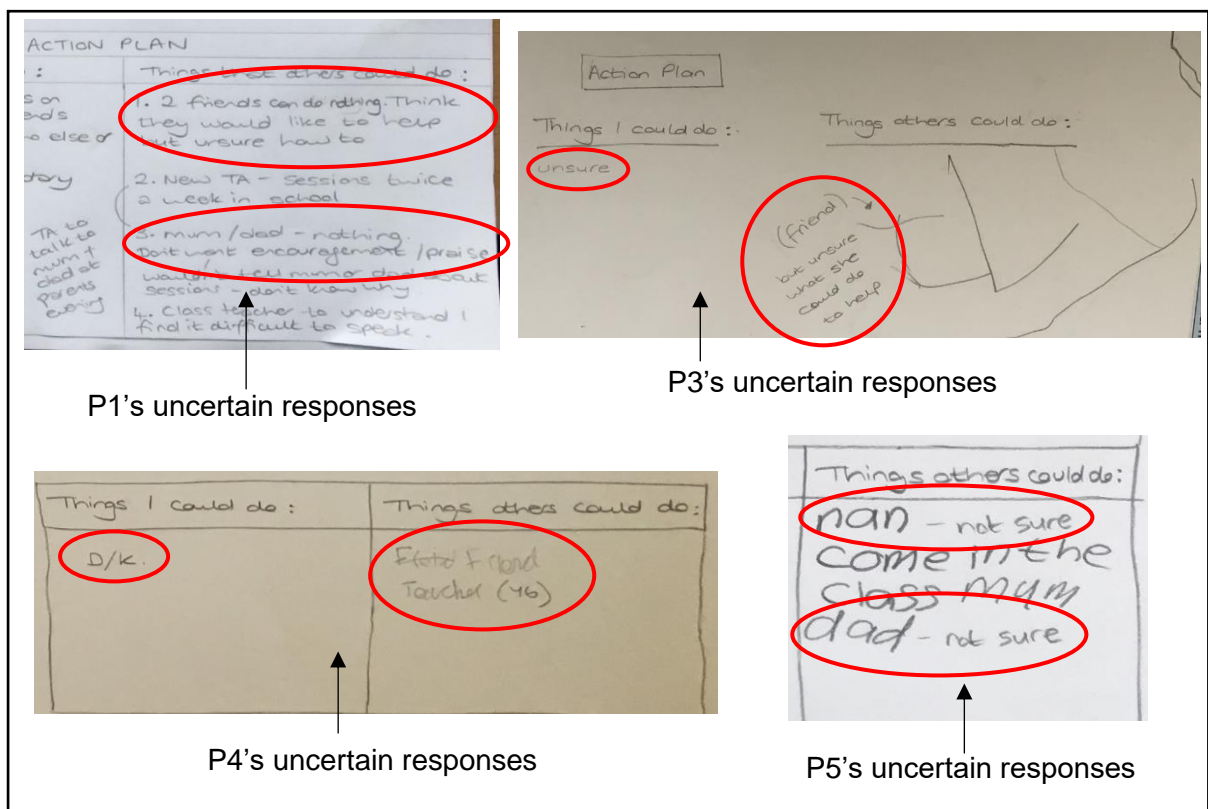
Furthermore, P2 articulated that she wanted her science teacher to change, as he often put her on the spot and expected her to give an answer, despite having been told that this was not helpful for her. This statement connected with the experiences of others with SM who had been made to shout out the teacher's name and been subject to hurtful comments about their non-speaking (Roe, 2011), as well as been forced to stand up and answer a question in front of the class (Albrigtsen, Eskeland and Mæhle, 2016). This may offer additional evidence for the role of 'traumatic' incidents in the development and maintenance of SM, contrary to existing literature assumptions (Black and Uhde, 1995; Dummit *et al.*, 1997).

Finally, P3 acknowledged how continued support from her mum, via sliding-in sessions, would facilitate progress towards the 'speaking' person.

### 5.5.3 Theme 3: Uncertainty

As shown in Box 20, four participants (P1, P3, P4, P5) appeared to have some difficulty with the action planning stage of the interview.

*Box 20: Data from P1, P3, P4 and P5's action plans (part C) highlighting uncertainty about actions for self and actions for others*



For example, P3 and P4 did not identify any actions for themselves, which may mirror feelings of uncertainty, helplessness and hopelessness, and further reflect how difficult it is to overcome SM as reported in other lived experience studies (Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016). Omdal's (2007) participants also referred to their "conscious decision to change" (p.237), which may not have been relevant for P3 (as he perceived he was already very much like the 'speaking' person) or may have been viewed as unrealistic by P4 (due to the

distance from his 'ideal' and 'settle for' ratings), hence explaining their blank responses.

Additionally, whilst P3 and P4 thought a friend and P4 thought a teacher could help, they were unsure what these individuals could do to support their progress.

Similarly, P1 referred to his friends and P5 identified certain family members who could help, but did not identify particular actions. This further highlighted uncertainty about specific roles for others, but reiterated the importance of peer and teacher involvement in the management of SM. This theme was also apparent in other pupil voice studies, including Roe (2011), where 20% of CYP reported school staff and 33% reported friends as being helpful, and Hill (2019), where 75% felt teachers played a significant part in developing self-esteem, and 100% referred to wanting a trusted friend in their class.

Interestingly, P1 did not feel his parents could do anything to help, sharing that he did not want encouragement or praise from them, and instead would prefer his TA to discuss his progress with them at parents' evening. This may have reflected his desire to avoid unwanted attention regarding speaking which has been recognised as a maintaining factor in itself (Omdal, 2007; Roe, 2011, Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Patterson, 2016; Hill, 2019; Vogel *et al.*, 2019). However, as Johnson and Wintgens (2016) advocate a holistic, multimodal approach when managing SM, a lack of parental involvement, as requested by P1, may present a barrier to progress.

This theme, whereby CYP wanted to change but were unsure how to, has direct implications for practice regarding a role for the key adults supporting them, both to address the speech anxiety and maintaining factors of SM (Johnson and Wintgens, 2016).

#### **5.5.4 Summary of RQ4**

The aforementioned themes highlight how three participants identified actions for themselves and others which would facilitate their progress, whilst the remaining participants were more uncertain about this.

#### **5.6 Chapter summary**

This chapter has presented the research findings in relation to the research questions and existing literature about SM. Key themes gave insight into how participants constructed their current and 'ideal' selves, the perceived causes of their SM, their 'movement' over time and their action plans for the future. Chapter 6 provides an overall conclusion of the research.

## CHAPTER 6: CONCLUSIONS

### 6.1 Chapter overview

This chapter provides a conclusion to the research, summarising how the findings addressed the original aims and research questions and contributed to the existing 'insider' knowledge of SM. The research is critically reviewed, its strengths and limitations considered, and future research suggestions and implications for EP practice discussed.

### 6.2 Summary of findings

The purpose of the research was to gain the views of CYP with SM to increase understanding of the condition from a lived experience perspective and extend the limited literature in this area (Omdall, 2007; Omdall and Galloway 2007; Patterson, 2011; Roe, 2011; Manassis, 2015; Walker and Tobbell, 2015; Albrigtsen Eskeland and Mæhle, 2016; Hill, 2019; Vogel *et al.*, 2019). The research questions were addressed using a non-verbal PCP technique which elicited participants' contrast poles of 'non-speaking' and 'speaking', and enabled exploration of how they constructed their current and 'ideal' selves, causes of SM, 'movement' over time and action plans for the future.

Following thematic analysis (Braun and Clarke, 2006), ten themes relating to the research questions were identified - acknowledgement of their 'non-speaking' selves, their desire to change, and flexibility and willingness to compromise regarding their 'ideal' self (RQ1); negative treatment from peers and uncertainty about a trigger (RQ2); factors which had helped and hindered progress (RQ3); and actions for self,



actions for others and uncertainty about what might facilitate change (RQ4). The research therefore achieved its aim.

## **6.3 Strengths**

### **6.3.1 Contributions to knowledge of SM from a lived experience perspective**

This study has addressed the paucity of research eliciting the subjective views of individuals with SM. As discussed in sections 1.2 and 2.10, existing knowledge of SM is dominated by “observer interpretations rather than experiential accounts” (Walker and Tobbell, 2015, p.457) which raises concerns about how the condition is conceptualised in the literature. Consequently, I was keen to explore personal accounts of SM to determine the credibility of such ‘outsider’ views.

Four of the five participants in the research acknowledged their SM - rating themselves as currently closer to the ‘non-speaking’ person than the ‘speaking’ person - which reflected willingness to disclose their SM as in the previous lived experience studies (Omdal, 2007; Omdal and Galloway, 2007; Roe, 2011; Manassis, 2015; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Patterson, 2016; Hill, 2019; Vogel *et al.*, 2019).

Additionally, participants’ use of adjectives such as ‘shy’, ‘quiet’ and ‘silent’ to describe themselves mirror other subjective accounts of SM (Omdal, 2007; Roe, 2011; Walker and Tobbell, 2015; Patterson, 2016), as well as introverted personality traits discussed in the wider SM literature (Salfield, 1950; Wright, 1968; Black and Uhde, 1995; Cline and Baldwin, 2004; Johnson and Wintgens, 2016). However,

positive attributes including 'not lonely' and 'happy' reflected the positive self-perceptions documented by Roe (2011), supporting Johnson and Wintgens' (2016) claim that social anxiety may not always coincide with SM and challenging the emphasis on negative personality traits (Cline and Baldwin, 2004).

Anxiety was a common theme amongst participants, supporting the role of voice-related fears (Vogel *et al.*, 2019) and expressive speech phobia (Omdal and Galloway, 2008; Johnson and Wintgens, 2016), as well as the DSM-V criteria (APA, 2013) and other studies, which highlight the impact of anxiety on the daily functioning of those with SM (Kristensen, 2000; Cunningham, McHolm and Boyle, 2006; Steinhausen *et al.*, 2006; Omdal, 2007; Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Hill, 2019).

Participants' desire to change, to be more like the 'speaking' person, connect closely with the findings of previous studies, including Omdal (2007) whereby recovered adults discussed their conscious determination to speak, and Patterson (2016) whereby five CYP construed a 'speaking' person as their 'ideal' self. Moreover, participants associating change with positive feelings and a positive future link to several other lived experience studies (Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Patterson, 2016), including 7% of Roe's (2011) sample who felt their life would be better once they had overcome SM. The research also offers novel insight regarding four of the participants' flexibility and willingness to compromise regarding their 'ideal' self, not explored in any of the previous nine papers (Omdal, 2007; Omdal and Galloway, 2007; Roe, 2011; Manassis, 2015;

Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Patterson, 2016; Hill, 2019; Vogel *et al.*, 2019).

Concerning the perceived causes of their SM, three participants referred to negative treatment from peers - including exclusion from social interactions when starting a new school, teasing and bullying, and pressure to speak - mirroring the experiences of previous SM participants (Omdal, 2007; Roe, 2011; Albrigtsen, Eskeland and Mæhle, 2016), and further highlighting the role of others in maintaining SM (Johnson and Wintgens, 2016). Due to the reported distress of these experiences, results challenge the current assumption - that there is no causal relationship between trauma and SM (Black and Uhde, 1995; Dummit *et al.*, 1997) - and support Omdal (2007) and more historical studies (von Misch, 1952, cited in Browne, Wilson and Laybourne, 1963; Parker, Olsen and Throckmorton, 1960) which proposed a link. Additionally, two participants did not identify a trigger, which was also evident amongst Omdal's (2007) participants who could not recall when their SM started.

Regarding factors which had facilitated progress, participants in this study referred to support from family, friends and school staff, behavioural interventions, and a personal decision to change. These reflect the views of other SM participants (Omdal, 2007; Roe, 2011; Manassis, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Hill, 2019) as well wider literature emphasising the importance of holistic multimodal interventions (Johnson and Wintgens, 2015; 2016).

Conversely, participants identified factors that had hindered their progress - including starting a new school, a friend moving school, being teased by peers, and a reduction in using their voice/making animal noises - mirroring the accounts in other lived experience studies (Omdal, 2007; Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016; Hill, 2019) and further reinforcing how others' behaviour can sustain SM (Johnson and Wintgens, 2016).

Three participants identified personal actions which they felt would facilitate progress towards their 'ideal' self, including speaking to more peers on the playground, joining an after-school club, and seeing peers outside of school. This supports the hypothesis that SM may not always be the result of social anxiety as some individuals want to interact (Bruce, 1996; Johnson and Wintgens, 2016), but are hindered by an expressive speech phobia (Omdal and Galloway, 2008).

Regarding actions for others, further sliding-in sessions and a greater understanding from staff were noted, supporting the efficacy of behavioural interventions (Cohan, Chavira and Stein, 2006; Roe, 2011; Bergman *et al.*, 2013; Manassis, 2015) and the importance of addressing maintaining factors within the child's environment (Johnson and Wintgens, 2016; Hill, 2019). Finally, four participants displayed some uncertainty about what might facilitate progress, mirroring findings of other SM participants regarding how difficult SM can be to overcome (Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016).

As outlined above, the research findings offer some support to existing literature, whilst challenging others and contributing a novel insight into participants' flexibility towards change that had not previously been explored. Furthermore, this study added to the paucity of research into current experiences of SM, particularly regarding CYP in the UK, using a qualitative face-to-face interview technique.

### **6.3.2 Contributions to PCP**

This study further illustrates how PCP is a flexible methodological approach which can be used creatively with different client groups and presenting needs (Howarth, 2014). The interview technique expands on previous methods exploring individuals' dichotomous constructs and elaborative choices (Moran, 2001; Williams and Hanke, 2007; Green, 2014; Morgan-Rose, 2015) by offering a novel way of eliciting the subjective experiences of SM.

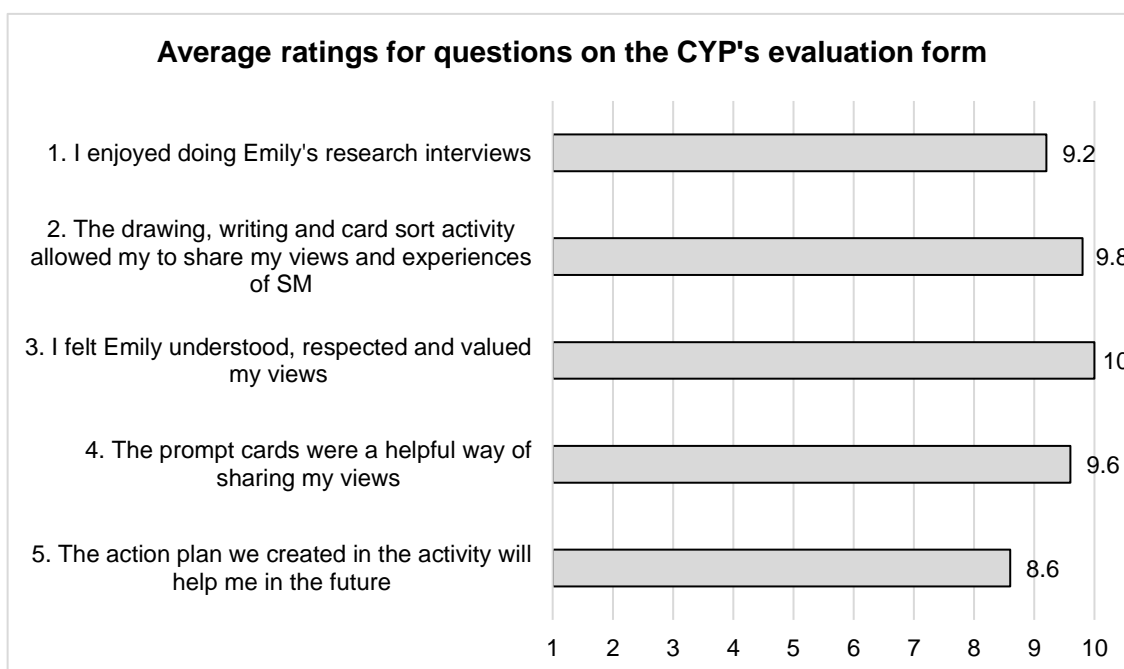
Whilst PCP tools such as Drawing the Ideal Self (Moran, 2001), the repertory grid (Kelly, 1955) and experience cycle questionnaire (Oades and Viney, 2000) have previously been used to access the views of CYP with SM (Howarth, 2014; Patterson, 2016), the current research developed a technique which is more specific to the SM population. Using a similar format to Moran (2001), CYP's contrast poles of 'non-speaking' and 'speaking' were explored, before identifying perceptions of their current and 'ideal' selves, 'movement' over time and action plans for the future. This was done without the need for verbal communication, using drawing, writing and prompt cards, reinforcing how PCP is "particularly effective in researching experiences that are hard for participants to articulate" (Burr, King and Butt, 2014,

p.343), and can be adapted to account for speech phobia (Humphreys and Leitner, 2007; Howarth, 2014). Due to the dynamic, collaborative, participant-led nature of PCP (Burr, King and Butt, 2014), it is hoped that this will be a valuable interview tool to help professionals understand the unique perspectives of those with SM, which ordinarily they may find difficult to communicate verbally.

### 6.3.3 Positive feedback

Following the interviews, evaluation forms completed by the five CYP and two parents (Appendices 16a/16b, 27) elicited valuable feedback about the research process, efficacy of the technique and my approach as a researcher. Figure 9 shows that participants expressed very positive views, with all statements scoring above 8.5/10.

Figure 9: Bar chart showing average ratings from the CYP's evaluation form

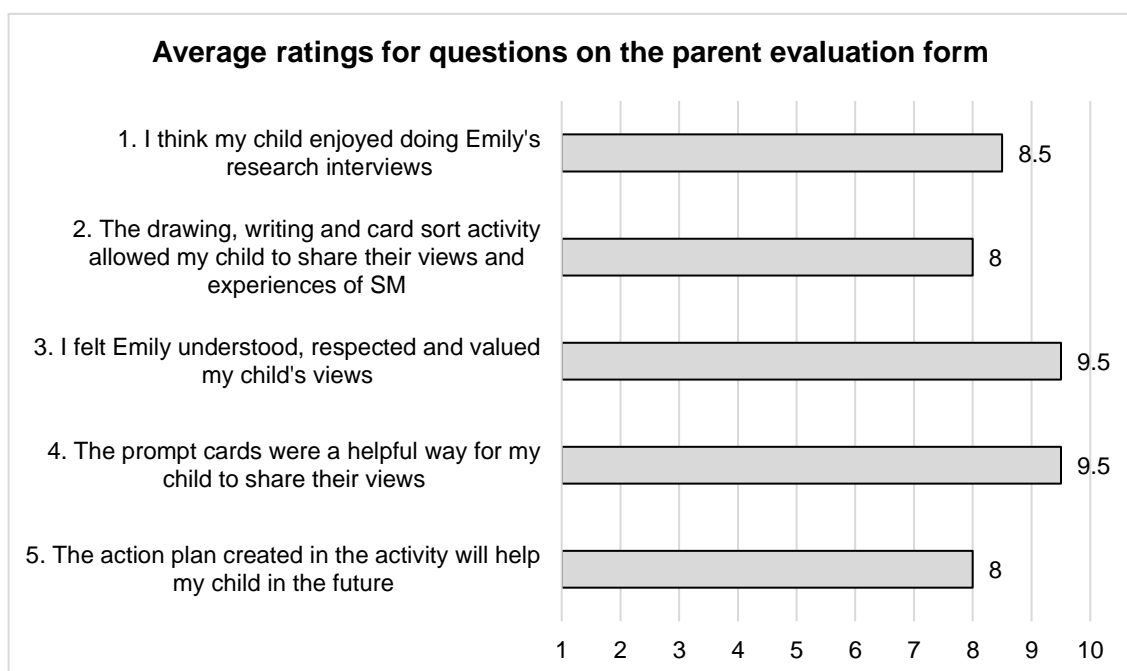


Responses illustrate that participants enjoyed the activity and felt it had enabled them to share their experiences of SM. They valued the prompt cards, thought the actions plans would help them in the future and felt I had understood, respected and valued their views. These positive ratings suggest that this may be a worthwhile technique to further develop for CYP with SM.

Additional feedback indicated that four participants (P2, P3, P4, P5) felt the activity was the right length, whereas one participant (P1) felt it was too long. Three participants (P1, P2, P5) identified people they would like to share their action plans with, whilst two (P3, P4) did not.

Similarly, two parents gave positive feedback about the interviews as shown in Figure 10.

*Figure 10: Bar chart showing average ratings from the parent evaluation form*



Additional comments from parents - as shown in Box 21 - further reflected positive views, particularly regarding how the technique had given them greater insight into their child's SM. This shows the value of collaborative working between the professional, parent and child with SM as Johnson and Wintgens (2016) suggest.

*Box 21: Additional comments from two of the parents on the parent evaluation form*

"It was interesting to find out about SM from P2's point of view. I didn't think she spoke at all in school" (P2's mother)

"Very good way of exploring views and experiences without pushing her, she seemed very relaxed. She usually shuts down if pressure is put on her, but no pressure made it easier for her to speak" (P2's mother)

"It was also very helpful for him to be able to use his cuddly toy to 'speak' through" (P5's mother)

"So pleased that you're carrying out this research. Really well planned too" (P5's mother)

Finally, Box 22 shows the positive feedback I received from SLTs after presenting my findings to the service (see Appendix 26 for slides), illustrating interest in the PCP approach and future collaboration between the EPS and SALTS to create a multidisciplinary SM pathway within the LA.



*Box 22: Feedback from SLTs following my presentation of the research findings*

“Timely and really useful research as we decide about our SM pathway in X”

“Thank you for doing this research – great to add to this UK-wide. Please can you feedback research to CAMHS team who I believe should be included in local multi-disciplinary approach for this client group”

“Very useful to know research details”

“Really excited and grateful for this research”

“It would be fantastic if the type of work that was offered in your research was available for current clients. The personal construct approach looks so useful”

“Really informative and interesting to hear about the research. Interested in collaborative working!”

“It would be really positive to have a bespoke service for SM children”

“Fascinating ideas. Nice to see Personal Construct Psychology being used in this way”

#### **6.4 Limitations**

There are several limitations to this study. Firstly, whilst the interview tool I developed is an adaptation of Moran’s (2001) Drawing the Ideal Self technique, it has a much narrower focus and target audience than the original format. As the method concentrates specifically on how individuals relate to the supplied polar constructs of ‘non-speaking’ and ‘speaking’, as opposed to the broader constructs of the ‘non-ideal’ and ‘ideal’ self donated by Moran (2001), it is therefore restrictive for use with the SM population only. However, this refinement was necessary to address the aims of the research and offers another topic-specific development of Drawing the Ideal Self in line with other researchers (Williams and Hanke, 2007; Green, 2014; Morgan-Rose, 2015).

A further limitation relates to the structured and deductive nature of the technique whereby the areas explored in parts A, B and C were decided prior to the interviews.

These shaped the questions asked at each stage of the process and therefore restricted the type of information participants were able to share about SM. Whilst topic areas in parts A, B and C were informed by previous literature findings (Appendix 4), this assumed their relevance to the CYP and that they would be able to respond. However, several 'don't know' responses suggested participants' uncertainty about certain themes and highlighted how the technique did not enable them to communicate freely about their SM due to the prescriptive topic areas.

Despite this, semi-structured questioning was used which allowed flexibility and further exploration of certain topics as appropriate, and question 11 on the evaluation form (Appendix 16a/16b) adopted an open-ended format to give participants the opportunity to share any additional information about their SM which was not covered in the interviews. However, as no further points were elicited at this stage, and feedback about the interviews was positive (see section 6.3.3), I felt confident that the technique was an effective way of eliciting views and experiences of SM. This said, I am mindful that the open-ended question on the evaluation form was not ideal as Johnson and Wintgens (2016) suggest the use of closed choices for the SM population.

Another limitation was the length of the interviews. Moran (2012a) suggests that the Drawing the Ideal Self process takes around an hour to complete, however each of my interviews took approximately three hours in total, which one of the participants felt was too long. As I had considerably underestimated the time needed to complete the task, the interviews had to be conducted over three to four sessions in a two-

week period to ensure it was manageable for the CYP and they were able to have a break. I felt that the gap between sessions disrupted the flow of the interviews, however this was managed by recapping responses from the previous session and rechecking the accuracy of my interpretations. Also, whilst I had the time to return on several occasions, I am mindful that this may not be possible in typical EP practice, due to high trading and statutory assessment work demands.

Additionally, following the interviews, participants were left to share their action plans with the key people they had identified on the evaluation form. However, I wonder whether their likely anxiety communicating both verbally and non-verbally may have hindered them from doing so, and therefore restricted future progress. I reflected that I could have been more proactive in ensuring the CYP were able to liaise with the relevant people (e.g. sending a copy to school/their SLT with their consent), however, as this was research, the purpose was to gain the CYP's views and experiences of SM as opposed to ongoing involvement as in typical EP casework.

Furthermore, use of just five CYP in the research limits the transferability of the findings, however this was not the aim of the study, but rather to elicit a rich and detailed phenomenological understanding (Cohen, Manion and Morrison, 2017) of SM. Despite the small sample size, identified themes connect with the findings of previous lived experience research, offering tentative transferability and supporting Verschuren (2003) and Yin's (2009) argument that multiple case studies can contribute to greater analytic generalisability due to lower variability.

Finally, I am mindful that by adopting an interpretative methodology, I played an active role in the research. Whilst I attempted to minimise researcher bias by applying a neutral stance, Thomas (2013) notes how researchers are never able to fully detach themselves from their own viewpoints. However, I hope that the quality-assurance measures detailed in Table 5 (pages 60-61) are sufficient in enhancing the trustworthiness of the data.

## 6.5 Further research suggestions

Table 10 outlines several areas which may be of interest for future research.

*Table 10: Possible areas for future research*

Suggestion for future research	Explanation
Production of standardised prompt cards (including more prompts for part C of the interview)	<p>Whilst written prompt cards for parts A, B and C were presented in the same format, the designs of the visual prompt cards were varied (Appendices 3a-3c). Therefore, for consistency and professionalism, it would be beneficial to use a standardised format for images e.g. use of the same design software.</p> <p>Additionally, I feel more prompt cards need to be developed for part C, particularly to help CYP express their 'movement' over time and identify points for their action plans, as 'don't know' responses indicated that free recall may have been difficult for them during this stage of the interview. Again, these would need to be informed by previous literature, to reduce researcher bias.</p>
Further use of this technique by other researchers to determine its dependability, and enhance transferability and authenticity by accessing a larger number of CYP with SM	Guba and Lincoln (no date, cited in Treharne and Riggs, 2014) state that triangulation and auditing by other researchers can be used to investigate the dependability of a technique. I am hoping to publish this technique, after which it would be interesting to gain feedback from any other researchers who trial the technique to determine its suitability for eliciting

	<p>the views of CYP and SM and to identify any areas that need to be further developed.</p> <p>It would also be helpful to gain additional feedback from more CYP as they complete the technique as this will enhance the credibility, transferability, confirmability and authenticity, and again inform any changes that need to be made.</p>
Further research into the link between SM and ASD	<p>Due to emerging evidence about the relationship between SM and ASD (Steffenberg <i>et al.</i>, 2018; Carroll, 2018; 2019), future research may wish to explore this comorbidity further. For example, it may be interesting to investigate whether the interview technique developed for this research is a helpful tool for exploring the 'non-speaking' and 'speaking' poles of CYP with ASD who also present with SM.</p>
Use of other PCP tools to explore the constructs of CYP with SM e.g. the self characterisation script (Kelly, 1955)	<p>Question 10 on the evaluation form (Appendix 16a/16b) asked participants if there were any other ways they thought researchers could gain the views of CYP with SM. One participant (P1) thought 'writing a self-profile' would be helpful in preparation for his transition to secondary school, identifying that this could be shared with his new teacher and TA so that they had a better understanding of his SM. P1's idea made me reflect on the applicability of the self-characterisation script (Kelly, 1955) for the SM population as this would be another way of eliciting an individual's personal constructs, without the need for verbal communication. As P1 suggested, this information could then be shared with key adults supporting the child to increase their understanding of the child's view of the world, and to ensure support is person-centred and tailored to their needs. This, therefore, is a research area which could be further explored.</p>
Adaptation of the 'ideal' and 'non-ideal' school technique (Williams and Hanke, 2007) for CYP with SM	<p>As environmental factors play a key role in maintaining SM (Johnson and Wintgens, 2016), it may also be interesting to explore CYP's constructs of the 'ideal' and 'non-ideal' school to understand perceived current barriers and their views on what desired provision would look like. As demonstrated in this research with the Drawing the Ideal Self technique (Moran, 2001), Williams and Hanke's</p>

	<p>method (2007) could be adapted so that CYP with SM can communicate their thoughts about school provision non-verbally. Results could then be shared with their key adults in school to consider appropriate environmental adjustments which account for the child's SM. This would be another way of appreciating CYP as the 'experts' in their lives, and ensuring support is person-centred.</p>
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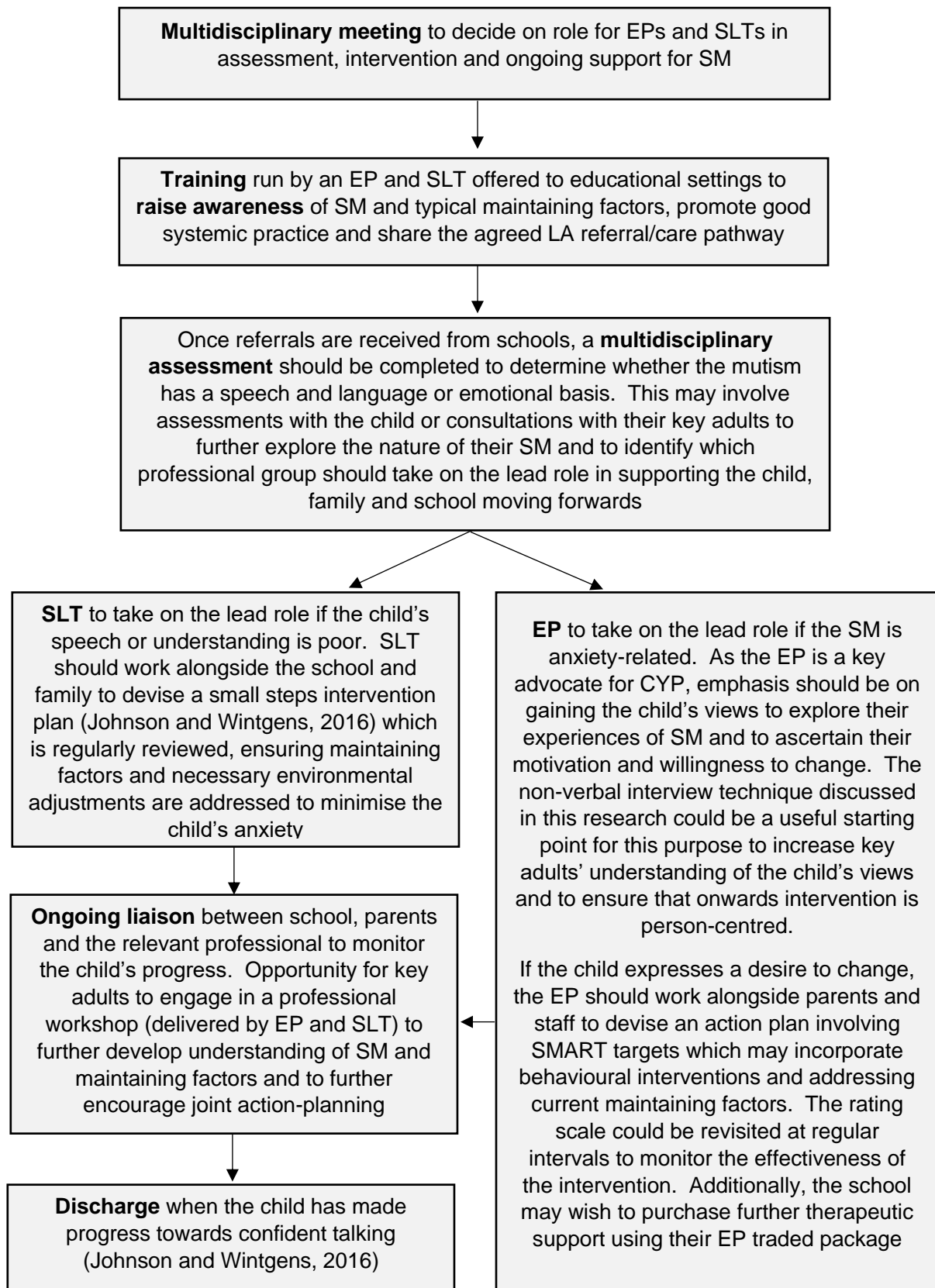
## 6.6 Implications for EP practice

The research findings have clear implications for EPs involved with CYP with SM.

Firstly, the study highlights the importance of appreciating those with SM as the 'experts' in their lives and empowering them to share their views and experiences, to ensure they are accurately understood by 'outsiders' and are at the centre of intervention planning. Whilst subjective accounts of SM are largely missing from the literature, likely due to the inaccessibility of traditional interview approaches, this research demonstrates the use of a novel non-verbal method to elicit CYP's unique perspectives, which currently may also be underrepresented in EP assessments for the same reason.

Secondly, findings emphasise the need for collaboration between the EPS and SALTS in my placement LA to develop a multidisciplinary care pathway for SM, in which CYP's views should play a key part. Johnson and Wintgens (2016) argue that a coordinated approach is vital for SM clients to explore individual, experiential and environmental factors, and to ascertain whether the mutism has a speech and language or emotional basis which has implications for future professional involvement. Figure 11 (page 141) outlines a proposed pathway, with a distinct role for the two professional groups, that I hope to develop further in the LA.

Figure 11: Proposed multidisciplinary care pathway for SM which I hope to further develop in my placement LA



The pathway notes how if the initial assessment identifies that SM is anxiety-related, the EP has a unique role in supporting this client group. With EPs being key advocates for CYP, and considering their wider collaborative role with staff and parents (Gersch, Lipscomb and Potton, 2017), the technique presented in this research may provide a useful starting point for them to consult directly with those with SM without the need for speech, before feeding back their views and identifying next steps with key stakeholders. It enables practitioners to explore how CYP conceptualise their 'non-speaking' and 'speaking' patterns, their 'movement' over time and their hopes for the future. More simply, it determines whether CYP acknowledge their SM (i.e. do they associate more closely to the 'non-speaking' or 'speaking' character?) and explores their motivation to change in relation to their 'ideal' self. These are important factors for EPs to consider, to ascertain whether talking is an important goal for CYP and whether they are ready for support in this area. Prochaska, DiClemente and Norcross (1992) note how understanding a child's viewpoint and their readiness to change are crucial in informing future intervention.

With the child's consent, the EP could then work with key adults to increase their understanding of the child's views and desired progress, and to devise a person-centred intervention plan based on ideas identified in their action plan. Additionally, as disseminating research findings and promoting evidence-based practice are other core functions of the profession (Frederickson and Miller, 2008), EPs should communicate key themes from this study, and the previous lived experience studies, to parents and staff to raise awareness of the tentative evidence regarding the prevalence of anxiety, CYP's desire to change, the role of staff and peers in the



causes and maintenance of SM, the importance of support and empathy from a trusted keyworker and the value of behavioural interventions. However, it should be noted that despite these common themes, the unique experiences of the participants in this study all varied, further emphasising the need for an individualised approach.

Subsequently, during consultations, EPs should explore current maintaining factors and necessary environmental adjustments, with emphasis placed on removing the pressure to speak and promoting alternative communication methods to reduce the child's anxiety (Hill, 2019). Furthermore, as some participants in this study struggled with the action planning stage, and other individuals acknowledged how difficult SM can be to overcome (Roe, 2011; Walker and Tobbell, 2015; Albrigtsen, Eskeland and Mæhle, 2016), the EP has a key consultative role to support staff and parents to identify SMART targets which are within the child's capability. The rating scale from part C could be revisited at regular intervals to monitor how effective the child feels the interventions have been in facilitating progress towards their 'ideal' self.

Whilst the interview technique should not be limited to EPs, I feel the profession are well-placed to use it due to their advocacy role for CYP and their primary focus on prompting psychological wellbeing, working systemically with key adults around the child and their value as a "key therapeutic resource" (Mackay, 2007, p.7) for schools. Additionally, since the gradual shift towards a traded service delivery model, EPs are now able to negotiate the services offered (Lee and Woods, 2017) and apply psychology more dynamically and creatively (Booker, 2013), thus should promote their unique contribution in SM casework.

## **6.7 Final comments**

This research used a novel PCP technique to elicit the ‘non-speaking’ and ‘speaking’ constructs of five CYP with SM. The study offers a unique contribution to the literature and adds to the limited evidence base regarding lived experiences of SM, identifying ten key themes relating to the research questions. Despite the limitations discussed in section 6.4, positive feedback was gained about the research process and efficacy of the technique, suggesting that it may be a worthwhile method to further develop for the SM population. Areas of future research and implications for practice have been discussed, including the importance of collaboration between the EPS and SALTS to develop a multidisciplinary care pathway, and the unique advocacy role of EPs when working with CYP with SM.

It was a privilege to conduct the research and empower CYP to tell their unique stories as, ultimately, they are the real ‘experts’ of Selective Mutism.

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## APPENDICES

### **APPENDIX 1: Crib sheet and instructions for the Drawing the Ideal Self method (Moran, 2001) taken from the prompt sheet (Moran, 2012b)**

#### **Equipment**

Three sheets of plain paper (A4 is a good size) and black pen.

#### **Instructions**

Throughout the task, the child does the drawings and the adult writes the labels. This ensures that the labels are recorded accurately. Detailed instructions and information about this technique are available in the Drawing the Ideal Self Manual: A Personal Construct Technique to Explore Self-Esteem (Moran, 2012a) which is downloadable from [www.drawingtheidealsself.co.uk](http://www.drawingtheidealsself.co.uk).

#### **PART A: Drawing the kind of person you would not like to be like**

##### **The person**

Think about the kind of person you would not like to be like. This is not a real person, but someone in your imagination (it could be made up of various people you have known). Make a quick sketch of this person in the middle of the page. How would you describe this person? What kind of a person are they? Tell me three things about what he/she is like? *Write the labels for the client next to the sketch.*

##### **The bag**

This person goes out to school or college each day and takes his/her bag. What kind of a bag would that be and what would be inside it? *Sketch and label the items.*

##### **The birthday present**

What would this person like for his/her birthday? *Sketch and label the present.*

##### **With family**

How would this person get on with his/her family? *Sketch and write descriptions.*

##### **With friends**

How would this person get on with his/her friends? *Sketch and write descriptions.*

##### **At school**

How would this person get on at school? *Sketch and write descriptions.*

### **Greatest fear**

Everyone is afraid of something. What would this person be afraid of? *Sketch and write descriptions.*

### **History**

How did this person come to be like this? What is his/her history? Was he/her always like this from birth or did he/she become like this? What happened to him/her? *Write what the child says.*

### **Future**

What will this person's future be like? What will become of him/her? *Write what the child says.*

### **PART B: Drawing the kind of person you would like to be like**

Using the same instructions as for part A above, make a further labelled drawing about the kind of person you *would like to be like*, discussing the person, the bag, the birthday present, with family, with friends, at school, their greatest fear, their history and their future.

### **PART C: Mapping development and 'movement' towards the person he/she wants to be like**

Place the two drawings on the table, with the first on the left. Place a piece of paper in a landscape position on the table in between the drawings and draw a horizontal line half-way down the page. The line should be the length of the page, joining the two pictures. Ask the child to mark where he/she would rate him/herself at various points in time and label each point. The most essential points are *where he/she would say he/she is now* and *where he/she would like to be (ideal self)*. It may be helpful to check *the point they would settle for* (is ideal the only option?)

### **Mapping development over time**

Map where the child would rate him/herself at different points in time. (E.g. Where were you as a child of 5? What about when you started secondary school?) Label each point. Ask about the differences between points in time.

### **How did you get there?**

Look at differences between points (e.g. between now and an earlier point). Ask the child for the reasons for these changes. How come you moved from here to here? What was happening to help you move up/what made you move down? This is especially useful for exploring any large changes.

### **How could you move towards your ideal?**

Ask for three things others can do to help the child move from where they are now to their ideal rating point. Ask for three things the child could do to help them get to their ideal point.

### **Mapping different views of the child**

Where would other people say you were along this line? Why would they say that? (E.g. Where would your mum say you were? What about your sister? Where would your friend say you were?) Ask about the differences in views. What effects do the various views have on the child?

### **Discussion**

The final step in the process is to consider what sense the work makes to you and to discuss that with the child. It is vital to this approach that you do not miss this part out: the whole approach is designed to explore the child's view and you cannot be certain that the child feels their views are represented unless you check it out with them. If the aim is to report back to other people on the child's views, this needs to be discussed with the child, outlining how you will present the explanation and information and whether the pictures can be shown to other people. It is good practice to offer to copy the pictures for the child but be cautious about when they will take them away and to whom they might be shown. It may be better to hold on to the copies until it is explained to other people so that they make sense when they are viewed.

## **APPENDIX 2: Crib sheet and instructions for the research interview technique adapted from Moran's Drawing the Ideal Self method (2001)**

### **Equipment**

Three large sheets of paper, a pencil and written/visual prompts relating to the areas being explored below (see Appendices 3a - c).

### **Instructions**

Throughout the task, the researcher will ask the CYP the questions below and they will be required to draw, write or use the prompt cards to express their views. Questions may be adapted/reworded depending on the child's age/understanding and further exploratory questions will be asked as necessary. There will be no pressure for the participant to speak at any point during the activity.

### **PART A: Drawing the kind of person who *does not speak***

#### **The Person**

Think about the kind of person who *does not speak* in some situations. This is not a real person but someone in your *imagination*. Make a quick drawing of this person in the middle of the page.

- How would you describe this person?
- Tell me three things about what they are like?

*Encourage the participant to draw, write or use the prompt cards to respond.*

#### **Situation/Activity**

- Where is this person?
- What are they doing?
- Are they like this in other situations too?

*Encourage the participant to draw, write or use the prompt cards to respond.*

#### **Communication Style**

- How does this person communicate?

*Encourage the participant to draw, write or use the prompt cards to respond.*

#### **Thoughts**

- What is this person thinking?

*Encourage the participant to draw, write or use the prompt cards to respond.*

#### **Feelings/Physiological signs**

- How is this person feeling?

- What physiological signs do they feel in their body?

*Encourage the participant to draw, write or use the prompt cards to respond.*

### **Interactions**

- Who is this person with?
- What would they say about this person?

*Encourage the participant to draw, write or use the prompt cards to respond.*

### **Greatest Fear**

- What is this person's greatest fear in life?

*Encourage the participant to draw, write or use the prompt cards to respond.*

### **History**

- How did this person come to be like this?
- Were they always like this or did something happen?

*Encourage the participant to draw, write or use the prompt cards to respond.*

### **Future**

- What will this person's future be like?
- What do they want to happen?

*Encourage the participant to draw, write or use the prompt cards to respond.*

### **PART B: Drawing the kind of person who *does speak***

Using the same instructions as part A, the researcher will ask the CYP about the kind of person who *does speak*, again exploring the *person, situation/activity, communication style, thoughts, feelings/physiological signs, interactions, greatest fear, history and future*. The participant will be encouraged to draw, write or use the prompt cards (see Appendices 3a – c) to respond. Again, there will be no pressure to speak.

### **PART C: Imaginary → Self, Mapping 'movement' over time and Action Plan**

When responses from part A (the kind of person who *does not speak*) and part B (the kind of person who *does speak*) are complete, these are placed side by side in front of the CYP. Another piece of paper is then placed between parts A and B in landscape position and a horizontal line is drawn across the middle of the page to join the two pictures.

Using the corresponding arrows (Appendix 3c) the CYP are then asked to rate where they are on the scale (between the kind of person who *does not speak* and the kind of person who *does speak*) **NOW** and where they would like to be in the future (their '**IDEAL**' self). They are also asked where they would **SETTLE FOR** (is 'ideal' the only option?).



When exploring their **NOW** and **IDEAL** ratings, the CYP are asked which aspects of the 'non-speaking' and 'speaking' characters they can currently, or want to, relate to in the future (description of the *person, situation/activity, communication style, thoughts, feelings/physiological signs, interactions, greatest fear, history and future*) by pointing, drawing, writing or using prompt cards as required.

### **Mapping 'movement' over time**

Using the corresponding arrows (Appendix 3c) the CYP are then asked to rate where they were on the scale (between the kind of person who *does not* speak and the kind of person who *does* speak) at various points in the past (e.g. **NURSERY, YEAR 2, 4, 6** etc.).

Differences between points in time are explored (i.e. what helped you move up from here to here? or what happened that made you move down from here to here?) The CYP are invited to draw or write their responses.

### **Mapping different views of the child**

Using the corresponding arrows (Appendix 3c) the CYP are asked where they think other people would rate them on the scale (i.e. **MUM, DAD, SIBLINGS, FRIEND, TEACHER** etc.). Differences in views are explored e.g. why would they say that? The CYP are invited to draw or write their responses.

### **Creating an action plan**

The CYP are then asked how they could progress towards their 'ideal self'. What three things could *they* do to help them move from where they are now to their 'ideal' rating? What three things could *others* do to help them move from where they are now to their 'ideal' rating? The CYP are invited to draw or write their responses in a table.

### **Summarising responses**

The final step is for the researcher to summarise their interpretations of the CYP's responses from the three stages of the interview. This is important to check their views have been accurately understood. Once copied for data analysis purposes part A, B and C responses are sent to the CYP by post along with a personalised written summary.

### APPENDIX 3a: Written prompt cards for parts A and B of the interviews

These were presented on individual cards and were available if participants wanted to express their views in this way. If this was the case, they were required to point to the **'prompt card'** sign (see below). Alternatively, they could select the **'I don't know'** card (see below) if they were unsure about their response to a question.

#### The Person/Feelings

<b>THE PERSON/FEELINGS</b>	Anxious	Worried	Nervous
Silent	Shy	Quiet	Introvert
Emotional	Sad	Unhappy	Self-conscious
Unconfident	Low Self-esteem	Sensitive	Stubborn
Devious	Isolated	Lonely	Left out
Stupid	Frustrated	Annoyed	Angry
Embarrassed	Relaxed	Happy	Loud
Assertive	Talkative	Sporty	Studios
Hard working	Creative	Artistic	Fun
Humorous	Sociable	Friendly	Thoughtful
Caring	Kind	Helpful	Confident
	Fine	Other	

#### Situation/Activity

<b>SITUATION</b>	In school	At home
Somewhere in public	Other	
<b>ACTIVITY</b>	Activity	Lesson
	Other	


#### Communication style

<b>COMMUNICATION STYLE</b>	Speaking normally	Nodding or shaking head
Pointing	Writing down answers	Drawing
Whispering	Speaking quietly	Speaking through another person
Recording voice	Text message	Symbol Card
Email	Sign Language	Telephone
	Other	

#### Thoughts

<b>THOUGHTS</b>	Speaking is difficult for me	I find it difficult to make friends
I don't want to go to school	I want to be able to talk	I struggle with learning because I can't ask for help
I'm scared to put my hand up	I feel invisible	Other

**Physiological signs**

<b>PHYSIOLOGICAL SIGNS</b>	Throat tightens	Feeling sick
Blushing	Heart beats fast	Sweating
Muscles feel tense	Feeling shaky	Feeling lightheaded
Feeling dizzy	Headache	Butterflies in tummy
Shaky voice	Difficulty breathing	Needing the toilet
Muscles feel relaxed	Smiling	Calm
Other		

**Interactions**

<b>INTERACTIONS</b>	No one	Parent(s)
Sibling(s)	Other relatives	Animal
Friend(s)	Teacher(s)	Other

**Greatest fear**

<b>GREATEST FEAR</b>	Talking to people at home	Talking to people in school
Talking to people out in the public	Other people hearing their voice	A certain activity
A certain lesson	A certain teacher	Other phobia – e.g. animal/place/food/object
Other		

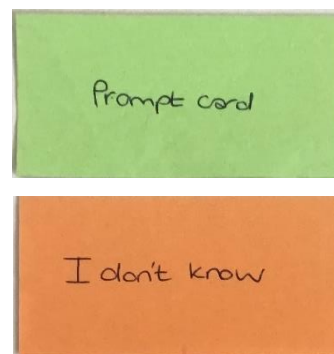
**History**

<b>HISTORY</b>	Starting Nursery	Starting School
Moving House	Moving School	Bullying
Teacher e.g. forcing them to speak/shouting	Other people spoke for them	Other people thought they wouldn't speak – conformed to expectations
Illness	Withdrew from social situations	Traumatic life event
Separation from parents	Other	

**Future**

<b>FUTURE</b>	Speaking person	Non-speaking Person
The same as now	Job	Family
Help with speaking	Other	

**'Prompt card' & 'I don't know' cards**





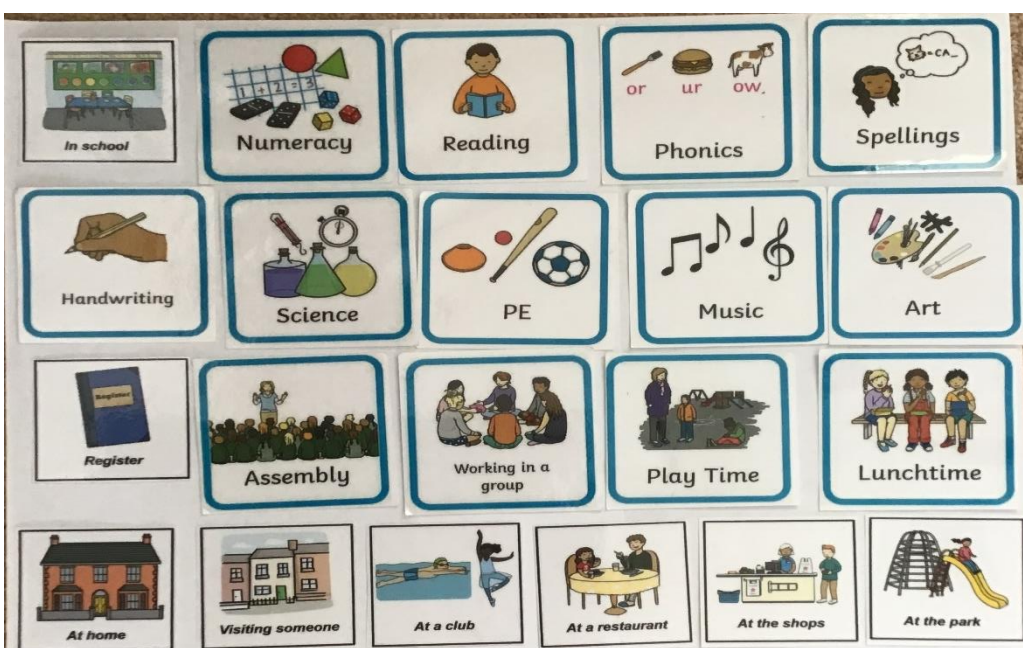
**APPENDIX 3b: Visual prompt cards that were developed for some of the part A and B areas following the pilot study to account for younger participants / poorer readers**

*These were presented on individual cards and were available if participants wanted to express their views in this way. If this was the case, they were required to point to the 'prompt card' sign (see above). Similarly, they could select the 'I don't know' card (see above) if they were unsure about their response to a question.*

**The Person/Feelings**

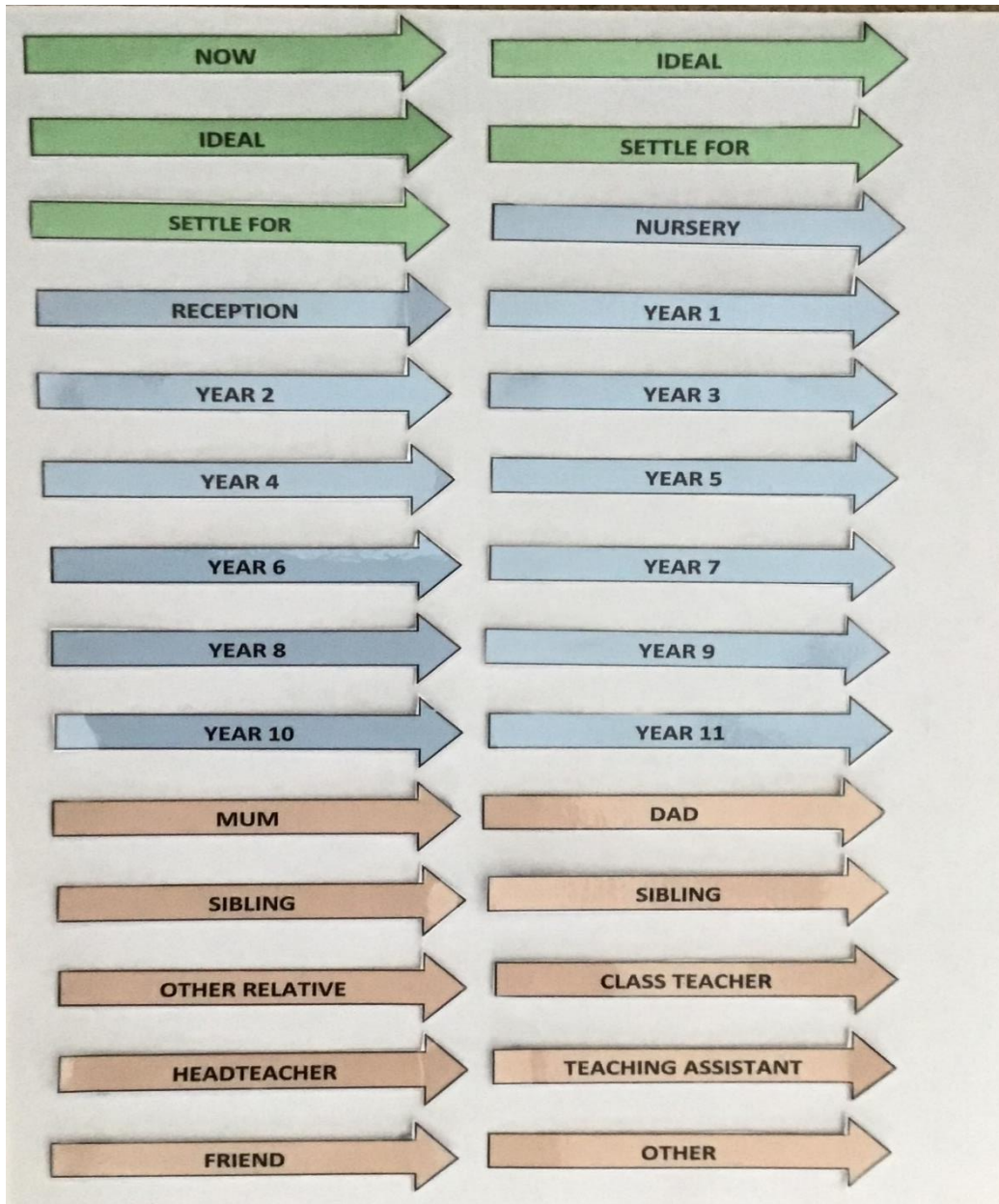


**Situation/Activity**

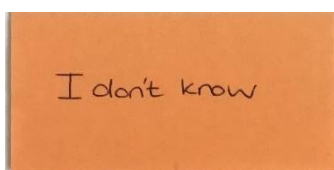


### **APPENDIX 3c: Prompt cards for part C of the interviews**

*These were presented on individual cards and were provided for participants to complete the rating scale part of the activity. Again, the 'I don't know' card (see below) was available if they were unsure about their response to a question.*



### **'I don't know' card**



**APPENDIX 4: Table representing the prompts available for each of the nine areas in parts A and B of the interviews, and the literature which informed these**

Area being explored	Written/visual prompts which were available if needed by participants and the literature which informed these
<p><b>The person</b></p> <ul style="list-style-type: none"> <li>• How would you describe this person?</li> <li>• Tell me three things about what he/she is like?</li> </ul>	<ul style="list-style-type: none"> <li>• Anxious/Worrier/Nervous (Roe, 2011; APA, 2013)</li> <li>• Silent (Cline and Baldwin, 2004)</li> <li>• Shy (Cline and Baldwin, 2004; Roe, 2011)</li> <li>• Quiet/Introvert (Roe, 2011)</li> <li>• Emotional (Roe, 2011)</li> <li>• Sad/Unhappy (Roe, 2011)</li> <li>• Self-conscious/Unconfident/Low Self-esteem (Roe, 2011)</li> <li>• Sensitive (Cline and Baldwin, 2004; Roe, 2011)</li> <li>• Stubborn (Cline and Baldwin, 2004; Roe, 2011)</li> <li>• Devious (Cline and Baldwin, 2004)</li> <li>• Isolated/Lonely (Roe, 2011)</li> <li>• Frustrated/Angry/Annoyed (Roe, 2011)</li> <li>• Embarrassed (Roe, 2011)</li> <li>• Happy (Roe, 2011)</li> <li>• Relaxed (Roe, 2011)</li> <li>• Assertive (Cline and Baldwin, 2004)</li> <li>• Loud/Talkative (Roe, 2011)</li> <li>• Sporty (Roe, 2011)</li> <li>• Studious/Hard working (Roe, 2011)</li> <li>• Creative/Artistic (Roe, 2011)</li> <li>• Fun/Humorous (Roe, 2011)</li> <li>• Sociable/Friendly (Roe, 2011)</li> <li>• Thoughtful/Caring/Kind/Helpful (Roe, 2011)</li> <li>• Confident (Roe, 2011)</li> <li>• Other (CYP can come up with their own descriptions)</li> </ul>
<p><b>Situation/Activity</b></p> <ul style="list-style-type: none"> <li>• Where is this person?</li> <li>• What are they doing?</li> <li>• Are they like this in other situations too?</li> </ul>	<ul style="list-style-type: none"> <li>• School</li> <li>• Home/with family</li> <li>• In public – where?</li> </ul> <p style="text-align: right;">} (Ford <i>et al.</i>, 1998; Bergman <i>et al.</i>, 2008)</p> <ul style="list-style-type: none"> <li>• Activity? Lesson?</li> <li>• Does their speaking differ from situation to situation (home/school/public)?</li> </ul>
<p><b>Communication style</b></p> <ul style="list-style-type: none"> <li>• How does this person communicate?</li> </ul>	<ul style="list-style-type: none"> <li>• Speaking normally</li> <li>• Nodding or shaking head</li> <li>• Pointing</li> <li>• Writing down answers</li> <li>• Drawing</li> <li>• Whispering</li> </ul> <p style="text-align: right;">} (Roe, 2011)</p>

	<ul style="list-style-type: none"> <li>• Speaking quietly</li> <li>• Speaking through another person</li> <li>• Recording voice</li> <li>• Text message</li> <li>• Symbol Card</li> <li>• Email</li> <li>• Sign Language</li> <li>• Telephone</li> <li>• Other (CYP can come up with their own answer)</li> </ul> <p style="text-align: right;">(Roe, 2011)</p>
<p><b>Thoughts</b></p> <ul style="list-style-type: none"> <li>• What is this person thinking?</li> </ul>	<ul style="list-style-type: none"> <li>• Speaking is difficult for me</li> <li>• I find it difficult to make friends</li> <li>• I don't want to go to school</li> <li>• I want to be able to talk</li> <li>• I struggle with learning because I can't ask for help</li> <li>• I'm scared to put my hand up</li> <li>• I feel invisible (Albrigtsen, Eskeland &amp; Maehle, 2016)</li> <li>• Other (CYP can come up with their own answer)</li> </ul> <p style="text-align: right;">(Roe, 2011)</p>
<p><b>Feelings</b></p> <ul style="list-style-type: none"> <li>• How is this person feeling?</li> </ul> <p><b>Physiological signs</b></p> <ul style="list-style-type: none"> <li>• What physiological signs do they feel in their body?</li> </ul>	<ul style="list-style-type: none"> <li>• Fine (Roe, 2011)</li> <li>• Left out (Roe, 2011)</li> <li>• Stupid (Roe, 2011)</li> <li>• Other feeling prompts in '<b>The person</b>' section (see above)</li> <li>• Other (CYP can come up with their own answer)</li> </ul> <ul style="list-style-type: none"> <li>• Throat tightens (Roe, 2011)</li> <li>• Feeling sick (Roe, 2011)</li> <li>• Blushing</li> <li>• Heart beats fast</li> <li>• Sweating</li> <li>• Muscles feel tense</li> <li>• Feeling shaky</li> <li>• Feeling lightheaded/dizzy/headache</li> <li>• Butterflies in tummy</li> <li>• Shaky voice</li> <li>• Difficulty breathing</li> <li>• Needing the toilet</li> <li>• Muscles feel relaxed</li> <li>• Smiling</li> <li>• Calm</li> <li>• Other (CYP can come up with their own answer)</li> </ul> <p style="text-align: right;">(Literature about general anxiety e.g. Stallard, 2005)</p>
<p><b>Interactions</b></p> <ul style="list-style-type: none"> <li>• Who is this person with?</li> </ul>	<ul style="list-style-type: none"> <li>• No one</li> <li>• Parent(s)</li> <li>• Sibling(s)</li> <li>• Other relatives</li> <li>• Animal</li> </ul> <p style="text-align: right;">(Roe, 2011)</p>

<ul style="list-style-type: none"> <li>• What would they say about this person?</li> </ul>	<ul style="list-style-type: none"> <li>• Friend(s) } (Roe, 2011)</li> <li>• Teacher(s) }</li> <li>• Other (CYP can come up with their own answer)</li> <li>• Use of prompts in <b>'The person'</b> section (see above)</li> </ul>
<p><b>Greatest fear</b></p> <ul style="list-style-type: none"> <li>• What is this person most afraid of in life?</li> </ul>	<ul style="list-style-type: none"> <li>• Talking to people at home (who?) } (Ford <i>et al.</i>,</li> <li>• Talking to people in school (who?) } 1998; Bergman</li> <li>• Talking to people out in public (who?) } <i>et al.</i>, 2008)</li> <li>• Other people hearing their voice (why?) (Roe, 2011)</li> <li>• Activity/lesson?</li> <li>• Other phobia – e.g. animal/place/food/object/activity? (Johnson and Wintgens, 2016)</li> <li>• Other (CYP can come up with their own answer)</li> </ul>
<p><b>History</b></p> <ul style="list-style-type: none"> <li>• How did this person come to be like this?</li> <li>• Were they always like this or did some happen?</li> </ul>	<ul style="list-style-type: none"> <li>• Starting Nursery/School (Roe, 2011)</li> <li>• Moving house (Roe, 2011)</li> <li>• Moving school (Roe, 2011)</li> <li>• Bullying (Roe, 2011)</li> <li>• Teacher e.g. forcing them to speak/shouting (Roe, 2011; Albrigtsen, Eskeland and Mæhle, 2016)</li> <li>• Other people spoke for them (Roe, 2011; Johnson and Wintgens, 2016)</li> <li>• Other people thought they wouldn't speak – conformed to negative expectations (Omdal, 2007)</li> <li>• Illness (Omdal, 2007)</li> <li>• Withdrew from social situations (Omdal, 2007)</li> <li>• Traumatic life event (Omdal, 2007)</li> <li>• Separation from parents (Omdal, 2007)</li> <li>• Other (CYP can come up with their own answer)</li> </ul>
<p><b>Future</b></p> <ul style="list-style-type: none"> <li>• What will this person's future be like?</li> <li>• What do they want to happen?</li> </ul>	<ul style="list-style-type: none"> <li>• Speaking person (Omdal, 2007; Manassis, 2015; Albrigtsen, Eskeland and Mæhle, 2016;)</li> <li>• Non-speaking person (Walker and Tobbell, 2015)</li> <li>• The same as now</li> <li>• Job (Omdal, 2007)</li> <li>• Family (Omdal, 2007)</li> <li>• Help with speaking (Roe, 2011; Albrigtsen, Eskeland and Mæhle, 2016)</li> <li>• Use of prompts in <b>'The person'</b> section (see above)</li> <li>• Other (CYP can come up with their own answer)</li> </ul>



**APPENDIX 5: Application for ethical review form completed prior to conducting the research** *(Separate references and appendices sections were attached to this form when it was submitted, however they have been removed to avoid repetition as they are included in the main references and appendices sections of this document)*

**UNIVERSITY OF BIRMINGHAM  
APPLICATION FOR ETHICAL REVIEW**

**Who should use this form:**

This form is to be completed by PIs or supervisors (for PGR student research) who have completed the University of Birmingham's Ethical Review of Research Self Assessment Form (SAF) and have decided that further ethical review and approval is required before the commencement of a given Research Project.

**Please be aware that all new research projects undertaken by postgraduate research (PGR) students first registered as from 1st September 2008 will be subject to the University's Ethical Review Process. PGR students first registered before 1<sup>st</sup> September 2008 should refer to their Department/School/College for further advice.**

**Researchers in the following categories are to use this form:**

1. The project is to be conducted by:
  - staff of the University of Birmingham; or
  - a research postgraduate student enrolled at the University of Birmingham (to be completed by the student's supervisor);
2. The project is to be conducted at the University of Birmingham by visiting researchers.

**Students undertaking undergraduate projects and taught postgraduates should refer to their Department/School for advice.**

**NOTES:**

- Answers to questions must be entered in the space provided.
- An electronic version of the completed form should be submitted to the Research Ethics Officer, at the following email address: [aer-ethics@contacts.bham.ac.uk](mailto:aer-ethics@contacts.bham.ac.uk). Please **do not** submit paper copies.
- If, in any section, you find that you have insufficient space, or you wish to supply additional material not specifically requested by the form, please put it in a separate file, clearly marked and attached to the submission email.
- If you have any queries about the form, please contact the [Research Ethics Team](#).

**Before submitting, please tick this box to confirm that you have consulted and understood the following information and guidance and that you have taken it into account when completing your application:**

- The information and guidance on the University's ethics webpages (<https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-of-Research.aspx>)
- The University's Code of Practice for Research ([http://www.as.bham.ac.uk/legislation/docs/COP\\_Research.pdf](http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf))

<b>UNIVERSITY OF BIRMINGHAM APPLICATION FOR ETHICAL REVIEW</b>	<i>OFFICE USE ONLY:</i> Application No: Date Received:
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**1. TITLE OF PROJECT**

We Do Have a Voice: Using Personal Construct Psychology to explore how children and young people with Selective Mutism construct their speaking and non-speaking selves
---

**2. THIS PROJECT IS:**

- University of Birmingham Staff Research project   
 University of Birmingham Postgraduate Research (PGR) Student project   
 Other  (Please specify):

**3. INVESTIGATORS**

**a) PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)**

Name: Title / first name / family name	Dr Colette Soan
Highest qualification & position held:	EdPsychD / Academic and Professional Tutor
School/Department	School of Education (Disability, Inclusion and Special Needs Department)
Telephone:	*****
Email address:	

Name: Title / first name / family name	Sue Morris
Highest qualification & position held:	M. Ed. (Ed Psych) / Programme Director of Professional Training in Educational Psychology
School/Department	School of Education (Disability, Inclusion and Special Needs Department)
Telephone:	*****
Email address:	

**b) PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)**

Name: Title / first name / family	
Highest qualification & position held:	
School/Department	
Telephone:	
Email address:	

**c) In the case of PGR student projects, please give details of the student**

Name of Course of study: Principal	Emily Strong	Student No:	
	Applied Educational and Child Psychology Doctorate	Email address:	
	Sue Morris		

**4. ESTIMATED START OF PROJECT**      Date:

**ESTIMATED END OF PROJECT**      Date:

## 5. FUNDING

List the funding sources (including internal sources) and give the status of each source.

<i>Funding Body</i>	<i>Approved/Pending /To be submitted</i>
N/A.	

**If you are requesting a quick turnaround on your application, please explain the reasons below (including funding-related deadlines). You should be aware that whilst effort will be made in cases of genuine urgency, it will not always be possible for the Ethics Committees to meet such requests.**

I am in Year 2 of a three-year, full-time postgraduate professional training programme, of which completion of this research forms one of the assessed research requirements. The thesis needs to be submitted in June 2019 for viva voce examination in July/August 2019. Therefore, the sooner I can begin the empirical/fieldwork components of the study, the more feasible my timely completion and submission of this work will be.

## 6. SUMMARY OF PROJECT

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

### **Purpose**

*\* These terms will be defined in the glossary (see end of ethical approval form)*

The purpose of the research is to explore how children and/or young people (CYP) diagnosed with Selective Mutism (SM) construct their speaking and non-speaking selves as there is limited existing research which has accessed these 'hidden views'. Much of the literature focuses on different intervention approaches for SM where 'speaking' is the goal, however this 'medicalises' SM and creates a discourse that CYP should want to, and be able to talk consistently, without considering their views, feelings, motivation, willingness or readiness to change. Using an adaptation of the 'Drawing the Ideal Self' technique\* (Moran, 2001), based on Personal Construct Psychology\* (PCP; Kelly, 1955), I aim to elicit participant's perceptions and polar constructs of situations in which they speak and do not speak, by exploring their thoughts, feelings, fears, interactions, history and hopes for the future. This will give a valuable insight into what (if any) impact they feel SM has had on their life and whether they value talking as an important goal for them in the future.

### **Background rationale**

SM is considered to be a low incidence condition (Johnson and Wintgens, 2016), affecting approximately 1 in 150 CYP (Forrester and Sutton, 2015), but it has been argued that this may be an underrepresentation due to a lack of knowledge about this phenomenon (Camposano, 2011). It is defined by the DSM-V\* (American Psychological Association, 2013) and ICD-11 Beta-draft\* (World Health Organisation, due in 2018) as an anxiety disorder where an individual presents a consistent speaking pattern in some situations but fails to speak in others and has also been conceptualised as a learned fear or phobia of speech in certain social situations such as school (Johnson and Wintgens, 2016).

Literature searches have identified very few studies which explore SM from individuals' lived experiences and perspectives. Walker and Tobbell (2015) highlight how much of the existing SM literature relies on "observer interpretations rather than experiential accounts" (p.457) raising

concerns that “methodologies which fail to take into account the perspectives of those with SM may be presenting a misleading or partial representation of SM by reporting only how it appears to outsiders” (p.456).

Following a systematic literature search, just five research papers were found which directly consulted with individuals with SM, with two studies focusing on adult participants (Omdall, 2007; Walker and Tobbell, 2015) and three studies involving CYP (Omdall and Galloway 2007; Roe, 2011; Albrigtsen Eskeland and Maehle, 2016). Of this research, two papers utilise subjects who have ‘recovered’ from SM (Omdal, 2007; Albrigtsen, Eskeland and Maehle, 2016), leaving just one study exploring the views of adults still experiencing SM (Walker and Tobbell, 2015) and two studies eliciting CYP’s current experiences of SM (Omdal and Galloway, 2007; Roe, 2011). A number of data collection methods have been used including semi-structured interviews both face-to-face (Omdall, 2007; Albrigtsen, Eskeland and Maehle, 2016) and online (Walker and Tobbell, 2015), postal/email questionnaires (Roe, 2011) and Raven’s Controlled Projection for Children\* (Omdall and Galloway, 2007).

These papers have provided interesting and insightful results about the perceived origins, maintaining factors, experiences, and recovery of SM, some of which have challenged widely accepted thinking in this area. For example, participants in one paper attributed a ‘traumatic’ event to the origin of their SM (Omdall, 2007), which contradicts the findings of previous studies where there was no evident link between early psychological or physical trauma and SM (Black and Udhe, 1995; Dummit et al, 1997). Additionally, retrospective studies exploring successful recovery identified personal shifts in thinking involving a conscious decision to change (Omdall, 2007), self-recognition of the positive impact of talking and feeling understood (Albrigtsen, Eskeland and Maehle, 2016) rather than a particular intervention itself. From a person-centred perspective, this emphasises the importance of enabling CYP with SM to share their stories to ensure their constructions, experiences and views are accurately understood, valued and acted upon when considering how best to support them, rather than professionals making decisions for them.

The research aims to address the following gaps in the existing literature:

- None of the existing research has been conducted by an Educational Psychologist (EP) or Trainee EP so this study will offer a unique contribution and psychological perspective to the literature as well as helping to inform the role of EPs in assessment and intervention for SM
- Two of the five identified studies focus on retrospective reports of SM (Omdall and Galloway, 2007; Albrigtsen, Eskeland and Maehle, 2016), highlighting the need for more research into current ‘lived’ experiences
- Only two of the five identified research papers were conducted in the UK (Roe, 2011; Walker and Tobbell, 2015) and just one of these accessed the ‘voices’ of CYP with SM regarding their current experiences (Roe, 2011), identifying the need for more UK-based research in this area
- Roe (2011) gathered quantitative and qualitative information about CYP’s experiences using an email/postal questionnaire but no UK research has been conducted with CYP face-to-face
- None of five studies used an adaptation of the PCP technique ‘Drawing the Ideal Self’ (Moran, 2001) to elicit the views of CYP with SM. This technique has previously been used successfully to gain the perspectives of those with communication difficulties (Moran, 2001; 2005; 2006; Williams and Hanke, 2007), so it is felt that it may be an appropriate method for individuals with SM, and would offer a new approach to research in this area

### **Research Questions**

1. How do CYP with SM construct their non-speaking selves?
2. How do CYP with SM construct their speaking selves?
3. What action plans do CYP with SM construct for themselves for the future?

### **Expected Outcomes**

The proposed research will directly access the 'hidden voices' of CYP with SM in the UK and will positively add to the limited evidence base in the existing literature. By enabling individuals to share their 'stories' about their speaking and non-speaking selves, this will increase understanding of SM from the perspective of those experiencing it and will help to inform the role of EPs in this area. This is important due to EPs holistic involvement with children, young people, parents, schools and other professionals, as well as their fundamental core values of advocating for CYP. It is likely that it will also be beneficial to share findings with other professionals such as school staff and Speech and Language Therapists (SLTs) to ensure that the child or young person's voice is at the heart of service delivery and that everyone is working towards a common goal.

*References are listed in the overall reference list and glossary of terms are shown at the end of the ethical approval form (\*)*

## **7. CONDUCT OF PROJECT**

### **Please give a description of the research methodology that will be used**

As the research will seek to gain an insight into how CYP with SM construct their world and experiences, it will reflect an interpretivist epistemology, where it is accepted that thoughts, attitudes and ideas about the world are constructed subjectively by each individual in a different way. The research will utilise creative drawing methods, based on Personal Construct Psychology (PCP, Kelly, 1955), to understand how CYP construct themselves in speaking and non-speaking situations.

The study aims to adopt individual face-to-face, qualitative, semi-structured interviews with 5-6 participants. An initial meeting will be arranged with participants and their parent(s) to explain the nature and purpose of the research in more detail, gain fully informed consent, gather demographic and background information (Appendix 13) and start to build a rapport before the data collection stage. This will be followed by an interview session of approximately 1 hour at a later date to complete the 'Drawing the Speaking and Non-Speaking Self' activity, an adaptation of Moran's 'Drawing the Ideal Self' PCP methodology (2001) – see Appendix 2 for a full description. This technique will follow four stages, where the participant is first required to imagine the kind of person who does not speak, using drawings and writing to explore their core constructs\* of what this person is like, their thoughts and feelings, the situation they are in, what activity they are doing, how they interact with others, their fears, their history and what this person hopes for the future. The second stage will then involve the participant being asked to imagine the contrasting pole of non-speaking - the kind of person who does speak, again eliciting their core constructs of their speaking selves in the same areas via drawings and writing. The third stage moves away from an imaginary person to the individual's personal experiences of themselves, asking them to identify on a rating scale how closely they can relate to the speaking and non-speaking characters they have constructed. The individual is asked to rate themselves now and at different points in time, as well as considering how change occurred and how they may move towards their 'ideal' self, by creating an action plan and identifying targets that may help with this. This stage also explores where others may place them on the rating scale (e.g. family/teachers/friends), which will give an insight into how CYP with SM believe they are perceived by others. The final stage involves the researcher summarising the information that has been elicited to ensure CYPs views have been understood accurately.

In Moran's original format (2001), the adult acts as the scribe and records discussions in the child's own language, however due to the likelihood that participants may not want to communicate verbally because of their SM, I plan to adapt the techniques so that children can write down their ideas themselves. There will be no pressure for CYP to speak during this activity. A set of visual and written prompts (Appendices 3a-3c) will also be available to support participants to express their views about each of the areas being explored if required, based upon

existing literature findings (see Appendix 4). A visual system will also be available so participants can indicate if they are happy to continue, need a break or want to end the interview for any reason (see Appendix 15).

A pilot interview will first be conducted with a child with SM who I have recently been involved with, where I will trial the 'Drawing the Speaking and Non-Speaking Self' technique, and use the child as co-researcher to elicit his views on the activity and its effectiveness in allowing him to share his experiences of SM. This will be an important stage of the research design and will determine whether any changes are needed to the methods prior to the main data collection phase.

Once all participants have completed the 'Drawing the Speaking and Non-Speaking Self' activity, thematic analysis (Braun and Clarke, 2006) will be used to identify key themes that emerge from the data. This will reflect a deductive, top down approach based on predetermined themes from the PCP activity, however other themes may emerge depending on the information and experiences they choose to share.

#### 8. DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE RESEARCHERS AND SUPERVISORS?

Yes  No

Note: "Participation" includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

**If you have answered NO please go to Section 18. If you have answered YES to this question please complete all the following sections.**

#### 9. PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

It is proposed that 5-6 participants will be interviewed for the main research, as well as an additional participant for the pilot aspect of the study. The sample will be purposive and opportunistic based on those with a diagnosis of SM who are willing to participate, and there will be no preference of particular characteristics e.g. gender or ethnicity. For ease, participants will be currently residing in the local authority (LA) in which I am on placement as a Trainee Educational Psychologist, or another LA within the [redacted] so that a convenient location for the interviews can be arranged. The recruiters (see next section) will have responsibility for identifying CYP whom they believe will be suitable to take part in the project by applying the following inclusion and exclusion criteria. If any details are not known, such as writing ability or stage of communication, I can clarify this with parents if they agree to be contacted to discuss the research further.

##### Inclusion Criteria

- CYP known to the Speech and Language Therapy Service who meet the DSM-V and ICD-11 diagnostic criteria\* for Selective Mutism and are aware that they find it difficult to speak
- CYP who attend a mainstream setting
- CYP in Key Stage 2 and above who are able to write or able to use visual prompt cards to express their views
- Children who are at or above the 'uses non-verbal and written communication' stage of confident talking (Johnson and Wintgens, 2016)

**Exclusion Criteria:**

- CYP who do not meet the DSM-V and ICD-11 diagnostic criteria for Selective Mutism
- CYP in a specialist setting
- Children in Key Stage 1 or younger
- Children who are at the 'absent' or 'frozen' stage of confident talking (Johnson and Wintgens, 2016) and are unable to communicate non-verbally

**10. RECRUITMENT**

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

*Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.*

Following ethical approval, the Speech and Language Therapy Service (SALTS) in my placement authority will be used as the third-party recruiter to identify potential participants from their current caseloads. This approach is felt to be more ethical than cold calling due to their existing familiarity, relationships, and trust with clients and protection of confidential information. If I am unable to recruit enough participants from my LA, I will approach SALTSS in other LAs in the [REDACTED]. An introductory email explaining the nature and purpose of the research will be sent to the lead SLT who will disseminate a recruitment letter (Appendix 7) to her team encouraging them to identify CYP who may be suitable to participate. It is hoped that the study can then be further discussed and explained to the SLTs during a SM Special Interest Group which I attend to address any questions they have about inclusion/exclusion criteria.

Following this, the SLTs will be asked to pass on the information sheets to any CYP and their parents who may be suitable and willing to take part (see Appendices 9 and 10). CYP and their parents will then be asked by the SLTs to read the information sheets and complete the 'initial consent' section including their contact details if they agree to be contacted by myself. Completed forms will be returned to me and I will then contact parents directly to arrange an initial meeting to meet them and their child at a convenient location. This will involve me further explaining the nature and purpose of the research, gaining fully informed written consent (see Appendices 11a/11b, 12), background information (see Appendix 13), ensuring they meet the DSM-V and ICD-11 criteria for SM (see Appendix 14), as well as giving CYP and parents the opportunity to ask any questions about the research. The focus of this session will also be to start to build a rapport with CYP prior to data collection so that they feel more comfortable and at ease engaging with an unfamiliar professional.

The interview session will then be arranged at a suitable time and location for participants, either in a quiet space at home, where CYP may feel more relaxed, a private meeting room in the building where I work, as a more neutral location, or another location that they suggest, if this is appropriate. A follow up visit may also be arranged to share research findings after data analysis.

## 11. CONSENT

a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent.

As I anticipate that the majority of CYP that will be recruited for the research will be under 16, consent will be needed from parents, as well as the CYP themselves. In the early stages, CYP and parents will receive an information sheet from their SLT, which will provide written information about the project, in an age appropriate format. They will be asked to read through the details and complete the 'initial consent' section of the parent information sheet if they are willing to participate (see Appendix 10). Parents will also be asked to provide their contact details in order for me to get in touch to arrange an initial meeting and the subsequent interview session.

At the initial meeting, I will explain the nature and purpose of the research again to the CYP and their parents and ask for voluntary participation. At this stage I will reiterate that they have the right to withdraw from the study at any time and that data will be confidential and will be stored securely. If CYP and their parents indicate that they understand the information and agree to be involved in the research verbally, I will ask them to provide written consent about participation using consent forms (see Appendices 11a/11b, 12).

Participants will be able to decide if they would like parents/carers to be present during the initial meeting and interview session. They will also be allowed to communicate in whatever way they feel most comfortable and they will be under no pressure to speak. Written prompt cards with accompanying visuals (Appendices 3a-3c) relating to the areas being explored and based on literature findings will be available in the 'Drawing the Speaking and Non-Speaking Self' activity if CYP would rather use these than write down their answers (see Appendix 4). Additionally, a visual system involving thumbs up, thumbs down and unsure signs with written prompts will be available (Appendix 15), so the participant can indicate if they are happy to continue, if they need a break or want to stop the interview for any reason.

The consent form and information sheet will be used in the pilot interview and will be adapted according to any feedback that is received. My contact details, as well as those of my research supervisor will also be given to the SLTs, participants and their parents both verbally and in writing if any further questions arise prior to or following the initial meeting or during the data collection/analysis stages.

*Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.*

b) Will the participants be deceived in any way about the purpose of the study? Yes  No

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and who will administer this feedback.

Not applicable.



## 12. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

The CYP who participate in the research will each receive a certificate to thank them for providing their views and experiences. Additionally, they will be asked if they would like to keep their drawings and responses from the 'Drawing the Speaking and Non-Speaking Self' activity, and if so they will be given back to them once they have been copied by the researcher for data analysis purposes. Following completion of the research, I will provide each participant with written feedback about my interpretations of their accounts, explaining how and to whom their information will be shared with and how their experiences will help EPs and other professionals working with CYP with SM. CYP will also be given the opportunity to ask any questions they have (verbally or non-verbally) so they feel fully informed about all aspects of the research. It will be CYP's decision as to whether they share the summary report with their parents.

A summary report of the key themes and findings will also be produced and will be shared with the Educational Psychology and Speech and Language Therapy teams, considering implications for future practice. Additionally, the research will be written up in my doctoral thesis, however in all cases, I will ensure that I anonymise quotations and that any information which risks personally identifying individuals will be omitted, to maintain confidentiality.

## 13. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

The information sheets will explicitly state that participants have the right to withdraw at any point prior to, during or after the research (see Appendices 9 and 10). Withdrawal time after the interview will be limited to one month as after this time data analysis will be underway so it will be difficult to remove participants' data during this stage. When signing the consent form, CYP and their parents will be informed about the one-month time limit and will be asked to indicate that they have been informed about their right to withdraw any time up to this point. This will also be emphasised verbally during the initial meeting with CYP and their parents and during the two interview sessions.

Given the fact that participants may not communicate verbally due to their SM, it will be important to take further steps to remind CYP about their rights to withdraw and to ensure they can express their views about this. A visual system with thumbs up, thumbs down and unsure signs and written prompts (Appendix 15) will be available so participants can indicate whether they are happy to continue, are unsure, need a break or want to stop the interview, with the option for CYP to write down any additional comments. The CYP will also be encouraged to tell their parents if they want to withdraw, so that their parents can then inform me at any stage up to one month after data collection.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

There will be no consequences for participants if they wish to withdraw from the research and this will be communicated when talking to them about this matter. If a participant does choose to withdraw, during or up to one month after the interview, copies of their drawings and responses will be identified and destroyed, as well as removing any processed information held on any encrypted storage devices. Any written field notes or reflections taken during or after the interview will also be shredded. The participant's data will not be included in the data analysis if this decision is made within the one-month time limit.

#### 14. COMPENSATION

Will participants receive compensation for participation?

i) Financial

Yes  No

ii) Non-financial

Yes  No

If **Yes** to **either** i) or ii) above, please provide details.

As already mentioned, CYP will receive a certificate to thank them for taking part in the research and will be able to keep their drawings and responses from the 'Drawing the Speaking and Non-Speaking Self' activity if they choose to do so.

If participants choose to withdraw, how will you deal with compensation?

If a participant chooses to withdraw after the interview session, they will still be given the opportunity to keep their drawings and responses from the 'Drawing the Speaking and Non-Speaking Self' activity if they would like to.

#### 15. CONFIDENTIALITY

a) Will all participants be anonymous?

Yes  No

b) Will all data be treated as confidential?

Yes  No

*Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.*

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

As I will be conducting individual face-to-face interviews, participants will not be anonymous, however I will be the only person who has direct contact with each participant for the purpose of the research. I do not feel that it is appropriate to video record the interviews due to the CYP's possible existing anxiety relating to their SM, or consequent anxiety that such an added observation tool may provoke. I will ensure confidentiality by assigning each participant with an ID code, meaning their full names will not be used at any point during the data collection, analysis or write up stages. These ID codes will be stored separately to the data on an encrypted and password-protected USB stick. Any names of children, family members, teachers or other professionals that are mentioned during the interviews, either verbally or in written format will not be reported and will be replaced with pseudonyms or general labels e.g. mum/teacher/SLT. Participants' drawings and responses from the PCP activities will be accessible only to myself and my research supervisor (Dr Colette Soan) during the analysis and write up stages and will be stored both in a locked filing cabinet and on an encrypted and password-protected USB stick once materials have been scanned in electronically. Whilst these images and responses will later be available for viewing by a wider audience once the thesis is submitted, there will no identifiable information which means participants could be traced.

For their own comfort and ease, participants and their parents will be given the option of where they would prefer the interview to take place, either within the home, at school or in a meeting room within the building in which I work, however it will be important to ensure that it is conducted in a quiet space that is unlikely to be overheard or interrupted by others. If conducted at home, this will be arranged at a convenient time which does not interfere with existing commitments and parents will be asked if a quiet space can be provided. If being conducted at my place of work, a sign will be put on the door so that colleagues are aware that a confidential research interview is taking place which should not be disturbed. In both cases, CYP will be asked if they would prefer their parent to be present or absent in the interview sessions, and this decision will be respected.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

As mentioned above, anonymity cannot be ensured as I will be interviewing participants on a face-to-face basis however the data collected will be treated confidentially. Both participants and their parents will be informed of issues concerning anonymity and confidentiality prior to the interviews taking place, at the initial meeting and on their respective information sheets. They will also be informed about where, how and to whom the findings will be shared with and made aware that ID codes, pseudonyms and general labels may be used when reporting on their case both individually and collectively, before deciding whether to give their consent to participate.

Potential limits to confidentiality regarding safeguarding will also be acknowledged and discussed with CYP and their parents. If anything is shared which relates to harm or potential harm to participants or others, I will adhere to the local authority's safeguarding policy and inform the designated safeguarding lead, after informing the CYP about this. I have recently attended a Level 1 safeguarding course so am aware of the key areas of concern and the relevant steps to take should a disclosure be made.

## **16. STORAGE, ACCESS AND DISPOSAL OF DATA**

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

All data will be kept and stored securely in adherence to the University of Birmingham's Data Protection Policy which complies with the Data Protection Act (1998). The initial consent form containing participant's full names will be stored in a locked filing cabinet, only accessible to myself, and the document listing names and ID codes saved on an encrypted and password-protected USB stick. I will inform participants that an ID code will be used on any materials produced before or during the interviews instead of their full names to ensure confidentiality. Full names and details of participants and their parents will only be included on consent forms, however these will be stored securely in a locked filing cabinet or will be scanned in electronically and saved on an encrypted and password-protected USB stick, only accessible to myself, with the originals being shredded.

Drawings and responses from each individual interview will be copied (originals to be given back to the CYP if they choose to keep them) and scanned in, with the hard copy being stored in a locked filing cabinet when not being used, and electronic copies being saved onto an encrypted and password-protected USB stick, both of which only be accessible to myself and my research supervisor during supervision sessions. Similarly, any written field notes or reflections taken before, during or after the interviews will be stored securely, in either a locked filing cabinet or on an encrypted and password-protected USB stick depending on its format.

Transcription data will also be saved onto an encrypted and password-protected USB stick.

All data (interview drawings/responses, field notes, transcripts) will be stored securely for 10 years on an encrypted and password-protected memory stick in adherence to the University of Birmingham's Code of Practice for Research, which will be accessible to myself, my research supervisor and thesis examiner. After this time, all electronic data will be erased and any hard copies of consent forms, interview materials and transcriptions will be shredded securely.

**17. OTHER APPROVALS REQUIRED?** e.g. Criminal Records Bureau (CRB) checks

YES  NO  NOT APPLICABLE

If yes, please specify.

As a Trainee Educational Psychologist, I have enhanced DBS clearance which is required to visit schools and work with (and interview) children and young people in schools.

**18. SIGNIFICANCE/BENEFITS**

Outline the potential significance and/or benefits of the research.

It is hoped that the research will be beneficial for a number of reasons. Firstly, directly for participants themselves, by giving them the opportunity to share their experiences of SM and constructs of their speaking and non-speaking selves and to develop an action plan relating to their future goals. There will be no pressure to communicate verbally in interviews, however participants will still be able to express themselves and their ideas using drawings, writing and card sorting activities. It is also hoped that participants will feel listened to, understood and valued by the researcher. Secondly, the research will benefit the research community by adding to the small number of existing studies eliciting the 'voices' of children and young people with SM, and in particular the UK population. The research may also be beneficial for other researchers wanting to work with CYP who do not communicate verbally by providing further insight into an adaptation of the 'Drawing the Ideal Self' (Moran 2001) technique. Findings are also likely to have implications for improved practice for Educational Psychologists, Speech and Language Therapists and school staff working with children and young people with SM by increasing knowledge about lived experiences. Finally, the research may have benefits to the wider population of individuals with SM, such as identifying key themes which can be used to improve and better identify suitable support for individuals with SM. Findings may also contribute to changing existing societal views about SM so that their thoughts, experiences, hopes and preferred communication methods are better understood.

**19. RISKS**

a) Outline any potential risks to **INDIVIDUALS**, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap

*Risks to the researcher:*

As there is a possibility that I will be conducting interviews in the participants' home, this involves a level of risk due to accessing an unknown environment and unfamiliar individuals. To minimise this risk, I will ensure that at least one parent/carer is within the home (or the building in which I work or the alternative location) for the duration of the interviews. Also, I will ask the SLTs to inform me of any safety issues they are aware of at the recruitment stage and adapt the location of the interview as necessary. CYP will have the option of whether they would like their parent/carer to be present or absent during the interviews, however even if parents are not physically present in the room, it will be important that I request for them to be in the building in case any concerns arise. I will also follow the LA's protocol for home visits, which involves ringing the administrator before entering the home to provide details of the address and the expected duration, and a further phone call when the visit has been completed to inform them that I am safe. If an emergency is encountered, I will follow the relevant procedure as outlined in the 'Lone Working Policy' (Appendix 22). Emotional personal risk while conducting the research will be minimal, however, to minimise this risk, I will ensure that I am self-aware and discuss any concerns regarding my own emotional responses or wellbeing in supervision with my university tutor (Dr Colette Soan).

b) Outline any potential risks to **THE ENVIRONMENT and/or SOCIETY** and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

I do not anticipate there being any risks to the environment and/or society as a result of this research.

**20. ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?**

Yes  No

If yes, please specify

Not applicable.

**21. CHECKLIST**

Please mark if the study involves any of the following:

- Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments
- Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life)
- Risk to the personal safety of the researcher
- Deception or research that is conducted without full and informed consent of the participants at time study is carried out
- Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants.
- Production and/or use of genetically modified plants or microbes
- Results that may have an adverse impact on the environment or food safety
- Results that may be used to develop chemical or biological weapons

Please check that the following documents are attached to your application.

	<b>ATTACHED</b>	<b>NOT APPLICABLE</b>
Recruitment advertisement	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Participant information sheet	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Consent form	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Questionnaire	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Interview Schedule (Drawing PCP activities)	<input checked="" type="checkbox"/>	<input type="checkbox"/>

## 22. DECLARATION BY APPLICANTS

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:

- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by University Code of Practice for Research ([http://www.as.bham.ac.uk/legislation/docs/COP\\_Research.pdf](http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf)) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer.

**Name of Principal investigator/project supervisor:**

Dr. Colette Soan
19 <sup>th</sup> February 2018

**Date:**

Please now save your completed form, print a copy for your records, and then email a copy to the Research Ethics Officer, at [aer-ethics@contacts.bham.ac.uk](mailto:aer-ethics@contacts.bham.ac.uk). As noted above, please do not submit a paper copy.

## GLOSSARY OF TERMS

- **‘Drawing the Ideal Self’** - This is a creative drawing and talking technique created by Moran (2001), based on Personal Construct Psychology, which explores children’s core constructs and how they make sense of their world. The researcher seeks to understand the individual’s unique perspective and experiences through collaborative discussions about an ideal and non-ideal person, before asking them to identify how closely they can relate to each person and where their ‘ideal self’ is. The therapist then works with them to explore how their core constructs may be influencing their behaviour and to create an action plan by discovering new understandings and possibilities that may be more helpful for them. This technique has been used successfully with children with anxiety (Moran, 2001), anger (Moran, 2005) and autistic spectrum conditions (Moran, 2006) and has also been adapted to elicit views about school amongst a group of pupils with an autistic spectrum condition (Williams and Hanke, 2007).
- **DSM-V** - This is the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, a tool published by the American Psychiatric Association in 2013 to diagnose psychiatric disorders.
- **DSM-V and ICD-11 Beta-draft Diagnostic Criteria for Selective Mutism** – Selective Mutism is defined by the DSM-V and ICD-11 as an anxiety disorder, where the following essential behaviour characteristics are evident:
  1. Individuals present a consistent pattern of speaking in some situations where speech is expected but not in others
  2. The failure to speak is persistent, lasting more than one month, but not including the first month in a new environment such as school
  3. The failure to speak has a significant impact on educational or occupational achievement or social communication
  4. Lack of knowledge or comfort with the required spoken language, or a disorder of communication or a condition like social anxiety disorder, may also be present, but is not the cause and does not explain the mutism
- **ICD-11 Beta-draft** – This is the most current revision of the International Classification of Diseases, a diagnostic tool published by the World Health Organisation. It is currently in draft format, with the final draft expected to be published in 2018.
- **Personal Construct Psychology** - A theory developed by Kelly (1955) where it is proposed that individuals form unique constructs of the world based on their experiences. The idea is that these constructs enable individuals to develop theories about themselves, others and events based on noticing similarities and differences which represent the person’s model of the world and behaviour. It is believed that constructs are on a bi-polar dimension, where we have a pole preference which shapes attitudes, values and beliefs, and a less preferred pole which represents the contrasting construct. **Core constructs** are the ideas we hold about ourselves which form our identity based on our experiences of whether those thoughts have been confirmed or challenged. If an individual experiences an event which supports the preferred pole of their core construct and confirms their identity, this provides reassurance. However, if experience provides supporting evidence for the less preferred pole of their construct, this can challenge their identity and cause distress. PCP aims to explore and reframe the construct system by offering alternative and more helpful perspectives.
- **Raven’s Controlled Projection for Children** - A creative drawing and story writing technique introduced by Raven (1951) and used by Omdall and Galloway (2007) to interview children with selective mutism. In this method the child is asked to draw, imagine and describe a series of events with the aim of studying the meaning and significance attached to everyday situations and providing an insight into how individuals organise their thoughts and behaviour.

## **APPENDIX 6: Email confirming ethical approval for the research study**

### **Application for Ethical Review ERN\_18-0249**

From: SW

Fri 23/03/2018, 14:04

Colette Soan; Sue Morris (School of Education); Emily Strong; Emily Strong (Email address)

Inbox

You replied on 26/03/2018 11:30.

Dear Dr Colette Soan & Sue Morris

**Re: “We Do Have a Voice: Using Personal Construct Psychology to explore how children and young people with Selective Mutism construct their speaking and non-speaking selves”**

**Application for Ethical Review ERN\_18-0249**

Thank you for your application for ethical review for the above project, which was reviewed by the Humanities and Social Sciences Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee’s attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University’s Code of Practice for Research and the information and guidance provided on the University’s ethics webpages (available at <https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx> ) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (<https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx> ) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University’s guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University’s H&S Unit at [healthandsafety@contacts.bham.ac.uk](mailto:healthandsafety@contacts.bham.ac.uk).



Kind regards,

**Ms SW**

Deputy Research Ethics Officer

Research Support Group

Address

Address

Tel:

Email:

Web: <https://intranet.birmingham.ac.uk/finance/RSS/Research-Support-Group/Research-Ethics/Research-Integrity-at-the-University-of-Birmingham.aspx>

Please remember to submit a new Self-Assessment Form for each new project.

Click Ethical Review Process for further details regarding the University's Ethical Review process, or email [ethics-queries@contacts.bham.ac.uk](mailto:ethics-queries@contacts.bham.ac.uk) with any queries.

Click Research Governance for further details regarding the University's Research Governance and Clinical Trials Insurance processes, or email [researchgovernance@contacts.bham.ac.uk](mailto:researchgovernance@contacts.bham.ac.uk) with any queries

*Notice of Confidentiality:*

*The contents of this email may be privileged and are confidential. It may not be disclosed to or used by anyone other than the addressee, nor copied in any way. If received in error please notify the sender and then delete it from your system. Should you communicate with me by email, you consent to the University of Birmingham monitoring and reading any such correspondence.*

**APPENDIX 7: Recruitment letter sent to SLTs**



**UNIVERSITY OF  
BIRMINGHAM**

**LOCAL AUTHORITY LOGO**

**‘We Do Have a Voice: Using Personal Construct Psychology to explore how children and young people with Selective Mutism construct their speaking and non-speaking selves’**

My name is Emily Strong and I am a trainee Educational Psychologist on placement with [NAME OF SERVICE] Educational Psychology Service. I am also a postgraduate research student at the University of Birmingham and am currently planning a research project about the views and experiences of children and young people (CYP) with Selective Mutism (SM), which will form part of my qualifying Doctorate in Applied Educational and Child Psychology.

You have been sent this information sheet in the hope that you may be able to help me recruit participants for my research from your current caseloads.

**Purpose and details of the study**

This research project will aim to explore how CYP with SM construct their speaking and non-speaking selves as there is limited existing research which has accessed their views. It is hoped that findings will increase knowledge and understanding of lived experiences of SM and may help to further develop the role of Educational Psychologists and Speech and Language Therapists when completing assessments and planning interventions in this area.

I am hoping to interview 5-6 CYP who already have, or are likely to be given, a diagnosis of SM from the Speech and Language Therapy Service. I aim to use a creative drawing technique, ‘Drawing the Speaking and Non-Speaking Self’ (an adaptation of Moran’s ‘Drawing the Ideal Self’, 2001), to elicit perceptions of situations in which they speak and do not speak, and to explore their associated thoughts, feelings, fears, interactions, history and hopes for the future in the two scenarios. This will give a valuable insight into whether they feel SM has had an impact on their life and if they value talking as an important goal for them. Interviews will be conducted either at the participant’s home, at my place of work [NAME OF BUILDING AND LOCATION] or another preferred location. There will be no pressure to speak in the interviews as participants will be able to engage via drawing, writing and card sorting activities.

<p><b>To be involved in the research, participants should meet the following <u>INCLUSION</u> criteria:</b></p>	<p><b>Due to the planned interview methods, participants who meet the following <u>EXCLUSION</u> criteria WILL NOT be able to be involved:</b></p>
<p>✓ CYP known to Speech and Language Therapy Service who meet the DSM-V diagnostic criteria for Selective Mutism (*see end of letter for criteria) and are aware that they find it difficult to speak - <i>if this is not known I can check with parents at a later stage</i></p>	<p><input checked="" type="checkbox"/> CYP who do not meet the DSM-V diagnostic criteria for Selective Mutism (*see following page for criteria)</p>

<input checked="" type="checkbox"/> CYP who attend a mainstream setting	<input checked="" type="checkbox"/> CYP in a specialist setting
<input checked="" type="checkbox"/> CYP in Key Stage 2 and above (age 7+) who are able to write or could use visual prompt cards to express their views – <i>if this is not known I can check with parents at a later stage</i>	<input checked="" type="checkbox"/> Children in Key Stage 1 or younger (under 7 years)
<input checked="" type="checkbox"/> CYP who are at or above the ‘uses non-verbal and written communication’ stage of confident talking (Johnson and Wintgens, 2016) – <i>if this is not known I can check with parents at a later stage</i>	<input checked="" type="checkbox"/> CYP who are at the ‘absent’ or ‘frozen’ stage of confident talking (Johnson and Wintgens, 2016) and are unable to communicate non-verbally – if this is not known I can check with parents

**If you know of any children/young people who fit the above brief for this study, and may be willing to take part, I would be really grateful if you could contact me directly (Email: EMAIL ADDRESS or Phone: PHONE NUMBER) to let me know.** I will then provide you with a hard copy of the Parent and Child Information Sheets to distribute to parents/carers either by post or in person, along with stamped addressed envelopes for them to respond. You will not be required to do anything else after this point as I will then liaise directly with parents to arrange the interviews etc.

I am hoping to start data collection after half term so would really appreciate if you could contact me by **Friday 27<sup>th</sup> April 2018**. Please note, due to confidentiality, I will not need names, addresses or other contact details at this stage, just an indication of **how many eligible families you have**.

If you have any questions about the research project or would like to discuss it further, please feel free to contact myself or my university supervisor using the details below:

<b>Contact Details</b>	
<p><b>Emily Strong</b> Trainee Educational Psychologist</p> <p>[PLACEMENT EDUCATIONAL PSYCHOLOGY SERVICE ADDRESS] Phone: [PHONE] Email: [EMAIL]</p>	<p><b>Dr. Colette Soan</b> Research Supervisor and University Tutor</p> <p>[UNIVERSITY ADDRESS] Phone: [PHONE] Email: [EMAIL]</p>

Thank you for your time, and I do hope you will be able to help me recruit participants, so I can conduct my research project to positively add to the limited evidence base regarding SM.

**Emily Strong**  
Trainee Educational Psychologist with [NAME OF EDUCATIONAL PSYCHOLOGY SERVICE]  
Postgraduate Researcher at the University of Birmingham

**Dr Colette Soan**  
Research Supervisor and  
& University Tutor at the University of Birmingham

**\* DSM-V Diagnostic Criteria for Selective Mutism**

1. Individuals present a consistent pattern of speaking in some situations where speech is expected but not in others
2. The failure to speak is persistent, lasting more than one month, but not including the first month in a new environment such as school
3. The failure to speak has a significant impact on educational or occupational achievement or social communication
4. Lack of knowledge or comfort with the required spoken language, or a disorder of communication or a condition like social anxiety disorder, may also be present, but is not the cause and does not explain the mutism

**APPENDIX 8: Cover letter sent to potential participants by SLTs**

**LOCAL AUTHORITY LOGO**

Educational Psychology Service  
Address  
Address

Tel:

Email:

Date:

Dear Child/Young Person and Parent/Carer,

My name is Emily Strong and I am a Trainee Educational Psychologist studying for a Doctorate in Applied Educational and Child Psychology at the University of Birmingham. I am also currently on placement with [NAME OF AUTHORITY] Educational Psychology Service and as part of my qualification am hoping to conduct some research about children and young people's views and experiences of Selective Mutism.

I have asked the Speech and Language Therapy Service to pass this information pack onto any families on their caseload whose children have Selective Mutism or find it difficult to talk in some situations.

I would appreciate if you and your child would read the attached child/young person and parent/carer information sheets and, if you are willing to be contacted to discuss my research project in more detail, if you could complete and return the enclosed consent form in the stamped address envelope provided by [DATE].

Thank you in advance for taking the time to read the attached information. I hope to hear from you soon.

Yours faithfully

***Emily Strong***

Trainee Educational Psychologist with [NAME OF AUTHORITY] Educational Psychology Service and Postgraduate Researcher at the University of Birmingham

## **APPENDIX 9: Child and Young Person Information Sheet sent to potential participants by SLTs**



**UNIVERSITY OF  
BIRMINGHAM**

**LOCAL AUTHORITY LOGO**

Hello! My name is Emily and that is me in the picture.

I am currently training to become an Educational Psychologist. This is a job where I work with lots of children and young people in school and at home to listen to their experiences and help them with their learning, friendships, feelings and behaviour.



As part of my training, I am going to be doing some research with children and young people who have Selective Mutism and would therefore like to invite you to take part. Selective Mutism is when children or young people are happy to talk in some situations, such as home, but find it really hard to talk in other situations, such as school. I understand that you and your family are currently (or have been) working with a Speech and Language Therapist to try and help make things easier for you. I have worked with a few children with Selective Mutism before and have really enjoyed it.

I am interested in finding out about how children with Selective Mutism feel about themselves in different situations and if there is anything they would change to make things better for them. If you agree to take part in my project, you will be invited to meet with me, so I can tell you more about my research, and then we will arrange an interview so you can tell me about your views and experiences. I will ask you to draw some pictures and do some writing about two imaginary characters who do and do not speak. I promise there won't be any pressure to talk if you don't feel comfortable to and there will also be some cards that might help you to share your views if you need them. Other children and young people will also be invited to take part in my research.

I hope that you will help me to learn more about Selective Mutism, so that other Educational Psychologists, Speech and Language Therapists and maybe even school staff can better understand how to support other children and young people like you.

Here are some more things that you might like to know about my research:

- The initial meeting and interview can be done either at home, at the place where I work [NAME OF BUILDING AND LOCATION], or another preferred location, wherever you feel most comfortable, and at a convenient time for you
- The initial meeting will last about 30 minutes and the interview about 1 hour
- Your parent/carers(s) can sit with you during the initial meeting and interview if this would help you to feel more comfortable and relaxed
- There are no right or wrong answers – I am interested in how you feel in situations where it is easy or difficult for you to speak
- There will be no pressure to speak as you will be able to share your views by drawing, writing or picking cards that represent how you are feeling (but it is also ok to talk if you would like to!)

- If you change your mind, we can stop the interviews at any time and you won't have to continue, and if there are some questions you don't want to answer, that is fine. You can also let me know, up to a month after your interview, if you do not want your data to be included in my research and this is fine too
- I will write up my findings from the research in a report for university, but I will not use your name to keep your identity and responses confidential

As well as making sure that you are happy to take part in this project, I have also asked for permission from your parents/carers. If you are happy to be involved, they will complete a consent form and I will then arrange to come and visit you. If you or your parent/carer have any questions, you can get in touch with me or my supervisor (your parent/carer has our contact details), or we can discuss these when we meet.

Thank you for taking the time to read or listen to this information! I really hope you will be able to help me with my research and I look forward to hearing from you soon.

Yours faithfully,

***Emily Strong***

Trainee Educational Psychologist with  
[NAME OF AUTHORITY] Educational  
Psychology Service & Postgraduate  
Researcher at the University  
Of Birmingham

***Dr Colette Soan***

Research Supervisor and University Tutor  
at the University of Birmingham

## **APPENDIX 10: Parent Information Sheet sent to the parents of potential participants by SLTs**



UNIVERSITY OF  
BIRMINGHAM

LOCAL AUTHORITY LOGO

### **We Do Have a Voice: Using Personal Construct Psychology to explore how children and young people with Selective Mutism construct their speaking and non-speaking selves**

Dear Parent/Carer,

My name is Emily Strong and I am a Trainee Educational Psychologist, studying for a doctorate in Applied Educational and Child Psychology at the University of Birmingham. As part of my qualification, I am also on placement with [NAME OF AUTHORITY] Educational Psychology Service and am required to conduct a research project in an area of interest.

I have recently had the opportunity to deliver some therapeutic work to a child with a Selective Mutism (SM) and have since developed a keen interest in this area. I would therefore like to invite your child to take part in a research project exploring the views and experiences of children and young people with SM.

I have asked the Speech and Language Therapy Service to pass this letter onto any families on their caseload whose children have a diagnosis of SM. Please read the following information which provides further details about the research project. If your child is willing to participate, **please sign the attached consent form and return it to myself** in the stamped addressed envelope enclosed by [INSERT DATE]. I will then contact you directly to discuss the project in more detail and arrange a time for an initial meeting and an interview session with your child. I will also seek your child's consent prior to the interview.

#### **What is this research for?**

The aims of the research are:

- To understand how children and young people with SM construct their speaking and non-speaking experiences and to explore their hopes for the future
- To consider how Educational Psychologists and other professionals (such as the Speech and Language Therapy Service) can better support children, young people, parents and schools when working with individuals with SM
- To add to the limited existing evidence base in the SM literature

#### **What will participation involve?**

- An **initial meeting** (of approximately 30 minutes) with you and your child to explain the research in more detail, ask for further consent for your child to participate and gather some background information. The meeting can be held either at home, at my place of work – [NAME OF BUILDING AND LOCATION], or another preferred location, depending on where your child feels most comfortable. It will also give you and your child the opportunity to ask any questions about the research or to discuss any concerns, as well as building rapport before the research begins but **there will be no pressure for your child to speak.**



- **An interview session** (of approximately 1-2 hours), with your child to complete the 'Drawing the Speaking and Non-Speaking person' activity. In this task, your child will be asked to think, draw and write about two imaginary characters – the kind of person who does not speak and the kind of person who does speak, and in turn we will explore what these people are like, where they are and what activity they are doing, how they communicate, their thoughts and feelings, their interactions with others, their greatest fear, their history and their hopes for the future. Your child will then be asked if they can relate to either character now or at various points throughout their life and rate where they would like to be in the future, devising an action plan and identifying people who could help them make progress. The interview can be conducted either at home or my place of work [NAME OF BUILDING AND LOCATION] depending on where your child feels most comfortable. If your child prefers, you can also be present during the interviews, but can I please ask that if your child is happy to engage by themselves, that you are still available for the duration of the interviews in case you are needed? There will be no pressure for your child to speak during the interviews as they will be able to share their views and experiences by drawing, writing and using prompt cards (but talking is also ok if your child is comfortable with this).
- Your child will receive a certificate for taking part in the research as well as their drawings and responses from the 'Drawing the Speaking and Non-Speaking person' activity to keep

#### **What will happen to my child's data?**

- **'Drawing the Speaking and Non-Speaking person' data** – drawings and responses produced in this activity will be stored securely in a locked drawer when not being used and will only be accessible to myself and my research supervisor. They will also be scanned and saved onto an encrypted USB memory stick, so that original copies can be returned to your child if they would like to keep them
- **Other notes** – any other notes taken during the interviews will be stored securely in a locked cupboard when not being used, only accessible to myself and my research supervisor
- All research data will be stored securely in adherence to the 1998 **Data Protection Act** for 10 years, after which all electronic data will be deleted and hard copies will be shredded

#### **Will the data be confidential?**

- **Yes!** Anything your child shares during the session will be treated as confidential. A pseudonym will be used rather than their actual name meaning that they will not be identifiable at any point during the data collection, analysis or write up stages
- Anonymity cannot be guaranteed due to interviews being conducted face-to-face, however I will be the only person who has direct contact with each participant during the research
- Any names of children, family members, teachers or other professionals that are mentioned during the interviews, will not be reported and will be replaced with pseudonyms or general labels e.g. mum/teacher/friend to protect identifiable details
- If for any reason I am concerned about your child's or others' safety and/or well-being during the interviews, I am obliged to follow [NAME OF AUTHORITY] Educational Psychology Service's Safeguarding Policy, and report such information, but I would inform you and your child before doing this

**How will the research be reported?**

- **Doctoral Thesis report** - This research study will be written into a 25,000 word doctoral thesis report for the University of Birmingham, which will be published, in full, online on the e-theses database, however responses will be anonymised to ensure participant confidentiality
- **Reporting to the Educational Psychology and Speech and Language Therapy Services** – An oral presentation and short written summary may be presented to Educational Psychologists and Speech and Language Therapists in [NAME OF AUTHORITY], however individual participants will not be identifiable as pseudonyms will be used
- **Reporting to participants** – Children and young people who take part in the research project will receive certificates for taking part and personalised letters which will include a short summary of the findings from their interviews
- **Overall findings** – it will also be possible for you and/or your child to receive a follow up report after completion of the project summarising key findings and overall conclusions from the research

**What if either my child or myself change our minds during the study?**

- Your child’s participation in the research is entirely **voluntary** so you and/or they will have the right to stop or withdraw from the project before, during or after the final interview, without having to give a reason and without any consequence. Withdrawal time after the final interview will be limited to **one month** as after this time data analysis will be underway so it will be difficult to remove data during this stage. During the interviews, a visual system involving ‘thumbs up’, ‘thumbs down’ and ‘unsure’ signs will be available so your child can indicate if they are happy to continue, need a break, or want to end the interview entirely, and this decision will be respected
- If you and/or your child chooses to completely withdraw from the research after the interview, they will still be given the opportunity to keep their drawings and responses from the ‘Drawing the Speaking and Non-Speaking person’ activity, however any electronic and hard copies I have will be deleted immediately

**What are the benefits and/or risks of my child participating?**

Benefits	Risks
Your child will be able to share their views and experiences of Selective Mutism using drawing, writing and card sorting activities	The interviews may involve your child thinking about difficult experiences relating to their Selective Mutism. However, to reduce the risk of distress, the purpose and nature of the interviews will be framed positively and openly so that your child feels empowered to share their views and experiences. I will be sensitive and vigilant to any changes in body language or mood, and will offer a break, parental comfort, or continuing the interview at another time if your child appears distressed. A visual system involving thumbs up, thumbs down and unsure signs will also be available, so
The information they share will help Educational Psychologists and Speech and Language Therapists understand more about Selective Mutism and will help to plan future support in this area	
The findings will contribute to the small amount of research into children/young people’s experiences of Selective Mutism	

	your child can inform me if they are happy to continue, need a break or want to stop the interview entirely.
--	--

**How can my child become involved?**

If you and your child are both willing for your child to be involved in the research, please fill out the **initial consent form** on the following page and post it back to myself in the enclosed stamped addressed envelope by [INSERT DATE]. Once I have received your form, I will get in touch to arrange an initial meeting with you and your child to explain the research in more detail and to ensure your child is still willing to participate. At this meeting I will ask you and your child to sign to indicate your freely-given, informed consent to take part in the research, before arranging the interview session.

**Questions/Concerns**

If you have any questions about the research project or would like to discuss it further, please feel free to contact myself or my university supervisor using the details below:

<b>Contact Details</b>	
<p><b>Emily Strong</b> Trainee Educational Psychologist</p> <p>[PLACEMENT EDUCATIONAL PSYCHOLOGY SERVICE ADDRESS] Phone: [PHONE] Email: [EMAIL]</p>	<p><b>Dr. Colette Soan</b> Research Supervisor and University Tutor</p> <p>[UNIVERSITY ADDRESS]</p> <p>Phone: [PHONE] Email: [EMAIL]</p>

Thank you for taking the time to read this information. I hope to hear from you soon.

Yours faithfully,

**Emily Strong**  
Trainee Educational Psychologist,  
[NAME OF LA] Educational Psychology Service &  
Postgraduate Researcher at University of Birmingham

**Dr Colette Soan**  
Research Supervisor and  
University Tutor, University of  
Birmingham

-----  
**Initial Consent from Parents**

**My child and I have read the information sheets provided and are willing to take part in Emily Strong's research study.**

**I agree to be contacted by Emily Strong to arrange an initial meeting to discuss the project in more detail and to gain consent from both myself and my child for the research interview.**

**My contact details are:**

**Name:** \_\_\_\_\_

**Child's Name:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_

**Email address:** \_\_\_\_\_

**Best day/time to contact me:** \_\_\_\_\_

**PLEASE COMPLETE AND RETURN THIS FORM IN THE STAMPED ADDRESSED ENVELOPE PROVIDED BY [DATE] IF YOUR CHILD IS WILLING TO BE INVOLVED IN THE RESEARCH**

**APPENDIX 11a: Child and Young Person consent form completed by participants before the research interviews**

**Child/Young Person's Consent Form**

Dear \_\_\_\_\_

Please make sure you have read (or listened to) the Information Sheet before filling in this form. Please read and tick (✓) the boxes, and sign your name at the bottom of the page if you agree to take part in the research project.

I have read (or listened to) and understood the Information Sheet about Emily's project.	
I would like to take part in this project about children and young people's views and experiences of Selective Mutism and have not been pressured to take part.	
I understand that my parent/carer can be present in the interview if this would make me feel more comfortable.	
I understand that I can stop the interview at any point and can let Emily know, up to one month after the final interview, if I do not want my data to be included in the research.	
I understand that I do not have to answer any questions during the session(s) that I do not want to or feel able to, and that I do not have to speak.	
I understand that the things I share in this project will be written in a report but that my full name will not be used so no one will know what I said.	

**Signed:**

**Date:**

**Initials:**













**Child's Pseudonym:**

**APPENDIX 11b: Child and Young Person consent form including visuals which was adapted following the pilot study to account for younger participants**

**Child/Young Person's Consent Form**

Dear \_\_\_\_\_

Please make sure you have read (or listened to) the Information Sheet before filling in this form. Please read (or listen to) the statements below and put a circle around the face that you most agree with then sign your name at the bottom of the page if you are happy to take part in Emily's project.

I have read (or listened to) and understood the Information Sheet about Emily's project.		
I would like to take part in this project about children and young people's views and experiences of Selective Mutism (finding it hard to speak in some situations) and have not been pressured to take part.		
I understand that my parent/carer can be present in the interview if this would make me feel more comfortable.		
I understand that I can stop the interview at any point and can let Emily know, up to one month after the final interview, if I do not want my data to be included in the research.		
I understand that I do not have to answer any questions during the session(s) that I do not want to or feel able to, and that I do not have to speak.		
I understand that the things I share in this project will be written in a report but that my full name will not be used so no one will know what I said.		

**Signed:**

**Date:**

**Initials:**

**Child's Pseudonym:**

**APPENDIX 12: Parental consent form completed by parents prior to their child participating in the research**

**Parental Consent Form**

- ✓ If you agree for your son/daughter to participate in the research, please tick to indicate that you are happy with the following statements and sign below to give your informed consent:

I have read and understood the information sheet provided and understand the nature of Emily's research.	
I consent to my son/daughter taking part in this research regarding the views and experiences of children and young people with Selective Mutism.	
I understand that this project forms part of Emily's doctorate in Applied Educational and Child Psychology at the University of Birmingham and her findings will be written up for her thesis.	
I will support my child if they want me to be present in the interviews, but if they are happy to engage by themselves, I will also be available for the duration of the interviews in case I am needed.	
I understand that me and/or my child can withdraw from the research at any point, before, during, or up to one month after the interviews and this will mean that information provided will be removed from the project and erased.	
I understand that my child's data will be confidential meaning that they will not be identifiable in the data collection, analysis or write up stages and instead pseudonyms will be used.	

**Signed:**

**Date:**

**Initials:**

**Child's Pseudonym:**

**APPENDIX 13: Form used to gather demographic and background information from parents about their child before the interviews**

**Demographic and Background Information**

<b>Child's Pseudonym</b>	
<b>Gender</b>	
<b>Age</b>	
<b>Year Group</b>	
<b>Ethnicity</b>	
<b>First Language</b>	
<b>Age of Diagnosis</b>	
<b>Family Information</b>	
<b>Involvement from other professionals and support received</b>	
<b>Any additional information that is shared (including other diagnoses)</b>	



**APPENDIX 14: Eligibility checklist used with parents prior to the interviews to ensure their child met the DSM-V criteria for SM (APA, 2013)**




**DSM-V diagnostic criteria for Selective Mutism**

Child's Pseudonym: \_\_\_\_\_

Essential characteristics of SM behaviour as described by the DSM-V	Please circle YES/NO in relation to your/your child's speaking patterns	
Individuals present a consistent pattern of speaking in some situations where speech is expected but not in others	<b>YES</b>	<b>NO</b>
The failure to speak is persistent, lasting more than one month, but not including the first month in a new environment such as school	<b>YES</b>	<b>NO</b>
The failure to speak has a significant impact on educational or occupational achievement or social communication	<b>YES</b>	<b>NO</b>
Lack of knowledge or comfort with the required spoken language, or a disorder of communication of communication or a condition like social anxiety disorder, may also be present, but is not the cause and does not explain the mutism	<b>YES</b>	<b>NO</b>

**APPENDIX 15: Visual system used with participants during the interviews**

*At frequent intervals, participants were encouraged to indicate (using a counter) whether they were happy to continue, needed a break or wanted to end the interview entirely. They were also given a pen in case they wanted to write anything down.*

	<p><b>I'm ok and happy to continue</b></p> <p>(Please write down if there is anything else you would like me to know)</p> <hr/> <hr/> <hr/>
	<p><b>I'm unsure and may need a break</b></p> <p>(Please write down if there is anything else you would like me to know)</p> <hr/> <hr/> <hr/>
	<p><b>I need a break/don't want to continue</b></p> <p>(Please write down if there is anything else you would like me to know)</p> <hr/> <hr/> <hr/>

**APPENDIX 16a: Child and Young Person evaluation form completed by participants after the research interviews**

**CYP's Evaluation of Emily's Research Project:**

*'We Do Have a Voice: Using Personal Construct Psychology to explore how children and young people with Selective Mutism construct their speaking and non-speaking selves'*

Child's Pseudonym: \_\_\_\_\_

Date: \_\_\_\_\_

Please read the following statements about the research interviews and use the rating scale to indicate how much you agree or disagree with each one (1 = Strongly Disagree, 10 = Strongly Agree):

**1. I enjoyed doing Emily's research interviews**

1	2	3	4	5	6	7	8	9	10

Strongly  
Disagree

Strongly  
Agree

**2. The drawing, writing and card sort activity allowed me to share my views and experiences of Selective Mutism**

1	2	3	4	5	6	7	8	9	10

Strongly  
Disagree

Strongly  
Agree

**3. I felt Emily understood, respected and valued my views**

1	2	3	4	5	6	7	8	9	10

Strongly  
Disagree

Strongly  
Agree

**4. The prompt cards were a helpful way of sharing my views**

1	2	3	4	5	6	7	8	9	10

Strongly  
Disagree

Strongly  
Agree

**5. This action plan we created in the activity will help me in the future**

1	2	3	4	5	6	7	8	9	10

Strongly  
Disagree

Strongly  
Agree

I would like my action plan to be shared with: \_\_\_\_\_

**6. The activity was:**

Too short	The right amount of time	Too long

**7. My favourite part of the activity was:** \_\_\_\_\_

\_\_\_\_\_

**8. My least favourite part of the activity was:** \_\_\_\_\_

\_\_\_\_\_

**9. If I did the research interview again, I would change or do differently:** \_\_\_\_\_

\_\_\_\_\_

**10. Another way researchers could gain the views of children and young people with Selective Mutism may be:** \_\_\_\_\_

\_\_\_\_\_

**11. Anything else I would like Emily to know about my Selective Mutism:** \_\_\_\_\_

\_\_\_\_\_

**I would like a copy of my drawings and writing from the interviews to keep:**

Yes	No

**I would like Emily to do me a written summary about what I shared in the interviews:**

Yes	No

**I am still happy for Emily to write about my research interview for her Thesis:**

Yes	No

**Thank you for taking part in my research interviews and for completing the evaluation!**  
Emily

**APPENDIX 16b: Child and Young Person evaluation form including visuals which was adapted following the pilot study to account for younger participants**

**Evaluation of Emily’s Research Project:**




*‘We Do Have a Voice: Using Personal Construct Psychology to explore how children and young people with Selective Mutism construct their speaking and non-speaking selves’*

Child’s Pseudonym: \_\_\_\_\_

Date: \_\_\_\_\_

Please read (or listen to) the following statements about the research interviews and rate how much you agree or disagree with each one:



**1. I enjoyed doing Emily’s research interviews**

									
1	2	3	4	5	6	7	8	9	10

Strongly Disagree

Strongly Agree




**2. The drawing, writing and card sort activity allowed me to share my views and experiences of Selective Mutism (finding it hard to speak in some situations)**

									
1	2	3	4	5	6	7	8	9	10

Strongly Disagree

Strongly Agree




**3. I felt Emily understood, respected and valued my views**

									
1	2	3	4	5	6	7	8	9	10

Strongly Disagree

Strongly Agree




**4. The picture and prompt cards were a helpful way of sharing my views**

									
1	2	3	4	5	6	7	8	9	10

Strongly Disagree

Strongly Agree

**5. The action plan we created in the activity will help me in the future**

									
1	2	3	4	5	6	7	8	9	10

Strongly Disagree

Strongly Agree

I would like my action plan to be shared with: \_\_\_\_\_

**6. The activity was:**

Too short	The right amount of time	Too long

**7. My favourite part of the activity was:** \_\_\_\_\_

\_\_\_\_\_

**8. My least favourite part of the activity was:** \_\_\_\_\_

\_\_\_\_\_

**9. If I did the research interview again I would change or do differently:** \_\_\_\_\_

\_\_\_\_\_

**10. Another way researchers could gain the views of children and young people with Selective Mutism may be:** \_\_\_\_\_

\_\_\_\_\_

**11. Anything else I would like Emily to know about my Selective Mutism:** \_\_\_\_\_

\_\_\_\_\_

**I would like a copy of my drawings and writing from the interviews to keep:**

Yes	No

**I would like Emily to do me a written summary about what I shared in the interviews:**

<b>Yes</b>	<b>No</b>

**I am still happy for Emily to write about my research interview for her Thesis:**

<b>Yes</b>	<b>No</b>


**Thank you for taking part in my research interviews and for completing the evaluation!**

**Emily**

**APPENDIX 17a: P1's part A response**

Situation / Activity

In shops,  
on the street.  
School.  
all  
✓ maths  
X P.E.  
the things  
they do  
are boring.



in public

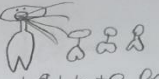
Communication Style

<u>Public</u>	<u>School</u>
- whispering	- nodding/shaking head
- nodding/shaking head	- pointing
- pointing	- writing down notes
- speaking through mum	
- email	
- text message	

Future

He can talk.  
Happy

Talk to people  
15 Years  
His friends



Secondary school

Thoughts

I am different. He doesn't talk  
out loud.

**I want to be able to talk**


**I'm scared to put my hand up**

**I find it difficult to make friends**

The kind of person who does not speak

5 David

friendly  
lonely



1 quiet  
2 shy  
3 unconfident

History

born like it  
never spoken in public/school

Feelings

In public and school  
World  
Sad

**Feeling lightheaded**

**Feeling shaky**

**Heart beats fast**

Physiological signs

**Sweating**

**Muscles feel tense**

Interactions

MOM whisper  
no one

**Shy**

**Happy**

**Confident**

**Creative**

Greatest fear

the dark

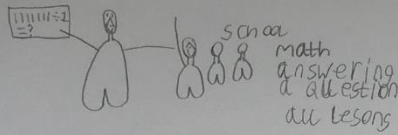
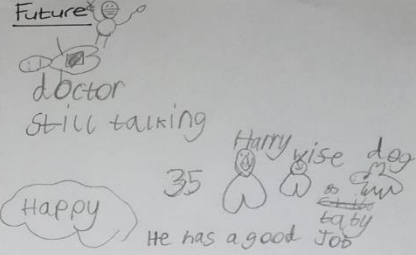
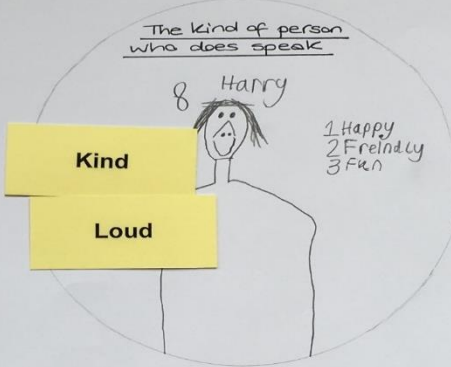
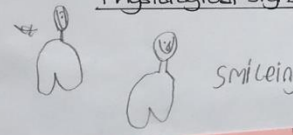

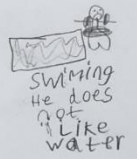
**Other phobia - e.g. animal/place/food/object**

**Talking to people out in the public**

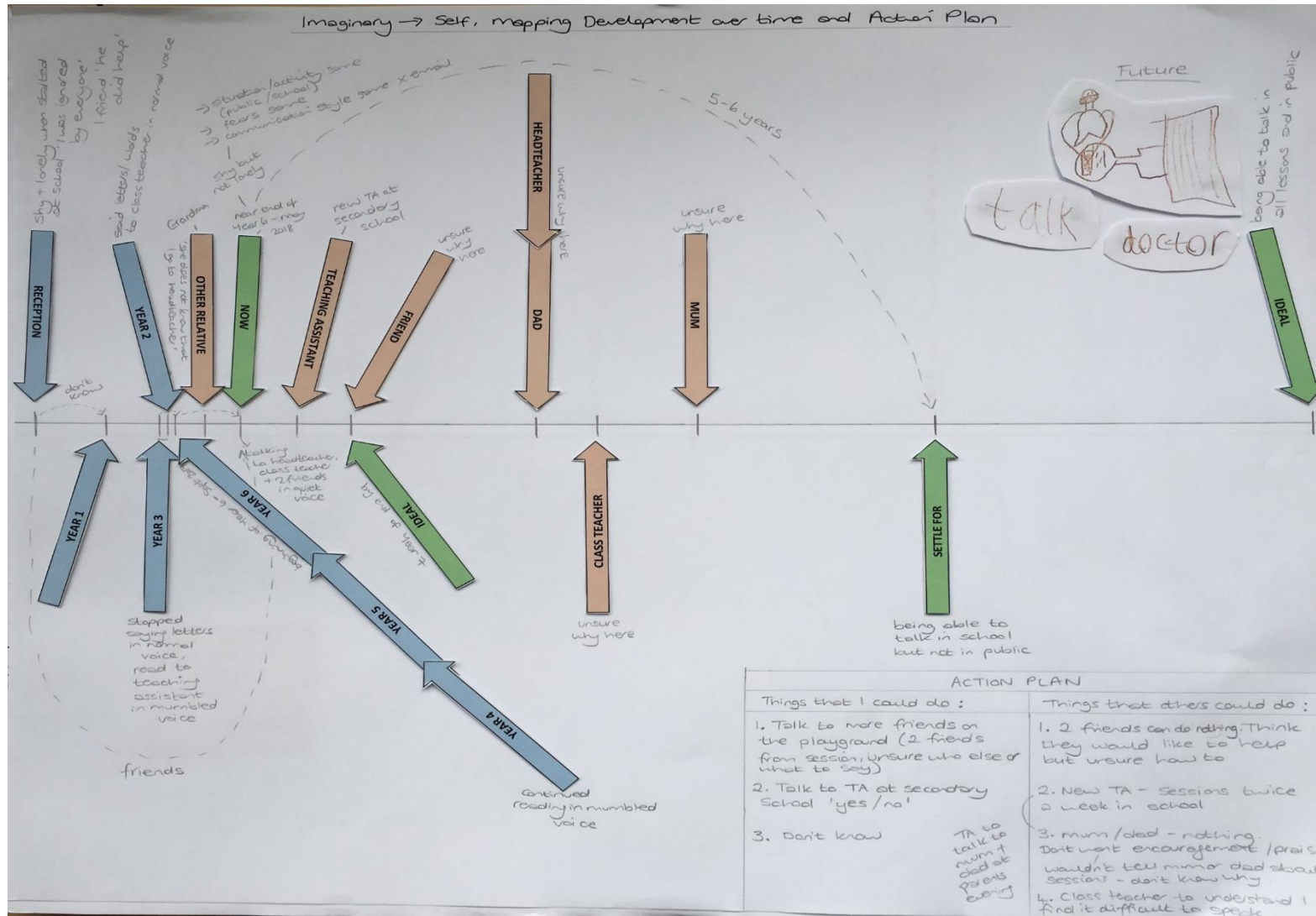
**Talking to people in school**



**APPENDIX 17b: P1's part B response**

<p><u>Situation / Activity</u></p>  <p>In public and at home.          ✓ Math          ✗ art he can't do it.</p>	<p><u>Communication style</u></p> <p>Talk</p>	<p><u>Future</u></p> 
<p><u>Thoughts</u></p> <p>Speaking is easy for me.          I like going to school.</p>	<p><u>The kind of person who does speak</u></p> 	<p><u>History</u></p> <p>always been like it</p>
<p><u>Feelings</u></p> <p>Happy calm</p> <p><u>Physiological signs</u></p>  <p>Muscles feel relaxed</p>	<p><u>Interactions</u></p>  <p>Fine</p> <p>Friendly</p> <p>Fun</p> <p>Talkative</p> <p>Relaxed</p> <p>Hard working</p>	<p><u>Greatest fear</u></p> 

**APPENDIX 17c: P1's part C response**



**APPENDIX 18a: P2's part A response**

Situation/Activity

English Maths } better, more crowded, every

science/Art } sometimes friends/teacher

public } easier, less scary, less people.

Communication Style

school

- she writes it down on paper + shows teacher
- she puts her hand up to show the teacher she needs them
- if other CMF speak to her, she tries to speak normally to them (few words)

public

- easier to speak to adults so she would speak to them. children are more loud + needed to.

Future

- be able to speak to people easily
- lots of friends
- happy

police's

- be more confident
- talk to more people
- others could be near to her

Thoughts

English/maths

- Too loud
- don't want to be here.

science/art - 'ok'

History

she has always been quiet - scared of others judging her for what she says. someone judged her for her opinion.

beginning of secondary school.

primary school = talked in all lessons.

**Lonely**

**Embarrassed**

**Shy**

**Creative**

**Silent**

**Fine**

**Unconfident**

**Kind**

**Friendly**

**Quiet**

**The kind of person who does not speak**

Amy 14

Feelings

sad  
annoyed - too loud/ too many people  
anxious  
Science/art - happier

Feeling lightheaded	Headache
Feeling sick	Feeling dizzy
Heart beats fast	Difficulty breathing
Sweating	Feeling shaky

Interactions

Makes/Me

speaks to Ashley in maths, sometimes starts conversations with her.

she likes when she is with Ashley

she tries to find a quiet place and avoid people

Teachers:

- shy
- quiet
- lonely

Greatest fear

**A certain lesson** - english/maths

**Talking to people in school** - even though she does speak - finds it difficult

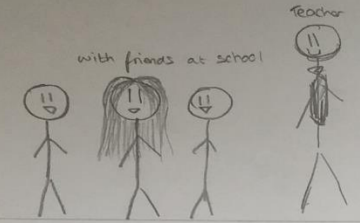
**Other phobia - e.g. animal/place/food/object** - popular, crowded, noisy places like school in busy public places - 'really anxious'

**APPENDIX 18b: P2's part B response**

Situation/Activity

- In public & at home
- likes science
- likes school

with friends at school

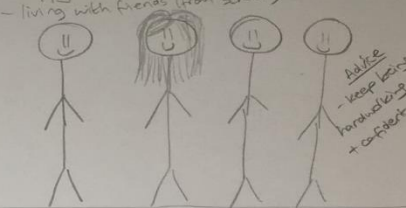


Communication style

She can talk to people normally  
She can say up to people + speak.

Future


- become a teacher (primary)
- still have lots of friends + able to speak
- happy
- living with friends (from school)



Advice  
- keep being  
hardworking  
+ confident

Thoughts

- happy  
- I like it at school  
- I can talk to other people. (easy)



The kind of person who does speak


Hard working

Fine

Confident

Talkative

Happy



HANNAH IS

Assertive

Friendly

Creative

Fun

Relaxed

History

- always been able to speak

Feelings

happy (in school, public & home)

Physiological signs

Calm

Muscles feel relaxed

Smiling


Interactions

She interacts with friends & teachers  
She can interact with anyone in public

Best friend: - confident, - friendly, - happy  
Science teacher: - hardworking, - nice, - friendly  
older sister: - fun, - cheerful

Greatest fear

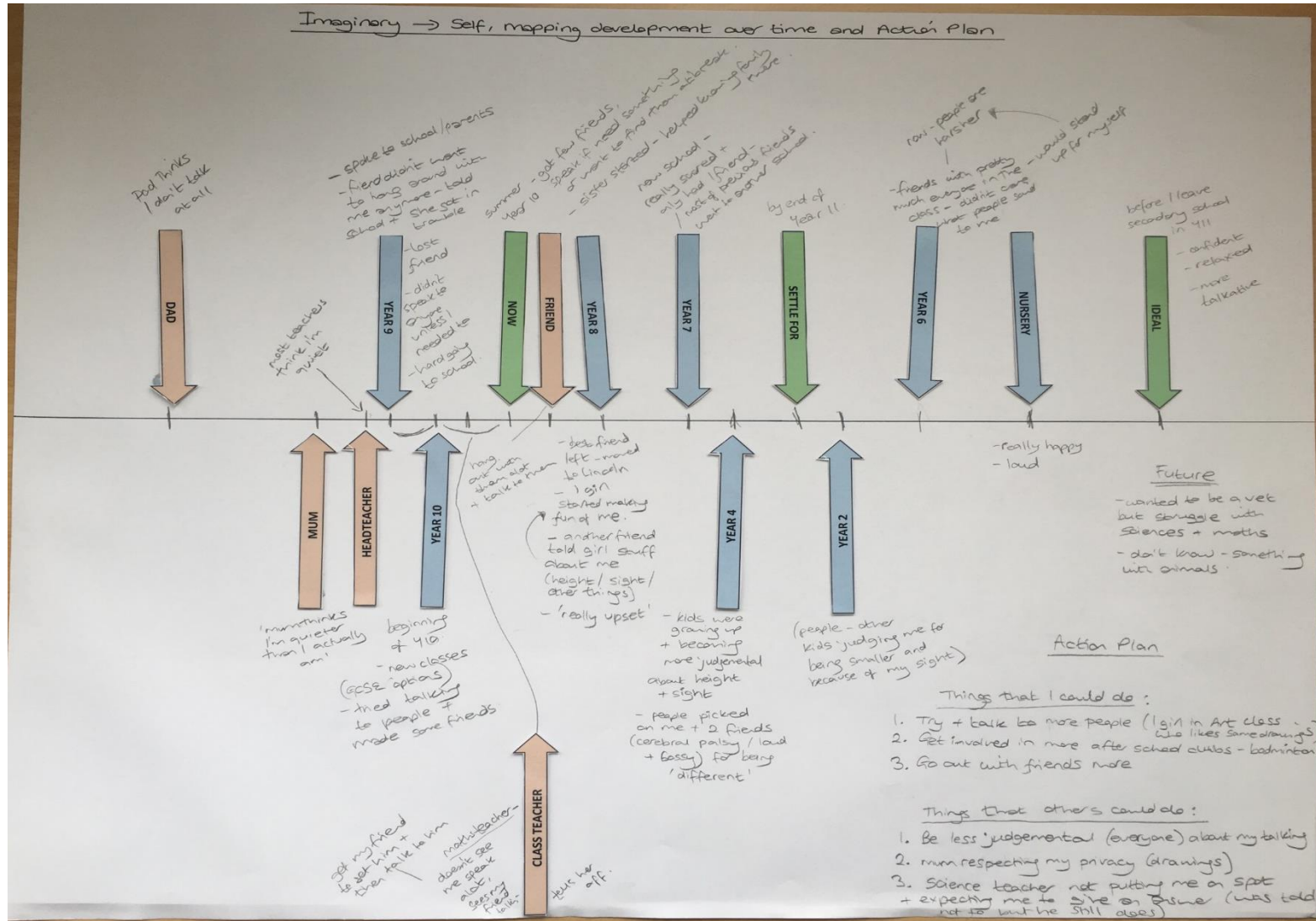
- scared of losing her friends / being lonely



- lost friends before because she was too loud/overly-confident.  
- she has now tried not to be so loud / pushy to her friends but it might happen again.  
- she would try to fix the problem - by speaking to them



**APPENDIX 18c: P2's part C response**



**APPENDIX 19a: P3's part A response**

Station / Activity

At home  
Visiting someone  
At a restaurant  
In school  
At the shops

Communication Style

Symbol Card - photo book  
Sign Language  
Nodding or shaking head  
Pointing  
Speaking normally - happy face  
to his brother  
very happy

Future

Speaking person  
Help with speaking  
(mum)  
(dad)

Thoughts

I want to be able to talk  
Speaking is difficult for me  
I don't want to go to school

History

Starting Nursery  
Starting School  
Separation from parents  
Teacher e.g. forcing them to speak/shouting  
Moving School  
Traumatic life event

The kind of person who does not speak

Great  
Sam  
Mean  
Clever  
Loud (babbling noises means)

Feelings

Happy

Body signs

Interactions

Play Time  
Lunchtime  
- talks with mum (sometimes)  
- no brothers or sisters  
- talks to no one in school

Greatest fear

Talking to people in school  
A certain lesson  
A certain teacher  
Talking to people out in the public  
Other phobia - e.g. animal/place/food/object  
Other people hearing their voice  
class teacher

**APPENDIX 19b: P3's part B response**

Situation / Activity

At home      At the park      In school

At a club      Visiting someone

craft club

Communication Style

Speaking normally

Future

The same as now

Family

speaking person

10

very happy

Thoughts

Speaking is easy for me

I like going to school

The kind of person who does speak

Kind

Caring

Chatty

History

always been able to speak

Feelings      Body signs

very happy

Interactions

Parent(s)

Friend(s)

Teacher(s)

Other relatives

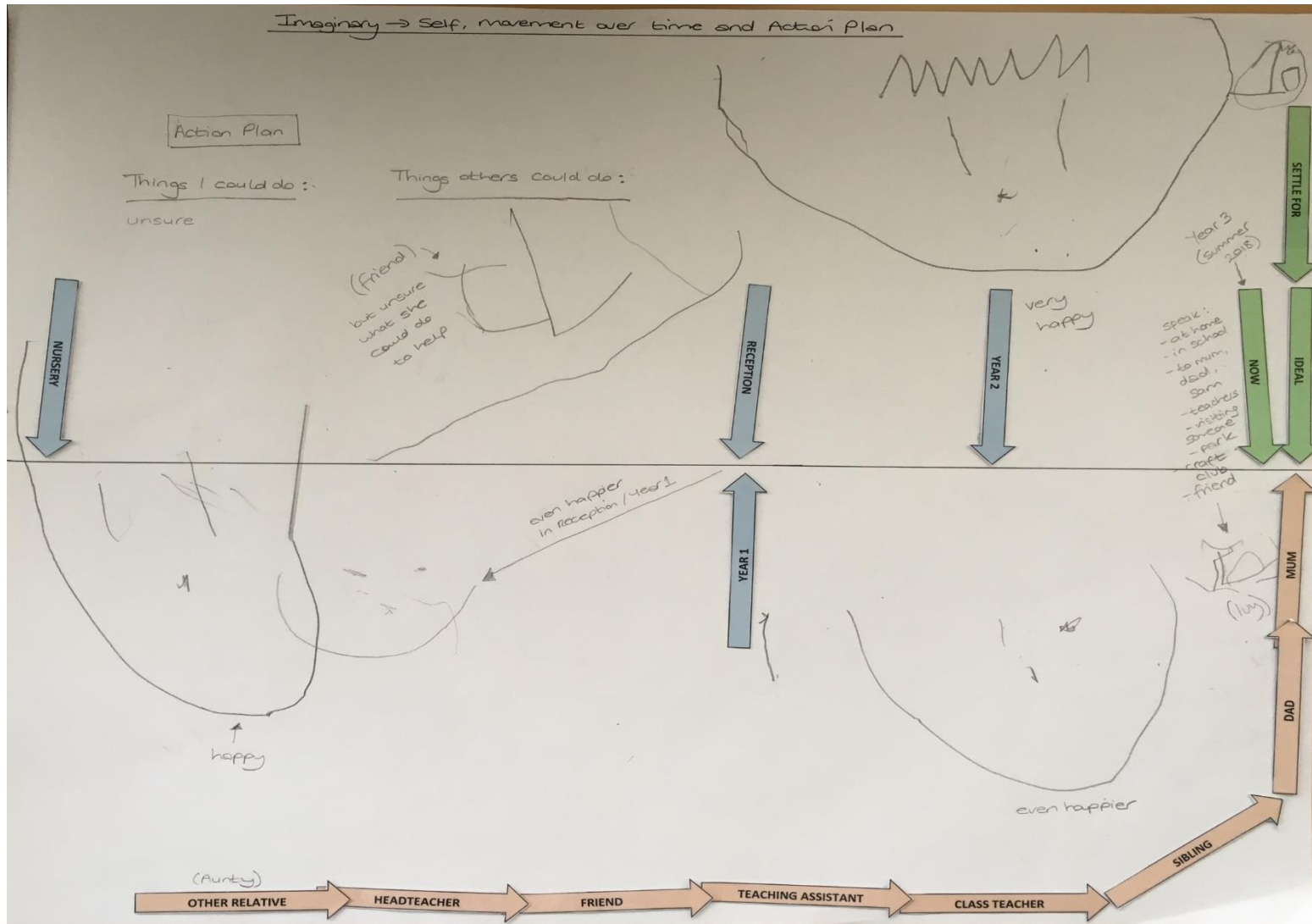
Animal

Greatest fear

X nothing



**APPENDIX 19c: P3's part C response**





**APPENDIX 20a: P4's part A response**

Situation/Activity

Sometimes doesn't speak in:

- phonics
- spellings
- science
- working in a shop
- carpet time
- outdoor time

**In school**

**Somewhere in public**

At a club

At a restaurant

Sometimes

At the shops

Communication style

Pointing

Drawing

Text message

Speaking quietly

Nodding or shaking head

Whispering

Writing down answers

Future

**Job**

Speaking person

- ✓ job
- ✓ public
- ✓ home
- ✓ friends
- ✓ family

not sure what job will be.

happy to speak

Thoughts

Speaking is difficult for me

I'm scared to put my hand up

I want to be able to talk

I find it difficult to make friends

I don't want to go to school

I struggle with learning because I can't ask for help

Feelings

Physiological signs

Butterflies in tummy

Calm

Smiling

noisy

unstable

ok

Interactions

No one - no friends

people in public

History

Starting School

Starting Nursery

Greatest fear

Talking to people out in the public

The kind of person who does not speak

Shy

Happy

Fun

Silent

Kind

Quiet

Friendly




Hard working

Sporty

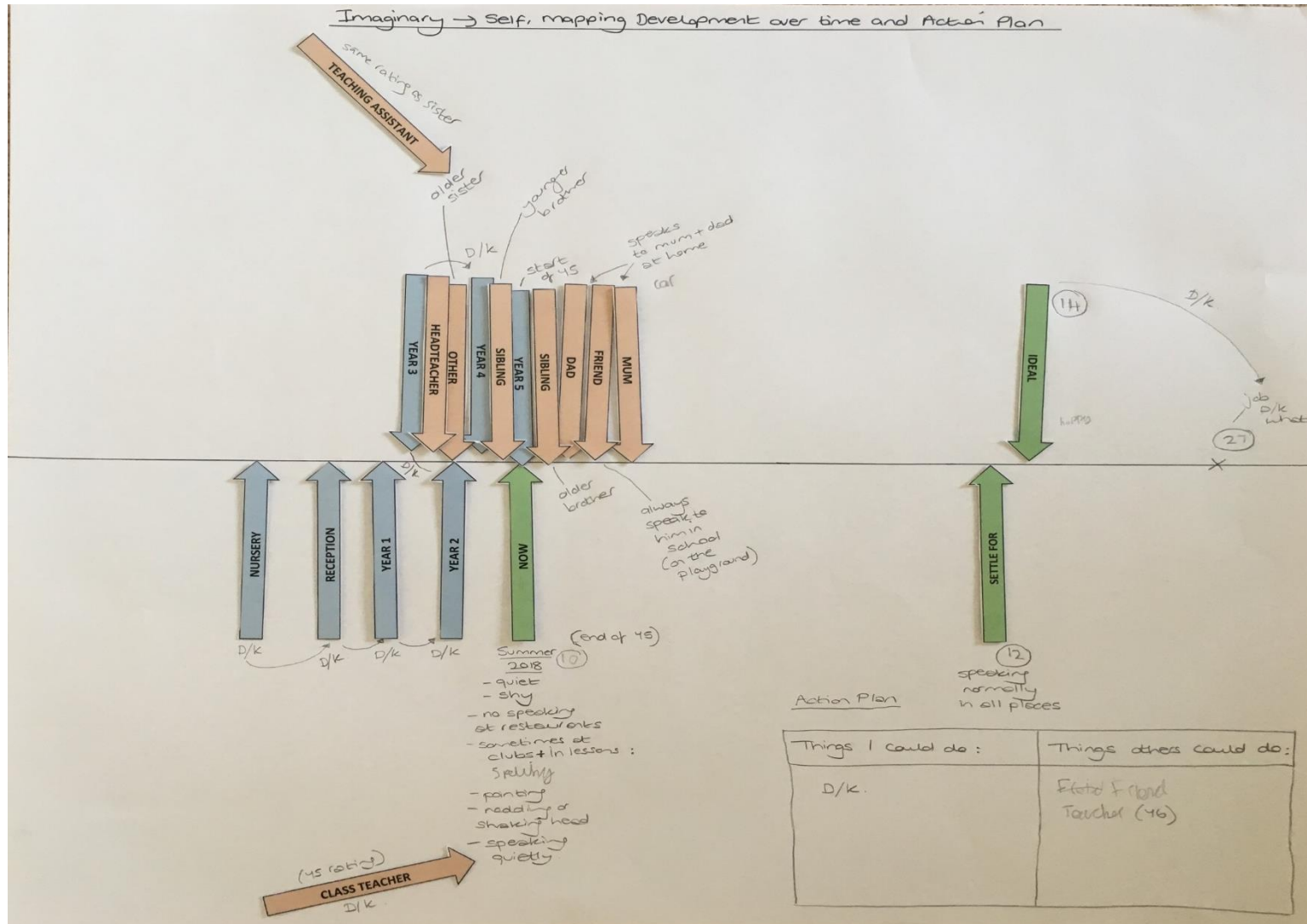
Self

9

**APPENDIX 20b: P4's part B response**

<p><u>Situation/Activity</u></p> <p>speaks in all situations</p> <p>(with friends) home with friends</p> <p>street public / all places</p>	<p><u>Communication style</u></p> <p>Speaking normally</p> <p>Email</p> <p>Text message</p> <p>Drawing</p>	<p><u>Future</u></p> <p>still talking</p> <p>job - unsure what</p>  <p>happy</p>
<p><u>Thoughts</u></p> <p>li ka short</p>	<p>The kind of person who does speak</p>  <p>Funny happy calm</p>	<p><u>History</u></p> <p>His parents and family</p> <p>always been able to speak</p>
<p><u>Feelings</u></p> <p>Physiological signs</p> <p>smiling</p> 	<p><u>Interactions</u></p> <p>← Family</p> <p>Logan</p> <p>← Joyful →</p> <p>← Friends</p> <p>← People like him</p> <p>← Teachers</p>	<p><u>Greatest fear</u></p> <p>Nothing</p>

**APPENDIX 20c: P4's part C response**



**APPENDIX 21a: P5's part A response:**

**Situation/Activity**

doesn't speak at all in school

School

At a restaurant

At the shops

At the park

**Communication Style**

Speaking quietly

Whispering

Nodding or shaking head

Writing down answers

Speaking through another person

Symbol Card

Text message

Drawing

Email

Pointing

**Future**

Non-speaking Person

The same as now

Job

Family

shop keeper - unsure how will make progress with speaking

will speak

**Thoughts**

I want to be able to talk

I struggle with learning because I can't ask for help

Speaking is difficult for me

**History**

Illness

Separation from parents

Withdrew from social situations

Traumatic life event

Being sad

unsure what about

**Feelings**

Sad

Muscles feel tense

Feeling shaky

Butterflies in tummy

**Physiological signs**

Heart beats fast

Headache

Throat tightens

**Interactions**

Toby

all teachers

Helpful

Hard working

Shy

Silent

**Greatest fear**

Scary noises

people coming up the stairs

**Characteristics and Relationships:**

Happy

Shy

Silent

Quiet

Helpful

Hard working

Toby Best friend

The kind of person who does not speak

style

10

can't help?



**APPENDIX 21b: P5's part B response**

Situation/Activity

Speaks everywhere

home

School

lets go to the park

She is not with her family

Thoughts

I don't want to go to school → it is work

I feel invisible → his pets dont see him

I dont struggle with learning because I can ask for help

Speaking is ok for me

Future

he is going to be a little police man

Still super happy

Speaking person

Communication Style

Speaking normally

Recording voice

To his family

games

History

Toby has all ways been able to speak

Feelings

super happy because he speaks

Physiological signs

Smiling

Nice feeling in his tummy

Interactions

skye

Luxy sister

teachers

Nice Brave mum

well behaved dad

Funny happy confident

Hard working

Greatest fear

people knocking on the door

he thinks that it is people coming in to steal him

The Kind of person who does speak

Hard working

Nice

Well behaved

Happy

Brave

Funny

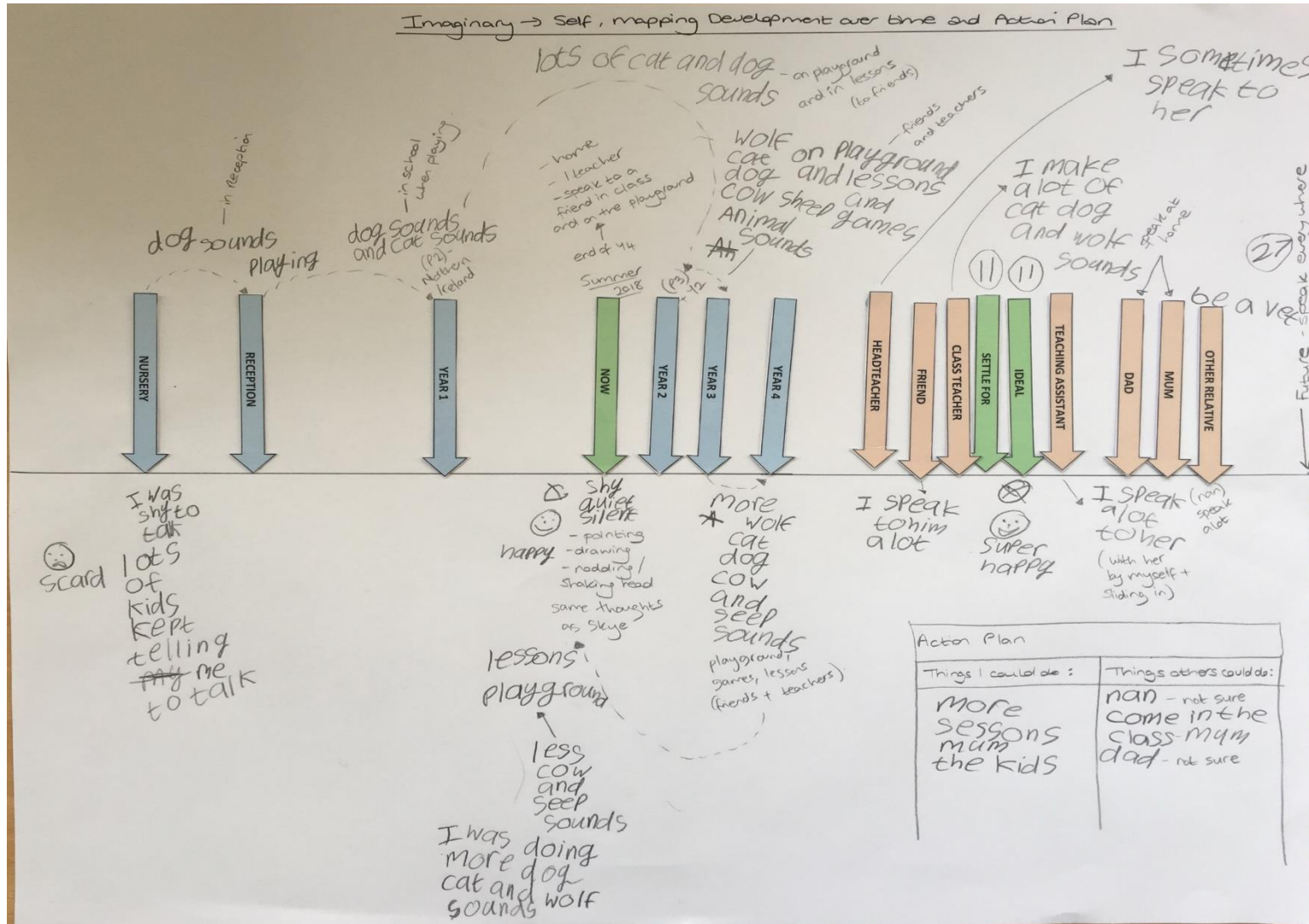
Confident

Toby (12)

He saved skye

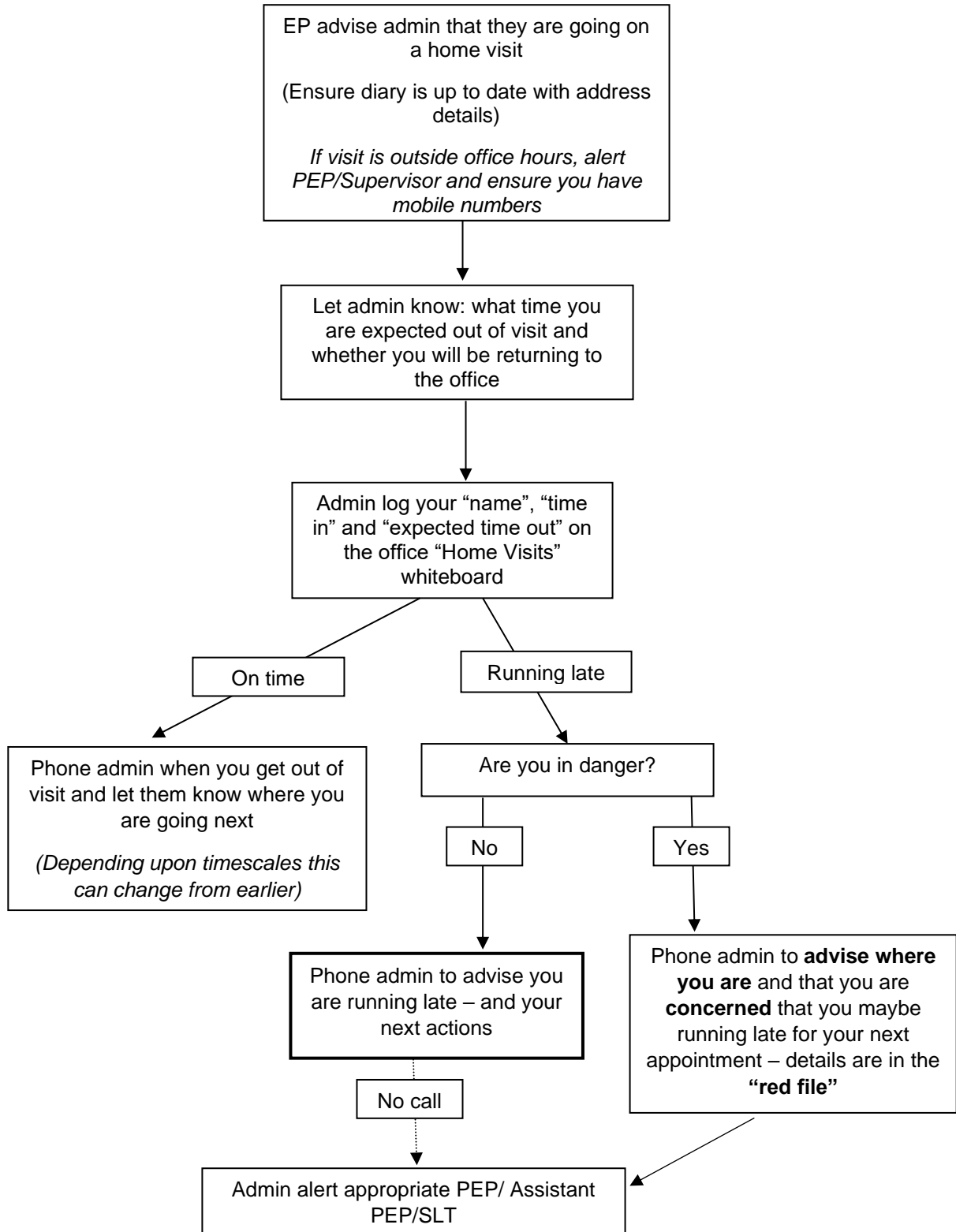
He stop skye from falling off a cliff

**APPENDIX 21c: P5's part C response**



**APPENDIX 22: Lone Working Policy used by my placement local authority**

**EPS Lone Working Process**



**APPENDIX 23: Notes from the external review of my data with a TEP colleague**

THE KIND OF PERSON WHO <u>DOES NOT</u> SPEAK		
Area	Theme	Sub Theme
Person – Descriptions	Positive attributes	Friendly Kind Creative Fine Clever Hardworking Happy Helpful Fun Sporty ? Neutral ?
	Negative attributes	Shy ? Unconfident Lonely Embarrassed Mean
	Unsure/Neutral attributes	Quiet Loud Silent
Communication Style	Verbal methods	Whispering Speaking through another person Few words Speaking normally Speaking quietly



	Non-verbal methods	Nodding/shaking head Pointing Writing down answers Drawing Email Text message Hand up Symbol card Sign Language
Situation/Activity	Public	General At the shops On the street Restaurant Visiting someone At a club At the park
	School	All areas of school Context specific (English/Maths as louder, more crowded, scary) Particular lessons (sometimes in phonics, spellings, science, working in a group, carpet time, golden time)
	Home	Home

<b>Thoughts</b>	Anxiety based	I am different (doesn't talk out loud) I'm scared to put my hand up I find it difficult to make friends Don't want to be here Too loud Some lessons are ok (Science/Art)? <i>streyt-s</i> Speaking is difficult for me <i>faused?</i> I don't want to go to school I struggle with learning because I can't ask for help
<b>Feelings</b>	Desire to change	I want to be able to talk
	Anxiety based	Worried Sad Annoyed (too many people/too loud) Anxious Nervous Unsure
	Non-anxiety based	Happier (in Science/Art) Happy Ok

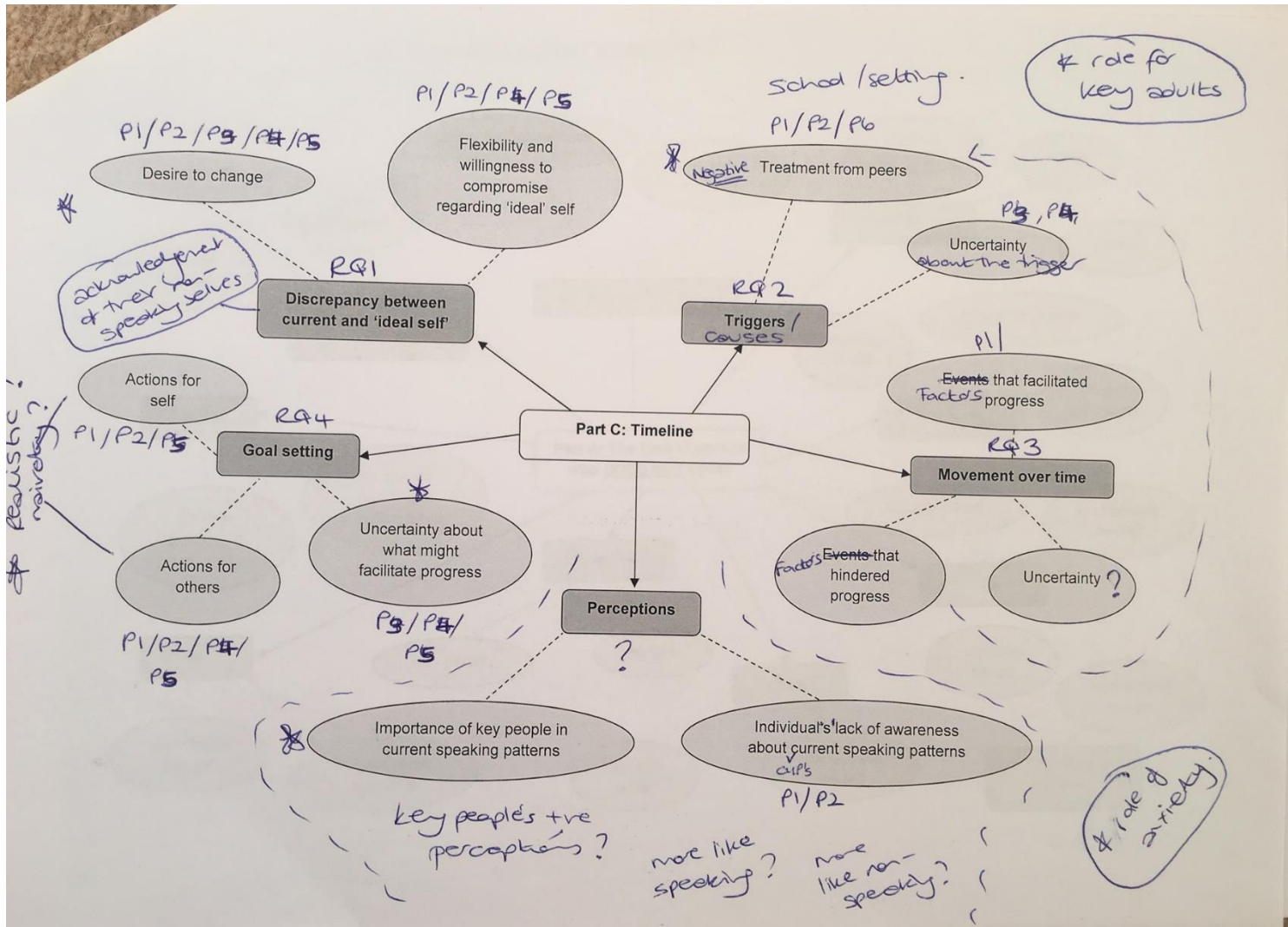
<b>Interactions</b>	Key person	mum, friend
	No one	3 reported "no-one"
<b>History</b>	Identifiable trigger	Moving School Starting School Starting Nursery Teacher (forcing to speak/ shouting) Illness (age 1) Separation from parents Traumatic life event (being sad/something sad happened) Withdrew from social situations
	Always been like it	Born like it (never spoken in public/school)
<b>Future</b>	Change resulting in positive future	Speaking freely - 'happy' Family Job Interactions Help with speaking
	No change resulting in negative future	'Sad' - no change (still won't speak at restaurant)

THE KIND OF PERSON WHO <u>DOES</u> SPEAK		
Area	Theme	Sub Theme
Person	Positive attributes	Happy Friendly Fun Kind Confident Hardworking Fine Assertive ✕ Creative Relaxed Caring Funny Nice Well behaved Brave ✕
	Unsure/neutral attributes	Loud ? +ve ? Talkative Chatty
Communication Style	Verbal methods	Speaking normally Recording voice (in a game)
	Non-verbal methods	Email Text message Drawing

<b>Situation/Activity</b>	All situations	Public Home School
<b>Thoughts</b>	Speech related	Speaking is easy/ok for me
	Not related to speech	I like going to school I don't want to go to school (school work) I feel invisible (pets don't see him) I don't struggle with learning because I can ask for help + <i>speech related</i>
<b>Feelings</b>	Non-anxiety based	Happy Calm
<b>Physiological Signs</b>	Non-anxiety based	Smiling Muscles feel relaxed Nice feeling in tummy
<b>Fears</b>	Speech related	Losing her friends/being lonely (was previously too loud/overly confident)
	Unrelated to speech	Swimming People knocking on the door (thinks people are coming to steal him)
<b>Interactions</b>	Key person	<i>mom, (friend), (sibling)</i> <i>(teacher)</i>
	Everyone	<i>everyone - friends,</i> <i>family, teachers</i>

<b>History</b>	Always been like it	
<b>Future</b>	Continuation of speaking resulting in positive future	Still speaking person Job (doctor, teacher, unsure, policeman) Family Friends 'Happy' (very/super)





**APPENDIX 24: Certificate given to participants after completion of the interviews**



UNIVERSITY OF  
BIRMINGHAM

LOCAL AUTHORITY LOGO

This is a certificate to say a  
big WELL DONE and  
THANKYOU to

---

for taking part in Emily's  
research study



I have really enjoyed working with you and am very grateful for you sharing your views and experiences. You have helped me to much better understand what it is like to have Selective Mutism and I hope that my research will help other professionals working with children and young people like you.

I wish you all the best in the future,

Emily 😊



## **APPENDIX 25: Example written summary letter sent (to P1) after the interview**



**UNIVERSITY OF  
BIRMINGHAM**

**LOCAL AUTHORITY LOGO**

Date: 5<sup>th</sup> June 2018

Dear P1,

Thank you again for taking part in my research study. I really enjoyed working with you and am very grateful for you sharing your views and experiences.

During the interviews we thought about two imaginary characters, the kind of person who does not speak and the kind of person who does speak. You did some drawings, writing and card sorting activities to explain what these people were like, and I then asked you to rate yourself now, in the future and at various points in time on a scale between the two characters. We looked at the progress you had made, and you also thought about where your family, friends and teachers would rate you on the scale. Finally, we created an action plan that you thought might help you to move towards your 'ideal' self in the future.

Here is a summary of the information you shared during our interviews:

- You rated yourself as more like David (the kind of person who does not speak) at the moment (May 2018) but your 'ideal' self is to be like Harry (the kind of person who does speak)
- You described yourself as shy but not lonely now (May 2018) as you have friends
- You told me that you have the same fears and communication style as David and that speaking is difficult for you in school and in public like it is for him
- In the future you would like to be able to talk in all lessons in school and in public, so you can become a Doctor but you would settle for talking in school but not in public and think this could happen over the next 5-6 years
- In Reception you were very much like David. You felt shy and lonely when you started school as you were 'ignored by everyone' but one friend helped you
- You made some progress in Year 1 but were not sure how this happened
- You also made progress in Year 2 as this is when you said letters and words to Mrs S in a normal voice
- In Year 3 you went back a step as you stopped saying letters and words in a normal voice but started reading to Mrs B in a mumbled voice
- You then made some progress in Years 4, 5 and 6 as you continued to read to staff in a mumbled voice
- You have made progress between September and May of Year 6 as you have been talking to Mrs H, Mrs L and two of your friends in a quiet voice
- By the end of Year 7 you want to have made more progress with speaking in school
- You think mum would rate you as most like Harry, but that dad, Mrs H, Mrs L, your friends and Mrs H also think you are more like Harry than you do
- You think the only person who would rate you as more like David is Grandma as 'she does not know that I go to Mrs H'

- We thought about what might help you to make more progress and put together the following action plan:

Things that I could do:	Things that others could do:
1. Talk to more friends on the playground (2 friends from sessions but unsure who else or what to say)	1. 2 friends can do nothing. Think they would like to help but unsure how to
2. Talk to Mrs H at secondary school so I can say 'yes/no'	2. Sessions twice a week in school with Mrs H
3. Don't know	3. Mum/dad can do nothing. Don't want encouragement or praise and wouldn't tell them about sessions but Mrs H can talk to them at parents evening
	4. Class teacher to understand that I find it difficult to speak

I have attached a copy of your work from the interviews for you to keep. I hope I have understood your views, experiences and hopes for the future correctly.

It seems like you are really motivated to continue making progress with speaking at secondary school and that Mrs H will be a key person to help you with this during your sessions together. You also told me that it is important to you that other teachers know that you find it difficult to speak. You suggested that writing a self-profile might be another way of gaining the views of children and young people with Selective Mutism, so maybe this is something you could do to share with staff at secondary school?

You told me that you would like to share your action plan with Mrs H, Mrs H and Mrs L, so maybe you could take it in to show them so they know what steps you want to work on next.

Thank you again for participating, you have helped me to much better understand what it is like to have Selective Mutism. Once I have completed all of the interviews, I will write up my findings into a report for university, but I will use your pseudonym rather than your real name to keep your identity and responses confidential. I hope that my research will help other professionals working with children and young people like you.

I wish you all the best for the future.

Yours sincerely,

Emily

**Emily Strong**

Trainee Educational Psychologist with [NAME OF AUTHORITY] Educational Psychology Service & Postgraduate Researcher at the University of Birmingham

## APPENDIX 26: PowerPoint presentation delivered to SLTs to feedback research findings

LOCAL AUTHORITY LOGO

UNIVERSITY OF BIRMINGHAM

**'We do have a voice': Using a Personal Construct Psychology technique to explore how children and young people with Selective Mutism construct the 'speaking' and 'non-speaking' person, and their hopes for the future**

**Feedback to Speech and Language Therapists**

Emily Strong, Trainee Educational Psychologist

2<sup>nd</sup> April 2019

1

### DSM-V criteria for Selective Mutism

- ▶ Individuals present a consistent pattern of speaking in some situations where speech is expected but not in others
- ▶ The failure to speak is persistent, lasting more than one month, but not including the first month in a new environment such as school
- ▶ The failure to speak has a significant impact on educational or occupational achievement or social communication
- ▶ Lack of knowledge or comfort with the required spoken language, or a disorder of communication or a condition like social anxiety disorder, may also be present, but is not the cause and does not explain the mutism

2

### Aetiology of SM

1. A genetic predisposition i.e. a sensitive personality which increases the likelihood of experiencing anxiety
2. An association between the expectation to speak and distress which results in a learned fear and repeated avoidance of speech in certain situations
3. Maintaining factors where other people's reactions to Selective Mutism reinforce the fear of speaking

(Johnson and Wintgens, 2016)

3

### Aims of Research

- ▶ To gain the views of children and young people with Selective Mutism
- ▶ To address a gap in the UK literature
- ▶ To develop a novel technique based on Personal Construct Psychology

4

### Rationale

Existing knowledge about SM is largely based on:

*"observer interpretations rather than experiential accounts" which raises concerns that "methodologies which fail to take into account the perspectives of those with SM may be presenting a misleading or partial representation of SM by reporting only how it appears to outsiders"*

(Walker and Tobbell, 2015, p.456-457)

5

### Methodology

- ▶ Personal Construct Psychology - dichotomy corollary (Kelly, 1955)

Non-speaking person Speaking person

- ▶ Adaptation of 'Drawing the Ideal Self' technique to explore CYPs:
  - ❖ *Constructs of the 'speaking' and 'non-speaking' person*
  - ❖ *Beliefs about how they are perceived by others*
  - ❖ *Their development over time*
  - ❖ *Their goals for the future*

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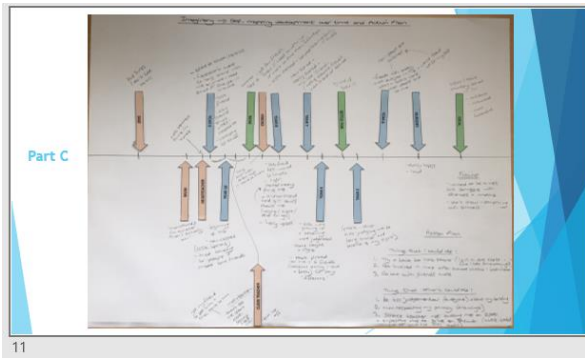
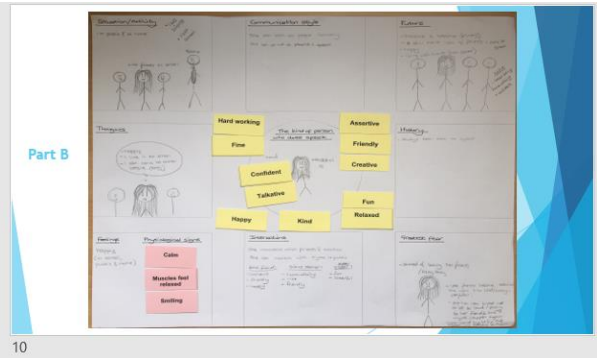
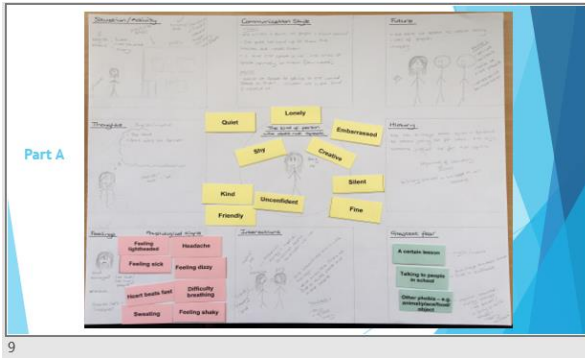
### Sample

- ▶ 5 CYP aged 8-14
- ▶ 2 girls, 3 boys
- ▶ 1 at Stage 6/7 of confident talking - *Communicates using single words/sentences*
- ▶ 4 at Stage 3 of confident talking - *Uses non-verbal and written communication*
- ▶ Interviews conducted at home over 3 sessions
- ▶ 4/5 parents were present during the interviews

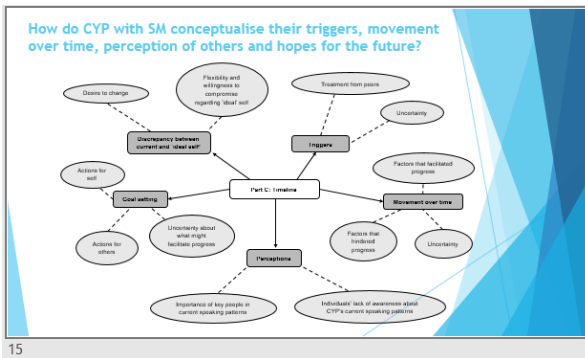
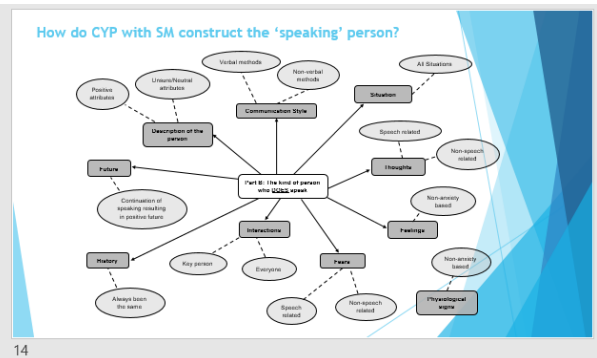
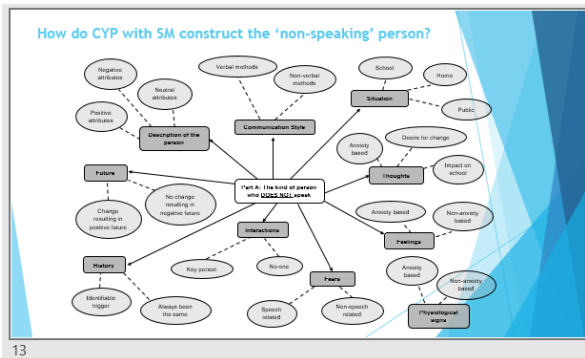
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### Example of interview data

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## Data Analysis & Findings

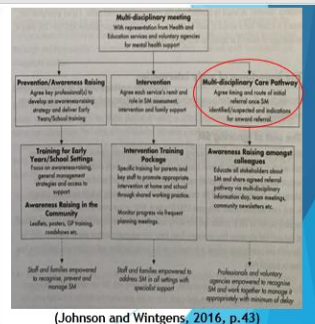
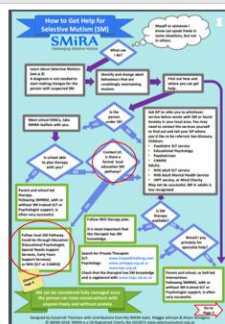


- ## Superordinate themes
- ▶ Role of anxiety
  - ▶ Role of others in trigger/maintenance of SM
  - ▶ Desire to change
  - ▶ Positive future as a result of talking
  - ▶ Uncertainty/naivety about how to change
  - ▶ Importance of key people to facilitate progress

## Conclusions and Implications for practice

- ▶ Novel technique to gain the 'hidden views' of CYP with SM
- ▶ Positive feedback from CYP and parents about method
- ▶ Importance of person-centred and coordinated approach
- ▶ Role of key adult
- ▶ EPs are well placed to complete holistic assessment:
  - ❖ To gain CYPs views and support with anxiety reduction
  - ❖ Work with schools/parents other professionals re environmental adjustments
- ▶ SLTs are well placed to explore causes of SM/management
- ▶ SM Pathway for LA? Collaboration between services?

17



18

Thank you for listening  
Any thoughts/questions?

Emily Strong  
X Educational Psychology Service

Website:  
Email:  
Tel:

19

**APPENDIX 27: Evaluation form completed by parents after their child had participated in the research interviews**

**Parent Evaluation of Emily’s Research Project:**

*‘We Do Have a Voice: Using Personal Construct Psychology to explore how children and young people with Selective Mutism construct their speaking and non-speaking selves’*

Child’s Pseudonym: \_\_\_\_\_

Date: \_\_\_\_\_

Please read the following statements about the research interviews I did with your child and use the rating scale to indicate how much you agree or disagree with each one (1 = Strongly Disagree, 10 = Strongly Agree):

**1. I think my child enjoyed doing Emily’s research interviews**

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Strongly  
Disagree

Strongly  
Agree

**2. The drawing, writing and card sort activity allowed my child to share their views and experiences of Selective Mutism**

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Strongly  
Disagree

Strongly  
Agree

**3. I felt Emily understood, respected and valued my child’s views**

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Strongly  
Disagree

Strongly  
Agree

**4. The prompt cards were a helpful way for my child to share their views**

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Strongly  
Disagree

Strongly  
Agree

**5. The action plan created in the activity will help my child in the future**

1	2	3	4	5	6	7	8	9	10

Strongly  
Disagree

Strongly  
Agree

**6. The activity was:**

Too short	The right amount of time	Too long

**7. Any changes I think should be made to the research interviews:** \_\_\_\_\_

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**8. Another way researchers could gain the views of children and young people with Selective Mutism may be:** \_\_\_\_\_

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**9. Any other comments about the research interviews:** \_\_\_\_\_

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**Thank you for agreeing for your child to take part in my research interviews and for completing the evaluation.**

**Emily**

**APPENDIX 28: Letter sent to E1 giving her the opportunity to express her views and experiences of SM without participating in the interviews**



**UNIVERSITY OF  
BIRMINGHAM**

**LOCAL AUTHORITY LOGO**

Dear E1,

Thank you for letting me visit you at home, I really enjoyed meeting you 😊

I could see it was difficult for you and am sorry if I made you feel uncomfortable or worried.

I thought it might be easier for you to write and draw how you feel in your own time when I am not there. Would this be ok?

If you are happy to, can I ask you to do some drawings and writing in the spaces below please? I've written a few questions and they are in two parts. This will help me to better understand what it is like to have Selective Mutism (finding it difficult to speak in some places). Mum or dad might be able to help you if you get stuck.

**Part A**

First, can you think about when you find it easy or ok to talk and draw a picture of yourself for me please:

Can you tell me three things about you? How would you describe yourself when you find it easy or ok to talk? You can do some drawings too if you would like:

- 1.
- 2.
- 3.



Where are you when you find it easy or ok to talk? Are you at home, in school (are there certain lessons/activities?), at the shops, at the park, at a restaurant, at a club you go to, or somewhere else? Is there more than one place? Can you draw a picture below to show me:

How do you feel when you find it easy or ok to talk? You can draw a picture or write about this if you would like:

What are you thinking when you find it easy of ok to talk? You can draw a picture or write about this if you would like:

How do you communicate when it is easy or ok to talk? Please write or draw about this if you can:

Who are you with when you find it easy or ok to talk? Are you with your mum, dad, sisters, other family members, friends, teachers, teaching assistants or someone else?

**Part B**

Now, can you think about when you don't talk or find it difficult to talk and draw another picture of yourself for me please:

Can you tell me three things about you now? How would you describe yourself when you don't talk or find it difficult to talk? You can do some drawings too if you would like:

- 1.
- 2.
- 3.

Where are you when you don't talk or find it difficult to talk? Are you at home, in school (are there certain lessons/activities?), at the shops, at the park, at a restaurant, at a club you go to, or somewhere else?) Is there more than one place? Can you draw a picture below to show me please:

How do you feel when you don't talk or find it difficult to talk? You can draw a picture or write about this if you would like:

What are you thinking when you don't talk or find it difficult to talk? You can draw a picture or write about this if you would like:

How do you communicate when you don't talk or find it difficult to talk? Please write or draw about this if you can:

Who are you with when you don't talk or find it difficult to talk? Are you with your mum, dad, sisters, other family members, friends, teachers, teaching assistants or someone else?

Can you remember the first time you didn't talk or found it difficult to talk? Do you know if something happened? Can you draw or write about this please:

Does anyone help you when you don't talk or find it difficult to talk? What do they do? Can you draw or write about this please:

Can you tell me about what you hope for the future? Is there anything you would like to change? Please write or draw about this below:

If there is anything else you would like me to know, you can draw or write about it here:

I wish you all the best for the future.

Yours sincerely,

**Emily Strong**

Trainee Educational Psychologist with [NAME OF AUTHORITY] Educational Psychology Service & Postgraduate Researcher at the University of Birmingham

## **APPENDIX 29: Pen portraits of the five participants**

### **Introducing P1**

At the time of the interviews, P1 was 11 years old and in his final year of primary school (Year 6). He lived with his mum, dad and two younger sisters and was reported to speak freely at home. His mum explained that herself and her husband were in the military when P1 was growing up and were relocated as P1 was starting school. He had struggled with speaking in school since joining midway through Reception. P1 was currently having sliding-in sessions with his head teacher and two friends, and had met with the TA who would be supporting him in secondary school. He was pleased with his progress with speaking in school and wanted this to continue in Year 7.

During the interviews P1 appeared happy to communicate with me non-verbally and expressed his views by drawing, writing down his answers and pointing to the relevant prompt cards.

### **Introducing P2**

At the time of the interviews, P2 was 14 years old and in Year 10. She lived with her mum, dad, younger sister and younger brother who attended a specialist provision. P2 was reported to speak freely at home, although she was much quieter when anxious. I learnt that P2 struggled to communicate with extended family members who lived some distance away, but would say a few words after being in their company for a few days and gradually increasing confidence. She was reported to have a couple of friends in school, although there had been bullying issues in the past due to her growth deficiency and related eye condition. A SLT had been involved with P2 for a year and was working alongside parents and school staff regarding how to support her SM. Her mum reported that P2 did not like it when teachers put pressure on her to speak in class.

During the interviews, P2 initially communicated using single words but this increased to short phrases and longer exchanges as the sessions went on and she felt more relaxed. She also drew pictures, wrote down her answers and used prompt cards to express her views.

### **Introducing P3**

At the time of the interviews, P3 was 8 years old and in Year 3. He lived with his mum, dad, and younger brother who attended a specialist provision, and was reported to speak freely at home. P3 had had SLT input since he was 2 ½ years old due to speech delay, which his mum felt had caused his speech anxiety as he was not sure how words would come out. His mum also had speech anxiety as a child. I learnt that when P3 started Reception he would not communicate with staff verbally or non-verbally and would not speak to his mum or dad on the playground, often displaying a 'freeze' response. After support from the Specific Speech and Language Impaired Children's team in Year 2, he started to make progress by answering simple yes/no questions from staff. In Year 3 he responded to others using short phrases but would still not initiate conversation himself or indicate when he needed the toilet.

During the interviews, P3 communicated through a toy goat which nodded/shook his head, drew pictures, wrote down his answers and selected the relevant prompt cards.

### **Introducing P4**

At the time of the interviews, P4 was 10 years old and in Year 5. He lived with his mum, dad, older sister, older brother and younger brother. He was described as a shy and anxious individual who worried about a lot of things. I learnt that P4 spoke normally to his mum but in a mumbled voice or using non-verbal gestures to other family members. His speech patterns were felt to be closely related to his mood and anxiety. A SLT had been involved since he was 2 years old and was working alongside his mum and school staff regarding supporting his SM.

During the interviews, P4 was initially reluctant to engage by drawing or writing and relied heavily on the prompt cards. When I arrived for the second visit, his mum informed me that he had had a bad day at school and consequently he was hiding under a trampoline in the garden and would not communicate with me non-verbally. At this point, I decided to postpone the session and returned the following week. During the final two sessions, P4 engaged by nodding/shaking his head, drawing, writing and using prompt cards to express his views.

### **Introducing P5**

At the time of the interviews, P5 was 9 years old and in Year 4. She lived with her mum and dad and was reported to speak freely at home and in public to her parents, but not to strangers e.g. shop assistants or her doctor. I learnt that the family had moved around a lot whilst P5 was growing up due to her dad's career in the military and consequently she had attended four different schools. Concerns were first raised about her speaking patterns when she started nursery aged 3. Her mum explained that she had always been shy and did not like people watching her (e.g. when dancing) or hearing her voice. She hated the telephone and would not speak to her mum this way. P5's mum explained that her husband (P5's dad) had also experienced speech anxiety in certain environments when he was younger.

A SLT had been involved for the last two years and her mum was currently supporting her in school via weekly sliding-in sessions with several of her friends. This was reported to be going well and had resulted in her speaking to one friend at home and in school. She had also recently made a new friend who would come to play and, whilst she was not yet communicating with him using words, she was using voice by laughing and making noises.

During the interviews, P5 appeared happy to communicate with me non-verbally and expressed her views by drawing, writing down her answers and pointing to the relevant prompt cards. She also made some noises which I felt indicated agreement/excitement but did not use any words.

**APPENDIX 30: Coding process for data gathered in parts A, B and C of the interviews**

*Whilst themes were generated for responses from all three stages of the interviews, focus was on part C data due to their higher trustworthiness and applicability to the self, and relevance to the research questions.*

<b>Coding for Part A: The kind of person who DOES NOT speak</b>					
<b>Area</b>	<b>Theme</b>	<b>Data items</b>	<b>No of participants</b>	<b>Participant</b>	
<b>The Person – descriptions</b>	<i>Positive attributes</i>	Friendly	3	P1, P2, P4	
		Kind	2	P2, P4	
		Creative	1	P2	
		Fine	1	P2	
		Clever	1	P3	
		Hardworking	2	P4, P5	
		Happy	2	P4, P5	
		Helpful	1	P5	
		Fun	1	P4	
Sparty	1	P4			
<i>Negative attributes</i>	<i>Negative attributes</i>	Shy	4	P1, P2, P4, P5	
		Unconfident	3	P1, P2, P4	
		Lonely	2	P1, P2	
		Embarrassed	1	P2	
		Mean	1	P3	
<i>Unsure/Neutral attributes</i>	<i>Unsure/Neutral attributes</i>	Quiet	4	P1, P2, P4, P5	
		Loud	1	P3	
		Silent	3	P2, P4, P5	
<b>Communication Style</b>	<i>Verbal methods</i>	Whispering	3	P1, P4, P5	
		Speaking through another person	2 (mum/best friend)	P1, P5	
		Few words	1	P2	
		Speaking normally	2 (to brother/ adults in public)	P2, P3	
		Speaking quietly	2	P4, P5	
	<i>Non-verbal methods</i>	<i>Non-verbal methods</i>	Nodding/shaking head	4	P1, P3, P4, P5
			Pointing	4	P1, P3, P4, P5
			Writing down answers	4	P1, P2, P4, P5
			Drawing	2	P4, P5
			Email	2	P1, P5
Text message	3	P1, P4, P5			
Hand up	1	P2			
Symbol card	2	P3, P5			
Sign Language	1	P3			
<b>Situation/Activity</b>	<i>Public</i>	General	1	P2	
		At the shops	4 (1 – sometimes)	P1, P3, P4, P5	
		On the street	1	P1	
		Restaurant	3	P3, P4, P5	
		Visiting someone	1	P3	
		At a club	1 (sometimes)	P4	
At the park	1	P5			

	<i>School</i>	All areas of school Context specific (English/Maths as louder, more crowded, scary) Particular lessons (phonics, spellings, science, group work, carpet time, golden time)	3 1  1 (unable to identify why)	P1, P3, P5 P2  P4
	<i>Home</i>		1 (younger brother with LD – non-speaking not related to anxiety but discrepancy – speaks to brother?)	P3
<b>Thoughts</b>	<i>Anxiety based</i>	I am different (doesn't talk out loud) Speaking is difficult for me	1 3	P1 P3, P4, P5
	<i>Impact at school</i>	I'm scared to put my hand up I find it difficult to make friends Don't want to be here Too loud Some lessons are ok (Science/Art)  I don't want to go to school I struggle with learning because I can't ask for help	2 2 (1 sometimes) 1 1 1 (speech is easier due to quieter environment) 3 (1 sometimes) 2 (1 sometimes)	P1, P4 P1, P4 P2 P2 P2  P2, P3, P4 P4, P5
	<i>Desire to change</i>	I want to be able to talk	4 (1 sometimes)	P1, P3, P4, P5
<b>Feelings</b>	<i>Anxiety based</i>	Worried Sad Annoyed (too many people/too loud) Anxious Nervous Unsure	1 3 1 1 1 1	P1 P1, P2, P5 P2 P2 P5 P4
	<i>Non-anxiety based</i>	Happier (in Science/Art) Happy Ok	1 1 1	P2 P3 P4



<b>Physiological Signs</b>	<i>Anxiety based</i>	Feeling shaky	3	P1, P2, P5	
		Heart beats fast	3	P1, P2, P5	
		Feeling lightheaded	2	P1, P2	
		Sweating	2	P1, P2	
		Muscles feel tense	2	P1, P5	
		Feeling sick	1	P2	
		Headache	2	P2, P5	
		Feeling dizzy	1	P2	
		Difficulty breathing	1	P2	
	Butterflies in tummy	2	P4, P5		
		Throat tightens	1	P5	
	<i>Non-anxiety based</i>	Calm – fine?	1	P4	
		Smiling	1	P4	
<b>Greatest fear</b>	<i>Speech related</i>	Talking to people in school	3	P1, P2, P3	
		Talking to people in public	3	P1, P3, P4	
		Certain lesson activity (English/maths & playtime/lunchtime – social anxiety?)	2	P2, P3	
		Certain teacher (class teacher)	1	P3	
		Other people hearing their voice	1	P3	
		Other (crowded/noisy places – increases anxiety)	1	P2	
	<i>Non-speech related</i>	The dark	1	P1	
		Spiders	1	P1	
		Scary noises (people coming up the stairs)	1	P5	
Other (couldn't identify what)		1	P3		
<b>Interactions</b>	<i>Key person</i>	Mum	2	P1, P3	
		Friend	2	P2, P5	
	<i>No one</i>	In school	2	P3, P4	
In public		1	P4		
<b>History</b>	<i>Identifiable trigger</i>	Moving School	2 (1 beginning of secondary school when someone judged her for her opinion)	P2, P3	
		Starting School	2	P3, P4	
		Starting Nursery	2	P3, P4	
		Teacher (forcing to speak/ shouting)	1	P3	
		Illness (age 1)	1	P5	
		Separation from parents	2	P3, P5	
		Traumatic life event (being sad/something sad happened)	2	P3, P5	
		Withdrew from social situations	1	P5	

	<i>Always been the same</i>	Born like it (never spoken in public/school)	1	P1
<b>Future</b>	<i>Change resulting in positive future</i>	Speaking freely – ‘happy’	4	P1, P2, P3, P4
		Family Job	2 3 - secondary teacher, vet, unsure	P1, P5 P1, P2, P4
		Interactions	2 - Friends 3 - Family	P1, P2 P1, P4, P5
		Help with speaking	1 (mum and dad)	P3
	<i>No change resulting in negative future</i>	‘Sad’ - no change (still won’t speak at restaurant)	1 - Job (shopkeeper)	P5

<b>Coding for Part B: The kind of person who DOES speak</b>				
<b>Area</b>	<b>Theme</b>	<b>Data items</b>	<b>No of participants</b>	<b>Participants</b>
<b>The Person - descriptions</b>	<i>Positive attributes</i>	Happy	4	P1, P2, P4, P5
		Friendly	2	P1, P2
		Fun	2	P1, P2
		Kind	3	P1, P2, P3
		Confident	2	P2, P5
		Hardworking	2	P2, P5
		Fine	1	P2
		Assertive	1	P2
		Creative	1	P2
		Relaxed	1	P2
		Caring	2	P3, P4
		Funny	2	P4, P5
		Nice	1	P5
		Well behaved	1	P5
		Brave	1 (saved best friend from falling off a cliff)	P5
	<i>Unsure/neutral attributes</i>	Loud	2	P1, P2
		Talkative	1	P2
		Chatty	1	P3
<b>Communication Style</b>	<i>Verbal methods</i>	Speaking normally	5	P1, P2, P3, P4, P5
		Recording voice (in a game)	1	P5
	<i>Non-verbal methods</i>	Email	1	P4
		Text message	1	P4
		Drawing	1	P4
<b>Situation/Activity</b>	<i>All situations</i>	Public	5	P1, P2, P3, P4, P5
		Home	5	P1, P2, P3, P4, P5
		School	5	P1, P2, P3, P4, P5
<b>Thoughts</b>	<i>Speech related</i>	Speaking is easy/ok for me	4	P1, P2, P3, P5

	<i>Non-speech related</i>	I like going to school I don't want to go to school (school work) I feel invisible (pets don't see him) I don't struggle with learning because I can ask for help	4 1 1 1	P1, P2, P3, P4 P5 P5
<b>Feelings</b>	<i>Non-anxiety based</i>	Happy Calm	5 (very/super) 3	P1, P2, P3, P4, P5 P1, P2, P4,
<b>Physiological Signs</b>	<i>Non-anxiety based</i>	Smiling Muscles feel relaxed Nice feeling in tummy	4 2 1	P1, P2, P4, P5 P1, P2 P5
<b>Greatest fear</b>	<i>Speech related</i>	Losing her friends/being lonely (was previously too loud/overly confident)	1	P2
	<i>Non-speech related</i>	Swimming People knocking on the door (thinks people are coming to steal him)	1 1	P1 P5
	<i>Nothing</i>		2	P3, P4
<b>Interactions</b>	<i>Key person</i>	Mum	1	P1
	<i>Everyone</i>	All situations	4	P2, P3, P4, P5
<b>History</b>	<i>Always been the same</i>		5	P1, P2, P3, P4, P5
<b>Future</b>	<i>Continuation of speaking resulting in positive future</i>	Still speaking person	5	P1, P2, P3, P4, P5
		Job (doctor, teacher, unsure, policeman)	4	P1, P2, P4, P5
		Family	2	P1, P3
		Friends	1	P2
		'Happy' (very/super)	5	P1, P2, P3, P4, P5

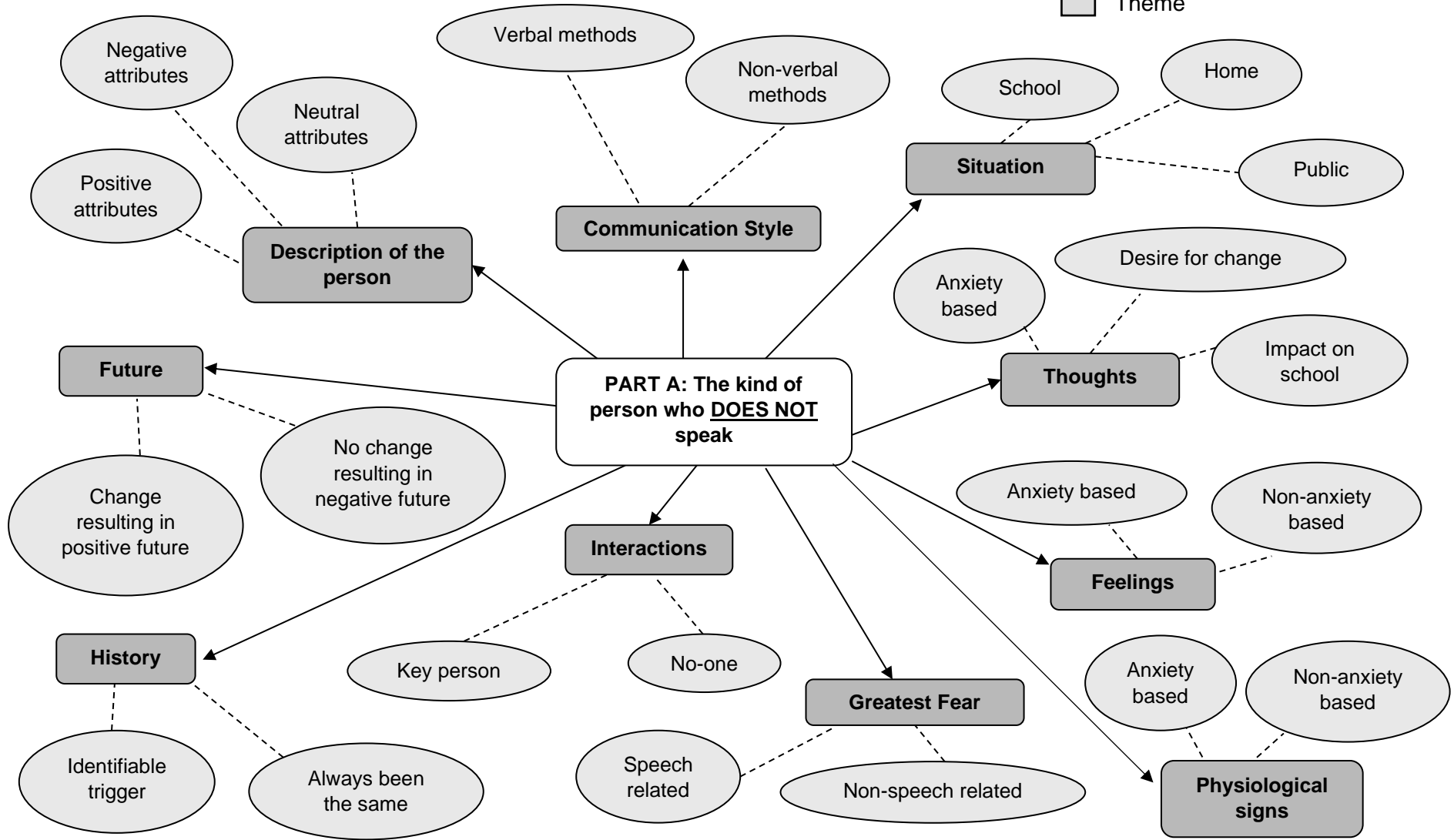
<b>Coding for Part C: Imaginary → Self, Mapping 'movement' over time and Action Plan</b>				
<b>Research Question</b>	<b>Theme</b>	<b>Data items</b>	<b>No of participants</b>	<b>Participants</b>
<b>RQ1: How do CYP with SM construct their current and 'ideal' selves?</b>	<i>Acknowledgement of their 'non-speaking' selves</i>	Current rating closer to the 'non-speaking' person than the 'speaking' person	4	P1, P2, P4, P5
		Introverted personality traits – part C	3	P1, P4, P5

		Introverted personality traits – part A	4	P1, P2, P4, P5
		Anxiety	2	P1, P5
		Positive personality traits	3	P1, P3, P5
	<i>Desire to change</i>	'Ideal' rating closer to the 'speaking' person than their current rating	5	P1, P2, P3, P4, P5
		Desire to talk more in school	3	P1, P2, P4
		Desire to talk more in public	2	P1, P4
		Change associated with positive feelings/positive future	5	P1, P2, P3, P4, P5
		Jobs involving speech	3	P1, P2, P5
	<i>Flexibility and willingness to compromise regarding their 'ideal' self</i>	'Settle for' rating lower than 'ideal' rating (however degree to which they were willing to compromise varied)	4 2 – high flexibility 2 – low flexibility	P1, P2, P4, P5 P1, P2 P4, P5
<b>RQ2: What factors do CYP attribute to the causes of their SM?</b>	<i>Negative treatment from peers</i>	Excluded from peer interactions	1	P1
		Judged/picked on	1	P2
		Pressured to talk	1	P5
		Associated negative feelings	3	P1, P2, P5
	<i>Uncertainty about the trigger</i>	Closest association to non-speaking person in Nursery but uncertainty about why	2	P3, P4
<b>RQ3: How do CYP with SM construct their 'movement' over time?</b>	<i>Factors that facilitated progress</i>	Friends	2	P1, P2
		TA support	1	P1
		Sliding in	1	P1
		New classes/school	2	P1, P2

		Family	1	P2
		Personal factors – a) standing up for self	1	P2
		b) happiness	1	P3
		c) frequency of animal noises	1	P5
	<i>Factors that hindered progress</i>	Stopped saying letters/words (change of teacher/ understanding?)	1	P1
		Treatment from peers/fall out	1	P2
		New school	1	P2
		Best friend moving away	1	P2
		Less animal noises	1	P5
		Perception/ understanding of others? Family members/ teachers	2	P1, P2
<b>RQ4: What action plans do CYP with SM create for their future?</b>	<i>Actions for self</i>	Speak to more friend on the playground/in lessons	2	P1, P2
		Join afterschool club	1	P2
		See friends outside of school	1	P2
		Further sliding-in sessions (behavioural approach)	2	P1, P5
	<i>Actions for others</i>	Sliding-in sessions	2	P1, P5
		Understanding from staff/family (less pressure to speak, respecting privacy)	2	P1, P2
	<i>Uncertainty</i>	Identified friend/teacher/ family but unsure of particular actions	4	P1, P3, P4, P5 P3, P4

**APPENDIX 31: A thematic map representing data gathered from part A of the interviews**

Area being explored  
 Theme



**APPENDIX 32: A thematic map representing data gathered during part B of the interviews**

Area being explored  
 Theme

