Examining Clinical Homologues of "Hikikomori": Development of a Scale Assessing Social Withdrawal in Young People in Scotland

And Clinical Research Portfolio

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Chapter 1 Systematic Review

Treatments for children and young people presenting with social withdrawal: A Systematic Review.

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Abstract

Background: Social withdrawal in children and young people co-occurs with a variety of mental health difficulties. It has a great impact on day-to-day functional and social outcomes. This review examines the current state of evidence for the efficacy/effectiveness of the available treatments for this problem.

Methods: The systematic search was conducted in five electronic databases. Ten relevant papers examining the efficacy/effectiveness of an intervention for children and young people experiencing social withdrawal were identified. The Crowe Critical Appraisal Tool Version 1.4 (Crowe & Sheppard, 2011) was used to assess the quality of the articles.

Results: The selected studies utilised a variety of research designs. Five papers employed SCED methodology, while others used experimental and quasi-experimental designs. The quality of the articles varied significantly, and a number of methodological limitations were identified.

Conclusions: The majority of studies included in the review provide some evidence of effective treatments for social withdrawal. However, due to the variable quality of the evidence base and high heterogeneity of the methodological designs, it was not possible to compare the effects of treatments. No treatment is currently well supported by good quality of evidence but given the harmful impact of social withdrawal and isolation there is a need for further research employing robust methodology.

Keywords: social withdrawal, social skills training, peer mediation, shyness, treatment effectiveness

Introduction

Social withdrawal occurs in conjunction with many mental health difficulties, such as psychosis, major depressive disorder, autism, anxiety disorders and personality disorders (Coplan & Armer, 2007; Merrel, Crowley, & Walters, 2007). Its presence is often linked to significant impairments in day-to-day life and occupational and social functioning (Merrel et al., 2007; Teo et al., 2015). Nonetheless, social withdrawal has not attracted much attention in empirical studies (Merrel et al., 2007).

Theoretical and empirical literature does not provide a unified definition of social withdrawal (Rubin, Coplan, & Bowker, 2009). Use of the term often overlaps with constructs such as shyness, loneliness, isolation and peer rejection (Boivin, Hymel, & Bukowski, 1995; Rubin et al, 2009). The lack of conceptual and terminological clarity highlights the need for closer examination of the social withdrawal research literature.

Rubin et al. (2009) conceptualised social withdrawal as solitary behaviours resulting in a lack of social interaction. It can develop as a result of a variety of factors (e.g. biological and temperamental factors, parenting, peer exclusion) and may lead to long-term social impairments in the areas of peer relationships and academic attainment. Other work on social withdrawal distinguished its three subtypes: shyness, social disinterest/unsociability (which relates to the preference for solitude that is not driven by fear) and social avoidance (Coplan & Armer, 2007; Coplan et al., 2013).

Studies suggest that social withdrawal remains stable from early childhood (0-8 years of age) to early adolescence (Hymel, Rubin, Rowden, & LeMare, 1990). Childhood social withdrawal predicts loneliness and depression in adolescence with negative peer experiences as a mediator (Boivin et al., 1995) and is a predictor of social difficulties in adolescence, which in turn mediate depression in early adulthood (Katz, Conway, Hammen, Brennan, & Najman, 2011).

Given the debilitating nature of social withdrawal, its high association with mental health disorders and its impact on children and adolescents, there is a need for an increased number of evidence-based, effective treatments that can be applied in a clinical setting.

The past review evaluating the efficacy of early intervention treatments for social withdrawal in pre-school children included eighteen studies, which employed SCED methodology (Mastropieri & Scruggs, 1985). The authors found that the most effective interventions utilised reinforcement of participants' behaviours. They concluded that the reviewed literature did not provide evidence for the generalisation and maintenance of treatment gains and that the information regarding the characteristics of participants was limited. Greco and Morris (2001) in their review described interventions targeting childhood shyness and related difficulties, including social withdrawal. They also reviewed empirical findings of the selected studies published between 1980 and 2001. They found that the evaluated literature fails to provide evidence for the long-term gains of available treatments and their generalisation to other settings. The most recent review of youth social withdrawal was written in the context of the *Hikikomori* syndrome (Li & Wong, 2015), which is a form of social withdrawal that emerged in Japan. *Hikikomori* is defined as withdrawal from participation in social activities and relationships for a period of minimum six months (Krieg & Dickie, 2013; Teo & Gaw, 2010). Young people affected by *Hikikomori* tend to seclude themselves and spend the majority of their time in their homes. The Japanese Cabinet Office's 2016 Survey indicates that the onset of *Hikikomori* occurs in adolescence and early adulthood (Tajan, Yukiko, & Pionnié-Dax, 2017). Li and Wong (2015) present an analysis of existing studies on youth social withdrawal that addresses four main issues: definitions of youth social withdrawal, theories of its development, psychological, social and biological factors linked to youth social withdrawal and description of available interventions targeting youth social withdrawal. They concluded that the evidence base for the treatments of youth social withdrawal is scarce.

This systematic review aims to fill the gaps in the literature by focusing on the current state of evidence available for interventions for children and young people published from 2000 until present. Specifically, this review synthesises studies that evaluate the efficacy of treatments targeting social withdrawal published in the recent years. In addition, the studies that focus on the recent conceptualisation of youth social withdrawal, *Hikikomori,* are included to provide a comprehensive overview of current literature examining treatments for social withdrawal occurring in children and young people.

Review aim and questions

The aim of this study is to review the available treatment approaches for social withdrawal and to explore their effectiveness for children and young people.

This review will focus on addressing the following questions:

1. How social withdrawal is operationalised? What standardised questionnaires are used to measure social withdrawal?

2. What treatment options have been evaluated and what are their components?

3. What is the effectiveness/efficacy of the treatment options?

Methods

Information sources

The following electronic databases were searched: PsycINFO, PsycARTICLES, Psychology and Behavioral Sciences Collection, CINAHL (EBSCOhost), MEDLINE (Ovid) and The Cochrane Library on 16/04/2019.

Search terms

The following terms were applied:

1. social* withdraw* or social* isolat*

2. child* or adoles* or teen* or youth or young or student* or pupil*

3. psychotherap* or interven* or therap* or cbt or cognitive behavio?r* therap* or social skills or online therap* or communication skills or computer* therap*

The search phrases were amalgamated using a Boolean operator “and”. In addition, truncations (*) and wildcards (?) were used to increase the accuracy of conducted searches. The database filters were also applied as follows: English language, published date 2000-2019.

Study selection

Inclusion criteria

The following inclusion criteria were applied:

1. studies written in English;
2. children and young people between 2 – 24 years old;
3. peer reviewed journals;
4. year of publication between 2000 and present;
5. patients presenting with social withdrawal;
6. studies investigating the efficacy/effectiveness of an intervention for this population.

Exclusion criteria

The exclusion criteria were as follows:

1. paper not available in English;
2. paper that is a book chapter, review, case study, unpublished study, dissertation, discussion article or protocol.

Study selection method

The initial searches yielded 2243 results. After the removal of duplicates and screening of titles and abstracts, the full text of the 35 identified papers was assessed for eligibility. Nine papers were selected as meeting the eligibility criteria and one additional paper was included following the review of the reference lists of the included papers. Finally, ten papers were included in the final synthesis.

Additional searches

The reference lists of the selected studies and the journals in which they were published were hand searched to ensure that the relevant papers were not omitted in the search. One article was identified in this process and was included in this review.

Figure 1 presents the study selection process.

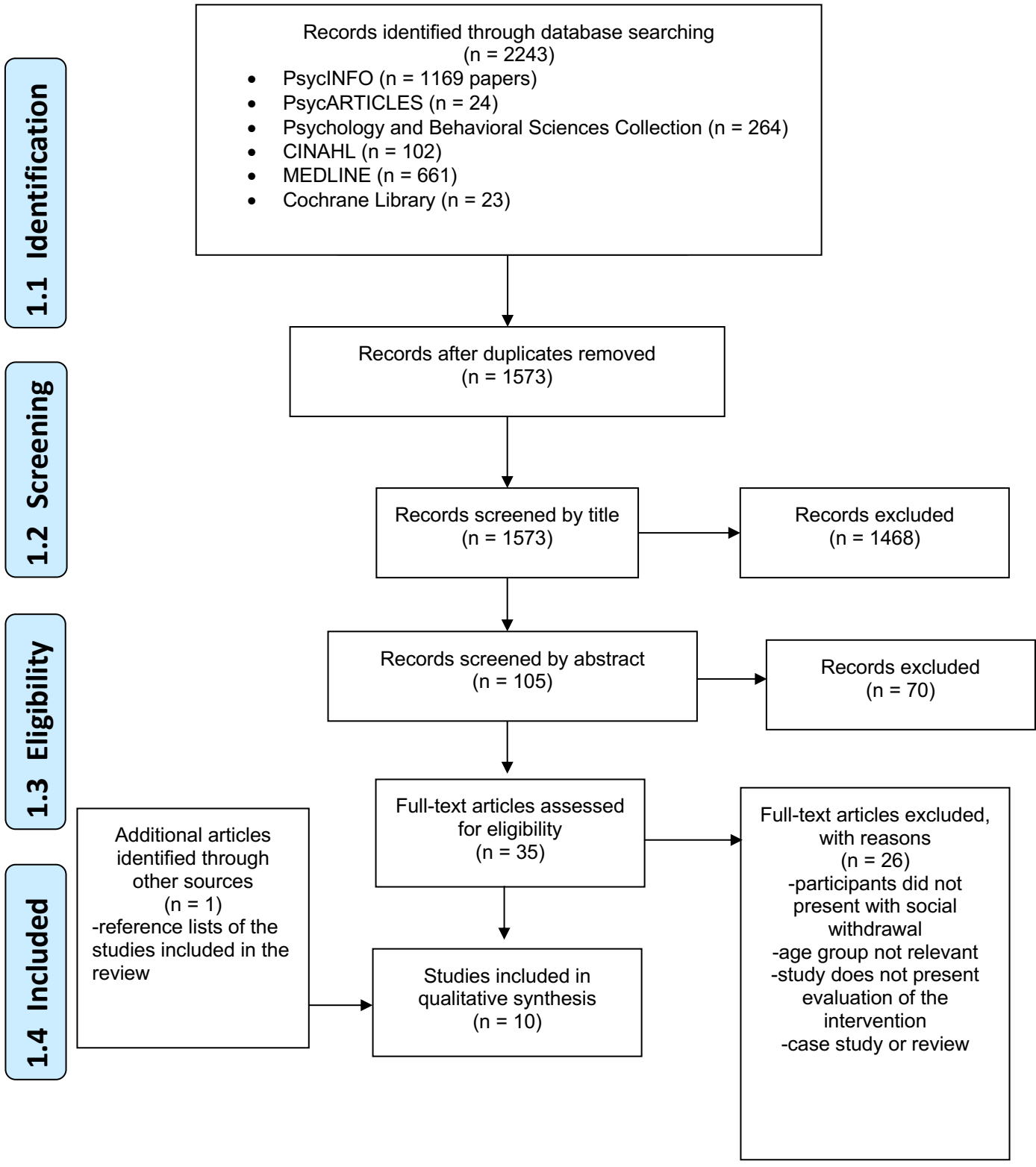

Figure 1: Study selection process presented in accordance with the PRISM guidelines

Quality rating

Because the articles identified for the purpose of this review present heterogeneous designs, the Crowe Critical Appraisal Tool Version 1.4 (CCAT, Crowe & Sheppard, 2011) was used to assess quality. This tool has a good construct validity and good inter-rater reliability with an interclass correlation coefficient of .83 for combined research designs (Crowe & Sheppard, 2011; Crowe, Sheppard & Campbell, 2012).

A second rater assessed 60% of the selected papers to appraise the quality of their design. The agreement rate between the two assessors was 85%. Where disagreements occurred, they were resolved through discussion and consequently, a 100% agreement was reached.

The methodological quality of the articles selected for this review is highly variable, with score range of 43% - 78%. Table 1 presents the scores obtained by each paper.

Table 1: Scores from the methodological quality assessment

Article	Preliminaries	Introduction	Design	Sampling	Data collection	Ethical matters	Results	Discussion	Total	Total %
Anderson et al., 2018	4	5	3	3	2	1	3	3	24	60
Christensen et al., 2007	4	5	3	3	3	0	3	3	24	60
Fantuzzo et al., 2005	2	5	3	2	3	0	2	3	20	50
Kvarme et al., 2010	5	5	4	4	3	3	3	4	31	78
Lee et al, 2013	2	4	1	2	1	2	2	3	17	43
Marchant et al., 2007	4	5	4	4	4	2	3	5	31	78
Mathews et al, 2009	4	4	4	4	3	2	3	5	29	73
McKenna et al., 2014	4	5	3	2	3	3	3	4	27	68
Moroz & Jones, 2002	4	5	4	4	3	2	3	5	30	75
Wettig et al., 2011	3	4	3	2	2	0	3	4	21	53

Results

The results section presents a summary of the research design quality of the selected papers. A data extraction table (Table 2) was designed to present articles' characteristics and their findings.

Table 2: Data extraction table

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Anderson, Trinh, Caldarella, Hansen & Richardson 2018 USA	To examine the effectiveness of intervention to improve social interaction.	Age 5-6 years old N=3 Three students presenting as socially withdrawn.	Single-subject design Multiple baseline across participants design	Early Screening Project (ESP; Walker et al. 1995) Preschool and Kindergarten Behavior Scales (PKBS-2; Merrell, 2002)	Playground intervention: 1) social skills instruction, 2) adult mediation, 3) self- evaluation and reinforcement, 4) parent involvement through home notes.	Functional relationship between the intervention and increased positive social interaction detected for all three participants. Favourable results for the mean percentage of positive social interaction recorded across phase intervals and significant difference in performance indicated by the Tau-U analysis of the effect size.

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Christensen, Young & Marchant 2007 USA	To examine the effects of an intervention on the behaviour in classroom.	8 years old N=1 Socially withdrawn student with learning disability; shy, avoidant of peers, not making assistance needs known, not initiating social interaction with peers. Comparison sample: N=21 Students socially appropriate and non-disruptive in class.	Single-subject design ABAB withdrawal design	SSBD (Walker & Severson, 1992)	Behavioural Intervention Package (BIP): 1) skills development, 2) peer mediation, 3) self-management system, 4) positive reinforcement.	BIP was effective in improving peer interaction and increasing socially appropriate classroom behaviour. Increase of socially appropriate behaviours from 48% (baseline) to 94% (intervention). Outcomes were maintained at the re-introduction of intervention phase.

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Marchant, Solano, Fisher, Caldarella, Young & Renshaw 2007 USA	To reduce socially withdrawn behaviour, increase positive social communication and appropriate peer play in the school playground.	Age 7-11 years old N=3 Participants at risk for internalising behaviour problems, specifically, social withdrawal.	Single-subject design Multiple baseline across participants design	SSBD (Walker & Severson, 1992) Internalizing Symptoms Scale for Children (ISSC; Merrell & Walters, 1998) Preschool and Kindergarten Behavior Scales, Second Edition (PKBS-2; Merrell, 2002)	Social skills training programme: 1)social skills training, 2)peer and adult mediation, 3)self-management.	For all three participants the mean percentage of appropriate peer play increased from baseline to the last intervention phase.

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Mathews, Fawcett & Sheldon 2009 USA	To investigate the effects of intervention on social interactions.	Age 7-10 years old N=3 Inclusion criteria: history of maltreatment, behaviour problems including social withdrawal.	Single-subject design Multiple baseline across participants design	Child Behavior Checklist–Parent Version (CBCL-P; Achenbach & Rescorla, 2001) Social Skills Rating Scale–Parent Version (SSRS-P; Gresham & Elliot, 1990)	Peer Engagement Program: 1)peer mentoring, 2) social skills training, 3)positive reinforcement.	The frequency of oral interactions with peers increased from baseline to intervention for all three participants. These gains were maintained at follow-up.

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Moroz & Jones 2002 USA	To examine the effects of treatment in the classroom and during recess.	Age 7-10 years old N=3 Participants were socially withdrawn and presenting low rates of peer interaction.	Single-subject design Multiple baseline with a reversal	Adjustment Scales for Children and Adolescents (ASCA; McDermott, Marston & Stott, 1993).	Positive Peer Reporting: 1)teaching in giving praise, 2)praising each appropriate peer comment.	Increase in mean percentage of social involvement was observed from baseline to intervention for all participants. During the withdrawal of intervention phase, results were inconsistent (improvement for one participant and decrease in involvement for two participants as compared with intervention). Mean percentage of nonoverlapping data (PND) score for all three participants was 66%, which indicates a mildly effective treatment.

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Fantuzzo, Manz, Atkins & Meyers 2005 USA	To explore effectiveness of Resilient Peer Treatment (RPT) on social competence.	Mean age=4.35 years (SD=.47 years) N=82 Participants identified as the most socially withdrawn children in classrooms. Child maltreatment reported for 37 of the participants.	Randomised controlled trial: 1)non-maltreated attention control, 2)maltreated attention control, 3)non-maltreated RPT, 4)maltreated RPT	The Interactive Peer Play Observational Coding System The Penn Interactive Peer Play Scale (Fantuzzo et al., 1995) The Social Skills Rating System (Gresham & Elliott, 1990)	RPT: 1)arrangement of the play corner, 2)Play Supporter prepares the Play Buddy for the play session, 3)play session, 4)Play Supporter makes supportive comments to the target child and the Play Buddy.	Reported higher levels of Collaborative Play and lower levels of Solitary Play at post-testing for children in the treatment group, regardless of maltreatment status, as compared to children in the control group, $F(1, 77) = 39.1$, $p < .0001$, $\eta^2 = .36$.

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Kvarme, Helseth, Sørum, Luth-Hansen, Haugland & Natvig 2010 Norway	To examine the effects of a group intervention Solution-Focused Approach (SFA) on the self-efficacy and to explore gender-based differences.	Age 12–13 years old N=156: Experimental group: N=91 Socially withdrawn children with few or no friends, speak rarely in the class, spend time alone for intervals of time, manifest anxiety, show avoidance and passivity. Control group: N=65	Non-randomised controlled trial: experimental group and control group Data collection points: baseline, post-treatment, 3-months follow-up	General Self-Efficacy Scale (GSE; Schwarzer et al., 1997) Multidimensional Scales of Perceived Self-Efficacy (Choi et al., 2001): Social Self-Efficacy (SSE) and Self-Assertive Self-Efficacy (ASE)	Solution Focused Approach: 1)describing dreams for the future, 2)describing current lives and how to attain dreams, 3)selecting a personal goal, 4)monitoring progress in goal achievement, 5)completion of homework.	GSE scores increased in the experimental group from baseline to the first post-intervention measure for the girls. The change in the mean score was significantly higher in the experimental group than in the control group among the girls (effect size of 0.60). GSE scores increased significantly in both groups from baseline to 3-month follow-up. Larger increase was observed in the children in the experimental group (mean change=8.3) compared with the control group (mean change=4.3).

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Lee, Lee, Choi & Choi 2013 South Korea	To evaluate the treatment outcomes after five sessions.	Age under 25 years old Average age:16.5 years (male) and 16.1 years (female). Treatment group: N=41 Inclusion criteria: socially withdrawn, school refusal or unemployed, mainly staying at home. Control group: N=239	Quasi experimental pre-test post-test design: treatment group and control group.	Global Assessment of Functioning (GAF)	Home visitation programme: five sessions of person-centered psychotherapy.	Average GAF scores post-treatment increased significantly (M=53.4, SD=13.2) as compared to pre-treatment (M=44.6, SD=11.1, p<.001).

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
McKenna, Cassidy & Giles 2014 Northern Ireland	To examine the effectiveness of Pyramid clubs.	Age 7 - 8 years N = 88 Intervention: group: N=57 Children who scored in the borderline and abnormal range on SDQ and did not display co-morbid externalizing problems. Children with SDQ scores within the non-clinical significance but displaying changes in behaviour such as withdrawal. Comparison group: N=31	A 2 X 2 mixed-model design: intervention group vs. comparison group (no intervention) Data collection points: pre-intervention, 10 weeks post-intervention, 12-week follow- up	Teacher-rated Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)	The Pyramid Plus model of intervention: naming and ownership of the class, circle time, art activity, co-operative games, role play, laughing yoga, closing circle time.	Longitudinal changes in Emotional Symptoms ($F(1.75,85) = 9.05$, $p < .001$) and Peer Problems ($F(1.92, 85) = 7.35$, $p < .001$) were dependent on group membership. 33.3% of Pyramid children were experiencing borderline to abnormal levels of Emotional Problems at time 1; this decreased to 6.3% at time 2 and showed a slight increase to 10% at time 3. A similar trend was observed for Peer Problems, with 22.8% children scoring within borderline and abnormal range at baseline. This decreased to 3.2% at time 2 and increased only slightly to 5.8% at time 3.

Article	Study Aims	Sample	Study design	Operationalisation of social withdrawal	Treatment option and components	Findings
Wettig, Coleman & Geider 2011 Germany	To investigate the efficacy of Theraplay.	Age 2-6 years old Longitudinal study: N=22 Diagnosis of clinically significant social anxiety (shyness and social withdrawal) and language disorder. Multicentred study: Treatment sample: N=167; diagnosis of clinically significant social anxiety and language disorder. Control sample: N=30	Study 1: Controlled longitudinal study Study 2: Multicentred study with a control group	German version of the Clinical Assessment Scale for Child and Adolescent Psychopathology (CASCAP-D)	Theraplay treatment: attachment-based play, guided challenge, social engagement, regulation of affect and nurturing.	Study 1: Post-treatment no significant differences between treatment and control groups were detected on shyness. Improvement was maintained at 2-year follow-up. Study 2: There was no significant difference between the clinical and control groups on measures of shyness post-treatment. There were significant differences between the groups for social withdrawal.

Definitions of social withdrawal

The majority of studies, with the exception of Fantuzzo et al. (2005), presented a definition of social withdrawal or described behaviours that were associated with this construct. Anderson et al. (2018) defined social withdrawal as a tendency to withdraw from the peer group for a specific reason, which could be related to internal factors. In Christensen et al. (2007) study socially withdrawn behaviours were described as shyness, timidity and disengagement from social interactions. Moroz and Jones (2002) selected participants who also exhibited shy behaviours, as well as presenting low levels of social skills. McKenna et al. (2014) focused on the concept of shyness as a form of social withdrawal that includes anxiety and vigilance related to novel situations. Similar definition was presented by Marchant et al. (2007). Wettig et al. (2011) conceptualised social withdrawal together with shyness as symptoms of social anxiety.

Mathews et al. (2009) defined social withdrawal as avoidance of peer interactions and presenting low levels of engagement in communication and activities. Meanwhile, Kvarme et al. (2010) linked this phenomenon to the concept of self-efficacy. They defined social withdrawal as a solitary form of behaviour presented consistently over time. Lee et al. (2013) definition of social withdrawal was rooted in the literature related to the youth social withdrawal phenomenon called *Hikikomori*. Young people were included in their study if they met the following inclusion criteria: staying at home all day for over three months, with no specific underlying cause and refusing to attend school or engage in work.

Available treatment options and their components

The majority of interventions examined in the studies consisted of social skills training, peer and/or adult mediation and self-management paired with reinforcement as components (Anderson et al., 2018; Christensen et al., 2007; Marchant et al., 2007; Mathews et al., 2009; Moroz and Jones, 2002; Fantuzzo et al., 2005). McKenna et al. (2014) evaluated intervention, which focused on involvement in social activities. Meanwhile, Kvarme et al. (2010) investigated the effects of Solution Focused Approach delivered in a group format. Lee et al. (2013) examined the effectiveness of the person-centred therapy. Finally, Wettig et al. (2011) focused on a play-based intervention.

Most of the studies delivered their interventions in the classroom or on a playground, with the exception of Wettig et al. (2011), who utilised therapy rooms. Treatment in Lee et al. (2013) study was delivered during home visits to facilitate the engagement of the severely socially withdrawn participants.

Reporting of the duration and frequency of treatments was inconsistent. Anderson et al. (2018), Fantuzzo et al., (2005), Lee et al., (2013), Mathews et al., (2009) and Wettig et al. (2011) provided information about the number of sessions delivered, which ranged between 2.8 (Lee et al., 2013) and 18 (Wettig et al., 2011). Six of the studies also reported the duration of each session, which was between 7-10 minutes (Moroz & Jones, 2002) and one hour (Christensen et al., 2007; Kvarme et al., 2010). Fantuzzo et al. (2005), Lee et al. (2013), McKenna et al. (2014) and Marchant et al. (2007) did not report how long each session lasted.

All of the SCED studies made efforts to ensure the treatment fidelity by collecting the data on accuracy of the treatment implementation (Anderson et al., 2018; Christensen et al., 2007; Marchant et al., 2007; Moroz & Jones, 2002). They also assessed the social validity of interventions. To strengthen the treatment fidelity, the majority of authors developed the intervention protocol, workbook or a script, or based their intervention on an existing manual (Anderson, et al., 2018; Christensen et al., 2007; Marchant et al., 2007; Mathews et al., 2009; Kvarme et al., 2010; Lee et al., 2013; McKenna et al., 2014; Wettig et al., 2011).

The majority of papers reported the reliability and validity of the outcome measures, apart from Lee et al. (2013) and McKenna et al. (2014). In addition, all of the SCED studies calculated the inter-observer agreement for the observations of their dependent variables. The reported inter-observer agreement was in the range of 89.8% (Mathews et al, 2009) and 92% (Anderson et al., 2018; Marchant et al., 2007; Moroz & Jones, 2002). Fantuzzo et al. (2005) also assessed the inter-observer agreement, which was estimated at the range of 80-96%.

Effectiveness of treatment options

Four of the SCED studies (Anderson et al., 2018; Christensen et al., 2007; Marchant et al., 2007; Mathews et al., 2009) reported significant increases in the levels of the observed dependent variable during the treatment and post-treatment. Christensen

et al.'s (2007) results were above the level of the target behaviours reported for the comparison group. In addition, Marchant et al. (2007) and Mathews et al. (2009) reported that their favourable results were maintained at the follow-up 4 months and 4-6 weeks respectively after their interventions ended. Furthermore, Marchant et al. (2007) found that the adult mediation was more effective than peer mediation. Contrary to other SCED studies, Moroz and Jones (2002) results were inconclusive. Improvements in social involvement were observed for all three participants, although for one of them they were moderate and for the other two the trends were highly variable. Authors hypothesised that these results could be associated with a high variability of individual behavioural characteristics that participants presented at baseline.

Fantuzzo et al. (2005), Kvarme et al. (2010), Lee at al. (2013), McKenna et al. (2014) and Wettig et al. (2011) provided evidence for the effectiveness of their interventions and reported significant improvements on their outcome measures. Fantuzzo et al. (2005) results were also generalised to less structured play sessions in classrooms at two-weeks post-treatment. In Kvarme et al. (2010) study the increase in scores was statistically significant at the 3-month follow-up, with boys presenting higher results than girls. McKenna et al. (2014) also provided evidence for the effectiveness of their treatment in the experimental group at 10-week post-treatment period and at 12-week follow-up. Although Lee at al. (2013) reported favourable findings for the efficacy of the employed intervention, they found that there was no change in the scores for 48.8% of participants. Finally, Wettig et al. (2011) results of their longitudinal study indicated the improvement of participants' levels of shyness however, social withdrawal symptoms remained at the lower level as compared to control group at post-treatment. In their multicentred study they found that participants in the treatment group improved significantly post-treatment on all of the measured variables, although the improvement on social withdrawal did not reach the level equivalent to the comparison group.

Discussion

The studies evaluated a broad range of various interventions, mostly focusing on the behavioural change. The majority of studies reported favourable results and significant improvements following the introduction of treatment. Where a comparison group was present, four studies reported equivalent or higher

improvements in the treatment group (Christensen et al., 2007; Fantuzzo et al., 2005; Kvarme et al., 2010; McKenna et al., 2014). In Wettig et al. (2011) study the decrease in shyness levels post-treatment and at follow-up was comparable to the control group, but social withdrawal levels remained higher in the experimental condition. Authors hypothesised that these results could be related to the high variability in the number of sessions that the participants received and the difference in the severity of the presenting problems at baseline. Similarly, Moroz and Jones (2002) found that there was a high variability of participants' behavioural characteristics prior to the introduction of treatment, which could explain the inconsistency of their results.

Marchant et al. (2007), Mathews et al., (2009), McKenna et al. (2014) and Wettig et al. (2011) reported that treatment gains were maintained at the follow-up period, which ranged between four weeks to two years. Marchant et al. (2007) found that their results were dependent on the person that mediated the treatment (adult versus peer), whilst Kvarme et al. (2010) reported that changes in the response to treatment were associated with the gender of participants (girls in their study presented greater improvement immediately after the intervention, whilst boys improvement was higher at follow-up).

There was a variability in the reviewed studies regarding the definition of social withdrawal and similar concepts were often used interchangeably. Most of the reviewed studies defined social withdrawal, although some of them focused on the behavioural operationalisation of this construct and did not provide an explicit definition (Moroz & Jones, 2002; Mathews et al., 2009). Fantuzzo et al. (2005) did not present a formal definition of this construct. Although well validated measures containing dimensions that capture social withdrawal exist (CBCL, PBK), there is no set of standard measures used as a gold standard in the research exploring this construct. In addition, there is no agreed threshold or outcome that can be utilised to produce comparable data on treatment effectiveness.

Five of the papers selected for this review implemented SCED methodology. In the context of the research aims focused on changing participants behaviours and broadening the understanding of the effects of treatments on the population that is hard to reach, this methodology is a suitable choice (Barnett et al., 2012; Manolov, Sierra, Solanas, & Botella, 2014). Application of SCED methodology is also

appropriate to evidence a concept approach to developing treatment strategies in the early phases of research.

The majority of studies delivered interventions in the classroom, playground or at participants' homes, apart from Wettig et al. (2011) who administered the treatment in the therapy room. Although these settings are appropriate for the studied population and increase the ecological validity of the findings, the produced outcomes may be difficult to generalise to other settings.

The focus of the majority of papers was not solely social withdrawal. The comorbid difficulties presented by the participants (history of maltreatment, externalising difficulties, language disorder and learning disability) pose another challenge to the generalisability of the outcomes. Comorbid difficulties may indicate a broad range of factors that contribute to the development and maintenance of social withdrawal. As a result, these co-occurring problems may affect clinical decision making related to the choice of appropriate treatment for young people who present with social withdrawal. Nevertheless, the authors of the selected studies did not examine this issue.

The majority of authors did not explicitly describe steps that were made to control for the extraneous variables, such as the severity of the presented symptoms and other treatments received by the participants prior to the start of the study. Moroz and Jones (2002) and Wettig et al. (2011) highlighted that these factors could have affected their findings.

Methodological designs of the studies did not make it possible to ascertain which treatment components contributed the most to their effectiveness. A number of authors highlighted the positive impact of peer-mediation on participants (Christensen et al., 2007; Marchant et al., 2007; McKenna et al., 2014; Kvarme et al., 2010). They emphasised the role of peers in modelling and reinforcing positive behaviours and in increasing social validity of interventions (Marchant et al., 2007). Peer mediation has been recommended with a caveat concerning the need for careful selection of peers who are well matched to reduce the risk of harm (Marchant et al., 2007, Mathews et al., 2009). Involving adults could also produce more favourable results. Marchant et al. (2007) and Wettig et al. (2011) noted that it may increase the generalisability of intervention gains.

Strengths and limitations of the review

One of the aims of the present review was to describe the state of the literature related to existing treatments targeting social withdrawal. The findings indicate that the research in this domain is at early stages and relies considerably on SCED methodology.

The search process in this review has been restricted to the articles written solely in the English language. Literature indicates that definitions of social withdrawal may differ across cultures (Rubin et al., 2009) and *Hikikomori,* which emerged in Japan, is one of its conceptualisations. It is possible that the literature written in other languages contains more data on the topic explored in this review.

This review utilised CCAT (Crowe & Sheppard, 2011) to assess the quality of published literature examining the effectiveness of treatments for social withdrawal. This tool allowed comparison of selected studies that utilised various methodological designs. As opposed to design-specific tools, CCAT enables appraisal of studies based on the appropriateness of the selected design in relation to the research question posed by the study. The choice of the tool was dictated by the heterogeneity of research designs employed in the selected papers. Half of the studies appraised in this review utilised SCED methodology. Although there are appraisal tools specific to this design (e.g. Risk of Bias in No-of-1 Trails, RoBiNT; Single Case Reporting Guideline In BEhavioural Interventions SCRIBE 2016 Checklist), they would not allow comparisons to be made between all ten of the selected papers. The choice of the tool was therefore a balancing act in selecting the tool that allowed for flexibility in the process of quality appraisal and simultaneously provided rigour necessary to make the appraisal process consistent and transparent. One of the limitations of using such generic tool however is the possibility that not all of its items are the most relevant to various methodologies that this tool assesses. Although the use of CCAT in the review enhanced the synthesis of the evidence base, it is vital to acknowledge that design-specific tools provide a more rigorous framework for the quality appraisal.

Another limitation of this systematic review is the inclusion of studies presenting a broad age range of the recruited participants. The age of participants has significant implications in relation to the choice of treatment modalities evaluated in the studies.

Treatments that are developmentally more appropriate for younger children are play based and often utilise parental and peer involvement as factors enhancing treatment effectiveness, whereas interventions more suitable for adolescents and young people are based on cognitive and psychotherapy approaches. These developmental factors that dictate the choice of treatment approach need to be taken into account when drawing conclusions from the selected studies. The high diversity of participants' age groups presented in the papers limits direct comparisons of treatment modalities between the studies and drawing general conclusions related to the employed intervention approaches. Therefore, the focus is on the review of the available treatment formats in the recently published literature.

One of the strengths of this study is the assistance of the second rater in the process of evaluating the quality of the selected articles. It is hoped that this improved the inter-rater reliability of this review.

Recommendations

The review identified several limitations of the current evidence base, which could be addressed in the future. Firstly, studies utilising the SCED methodology would benefit from introducing the higher number of trials in each phase to ensure the stability of baseline and better control for the presence of extraneous variables. Secondly, the implementation of the effect size calculations would allow for the comparisons between the outcomes. The experimental and quasi-experimental designs could be improved by introducing longer follow-up periods, which would allow for the evaluation of the durability and stability of achieved outcomes. Ensuring group equivalence could also strengthen the internal validity of the studies.

The current review pointed out the gaps in the literature related to the lack of streamlined definitions of social withdrawal and unified outcome measures employed in the research. Better defined construct of social withdrawal would facilitate the process of defining the eligibility criteria for the research purposes and subsequently, could improve the participant selection process. This would in turn increase the homogeneity of samples at baseline. The PRISM project (Kas et al., 2019) could provide a helpful framework for classifying social withdrawal, which was defined as a transdiagnostic domain underlined by the deficits in processes such as

attention, working memory and sensory processing. The aim of the PRISM project is the development of the approach that would allow the identification of neurobiological and behavioural markers that contribute to the occurrence of social withdrawal. Social withdrawal often appears as a first symptom of other mental health difficulties, for instance psychosis and major depression. Neurobiological research indicates that depending on the mental health issue in the context of which social withdrawal emerges, different cognitive and neurobiological processes give rise to the development of this behaviour, such as attention, working memory and sensory processing. Identifying processes that underlie social withdrawal in groups of people affected by various mental health difficulties could contribute to the development and refinement of treatments that focus on these specific processes. Consequently, pinpointing these processes would allow different groups of people affected by social withdrawal to be offered treatments that are better tailored to their needs and thus, more effective.

Literature related to the *Hikikomori* syndrome could also contribute to further developments in the area of the classification of social withdrawal. Some of the authors suggest that this concept could be cross-cultural (Kato et al., 2012) and therefore, could prove helpful in conceptualising social withdrawal in the literature written in English language.

The majority of papers presented in this review administered interventions in the format of a treatment package containing a number of different components. Study designs did not allow though to clarify which of these components directly contributed to the observed results (Christensen et a., 2007, Marchant et al., 2007). Therefore, future studies could focus on the evaluation of the separate treatment components to examine which are the most effective in producing therapeutic change and how their sequence and combination may influence outcomes. A more careful selection of research participants and applying clear eligibility criteria could ensure higher homogeneity of samples at baseline and result in more robust research outcomes.

Conclusions

This review presents the current state of evidence base for the effectiveness of the treatments aimed at improving mental health outcomes for the children and young

people affected by social withdrawal. The selected articles employed heterogeneous methodologies, therapy formats and ways of operationalising the construct under investigation. This heterogeneity should be taken into account when drawing conclusions. The results of the majority of studies show that the existing interventions improve social functioning of the socially withdrawn children and young people. However, several studies presented inconclusive outcomes. The quality of the reviewed papers varies, which indicates that their results need to be carefully considered in the light of their limitations. To sum up, the results of this review support the need for further research into this area, with a specific focus on addressing the limitations of the existing studies.

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Chapter 2 Major Research Project

Examining Clinical Homologues of "Hikikomori": Development of a Scale Assessing Social Withdrawal in Young People in Scotland

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Plain English Summary

Title

Examining Clinical Homologues of “Hikikomori”: Development of a Scale Assessing Social Withdrawal in Young People in Scotland.

Background

Social withdrawal occurs in a variety of mental health difficulties. It is associated with psychological distress and difficulties in day to day functioning (Teo & Gaw, 2010). In Japan social withdrawal affecting young people has been identified as a syndrome called *Hikikomori* (Saito, 2013). *Hikikomori* is characterised by social withdrawal and social isolation. Given the impact that social withdrawal has on young peoples’ functioning and the distress that it causes, further research into its occurrence is needed. Developing a measure of social withdrawal would help to understand the extent of social withdrawal problems in young people in Scotland.

Aims

The purpose of the study was to develop and refine a scale of social withdrawal, the Glasgow Hikikomori Scale (GHS). The second aim was to explore the feasibility of the testing of this new measure in the clinical setting.

The specific aims were:

1. To conduct initial cycles of refinement of the GHS to develop a scale that is ready to be tested on a clinical population.

2. To explore the use of the GHS in the assessment of social withdrawal in the clinical setting.

3. To explore how many potential participants were initially identified as meeting the eligibility criteria of this study.

4. To explore how many potential participants of those identified gave their consent to take part in the study.

5. In addition, to explore how many informants gave their consent to participate in the study and were able to complete study measures.

6. In light of the number of recruited participants and informants, to explore the feasibility of conducting preliminary investigation of the psychometric properties of this new tool.

Methods

The first part of this study was a further development of the GHS. Clinicians working in CAMHS were invited to take part in the online feedback survey regarding the scale. The second part involved recruiting young people to take part in the exploration of the psychometric properties of the GHS. Participants between the age of 13 and 17 were recruited from NHSGGC Child and Adolescent Mental Health Services (CAMHS). The GHS and several other scales were used to assess social withdrawal, apathy, mental health difficulties and coping mechanisms of the participants.

Main Findings

Forty-nine clinicians from the NHS GG&C area working in the CAMHS took part in the rating of the GHS items on the scale from 1 (very unclear) to 9 (perfectly clear). The median scores of the items ranged from 6 (IQR: 3, 7) to 9 (IQR: 8, 9). The GHS scale was refined in accordance with the feedback. We then attempted to test the utility and psychometric properties of the scale by applying it to the assessment of young people experiencing social withdrawal difficulties. Recruitment proved to be very challenging with only five people completing the measures in the period of three months. The data provide some preliminary indications of the challenges of accessing and understanding this sub-group of withdrawn young people.

Conclusions

Although a very small sample was recruited, it allowed to explore the feasibility of the recruitment of population. It also enabled to estimate the time scale necessary to increase the feasibility of the future studies and identify some of the factors that could hinder the recruitment process. Based on the collected data, the recruitment

period needed to get a full sample would be approximately 20 months. Future studies will either need to have very long recruitment timeframes or different research methods may need to be used to access usable data on this withdrawn and socially isolated population.

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Abstract

Background: Social withdrawal contributes to poor emotional, behavioural, social and occupational functioning. In Japan, social withdrawal affecting adolescents and young adults has been conceptualised as a syndrome called *Hikikomori* (Saito, 2013). At present no adequate measure exists that would support targeted assessment of the presence and severity of social withdrawal amongst adolescents in Scotland. The Glasgow Hikikomori Scale (GHS) is a new measure developed with the aim of providing an English language rating scale for social withdrawal in young people.

Aims: This study aimed to develop and conduct preliminary investigation of a new measure for assessing social withdrawal in young people, the GHS.

Methods: The first part of this feasibility study involved refinement of the GHS. Clinicians working in Child and Adolescent Mental Health Services (CAMHS) were invited to take part in the online feedback survey regarding the wording of this scale. The second part of this feasibility study involved recruiting the participants to explore the psychometric properties of the GHS. Participants between the age of 13 and 17 with varying levels of social withdrawal were sought from the NHS GG&C CAMHS. The GHS and a mixture of self-report and observer-report scales were used.

Results: Forty-nine clinicians from the NHS Greater Glasgow & Clyde (GG&C) area working in the CAMHS took part in the rating of the GHS items on the scale ranging from 1 (very unclear) to 9 (perfectly clear). The median scores of the items ranged from 6 (IQR: 3, 7) to 9 (IQR: 8, 9). The GHS scale was refined in accordance with the received feedback. We then attempted to examine the utility and psychometric properties of the scale by applying it to the assessment of young people with social withdrawal. Recruitment proved to be very challenging with only five people completing the measures in a period of three months. This sample size did not allow to use statistical methods of analysis that were planned to explore the psychometric properties of the GHS. However, the data provided useful information about the challenges of accessing and engaging this sub-group of withdrawn young people.

Conclusions: Although only a very small sample was recruited, it allowed to explore the feasibility of the recruitment of this hard to reach population. It also enabled to

estimate the time scale necessary to increase the feasibility of the future studies and identify some of the factors that could hinder the recruitment process. Based on the collected data, the recruitment period needed to get a full sample would be approximately 20 months. Future studies will either need to have very long recruitment timeframes or different research methods may need to be used to access usable data on this withdrawn and socially isolated population.

Keywords: social withdrawal, *hikikomori*, scale development, feasibility study

Introduction

Social withdrawal is a feature of a variety of mental health conditions, such as psychosis, major depressive disorder, autism, anxiety disorders and personality disorders (Teo & Gaw, 2010; Teo et al., 2015). It can be associated with considerable psychological distress, social and occupational impairment and difficulties in behavioural and emotional functioning (Teo et al., 2015). In Japan, a particular form of social withdrawal affecting youth has been identified as the syndrome *Hikikomori* (Saito, 2013).

Hikikomori is characterised by its two main features: social withdrawal and social isolation. Social withdrawal is defined as withdrawal from participation in social activities for a period of at least six months and social isolation is defined as ceasing of relationships outside of the family during the time of withdrawal (Krieg & Dickie, 2013). The psychosocial developmental model of *Hikikomori* proposed by Krieg and Dickie (2013) links the aetiology of the condition to factors such as ambivalent attachment, the experience of parental and peer rejection, bullying, and temperamental shyness.

The lifetime prevalence of *Hikikomori* is as high as 1 – 2% in East Asian countries (Teo et al., 2015). Koyama et al. (2010) in their study of participants aged 20 – 49 found that *Hikikomori* has a lifetime prevalence of 1.2%, with an average withdrawal duration of one year and the average age at the onset at 22.3 years old. In the recent Japanese Cabinet Office's 2016 Survey of acute social withdrawal 12.2% of respondents with *Hikikomori* stated the age of onset as before 14, 30.6% between 15 and 19 and 34.7% between 20 and 24 (Tajan, Yukiko, & Pionnié-Dax, 2017, p. 5).

Mental health professionals in other countries recognise the occurrence of *Hikikomori* (Kato et al., 2012). Cases of *Hikikomori* have been found in Spain (Garcia-Campayo, Alda, Sobradiel, & Sanz, 2007), India, South Korea and the United States (Teo et al., 2015). The occurrence of the condition in these countries has been linked to urbanicity and the global socioeconomic and cultural changes, such as slowing down of economic growth, values shifting towards increasing individualism and competitiveness and lack of job security (Stip, Thibault,

Beauchamp-Chatel, & Kisely, 2016). But there is much to be learned about the risk factors, phenomenology, and treatment of this clinical phenotype.

Mental health professionals and researchers' views regarding the causes and diagnosis of *Hikikomori* vary significantly (Tajan, 2015; Tateno, Park, Kato, Umene-Nakano, & Saito, 2012). Therefore, further research into its prevalence with a use of suitable measures is needed to understand the impact of this condition and to establish whether *Hikikomori* is a culture-bound syndrome or a cross-cultural phenomenon (Kato et al., 2012).

Although there are several measures that assess constructs similar to social withdrawal, such as apathy and amotivation, none of them captures all aspects of this phenomenon. This feasibility study aimed to develop and test a scale that could be utilised to measure youth social withdrawal. The purpose was for the GHS to characterise social withdrawal presentations more fully than existing measures but in a brief and easily usable format.

Aims

To date there is no screening measure that assesses the severity of social withdrawal in the English language population. This study attempted to fill this gap in research by developing and investigating the feasibility of the field-testing of a new measure for assessing social withdrawal, the Glasgow Hikikomori Scale (GHS).

The aims of this study were:

1. To conduct initial cycles of refinement of the GHS to derive a scale that is ready to be tested on a clinical population.

2. To explore the utility of GHS in the assessment of social withdrawal in the clinical setting.

3. To ascertain how many participants can be identified as meeting the eligibility criteria of this study.

4. To explore how many eligible participants would consent to take part in the study.

5. To explore how many informants would give their consent to participate in the study and complete the study measures.

6. In light of the number of recruited participants and informants, to explore the feasibility of conducting preliminary investigation of the psychometric properties of this new tool.

Methods

Design

An observational design was utilised to develop a measure of social withdrawal that can be administered to the population of young people. The study consisted of two phases. In the first phase the clinicians working in the CAMHS were invited to take part in an online survey used to develop and refine the scale items. In the Phase 2, the refined scale was administered to assess a sample of young people presenting with varying levels of social withdrawal. Subject to the feasibility of recruiting a sufficient number of participants, the plan was to examine the associations between the developed scale and other measures to determine validity and reliability of the GHS. Specifically, the study aimed to assess internal consistency, discriminant validity and convergent validity of the GHS in relation to other measures.

Ethics

This research project was granted ethical approval on 23/04/2019 by the West of Scotland Research Ethics Committee 4 (19/WS/0042). In addition, it has been approved by the NHS GG&C Research and Development Board on 23/04/19 (GN18MH675).

Participants

The clinicians who took part in the Phase 1 of this project were a range of professionals (Psychiatrists, Clinical Psychologists, Nurses and Occupational Therapists) with a varying length of work experience within NHS GG&C CAMHS. Eligible clinical participants were CAMHS patients aged between 13- and 17-years old, presenting with a range of social withdrawal symptoms as judged by referring clinicians. The aim was to recruit young people with a range of social withdrawal

problems, including those with extreme pattern of behaviours that resembled *Hikikomori.* Carers of patients presenting with social withdrawal and CAMHS clinicians involved in patients care were also invited to take part in this study as informants. Informants were asked to take part in the study to enhance the understanding of the participants' difficulties and to cross-validate the data. Patients and their family members were recruited in the GG&C area from four CAMHS teams: West, East, North and South. The participants were identified by the local CAMHS clinicians who were involved in their care, based on the eligibility criteria. CAMHS clinicians who identified potential participants were later asked to be involved in the study as informants.

Inclusion and exclusion criteria

The following inclusion criteria were applied to the clinical participants:

- age: 13-17 years old,
- current difficulties with social withdrawal lasting at least two months,
- social withdrawal contributes to noticeable functional impairment in daily life and self-care, social interactions and occupational roles, e.g. non-attendance or erratic attendance at school, parental reports of impaired social functioning and/or a pattern of socially isolated behaviour,
- patients presenting with varying levels of severity of social withdrawal, from reported concern regarding social withdrawal to severe social withdrawal, including young people who are house bound or not able to come to the clinic due to the functional impairment.
- capacity to give informed consent.

The exclusion criteria were as follows:

- social withdrawal due to a physical illness or injury,
- social withdrawal related to the head injury within the last 24 months,

- participants presenting significant risk,

- participants whose command of English required an interpreter to meaningfully participate in the study.

Recruitment procedures

Phase 1:

The first part of this feasibility study was a further development and refinement of the GHS. In order to achieve this, clinicians working in the CAMHS across NHS GG&C were invited via e-mail to take part in the online survey. Their feedback formed the basis of changes to the scale items, implemented before the start of the Phase 2 of this project.

Phase 2

Phase 2 of the project consisted of the GHS field testing and feasibility testing of the study methods. This involved recruiting the potential participants to take part in the preliminary exploration of the psychometric properties of the GHS. CAMHS clinicians within NHS GG&C area were contacted and provided with the information about the aims of this study. Potential participants were identified by the clinicians involved in their care and therefore, already having access to their identifiable information in their records.

The staff members (e.g. clinical psychologists, consultant psychiatrists, named community nurse key workers) were asked to identify participants that met the inclusion criteria of the study. They invited these potential participants and their carers to take part in the study by providing them with the Study Flyer, Participant Information Sheet and Family Member Information Sheet.

The potential participants were invited to contact the researcher via contact details provided in the Study Flyer and the Participant Information Sheet, if they wanted to gain more information about the study. If it was more suitable for the potential participants, their preferred person could make an initial contact with the researcher on their behalf.

Measures

As part of this study, the participants and informants completed the following measures:

Glasgow Hikikomori Scale (GHS)

The GHS is an observer rated instrument developed to assess social withdrawal amongst young people. It currently includes three subscales: Daily Life & Self Care, Social Interaction and Occupational Role. Daily Life & Self Care subscale consists of 4 items, Social Interaction subscale – of 5 items and Occupational Role – of 6 items. These domains were generated based on the expert clinical knowledge of *Hikikomori* presentations encountered in the clinical practice by the co-author of the GHS, Tadaaki Furuhashi (Furuhashi et al., 2013; Furuhashi & Vellut, 2015).

Children's Motivation Scale (CMS; Gerring et al., 1996)

CMS is a 16-item observer rated questionnaire, which assesses the levels of motivation in children. Its internal consistency, calculated using Spearman-Brown coefficient, is .79. This measure was completed by the family member.

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)

SDQ is a 25-item observer and self-rated instrument used to assess the emotional well-being and social behaviours of children and adolescents 4-17 years old. It comprises of five subscales. Psychometric studies have reported satisfactory internal consistency (Cronbach's $\alpha = .73$). This questionnaire can be administered to a parent or a young person. The scores on SDQ can be categorised as "close to average", "slightly raised", "high" and "very high" according to the cut-point scores, which have been established for each of the subscales.

Child Behavior Checklist for Ages 6-18 (CBCL/6-18; Achenbach & Rescorla, 2001)

CBCL (11-18 years old) is a scale completed by parents designed for the assessment of emotional and behavioural problems. It has good reliability (Cronbach's α ranging from .71 to .89) and satisfactory convergent and divergent validity. The scores on this scale can be classified into three ranges: normal range,

borderline range and clinical range, with separate cut-off T-scores established for subscales and for the total, internalising and externalising problems scales.

Beck Youth Depression Inventory (BDI-Y; Beck, Beck, Jolly, & Steer, 2005)

BDI-Y is a self-report measure consisting of 20 items, which measures negative thoughts, emotional and physical symptoms of depression in children and adolescents. It demonstrates high internal consistency with Cronbach's α above .90 and good convergent validity.

Adolescent Coping Orientation for Problem Experiences (ACOPE; Patterson & McCubbin, 1987)

ACOPE is a 54-items self-report scale assessing coping strategies used by adolescents. It utilises a 5-point scale ranging from 1 = never to 5 = most of the time. Research on its psychometric properties yielded partial evidence on the satisfactory reliability and concurrent validity.

Roberts Version of the UCLA Loneliness Scale (RULS-8; Roberts, Lewinsohn, & Seeley, 1993)

RULS-8 is an 8-items self-report scale developed to measure the experience of loneliness amongst adolescents. It demonstrates good internal consistency (Cronbach's α of .78 and .79).

Research procedures

Young people who expressed their wish to participate in the study attended an appointment with a researcher, during which an informed consent to participation was obtained in writing from each participant. Consent included the potential participants agreeing to carers and CAMHS clinicians' involvement in the completion of the study measures. If the potential participant provided their full consent, the family member and clinician were also asked to provide their consent to participate in the study as informants in writing. Following this process, potential participants, their family members and clinicians were asked to complete the project measures.

Clinicians completed observer rated measures at their NHS CAMHS bases. Patients and family members also completed measures at their local CAMHS. To facilitate the involvement of the participants who were moderately to severely socially withdrawn, home visits were arranged when required. During the recruitment process the researcher collected data at the participant's home on one occasion.

Data analysis

The first part of this study presents the results of the Phase 1 feedback survey regarding the views of the clinicians working in the CAMHS on the GHS. Next, the process of recruitment was described, including the number of young people who were identified as eligible to participate, approached, declined to participate and agreed to take part in the study. The characteristics of the participants were described, and their individual scores presented.

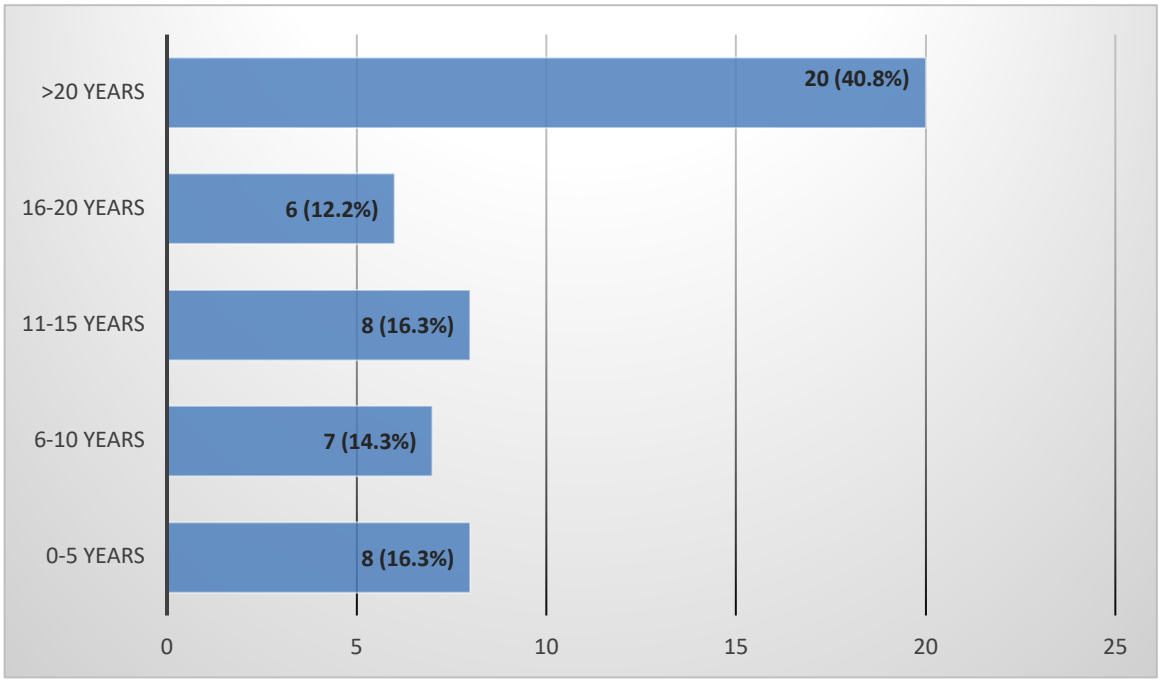
Results

Sample Characteristics

Phase 1

Forty-nine clinicians from the NHS GG&C area working in the CAMHS took part in the survey. Amongst them, 28 (57.1%) were Psychiatrists, 18 (36.7%) were Clinical Psychologists, 2 (4.1%) – Nurses and one (2%) was an Occupational Therapist. Table 3 presents the number of years they were qualified in their profession.

Table 3: The number and percentage of years qualified by the professionals who took part in the online survey on the GHS.



Five female participants were recruited between 22 May and 19 July 2019. The age of the participants ranged between 13 and 17 years old. Tables 4 and 5 summarise the type of the psychological difficulties presented by the young people and their duration. These difficulties were identified through clinicians' reports and their duration was recorded during the completions of the GHS questionnaires by the clinicians.

Table 4: Clinical characteristics of the participants

Presented difficulties	Number of Participants (total = 5)
Depression	4
Anorexia/ Restricted eating	2
Self - harm	2
ASD/ Query of ASD	2
PTSD	1
Withdrawal from peers	1

Table 5: Duration of the psychological difficulties as reported by the clinician.

Participant	Duration
1	6 years
2	over 24 months
3	12 months
4	12 months
5	5 years

Phase 1: Development of the scale

The initial set of the GHS items was developed by a psychiatrist and psychologist with expert knowledge of psychiatric and psychological phenomena, including extreme social withdrawal and *Hikikomori*. The scale consists of three domains: Daily Life & Self Care (4 items), Occupational Role (5 items) and Social Interaction (6 items) and has 15 items with overall scores ranging from 3 to 15. The lowest scores represent the severe levels of social withdrawal and the highest scores – the non-clinical levels. Items on the scale are ordered to mirror the dimensional character of the *Hikikomori* syndrome. The scale was constructed to be suitable for

observer-rating and it was modelled on the general format and approach of the Glasgow Coma Scale (Teasdale & Jennet, 1974; Teasdale et al., 2014).

A few key objectives were considered whilst developing the draft scale:

1. To provide a tool that is brief and easy to rate;

2. That can be completed by clinicians and family members;

3. That provides scores for each of the key dimensions of social withdrawal;

4. That allows for a quick assessment of the severity gradient of the social withdrawal phenomenon.

The first version of the GHS has been refined following the results of the feedback from the clinical professionals working in the CAMHS.

Phase 1: Clinician feedback on the GHS items

The feedback on the GHS included clinicians' ratings and qualitative appraisal of the individual items. Clinicians rated each of the items on the scale 1 to 9, where 1 was defined as "very unclear" and 9 as "perfectly clear". Table 6 presents the descriptive analysis of the scores obtained by each item of the scale.

The GHS items that were rated as the most clearly worded were: the fifth item in the Social Interaction domain - "No social interaction at all outside of home (+1)" (median = 9, IQR: 8, 9) and the first item in the Occupational Role domain - "Spontaneously and independently maintains an occupation (work/study/training) (+6)" (median = 9, IQR: 7.5, 9). The item perceived by the clinicians as the least clear and therefore, obtaining the lowest scores, was the first item in the Daily Life & Self Care domain - "Spontaneously engages with a social and regular life (+4)" (median = 6, IQR: 3, 7).

Clinicians were also invited to provide qualitative feedback. Table 10 in the Appendix 2.4 summarises professionals' comments regarding the GHS by categorising them into themes.

Table 6: Median and interquartile range scores obtained for draft items of the GHS.

Domain	Item Scale Value	Median Clarity Rating	25th Percentile	75th Percentile	IQR
Daily Life & Self Care	+4	6	3	7	4
	+3	7	5.5	8	2.5
	+2	7	6	8	2
	+1	8	6	9	3
Social Interaction	+5	8	7	9	2
	+4	7	5	8	3
	+3	8	5	8	3
	+2	8	6	8	2
	+1	9	8	9	1
Occupational Role	+6	9	7.5	9	1.5
	+5	8	7	9	2
	+4	8	6	9	3
	+3	7	5	8	3
	+2	7	4	9	5
	+1	8	5	9	4

NOTE: The wording of items is presented in Table 11 in the Appendix 2.5.

Following feedback, a number of the GHS items were re-written in accordance with comments received from the clinicians. One of the items was removed from the overall pool of the Occupational Role domain and one item was added to the Social Interaction domain to help distinguish between two gradients of the severity of social withdrawal. Subsequently, two Psychiatrists (one from Japan and one from United Kingdom), a Clinical Psychologist and a researcher reviewed the re-drafted items and came to an agreement on the final version of the scale that captured the key amendments. Table 11 in the Appendix 2.5 presents the items of the first version of the GHS and the corresponding items of its final version.

Phase 2: Recruitment of participants

The study participants were recruited over the period of nine weeks, between 22 May and 19 July 2019. The researcher approached all eight Tier 3 CAMHS services in the NHS GG&C area and Tier 4 Skye House Adolescent Inpatient Service. The number of young people that were treated in Tier 3 CAMHS within a period of twelve months (starting July 2018) was 8810. Four of the Tier 3 CAMHS invited the researcher to their team meetings to present the project within a time scale that would allow sufficient time for the recruitment of the participants. The East, South and North Tier 3 CAMHS teams in Glasgow City area were approached by the researcher between 24 April and 7 May 2019. The Chief Investigator presented the project to the West CAMHS team on the 23 April 2019. The first participant was recruited on the 22 May 2019. There were 3440 children attending the Tier 3 CAMHS in Glasgow City area in July 2019.

19 potential participants were identified in the four Tier 3 CAMHS teams. This number constitutes only 0.2% of the general population that participants were recruited from and 0.6% of the total number of young people that were attending Tier 3 CAMHS sites, where the recruitment took place. All of the identified young people were attending outpatient CAMHS clinics in their local areas. Out of 19 potential participants, 14 (73.7% of those identified) were approached by the clinicians involved in their care during their clinical appointments and were given the study information documents. The majority of the young people that were not approached did not attend their appointments in their CAMHS local clinics. Nine of the potential participants either did not express their interest in the study or did not contact the researcher after expressing their initial interest in the study. Five of the

approached young people (26% of the identified potential participants) decided to take part in the project. The overall recruitment rate was two participants per month.

All of the participants provided their written consent to take part in the project and for the informants to provide additional information about their difficulties. The collection of the data for the four participants took place in their local CAMHS clinics. For one of the participants home visit was organised to facilitate their engagement. In addition, five CAMHS clinicians completed the project outcome measures. Two of the family members did not complete the study questionnaires. One family member did not attend the appointment arranged with the researcher and further attempts to contact this person failed. Another family member became upset during the administration of the first questionnaire and as a result, the procedure was stopped by the researcher. Table 12 in Appendix 2.6 presents the matrix of the administered measures, which were fully completed, and the missing measures.

Phase 2: Results of the GHS field testing

This testing phase of the GHS revealed a number of key lessons about the challenges of engaging socially withdrawn young people and their families. There were only five participants that consented to take part in this study. This sample size did not allow to use statistical methods of analysis that were planned initially to explore the psychometric properties of the GHS. Therefore, the scores on the individual level are presented (Tables 7 - 8) and preliminary outcome patterns highlighted.

The full set of data (information from the participant, clinician and carer) was collected for only three participants. For the other two participants the data collected included self-report measures and the GHS scale scores completed by the clinicians.

Table 7: Comparison of the GHS total and subscale scores as rated by clinicians and family members.

Participant	GHS total score (clinician)	GHS total score (family member)	Daily Life & Self Care (clinician)	Daily Life & Self Care (family member)	Occupational Role (clinician)	Occupational Role (family member)	Social Interaction (clinician)	Social Interaction (family member)
1	6		2		1		3	
2	12	6	3	1	4	3	5	2
3	12		3		4		5	
4	10	11	2	2	3	4	5	5
5	10	3	2	1	4	1	4	1

The individual scores of the participants on the GHS scale and its subscales show the difference in the scoring between clinicians and parents. For participant 4, there was only a one-point difference between the total scores, but for the other two participants the differences between the two ratings were significant. Parents tended to ascribe lower scores than the clinicians on the total GHS scale and its subscales.

Table 8: Summary of the individual total GHS, CBCL and SDQ scores, and Internalising and Externalising problems scores on CBCL and SDQ.

Participant	GHS Clinician	GHS Carer	CBCL Total	CBCL Inter[1]	CBCL Exter[1]	SDQ-S Total	SDQ-S Inter[1]	SDQ-S Exter[1]	SDQ-P Total	SDQ-P Inter	SDQ-P Exter
1	-	6	63 borderline	71 clinical	49	22 very high	11	11	16 slightly raised	9	7
2	10	11	82 clinical	92 clinical	69 clinical	26 very high	16	10	26 very high	19	7
3	10	3	74 clinical	66 clinical	66 clinical	26 very high	15	11	27 very high	15	12

NOTE: 1CBCL Inter – CBCL Internalising, CBCL Exter – CBCL Externalising, SDQ-S Inter - SDQ-S Internalising, SDQ-S Exter – SDQ-S Externalising

For two of the participants, higher scores on the GHS rated by the clinicians corresponded with the higher scores on the CBCL scale (within the clinical level of severity). These two participants also scored within a clinical range on the Internalising and Externalising domains of the CBCL. In addition, their higher scores on the GHS are consistent with the higher total scores on SDQ-S and SDQ-P, which are within a "Very High" range for both of the participants. Due to the very low number of participants, it is not possible to draw any definite conclusions from these results. Nonetheless, these preliminary individual scores suggest a direction for the future exploration of the GHS properties.

Some of the challenges encountered during the recruitment process could be related to the protocol employed in this study, particularly to the recruitment process. The opt–in procedure, in which participants contact the researcher if they are interested in the project, seemed to hinder the recruitment. A number of clinicians reported that many young people expressed their reluctance to contact the researcher, even if they seemed interest in the project, due to anxiety related to contacting a person that they did not know. Another difficulty was related to ensuring that all three groups – participants, clinicians and family members – complete the questionnaires. Collection of the data from parents proved to be challenging, particularly for older participants who often attended clinical appointments in CAMHS on their own.

The acceptability of the measures employed in the study amongst the participants and their parents seemed to be good. None of the participants reported any issues during their completion and the feedback gathered after the scales' administration was positive from all of the participants. One parent commented on the length of the CBCL/6-18 (Achenbach & Rescorla, 2001), but it did not affect the completion of the measure.

Case Identification

At the planning stage for this project, a consultant psychiatrist at one of the recruitment sites was approached to estimate the likely number of eligible participants. The expectation was that 40 young people would meet eligibility criteria at any one time. This contrasts with the actual pool of 19 participants that were identified by the clinicians. Subsequently, 73.7% of those identified were

approached and only 26.3% consented to take part in the study. Given that the rate of the recruitment in this study was two participants per month, it could be estimated that 20 months would be required to recruit 40 participants.

Post-recruitment feedback survey results

Due to the low number of participants recruited for the purpose of this project, the clinicians involved in the identification and approaching the participants were invited to take part in a survey once the study recruitment phase had ended. The survey examined factors that impacted on recruitment and ten clinicians working in NHSGG&C CAMHS who had been involved in the identification and recruitment of participants were asked to complete a 6-item survey with additional space for written comments and observations. Items 1 to 6 were rated on the scale 0 ("strongly disagree") to 4 ("strongly agree"). Item 7 allowed clinicians to provide additional comments and observations regarding factors that hindered recruitment of the participants. Eight out of ten clinicians responded and the descriptive data from these responses are presented in Table 9.

Table 9: Median and interquartile range scores obtained for items of the post-recruitment feedback survey.

Survey Item	Median Rating (Range 0-4)	25th Percentile	75th Percentile	IQR
1. The number of participants that met the eligibility criteria for the study was lower than expected.	2	0.25	3	2.75
2. It was difficult to determine if young people on my caseload met the eligibility criteria for participation in the study.	0	0	0.75	0.75
3. There were young people that met the eligibility criteria but due to the nature of their difficulties and the level of risk presented by them it was deemed inappropriate to approach them regarding the participation in the study.	3	0.5	4	3.5
4. The number of young people who expressed interest in the study was lower than expected.	2	1.25	3	1.75
5. It is too difficult to engage young people who experience social withdrawal due to the nature of their difficulties.	2.5	1	3.75	2.75
6. The recruitment procedure that required the young person to opt into the study impeded the recruitment process.	3.5	2.25	4	1.75

The survey item with the strongest endorsement was number 6: “The recruitment procedure that required the young person to opt into the study impeded the recruitment process” (median = 3.5, IQR: 2.25, 4). Statement 3 was the next most strongly endorsed – “There were young people that met the eligibility criteria but due to the nature of their difficulties and the level of risk presented by them it was deemed inappropriate to approach them regarding the participation in the study” (median = 3, IQR: 0.5, 4). Importantly, there was no indication that confusion about study eligibility criteria affected recruitment as seen in the responses to statement 2 – “It was difficult to determine if young people on my caseload met the eligibility criteria for participation on the study” (median = 0, IQR: 0, 0.75).

Clinicians also provided comments on the factors that they believed contributed to low recruitment. These comments, summarised and thematically grouped, are presented below:

1. Lack of an incentive/ reward/ clear benefit for the young people to take part in the study (reported by two clinicians).
2. Longer recruitment period was needed to engage some of the socially withdrawn young people (reported by two clinicians).
3. Low staff levels and CAMHS team moving premises during the time of recruitment.
4. A number of young people who met the eligibility criteria were treated within the remit of the research site but were registered with another health board.
5. The severity of other mental health difficulties of the identified potential participants meant that it was not appropriate to invite them to participate in the study.
6. There were young people that could have met the eligibility criteria on the CAMHS waiting list but due to the lengthy wait for the initial assessment in CAMHS, it was not possible to approach them within the study’s time scale.

The post-recruitment survey was added to support a more systematic exploration of the reasons for low recruitment rates in the project and could provide a contribution to future studies exploring similar subject by informing their methodological designs.

Discussion

One of the aims of this study was to refine the GHS scale by using feedback obtained from the clinicians. The second purpose was to examine the feasibility of testing this scale in the clinical setting and, subject to the number of recruited participants, to investigate its psychometric properties.

Social withdrawal in young people is a significant problem and therefore, there is a need to find ways to assess it and describe it more effectively. The problem of social withdrawal appeared to be recognisable as clinically important. Moreover, the clinical phenotype of *Hikikomori* was relevant to a large number of clinicians, which was proved by their interest in rating the draft version of the GHS. The feedback from the CAMHS professionals allowed for the further refinement of the GHS. The scale development phase of this study suggested that there was an interest and engagement amongst clinicians in the topic of social withdrawal.

The refined version of the scale is practical, time-effective and easy to score. It is hoped that it will allow for the early assessment of social withdrawal and its severity. It also has a potential to increase the awareness and understanding of this phenomenon amongst the professionals as well as the understanding of the clinical correlates of social withdrawal.

The recruitment of participants presented a significant challenge. In this study we used clinicians' expertise and knowledge to arrive at a nominated target sample of 40 participants to perform the initial field testing and to examine the psychometric properties of the GHS. There are precedents for social withdrawal scale development based on small samples. Sample size of 44 participants with MND and arthritis, who also exhibited social withdrawal, was examined by Rigby et al. (1999) for the similar purpose of developing and evaluating a scale that measures social withdrawal. Based on the number of participants utilised in the Rigby et al. (1999) study and the recruitment rate of two participants per month achieved in this study, the recruitment in the future project would take approximately 22 months.

The number of young people recruited did not allow for the statistical analysis of the data and the results were reported at the individual level. The recruitment strategy based on the opt-in process appeared to be one of the obstacles for young people

to participate. The reports from the clinicians indicate that there could be a number of young people who were interested in the participation, but due to the nature of their difficulties, were not able to actively engage in the process. Difficulty in engagement of the socially withdrawn youth has been highlighted in the literature related to the *Hikikomori* phenomenon (Lee, Lee, Choi, & Choi, 2013; Wong, 2009; Wong 2012).

In the Lee et al. (2013) study, out of 65 participants referred to the home visit programme by mental health centres, 24 participants (36.9%) did not take part in the project. Some of the reasons reported for the lack of participation were not providing consent for the home visit to take place (3 participants), parental refusal to take part in the interviews (1) and missing data from surveys (4). An additional 9.7% (4 participants) of those who provided initial consent, refused to take part in the interviews during the intervention.

The experiences and lessons drawn from this feasibility study are similar to Lee et al. (2013) in that there was a significant percentage of young people eligible to participate in the study who were approached by clinicians but did not provide their consent (64.3%) to take part in the project. There were also data missing from the family members. The difficulties related to recruiting socially withdrawn young people also resonate with professionals' experiences of working clinically with this population. A number of CAMHS clinicians highlighted that one of the issues of engaging young people who present with social withdrawal is their lack of trust and the need to develop therapeutic relationship over a significant period of time.

The recruitment of the eligible participants was not feasible in the time scale of this project and future studies would require a much longer interval of time. What was learned from this study is that despite the recognition of social withdrawal as a problem and professionals' interest in it, the population affected by social withdrawal is hard to engage. Nonetheless, one of the gains of this study is enhancing the understanding of the practical challenges related to the recruitment of this population, such as initial engagement and consent to research. The results of this study also allowed to analyse and report the recruitment flow. Finally, this study helped to estimate the realistic time scale that needs to be considered for the recruitment purposes.

The recruitment strategy employed in this study was based on the opt-in process in which the potential participant or the person chosen by the potential participant contacted the researcher, if they were interested in taking part in the project. The initial recruitment strategy proposed for the consideration of the Ethics Committee involved clinicians asking the eligible potential participants for consent to share young person's contact details with the researcher, if the young person wished to gain more information about the project. The recruitment procedure was modified following the feedback from the Human Research Ethics Committee who expressed concern about the possibility of the perceived coercion involved in the original recruitment strategy. However, it seems that the opt-in recruitment process that was used created additional barriers that prevented socially withdrawn young people from engaging in the study. Due to the nature of their difficulties, a number of young people could have found it difficult and discomforting to initiate contact with a stranger. This outcome highlights the challenges of minimising any risk of coercion in research recruitment with clinical populations while also maximising the involvement of under-researched groups in studies.

Given the challenges encountered during the recruitment process, to increase the feasibility of the exploration of psychometric properties of the GHS, a careful consideration should be given to the design of the study. One of the suggestions is to broaden the scope of recruitment by recruiting a non-clinical sample. The future designs could also focus on the data obtained solely from the informants. In addition, gathering an additional feedback from the clinicians and other informants on the acceptability and practical utility of the scale in the clinical context would allow for its further refinement.

Strengths and limitations

The data collected in this project provide information about the feasibility of the recruitment of participants who experience difficulties related to social withdrawal.

The data were not sufficient to perform statistical analyses and explore the psychometric properties of the GHS. The recruitment process employed in the study affected the number of participants that opted in.

Another limitation of this study is the potential of a cultural bias present in the selected study questionnaires. The majority of the questionnaires employed in this project were adapted to be used for assessment of children and adolescents in the United Kingdom. Two exceptions are CMS (Gerring et al., 1996) and ACOPE (Patterson & McCubbin, 1987), which were developed for the population living in the USA. A number of ACOPE items (e.g. 21. Talk to a minister/priest/rabbi; 23. Go to church; 44. Pray) may not be relevant to adolescents who come from the minority backgrounds. To reduce this cultural bias in the future studies, it is recommended that the questionnaires' items are adapted to the needs of the population that is assessed. Alternatively, a use of a different scale is recommended, such as KidCOPE (Spirito, Stark & Williams, 1988).

The use of two different informants in this study, a clinician and a family member, is one of the advantages of the design of this project. The employment of more than one observer could allow to establish the rates of agreement and therefore, to further refine the scale in the future.

This study was also a first attempt at refining and field-testing a scale that has a potential to capture the construct of social withdrawal. In the context of existing measures, this would be the first scale developed in the English language population that focuses solely on the assessment of this phenomenon.

Conclusions

This study aimed to refine the GHS scale measuring social withdrawal and to explore the feasibility of recruiting the participants to investigate its psychometric properties. Although a very small sample was recruited, the project enabled to estimate the time scale necessary to increase the feasibility of the future studies and to identify some of the factors that could hinder the recruitment process.

Social withdrawal has a great impact on the functioning of young people; it affects their development of identity and ability to engage in the developmentally appropriate roles (Wong, 2009); it impairs social skills (Wong, 2012) and affects performance at school (Li & Wong, 2015). In light of the impact that this phenomenon may have on young people, it becomes increasingly important to raise awareness and broaden the understanding of social withdrawal. Hence, studies

focusing on the further development of the GHS, which could allow to assess social withdrawal, would be of great value.

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Appendix

Appendix 1.1 Author Guidelines for Infant and Child Development journal

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Sections
1. Submission
2. Aims and Scope
3. Preparing the Submission
4. Editorial Policies and Ethical Considerations
5. Author Licensing
6. Publication Process After Acceptance
7. Post Publication

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Infant and Child Development aims to publish the best contemporary research in developmental psychology through empirical, theoretical and methodological papers addressing psychological development from the prenatal period to adolescence. The journal welcomes brief empirical reports (up to 3000 words), and longer reports on a sequence of studies, reviews or theoretical papers (normally up to 8000 words). With a readership including researchers in developmental psychology, but also child practitioners in health and education, the journal publishes research addressing typical and atypical development across the range of human behaviour and experience including socio-emotional, cognitive, perceptual, motor, and language development. Infant and Child Development is particularly keen to publish research which elucidates processes and mechanisms of development, and which extends or challenges accepted ways of thinking.

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Acknowledgments

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Reference examples follow:

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Book
Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

Internet Document
Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from *http://www.youtube.com/watch?v=Vja83KLQXZs*

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Author Guidelines updated 9th October 2017

Appendix 1.2 Quality Rating Tool

Crowe Critical Appraisal Tool (CCAT) Form (v1.4) Reference Reviewer

This form must be used in conjunction with the CCAT User Guide (v1.4); otherwise validity and reliability may be severely compromised.

Citation	
	Year

Research design (add if not listed)		
❑ Not research	Article | Editorial | Report | Opinion | Guideline | Pamphlet | ...	
❑ Historical	...	
❑ Qualitative	Narrative | Phenomenology | Ethnography | Grounded theory | Narrative case study | ...	
❑ Descriptive, Exploratory, Observational	A. Cross-sectional | Longitudinal | Retrospective | Prospective | Correlational | Predictive | ...	
	B. Cohort | Case-control | Survey | Developmental | Normative | Case study | ...	
Experimental	❑ True experiment	Pre-test/post-test control group | Solomon four-group | Post-test only control group | Randomised two-factor | Placebo controlled trial | ...
	❑ Quasi-experiment	Post-test only | Non-equivalent control group | Counter balanced *(cross-over)* | Multiple time series | Separate sample pre-test post-test [no Control] [Control] | ...
	❑ Single system	One-shot experimental *(case study)* | Simple time series | One group pre-test/post-test | Interactive | Multiple baseline | Within subjects *(Equivalent time, repeated measures, multiple treatment)* | ...
❑ Mixed Methods	Action research | Sequential | Concurrent | Transformative | ...	
❑ Synthesis	Systematic review | Critical review | Thematic synthesis | Meta-ethnography | Narrative synthesis | ...	
❑ Other	...	

Variables and analysis		
Intervention(s), Treatment(s), Exposure(s)	Outcome(s), Output(s), Predictor(s), Measure(s)	Data analysis method(s)

Sampling									
Total size		Group 1		Group 2		Group 3		Group 4		Control	
Population, sample, setting									

Data collection (add if not listed)			
Audit/Review	a) Primary | Secondary | ... b) Authoritative | Partisan | Antagonist | ... c) Literature | Systematic | ...	Interview	a) Formal | Informal | ... b) Structured | Semi-structured | Unstructured | ... c) One-on-one | Group | Multiple | Self-administered | ...
Observation	a) Participant | Non-participant | ... b) Structured | Semi-structured | Unstructured | ... c) Covert | Candid | ...	Testing	a) Standardised | Norm-ref | Criterion-ref | Ipsative | ... b) Objective | Subjective | ... c) One-on-one | Group | Self-administered | ...

Scores									
Preliminaries		Design		Data Collection		Results		Total [/40]	
Introduction		Sampling		Ethical Matters		Discussion		Total [%]	

General notes

Appraise research on the merits of the research design used, not against other research designs.

Category Item	Item descriptors [☑ Present; ☒ Absent; ■ Not applicable]	Description [Important information for each item]	Score [0–5]
1. Preliminaries			
Title	1. Includes study aims ❑ and design ❑		
Abstract (assess last)	1. Key information ❑ 2. Balanced ❑ and informative ❑		
Text (assess last)	1. Sufficient detail others could reproduce ❑ 2. Clear/concise writing ❑, table(s) ❑, diagram(s) ❑, figure(s) ❑		
		Preliminaries [/5]	
2. Introduction			
Background	1. Summary of current knowledge ❑ 2. Specific problem(s) addressed ❑ and reason(s) for addressing ❑		
Objective	1. Primary objective(s), hypothesis(es), or aim(s) ❑ 2. Secondary question(s) ❑		
	Is it worth continuing?	**Introduction [/5]**	
3. Design			
Research design	1. Research design(s) chosen ❑ and why ❑ 2. Suitability of research design(s) ❑		
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen ❑ and why ❑ 2. Precise details of the intervention(s)/treatment(s)/exposure(s) ❑ for each group ❑ 3. Intervention(s)/treatment(s)/exposure(s) valid ❑ and reliable ❑		
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen ❑ and why ❑ 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) ❑ 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid ❑ and reliable ❑		
Bias, etc	1. Potential bias ❑, confounding variables ❑, effect modifiers ❑, interactions ❑ 2. Sequence generation ❑, group allocation ❑, group balance ❑, and by whom ❑ 3. Equivalent treatment of participants/cases/groups ❑		
	Is it worth continuing?	**Design [/5]**	
4. Sampling			
Sampling method	1. Sampling method(s) chosen ❑ and why ❑ 2. Suitability of sampling method ❑		
Sample size	1. Sample size ❑, how chosen ❑, and why ❑ 2. Suitability of sample size ❑		
Sampling protocol	1. Target/actual/sample population(s): description ❑ and suitability ❑ 2. Participants/cases/groups: inclusion ❑ and exclusion ❑ criteria 3. Recruitment of participants/cases/groups ❑		
	Is it worth continuing?	**Sampling [/5]**	
5. Data collection			
Collection method	1. Collection method(s) chosen ❑ and why ❑ 2. Suitability of collection method(s) ❑		
Collection protocol	1. Include date(s) ❑, location(s) ❑, setting(s) ❑, personnel ❑, materials ❑, processes ❑ 2. Method(s) to ensure/enhance quality of measurement/instrumentation ❑ 3. Manage non-participation ❑, withdrawal ❑, incomplete/lost data ❑		
	Is it worth continuing?	**Data collection [/5]**	
6. Ethical matters			
Participant ethics	1. Informed consent ❑, equity ❑ 2. Privacy ❑, confidentiality/anonymity ❑		
Researcher ethics	1. Ethical approval ❑, funding ❑, conflict(s) of interest ❑ 2. Subjectivities ❑, relationship(s) with participants/cases ❑		
	Is it worth continuing?	**Ethical matters [/5]**	
7. Results			
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen ❑ and why ❑ 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen ❑ and why ❑ 3. Suitability of analysis/integration/interpretation method(s) ❑		
Essential analysis	1. Flow of participants/cases/groups through each stage of research ❑ 2. Demographic and other characteristics of participants/cases/groups ❑ 3. Analyse raw data ❑, response rate ❑, non-participation/withdrawal/incomplete/lost data ❑		
Outcome, Output, Predictor analysis	1. Summary of results ❑ and precision ❑ for each outcome/output/predictor/measure 2. Consideration of benefits/harms ❑, unexpected results ❑, problems/failures ❑ 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) ❑		
		Results [/5]	
8. Discussion			
Interpretation	1. Interpretation of results in the context of current evidence ❑ and objectives ❑ 2. Draw inferences consistent with the strength of the data ❑ 3. Consideration of alternative explanations for observed results ❑ 4. Account for bias ❑, confounding/effect modifiers/interactions/imprecision ❑		
Generalisation	1. Consideration of overall practical usefulness of the study ❑ 2. Description of generalisability (external validity) of the study ❑		
Concluding remarks	1. Highlight study's particular strengths ❑ 2. Suggest steps that may improve future results (e.g. limitations) ❑ 3. Suggest further studies ❑		
		Discussion [/5]	
9. Total			
Total score	1. Add all scores for categories 1–8		
		Total [/40]	

Appendix 1.3 Scoring Guidance on Quality Rating Tool

Overview of scoring a paper

The Form is divided into eight categories and 22 items. Each item has multiple item descriptors that make it easier to appraise and score a category. Each category receives its own score on a 6 point scale from 0–5. The lowest score a category can achieve is 0, and 5 is the highest score. Categories can only be scored as a whole number or integer, i.e. 0, 1, 2, 3, 4, or 5, that is half marks are not allowed.

There are tick boxes (❑) beside item descriptors. The tick box is useful to indicate if the item descriptor is

- Present (☑) – For an item descriptor to be marked as present, there should be evidence of it being present rather than an assumption of presence.
- Absent (☒) – For an item descriptor to be marked as absent, it is implied that it should be present in the first place.
- Not applicable (■) – For an item descriptor to be marked as not applicable, the descriptor must not be relevant given the characteristics of the paper being appraised and is, therefore, not considered when assigning a score to a category.

Whether an item descriptor is present, absent, or not applicable is further explored in the section *Guidelines for scoring categories and items*. All categories must be scored because all categories are applicable in all research designs. Only item descriptors may be marked 'not applicable'.

While it may be tempting to add up all the present marks (☑) and all the absent marks (☒) in each category and to use the proportion of one to the other to calculate the score for the category, this is not appropriate. It is incorrect because not all item descriptors in a category have equal importance. For example, in the *Introduction* category there are two items (*Background* and *Objective*) and a total of five tick boxes. If a paper being appraised has all boxes marked as present (☑) except for *Primary objective(s), hypothesis(es), or aim(s)*, which is marked as absent (☒), should the paper be scored 4/5 for that category? It could be argued that a research paper without a primary objective, hypothesis, or aim is fundamentally flawed and, as a result, should be scored 0/5 even though the other four tick boxes were marked as present.

Therefore, the tick marks for present, absent, or not applicable are to be used as a guide to scoring a category and not as a simple check list. It is up to you as the appraiser to take into consideration all aspects of each category and based on both the tick marks and judgement assign a score to a category.

Similarly, the research design used in each paper should be appraised on its own merits and not relative to some preconceived notion of a hierarchy of research designs or 'gold standard'. What is most important is that the paper used an appropriate research design based on the research question being addressed, rather than what research design was used.

The total score given to a paper can be expressed as a percentage by dividing the *Total* by 40 (that is, eight categories multiplied by the maximum score of five) and writing the result on the first page of the Form. The *Total* % should be written to the nearest full percent (Table 1). There is no need for decimal places because they do not add anything to the accuracy of the score obtained.

Finally, the *Total* or *Total* % score a paper obtains is not the sole criterion on which an overall assessment of a paper is based. The *Total* or *Total* % score is a useful summary but may not be applicable in all cases. When reporting an appraisal using the CCAT, the score obtained in

every category must be stated along with the *Total* or *Total %* score. This prevents papers that score high overall but very poor in one or more categories being hidden amongst papers which scored high throughout all categories. Based on the reasons for the appraisal, some papers which have a low score in certain category but which have a high total score may be ranked lower than those with a lower total score but a high score in that particular category. These processes are up to you, as the appraiser, to detail before you begin appraising papers.

Table 1 *Total* and corresponding *Total %*

Total	Total %	Total	Total %	Total	Total %	Total	Total %
0	0	10	25	20	50	30	75
1	3	11	28	21	53	31	78
2	5	12	30	22	55	32	80
3	8	13	33	23	58	33	83
4	10	14	35	24	60	34	85
5	13	15	38	25	63	35	88
6	15	16	40	26	65	36	90
7	18	17	43	27	68	37	93
8	20	18	45	28	70	38	95
9	23	19	48	29	73	39	98

Appendix 2.1 Author Guidelines for Journal of Adolescence

GUIDE FOR AUTHORS

Introduction

The Journal of Adolescence is an international, broad based, cross-disciplinary journal that addresses issues of professional and academic importance concerning development between puberty and the attainment of adult status within society. Our focus is specifically on adolescent development: change over time or negotiating age specific issues and life transitions. The aim of the journal is to encourage research and foster good practice through publishing empirical studies, integrative reviews and theoretical and methodological advances. The Journal of Adolescence is essential reading for adolescent researchers, social workers, psychiatrists, psychologists, and youth workers in practice, and for university and college faculty in the fields of psychology, sociology, education, criminal justice, and social work.

Research Areas Encompassed:

- Adolescent development with particular emphasis on social, cognitive, and emotional functioning
- Resilience, positive development, and effective coping
- Disturbances and disorders of adolescence
- Public health approaches and interventions designed to reduce risk or support positive development

Types of contributions

Specific instructions for different manuscript types

Full research articles: The majority of the articles carried in the Journal are full research articles of up to 5000 words long, reporting the results of research (including evaluations of interventions). The word count relates to the body of the article. The abstract, references, tables, figures and appendices are not included in the count. Authors are encouraged to consult back issues of the Journal to get a sense of coverage and style, but should not necessarily feel confined by this. Articles should clearly make a new contribution to the existing literature and advance our understanding of adolescent development.

Review articles: We are keen to encourage authors to submit review articles on topics where there is a need for a new overview of existing research. As with other formats, the focus should be explicitly on adolescence, and on shedding light on young people's development. The journal is not prescriptive about how reviews should be undertaken, but the methods used should be clear. Reviews should not exceed 5000 words. The word count includes the body of the article, but not the abstract, references, tables, figures or appendices. Further information about writing reviews for the Journal of Adolescence can be found here. Occasionally the editors will commission review pieces if they feel there is a particular gap in the literature that needs filling, or to complement a Special Issue. If authors would like to discuss their plans for a review article, please contact the Editor through the journal mailbox joa@elsevier.com in the first instance.

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International notes: This format is for the very brief reporting of research replications from developing countries and places with a less well supported adolescence research field, where it may be difficult to find international publication outlets and bring the work to the attention of a wider audience. International notes would be published as a very brief summary in the Journal (up to 1000 words in length), with a fuller version available as on-line supplementary material (see above). The word count relates to the body of the text. The abstract, references, tables, figures and appendices are not included in the count. International notes are likely to focus on local replications of well-known phenomena or findings.

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Examples:
Reference to a journal publication:
Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications, 163*, 51–59. https://doi.org/10.1016/j.Sc.2010.00372.
Reference to a journal publication with an article number:
Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2018). The art of writing a scientific article. *Heliyon*, *19*, e00205. https://doi.org/10.1016/j.heliyon.2018.e00205.
Reference to a book:
Strunk, W., Jr., & White, E. B. (2000). *The elements of style.* (4th ed.). New York: Longman, (Chapter 4).
Reference to a chapter in an edited book:
Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). New York: E-Publishing Inc.
Reference to a website:
Cancer Research UK. Cancer statistics reports for the UK. (2003). http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/ Accessed 13 March 2003.
Reference to a dataset:
[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions*. Mendeley Data, v1. https://doi.org/10.17632/xwj98nb39r.1.
Reference to a conference paper or poster presentation:
Engle, E.K., Cash, T.F., & Jarry, J.L. (2009, November). The Body Image Behaviours Inventory-3: Development and validation of the Body Image Compulsive Actions and Body Image Avoidance Scales. Poster session presentation at the meeting of the Association for Behavioural and Cognitive Therapies, New York, NY.

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AFTER ACCEPTANCE

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Appendix 2.2 Research Ethics Committee Approval Letter

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Professor Hamish J McLeod
Institute of Health and Wellbeing
University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

West of Scotland REC 4
Research Ethics
Clinical Research and Development
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow
G3 8SJ
(Formerly Yorkhill Childrens Hospital)

Date 23 April 2019
Direct line 0141 232 1808
E-mail WoSREC4@ggc.scot.nhs.uk

Dear Professor McLeod

Study title: **Examining Clinical Homologues of "Hikikomori": Apathetic Social Withdrawal in Young People in Scotland**
REC reference: **19/WS/0042**
IRAS project ID: **251982**

Thank you for your submission of 4 April 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of

the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Covering Letter 19-WS-0042 251982]		11 March 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Glasgow insurance]		06 August 2018
GP/consultant information sheets or letters [Notification of Participation Letter for Clinician]	1	20 December 2018
GP/consultant information sheets or letters [Professional Information Sheet]	2	14 March 2019
IRAS Application Form [IRAS_Form_15022019]		15 February 2019
Letters of invitation to participant [Study Flyer]	2	14 March 2019
Non-validated questionnaire [Glasgow Hikikomori Scale]	1	07 August 2018
Other [Family Member Consent Form v1, 11.03.2019]	1	11 March 2019
Other [Professional Consent Form v1, 11.03.2019]	1	11 March 2019
Participant consent form [Assent Form for Young Person]	1	20 December 2018
Participant consent form [Participant Consent Form]	2	14 March 2019
Participant information sheet (PIS) [Participant Information Sheet]	2	14 March 2019
Participant information sheet (PIS) [Family Member Information Sheet]	2	14 March 2019
Research protocol or project proposal [Research Protocol]	2	14 March 2019
Summary CV for Chief Investigator (CI) [CI CV Hamish McLeod]		09 August 2018
Summary CV for student [Student CV Kamila Dzik]		
Summary CV for supervisor (student research) [Supervisor CV - Christabel Boyle]		
Validated questionnaire [Beck Depression Inventory for Youth_sample]		
Validated questionnaire [Child Behavior Checklist 6-18_sample]		
Validated questionnaire [Children's Motivation Scale]	1	07 August 2018
Validated questionnaire [Adolescent Coping Orientation for Problem Experiences_sample]		
Validated questionnaire [Roberts Version of the UCLA Loneliness Scale_RULS-8]	1	07 August 2018
Validated questionnaire [SDQ_English_p4-17_sample]		
Validated questionnaire [SDQ_English_s11-17_sample]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/WS/0042	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of
Dr Ken James
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"*After ethical review – guidance for researchers*"

Copy to: Miss Kamila Dzik, University of Glasgow
Ms Elaine O'Neill, NHSGGC R&D
Ms Emma-Jane Gault, University of Glasgow
nhsg.NRSPCC@nhs.net

West of Scotland REC 4

Attendance at Sub-Committee of the REC meeting in correspondence

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Mark McJury	Consultant Clinical Scientist	Yes	
Dr Ken James	Consultant Anaesthetist	Yes	Chair
Ms Patricia Young	Retired Business Manager	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Rozanne Suarez	REC Manager

Appendix 2.3 NHS Greater Glasgow and Clyde Research and Development Approval

Administrator: Mrs Elaine O'Neill
Telephone Number: 0141 232 1815
E-Mail: elaine.o'neill2@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
West Glasgow ACH
Dalnair Street
Glasgow G3 8SW

23 April 2019

Miss Kamila Dzik
Admin Building,
Ins of Health and Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

NHS GG&C Board Approval

Dear Miss K Dzik,

Study Title:	**Examining Clinical Homologues of "Hikikomori": Apathetic Social Withdrawal in Young People in Scotland**
Principal Investigator:	**Miss Kamila Dzik**
GG&C HB site	**NHS GG&C Child and Adolescent Mental Health Services**
Sponsor	**NHS Greater Glasgow and Clyde**
R&D reference:	**GN18MH675**
REC reference:	**19/WS/0042**
Protocol no:	**V2; 14/03/19**

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004

   a. During the life span of the study GGHB requires the following information relating to this site
      i. Notification of any potential serious breaches.
      ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

Appendix 2.4 Qualitative feedback on the GHS

Table 10: Qualitative feedback on the GHS provided by CAMHS clinicians in the online survey.

Theme	Clinicians' feedback
Need for more clear definition	"A bit general, not clear what a regular life means. Might be better to say spontaneously engages with friends and have a range of frequencies for this behaviour" "Needs more definitions about what a regular life is, and definitions of prompting" "Some individuals may be unclear as to the meaning of 'depleted'" "Is this face to face contact or does telephone/texting count?" "Might be helpful in this question and question above to clarify where contact via telephone, text, xBox games, etc fits
Replacement of the word	"Might be better to say parent/carer, rather than a mother" "Cyberspace may be a somewhat dated term? Perhaps just saying online would be more helpful?" "I'm not sure about cyberspace as a term which is widely used" "Most young people seen by child and adolescent services are at school therefore the term occupational, even though defined, may not feel correct to clinicians"
Need for defining frequencies of presented behaviours	"Quite complex language if used for young people or family members, more examples or idea of frequency might be helpful" "What constitutes minimum could be more clearly defined" "Again, might be more specific about frequency of this" "What do you mean by limited? Limited social contact but lots with cyberspace?" "'Few' is quite subjective-do you mean once a day, 10 times a week etc?" "How do you quantify limited?"

Appendix 2.5 Comparison of the wording of the GHS first and final version

Table 11: Comparison of the wording of the items on the first and final version of the GHS.

	Initial wording of the GHS by item	Final wording of the GHS by item
Daily Life & Self Care	Spontaneously engages with a social and regular life (+4)	Spontaneously engages in a social life and activities of daily living (e.g. grooming, eating, sleeping etc. (+4)
	Lives a regular life (e.g. eating, sleeping etc.) but only with the prompting and support of others (e.g. mother) (+3)	Engages in a social life and activities of daily living, but only with the prompting and support of others (e.g. parent/carer) (+3)
	Lives a restricted and socially depleted life despite prompting and encouragement from others (e.g. mother) (+2)	Displays restricted and diminished social life and daily living skills despite prompting and encouragement from others (e.g. parent/carer) (+2)
	Engages with only the minimum daily activities and tasks (e.g. toilet, eating, sleeping etc.) (+1)	Engages with only the minimum daily activities and tasks (e.g. hygiene, eating, sleeping etc.) (+1)
Occupational Role	Spontaneously and independently maintains an occupation (work/study/training) (+6)	Spontaneously and independently maintains age appropriate roles (e.g. work or study) (+5)
	Maintains an occupation but only with prompting and support by others (e.g. mother) (+5)	Maintains age appropriate roles but only with prompting and support from others (e.g. parent/carer) (+4)
	Limited engagement in occupational role despite prompting and support of others (e.g. mother) (+4)	
	Only engages in an occupational role that is well below their ability and expected main occupation (+3)	Engages in age appropriate roles that are well below their ability and expected attainment (+3)
	Only engages in a lower occupational role with prompting and support of others (e.g. mother) (+2)	Only engages in age appropriate roles that are well below their ability and expected attainment with prompting and support of others (e.g. parent/carer) (+2)
	No engagement in a developmental-age appropriate occupational role (+1)	No engagement in age appropriate roles (e.g. work or study) (+1)

Social Interaction	Spontaneously seeks out direct contact with others (+5)	Spontaneously seeks out direct contact with others, both familiar and unfamiliar (+6)
	Engages in limited indirect social contact (e.g. in cyberspace.) (+4)	Engages in limited direct (e.g. face to face) and indirect social contact (e.g. online, via mobile social media apps, mobile phone) (+5)
	Forms the intention to seek social interaction but he/she has abandoned attempts due to lack of success (+3)	Forms the intention to seek social interaction outside of home but has abandoned attempts at making social contact with others (+4)
	Few social interactions by any means (including in cyberspace) (+2)	Engages in infrequent social interactions (less than one contact per week) by any means (including with family members and/or online/social media) (+3)
	No social interaction at all outside of home (+1)	Has no social interaction at all outside of home and no interaction with family members (social interaction only online/via social media) (+2)
		Has no social interaction including via family members and indirect social contact in cyberspace (only engages in social uses of the Internet as an observer) (+1)

Appendix 2.6 Matrix of completed and missing measures

Table 12: Matrix of completed and missing measures.

Measure	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
GHS completed by clinician	C[1]	C	C	C	C
GHS completed by parent	M[2]	C	M	C	C
CMS (Gerring et al., 1996) completed by parent	M	C	M	C	C
CBCL/6-18 (Achenbach & Rescorla, 2001) completed by parent	M	C	M	C	C
SDQ (Goodman, 1997) completed by parent	M	C	M	C	C
SDQ (Goodman, 1997) completed by participant	C	C	C	C	C
BDI-Y (Beck et al., 2001) completed by participant	C	C	C	C	C
ACOPE (Patterson & McCubbin, 1987) completed by participant	C	C	C	C	C
RULS-8 (Roberts et al., 1993) completed by participant	C	C	C	C	C

NOTE: 1 – Completed, 2 - Missing

Appendix 2.7 Glasgow Hikikomori Scale

Participant ID_____

Glasgow Hikikomori Scale (GHS)
How long person has been withdrawn (please state the number of months):_____

Over the past six months, which of the statements below describes the best level of typical functioning?

Daily Life & Self Care
> Spontaneously engages in a social life and activities of daily living (e.g. grooming, eating, sleeping etc.) (+4)
> Engages in a social life and activities of daily living, but only with the prompting and support of others (e.g. parent/carer) (+3)
> Displays restricted and diminished social life and daily living skills despite prompting and encouragement from others (e.g. parent/carer) (+2)
> Engages with only the minimum daily activities and tasks (e.g. hygiene, eating, sleeping etc.) (+1)

Occupational Role (e.g. attending school, working etc.)
> Spontaneously and independently maintains age appropriate roles (e.g. work or study) (+5)
> Maintains age appropriate roles but only with prompting and support from others (e.g. parent/carer) (+4)
>Engages in age appropriate roles that are well below their ability and expected attainment (+3)
> Only engages in age appropriate roles that are well below their ability and expected attainment with prompting and support of others (e.g. parent/carer) (+2)
> No engagement in age appropriate roles (e.g. work or study) (+1)

Social Interaction
> Spontaneously seeks out direct contact with others, both familiar and unfamiliar (+6)
> Engages in limited direct (e.g. face to face) and indirect social contact (e.g. online, via mobile social media apps, mobile phone) (+5)
> Forms the intention to seek social interaction outside of home but has abandoned attempts at making social contact with others (+4)
> Engages in infrequent social interactions (less than one contact per week) by any means (including with family members and/or online/social media) (+3)
> Has no social interaction at all outside of home and no interaction with family members (social interaction only online/via social media) (+2)
> Has no social interaction including via family members and indirect social contact in cyberspace (only engages in social uses of the Internet as an observer) (+1)

Appendix 2.8 The Roberts Version of the UCLA Loneliness Scale (RULS-8)

INSTRUCTIONS: Indicate how often each of the statements below is descriptive of you.

Statement	Never	Rarely	Sometimes	Often
1. I feel in tune with people around me. (R)	0	1	2	3
2. I lack companionship.	0	1	2	3
3. I do not feel alone. (R)	0	1	2	3
4. I feel part of a group of friends. (R)	0	1	2	3
5. I am no longer close to anyone.	0	1	2	3
6. I feel left out.	0	1	2	3
7. I feel isolated from others.	0	1	2	3
8. I can find companionship when I want it. (R)	0	1	2	3

Roberts, R.E., Lewinsohn, P.M., & Seeley, J.R. (1993). A Brief Measure of Loneliness Suitable for Use with Adolescents. *Psychological Reports*, 72, 1379-1391.

Appendix 2.9 Children's Motivation Scale

Participant ID:

Directions: Circle the number on the scale below each question which best describes your child's motivation.

1. Starts playing (games, activities) on his/her own.
   For example, gathering materials for a game, cooking.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

2. Seems to put little effort into anything.
   For example, choosing clothing, getting ready for school, cleaning up.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

3. Does things on his/her own. For example, household chores, homework, getting ready for a trip.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

4. Finishes projects he/she starts.
   For example, coloring a picture, earning a scout badge, or pursuing a hobby.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

5. Approaches activities with intensity, energy, or enthusiasm.
   For example, wants to be best at a sport, excited about visiting a new place.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

6. Is interested in things.
   For example, new TV shows, new toys, new clothes, new books.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

7. Makes plans, asks to do things in the future.
   For example, taking a trip, having a party, getting a new toy.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

8. Is curious. For example, wants to understand, to know about different people, places, activities, or how things work.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

9. Is interested in learning new things. For example, learning the alphabet, learning a new sport, taking drivers' education.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

10. Shows expected emotional responses. For example, happy when rewarded or surprised, sad when hurt, angry when insulted.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

11. Has to be told what to do in his/her free time. For example, playing with a toy or game, or making a phone call to a friend.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

12. Wants to be with friends. For example, invites friends to play, calls on the phone, or arranges social events.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

13. Talks freely, sharing his/her ideas with those present.
    For example, likes to talk on the phone, talks a lot with family and friends, likes to express his/ her ideas on a topic.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

14. Does not appear interested or concerned about his/her own problems. For example, being silly at school, not doing homework, lying.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

15. Lacks energy and often appears fatigued. For example, when important activities occur, when requests are made.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

16. Does not appear interested or concerned about his/her family or friends. For example, illness of a family member, being rejected or ignored by a close friend, being included in social events.

0	1	2	3	4
Never or rarely occurs	1-3 times during the month	1-3 times a week	4-6 times a week	1 or more times a day

Gerring, J.P., Freund, L., Gerson, A.C., Joshi, P.T., Capozzoli, J., Frosch, E., Brady, K., Marin, R.S., & Denckla, M.B. (1996). Psychometric characteristics of the Children's Motivation Scale. *Psychiatry Research*, 63, 205-217.

Appendix 2.10 Research Proposal

Examining Clinical Homologues of "Hikikomori": Social Withdrawal in Young People in Scotland

Abstract

Background: Social withdrawal contributes to poor emotional, behavioural, social and occupational functioning. In Japan social withdrawal affecting adolescents and young adults has been conceptualised as a syndrome called *Hikikomori* (Saito, 2013). There is a growing body of research indicating that *Hikikomori* youth can be identified outside of Japan (Garcia-Campayo et al., 2007; Teo et al., 2015). At present no adequate measure exists that would allow to assess the presence and severity of social withdrawal amongst adolescents in Scotland. The Glasgow Hikikomori Scale (GHS) is a new measure developed with the aim of providing an English language rating scale for social withdrawal in young people.

Aims: This study aims to develop, refine, and conduct preliminary field tests of the GHS.

Methods: Participants between the age of 13 and 17 with varying levels of social withdrawal will be recruited from NHSGGC Child and Adolescent Mental Health Services (target sample n=40). The Glasgow Hikikomori Scale (GHS) and other measures will be completed to assess social withdrawal, apathy, functional impairment, mental health difficulties and coping mechanisms of the participants. A mixture of self-report and informant report scales will be used. The psychometric properties of the GHS will be explored (e.g. we will examine internal consistency and convergent validity).

Applications: The GHS has been developed with the aim of establishing a reliable English language measure of *Hikikomori*-type social withdrawal amongst children and adolescents. It will allow for the future research into the prevalence and correlates of social withdrawal.

Introduction

Social withdrawal presents across a variety of mental health conditions, such as psychosis, major depressive disorder, autism, anxiety disorders and personality disorders (Teo & Gaw, 2010; Teo et al., 2015). It can be associated with considerable psychological distress, social and occupational impairment and difficulties in behavioural and emotional functioning (Teo et al., 2015). In Japan, a particular form of social withdrawal affecting youth has been identified as a syndrome - *Hikikomori* (Saito, 2013).

Hikikomori is characterised by its two main features: social withdrawal and social isolation. Social withdrawal is defined as withdrawal from participation in social activities for a period of at least six months and social isolation is defined as ceasing of relationships outside of the family during the time of withdrawal (Krieg & Dickie, 2013). The psychosocial developmental model of *Hikikomori* proposed by Krieg and Dickie (2013) links the aetiology of the condition to factors such as ambivalent attachment, the experience of parental and peer rejection, bullying, and temperamental shyness.

Recent research emphasises the role of high neurobiological plasticity characteristic of early adolescence in the increase of vulnerability to engage in altered forms of social interaction, such as problematic internet use often observed in *Hikikomori* (Cerniglia et al., 2017). It has been highlighted that the problematic internet use may lead to the instability of relationships with peers, which further contributes to social isolation and withdrawal (Cerniglia et al., 2017; Stip et al., 2016). Problematic internet use appears to be associated with the development of the “geek culture” which is a growing subculture of people characterised by their enthusiasm for advanced technology, engineering and media (McCain et al., 2015).

Studies indicate that the lifetime prevalence of *Hikikomori* is as high as 1 – 2% in East Asian countries (Teo et al., 2015; Koyama et al., 2010). The recent Japanese Cabinet Office’s 2016 Survey of acute social withdrawal reported that amongst those affected by *Hikikomori,* 63.3% were men and 37.7% were women (Tajan et al. 2017). The largest number of people

suffering from *Hikikomori* were aged between 20—29 years. Cases of *Hikikomori* have been found in other countries including Spain (Garcia-Campayo et al., 2007), India, South Korea and the United States (Teo et al., 2015). The occurrence of the condition in these countries have been linked to urbanicity and the global socioeconomic and cultural changes (Kato et al., 2012). But, there is much to be learned about the risk factors, phenomenology, and treatment of this clinical phenotype.

Mental health professionals and researchers' views regarding the causes and diagnosis of *Hikikomori* vary significantly (Tajan, 2015; Tateno et al., 2012). Therefore, further research into its prevalence with a use of suitable measures is needed to understand the impact of this condition and to establish whether *Hikikomori* is a culture-bound syndrome or a cross-cultural concept (Kato et al., 2012).

Although there are several measures that assess constructs similar to social withdrawal, such as apathy and amotivation, none of them capture all aspects of this construct. This study aims to develop, test, and refine a scale that could be utilised to measure youth social withdrawal in clinical settings. It is hoped that GHS will characterise social withdrawal presentations more fully than existing measures but in a brief and easily usable format.

Aims

Despite the evidence that *Hikikomori* may be a phenomenon that is transferrable across cultures, to date there are no screening measures that assess the severity of its core feature - social withdrawal. This measure development study attempts to fill this gap in research by developing and field-testing a new measure for assessing social withdrawal, the Glasgow Hikikomori Scale (GHS).

The aims of this study are:

1) To conduct initial cycles of refinement and testing of the GHS to derive a scale that is ready to be tested on a clinical population.

2) To explore the utility of GHS in the assessment of social withdrawal in the clinical setting.

3) To conduct preliminary investigation of the psychometric properties of this new tool, such as convergent and discriminant validity and internal consistency.

Plan of investigation

1. **Participants**

Eligible clinical participants will be CAMHS patients aged between 13- and 17-years old presenting with a range of social withdrawal symptoms as judged by referring clinicians. The aim is to include young people with mild social withdrawal through to those with marked social withdrawal patterns that resemble the *Hikikomori* clinical homologue. Carers of patients presenting with social withdrawal and CAMHS clinicians involved in patients care will be also invited to take part in this study as informants, if participants provide consent. No personal information will be gathered regarding clinicians and family members apart from their consent to participate in the study. Informants will be asked to take part in the study to enhance the understanding of the participant's difficulties. Patients will be recruited in the Greater Glasgow and Clyde (GGC) area from Child and Adolescent Mental Health Services (CAMHS). The researcher will circulate an email inviting clinicians across GGC CAMHS to be involved in the study with the information sheet attached, which will outline the purpose, what is involved in the study and its inclusion and exclusion criteria. Study participants will be identified by the local CAMHS clinicians who are involved in their care based on the eligibility criteria. CAMHS clinicians who will identify potential participants will be later asked to be involved in the study as informants. The putative reasons for participants' social withdrawal (bereavement, neurodevelopmental disorder, severe mental health difficulties, early psychosis, misuse of substances) will be recorded.

2. **Inclusion and exclusion criteria**

The following inclusion criteria will be applied to the clinical participants:

- age: 13-17 years old,
- current difficulties with social withdrawal lasting at least two months,

- social withdrawal contributes to noticeable functional impairment in daily life and self-care, social interactions and occupational roles, e.g. non-attendance or erratic attendance at school, parental reports of impaired social functioning and/or a pattern of socially isolated behaviour,
- patients presenting with varying levels of severity of social withdrawal, from reported concern regarding social withdrawal to severe social withdrawal, including young people who are house bound or not able to come to the clinic due to the functional impairment.
- capacity to give informed consent.

The exclusion criteria will be as follows:

- social withdrawal due to a physical illness or injury,
- social withdrawal related to the head injury within the last 24 months,
- participants presenting significant risk,
- participants whose command of English requires interpreter to meaningfully participate in the study.

3. Recruitment procedures

Child and Adolescent Mental Health Services (CAMHS) clinicians within NHS Greater Glasgow and Clyde area will be contacted and provided with the information about the aims of this study described in the Professional Information Sheet. Potential participants will be identified by the clinicians involved in their care and therefore, already having access to their identifiable information in their records.

The staff members (e.g. consultant psychiatrists, named community nurse key workers) will be asked to identify participants that meet the inclusion criteria of the study. They will invite these potential participants and their carers to take part in the study by providing them with the Study Flyer, Participant Information Sheet and Family Member Information Sheet.

To ensure that the recruitment procedure is carried out on the purely opt-in basis, the potential participants interested in the study will be invited to contact the researcher via telephone number provided in the Study Flyer and the Participant Information Sheet, if they would like to gain more information about the study. If it is more suitable for the potential participants, their preferred family members can make an initial contact with the researcher on their behalf. This option will be presented to the potential participants in the Study Flyer.

During the telephone contact, the researcher will provide the potential participants with the necessary information to allow them to make an informed decision regarding their participation in the project, such as the aims of the study, what is involved in the participation, study's confidential nature and participants' right to withdraw from the study at any time. In addition, the researcher will ensure that participants meet the eligibility criteria for the participation in the study. After no less than one day, the researcher will re-contact the potential participants to confirm recruitment and (where relevant) to arrange a data collection appointment.

If the potential participants express their wish to take part in the study, an appointment with the researcher will be arranged to administer study measures. During this appointment informed consent to participation will be obtained in writing from each participant before administration of the questionnaires. Consent will include the potential participants agreeing to carers and CAMHS clinicians' involvement in the completion of the study measures. If the potential participant will provide their full consent, the family member and clinician will also be asked to provide their consent to participate in the study as informants in writing. Following this process, potential participants, their carers and clinicians will be asked to complete the project measures.

If the family member/carer refuses to take part in the study or if the young person will not give consent for the family member/carer to participate, but the clinician will agree to take part, the participant can still participate in the study, providing that there is no risk of harm.

The self-report questionnaires completed by the participants will allow to answer scientific questions posed by this study and therefore, the young person's participation will be valuable and ethically sound.

However, in the unlikely instance when both the family member/carer and the clinician refuse to participate or the young person will not consent to their participation, then the participant will be excluded from the participation in the study as it will affect the scientific value of the study. In this instance, patient's participation in the study would not be justifiable on the ethical grounds.

If the potential participants provide their consent, clinicians will complete observer rated measures at their NHS CAMHS bases. Patients and family members will also complete measures utilised in the study at their local CAMHS. To facilitate the involvement of the participants who are moderately to severely socially withdrawn, home visits may be required. In addition, data may be also collected in the home environment from the family members of these participants. NHS GGC has a Policy of Lone Working in operation, which states the conditions under which home visits can be carried out. Only participants whom are under care of the clinical staff from CAMHS and have a risk assessment carried out for them will be visited in their homes. The researcher will additionally follow University of Glasgow Lone Study Procedure which provides guidelines for students who carry out course activities by themselves for significant periods of time to ensure their health and safety.

4. Measures

Glasgow Hikikomori Scale (GHS, version 1 developed by Furuhashi & McLeod, 2017)

The GHS is an observer rated instrument developed to assess social withdrawal amongst young people. It currently includes three subscales: Daily Life & Self Care, Social Interaction and Occupational Role. Daily Life & Self Care subscale consists of 4 items, Social Interaction subscale – of 5 items and Occupational Role – of 6 items. These domains were

generated based on the expert clinical knowledge of *Hikikomori* presentations encountered in the clinical practice by the co-author of the GHS, Tadaaki Furuhashi (Furuhashi et al., 2013; Furuhashi & Vellut, 2015). Development of GHS reflects the aim of generating a scale that could be utilised in a clinical setting. Clinicians working in CAMHS across GGC were invited to take part in the feedback survey to obtain their views on the GHS and the wording of its items. The people involved in the development and refinement of the scale included practicing clinicians (e.g. CAMHS psychiatrists) and expert in *Hikikomori*, Professor Tadaaki Furuhashi from the University of Nagoya in Japan. On the basis of their feedback, GHS items were refined further before the measure will be tested in the clinical setting.

Children's Motivation Scale (CMS; Gerring et al., 1996)

CMS is a 16-item observer rated questionnaire which assesses the levels of motivation in children. Its items correspond to Apathy Evaluation Scale (Marin et al., 1991). It uses Likert scale with the responses varying from 0 = never occurs to 4 = 1 or more times a day. Its internal consistency calculated using Spearman-Brown coefficient is .79.

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)

SDQ is a 25-item observer and self-rated instrument used to assess the emotional well-being and social behaviours of children and adolescents 4-17 years old. It comprises of five subscales. Psychometric studies have reported satisfactory internal consistency (Cronbach's $\alpha = .73$).

Child Behavior Checklist for Ages 6-18 (CBCL/6-18; Achenbach & Rescorla, 2001)

CBCL is an observer rated (11-18 years old) and self-report scale (11-18 years old) designed for the assessment of emotional and behavioural problems. It is a 113 item scale with responses varying form 0 = not true to 2 = very true. It has good reliability (Cronbach's α ranging from .71 to .89) and satisfactory convergent and divergent validity.

Beck Youth Depression Inventory (BDI-Y; Beck et al., 2001)

BDI-Y is a self-report measure consisting of 20 items which measures negative thoughts, emotional and physical symptoms of depression in children and adolescents. The responses are coded on a 4-point scale (*never, sometimes, often* and *always*). It demonstrates high internal consistency with Cronbach's α above .90 and good convergent validity.

Adolescent Coping Orientation for Problem Experiences (ACOPE, Patterson & McCubbin, 1987)

ACOPE is a 54-items self-report scale assessing coping strategies used by adolescents. It utilises a 5-point scale ranging from 1 = never to 5 = most of the time. Research on its psychometric properties yielded partial evidence on the satisfactory reliability and concurrent validity.

Roberts Version of the UCLA Loneliness Scale (RULS-8, Roberts et al., 1993)

RULS-8 is an 8-items scale developed to measure the experience of loneliness amongst adolescents. It demonstrates good internal consistency (Cronbach's α of .78 and .79).

5. Design

A correlational design will be applied to examine associations between variables to determine validity and reliability of GHS. Specifically, the study will assess internal consistency, discriminant validity and convergent validity of GHS in relation to other measures.

6. Research procedures

Ethical approval will be sought from West of Scotland Research Ethics Committee and informed consent will be obtained from the participants prior to administration of the study measures. Next, the participants, their family members and clinicians will be asked to complete measures utilised in this study. Self-report measures will be administered to participants. Additionally, family members and CAMHS clinicians working with patients will

be also invited to take part in this study as informants and will complete observer rated measures, if participants provide consent. Informants will be asked to take part in the study to enhance the understanding of the participant's difficulties. The data will initially be screened and cleaned for errors and then entered into the IBM SPSS Statistics 24 software. Following this procedure, statistical analysis, such as correlational analysis, will be used to further explore relationships between variables.

Table 1 presents the administration procedure of each test in relation to participants' groups.

Table 1. Administration procedure of measures utilised in the study.

Measure	Completed by patient	Completed by carer	Completed by health professional	Approximate time of completion
Glasgow Hikikomori Scale (GHS)		X	X	10 minutes
Children's Motivation Scale (CMS; Gerring et al., 1996)		X		10 minutes
Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)	X	X		15-20 minutes
Child Behavior Checklist for Ages 6-18 (CBCL/6-18; Achenbach & Rescorla, 2001)		X		20-30 minutes
Beck Youth Depression Inventory (BDI-Y; Beck et al., 2001)	X			10 minutes
Adolescent Coping Orientation for Problem Experiences (ACOPE, Patterson & McCubbin, 1987)	X			20 minutes
Roberts Version of the UCLA Loneliness Scale (RULS-8, Roberts et al., 1993)	X			10 minutes

7. Data analysis

Data analysis will include using descriptive analysis of the data (e.g. measures of dispersion, central tendency, skew/kurtosis). Subsequently, the following psychometric properties of the GHS will be investigated:

- internal consistency – it will be established by calculating Cronbach's alpha;
- convergent and discriminant validity will be assessed by investigating associations between GHS and other measures used in this study; Pearson's or Spearman's correlation coefficient will be utilised for statistical analysis.

The data will be anonymised by assigning a study code to each participant. An ID log containing the list of patients' names and corresponding study codes will be created by the researcher and stored separately from the other data in a folder on the encrypted NHS computer. The anonymised data will be stored on the University of Glasgow encrypted and password protected computers. The data will be accessible by the researcher. Additionally, representatives of the study sponsor, NHS Greater Glasgow and Clyde, may access participants' personal data in the instance of conducting an audit of the data collection process. All data will be stored in accordance with the EU, UK, University of Glasgow and NHS policy for the duration of 10 years. After 10 years, the data will be destroyed.

8. Justification of sample size

This is the first study of the GHS and so the focus is on scale refinement and preliminary investigation of the psychometric properties of the scale. It is hoped that there will be approximately 40 participants recruited for the purpose of this study. This estimation is based on discussion with a field supervisor regarding the number of patients presenting with social withdrawal symptoms in CAMHS. Comparable sample size of 44 participants was used by Rigby et al. (1999) in their scale development study.

9. Settings and equipment

Clinicians will complete observer rated measures at their NHS CAMHS bases. Patients and family members will also complete measures utilised in the study at their local CAMHS. Home visits will be arranged to collect data from participants who are severely socially withdrawn. In addition, data may be also collected in the home environment from the family members of these participants. All measures will be completed using written format.

Health and safety issues

1. Researcher safety issues

Due to the nature of their presenting difficulties, patients recruited for this study are likely to be moderately to severely socially withdrawn and isolated. Therefore, to facilitate their involvement, home visits may be required. NHS GGC has a Policy of Lone Working, which states the conditions under which home visits are permitted.

Only participants whom are under care of the clinical staff from CAMHS and have a risk assessment carried out for them will be visited in their homes. The researcher visiting patients in their homes will be required to inform staff at the clinical base of the start of the home visit and the return to the clinical base afterwards. The researcher will discuss potential risk factors with a clinician who has seen the participant of the study recently prior to the home visit. The risk appraisal will take into account what is known about the participant, their living environment and consideration of the geographical area of the visit. This will include assessment of any risk related to travelling to and from the participant's home.

The researcher will additionally follow University of Glasgow Lone Study Procedure. In accordance with it, the researcher will consider the following risk factors when visiting patient in their home: known history of the person visited, family circumstances, living arrangements, travel to isolated areas, travel between appointments, communication availability and personal safety and security.

2. Participant safety issues

Study participants may experience distress because of the contact with clinicians. To minimise distress, risk assessment will be conducted by a clinical team member prior to the administration of the study measures. The participants presenting significant risk will not be included in the study. Participants and their family members will be aware of the nature of the project and potential risks related to their involvement prior to the start of data collection. Participants and carers will also be informed of their right to withdraw from the research project at any time.

The procedures used in the study are similar to those used by clinical psychologists with this group of participants. They are not typically associated with significant distress. However, taking part in the study may cause distress to participants and their family members due to the content of the measures. To minimise the risk related to procedures used in this study, participants and their family members will be informed of their right to withdraw from the research project at any time. The researcher will ensure that voluntary nature of participation will be emphasised. As participants are patients who were referred to CAMHS, they will have access to support of the clinicians working in CAMHS, if they become distressed. All participants and family members will be debriefed following their involvement to ensure that their wellbeing has not been compromised by the participation in the study and to allow them to address any questions and concerns related to the project.

The researcher will also ensure that information indicating risk to the patient, a family member or other member of public will be reported in line with the NHS risk management procedures. Furthermore, any risk identified during the administration of the questionnaires will follow the same reporting procedure.

Ethical issues

The participants of the study will be informed verbally and in writing about the aims of the study, its confidential nature and participants' right to withdraw from the study at any time.

Informed consent to participation will be obtained in writing from each participant. Consent process will include participant agreeing to the family member and CAMHS clinician to take part in the study as informants. As part of consent, informing participant's GP/clinician involved in their care will also be included.

Young person's capacity to give informed consent is one of the inclusion criteria of this study. If the potential participant will not be competent to give informed consent, they will not be included in this study. Therefore, capacity to give informed consent will be carefully assessed. In line with the Age of Legal Capacity (Scotland) Act 1991, young people over 16 years are presumed to be capable of giving consent on their own behalf. According to the Children (Scotland) Act, children who are age 12 and over are regarded as sufficiently mature to be able to form an opinion, although they are not viewed as fully competent to give informed consent (NHS Health Research Authority, n.d.). If the child or young person under the age of 16 will be assessed as able to form a view regarding the participation in the study, the researcher will consider their explicit wishes related to the participation in the study, including their refusal to take part, or their desire to withdraw from the study.

As a good practice, when discussing involvement in the study with potential participants under the age of 16, the presence and involvement of the person with parental responsibility will be encouraged. However, if a child will be assessed as having the capacity to consent, then they will be able to give or refuse consent.

With regards to young people over the age of 16, consent from a parent is not required. However, the researcher will encourage the involvement of parents in the decision-making process.

The collection of data will adhere to the Data Protection Act (2018) and the Information Governance Framework (2016). These policies outline the principles of maintaining the privacy and confidentiality of services users, limits of the confidentiality and appropriate data

collection, storage and communication procedures. To ensure that this research adheres to the policies and procedures of managing data securely and in confidence, participants' identifiable information will be anonymised by assigning a study code to each participant. Participants' consent forms will be stored in a locked filing cabinet within the NHS premises. An ID log containing the list of patients' names and corresponding study codes will be created by the researcher and stored separately from the other data in a folder on the encrypted NHS computer. The anonymised data will be stored on the University of Glasgow encrypted and password protected computers. The data will be accessible by the researcher. Additionally, representatives of the study sponsor, NHS Greater Glasgow and Clyde, may access participants' personal data in the instance of conducting an audit of the data collection process. All data will be stored in accordance with the EU, UK, University of Glasgow and NHS policy for the duration of 10 years. After 10 years, the data will be destroyed.

This project is funded by the NHS GGC. The researcher did not seek any external funding. Invitation to take part in the project will coincide with the patients' standard clinic appointment. Where home visits will be required, the researcher will travel to participants' homes.

Practical applications

Social withdrawal is linked with considerable psychological and socioeconomic costs in the areas of social and occupational functioning, psychological distress and behavioural and emotional functioning. Therefore, understanding this construct becomes increasingly important. Validation of the GHS will enable to enhance the understanding of social withdrawal as well as its links to other mental health conditions. This will not only allow to apply GHS to research on the prevalence of social withdrawal in Scotland, but also will contribute to the increase in awareness and understanding of this condition amongst mental health professionals.

Dissemination

The results of the study will be disseminated via scientific journals and conference presentations. They will be also published on the University of Glasgow library website. In addition, the results will be written-up as the University of Glasgow Doctorate in Clinical Psychology programme thesis. Participants will be given a choice, whether they would like to receive feedback regarding the results of the study. If they chose to be informed of the outcomes of this project, they will receive the Plain English Summary via mail.

Provisional Timetable

Table 1 presents a timetable for the major research project.

Table 1. Timetable for a research project

21st May 2018	Submission of final MRP Proposal
November 2018	Research Director approval
March 2019	Submission to Ethics Research Committee
March 2018 – August 2019	Data collection
June – July 2019	Write-up
July 2019	Submission of thesis
September 2019	Viva exam

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Appendix 2.11 Participant Information Sheet

University of Glasgow
Institute of Health & Wellbeing

NHS Greater Glasgow and Clyde

PARTICIPANT INFORMATION SHEET
Social Withdrawal in Young People in Scotland

What is the study about?
We would like to invite you to take part in the study of social withdrawal in young people in Scotland. Social withdrawal happens when a person starts to avoid their everyday activities. It may make people feel upset. Social withdrawal may also cause difficulties in various aspects of day to day live, such as social interactions and performance at school. In this study we are developing a new questionnaire that will help us to measure and better understand social withdrawal. This information sheet describes what is involved in the study to help you decide, if you would like to take part in it. Please read this information carefully and ask any further questions as needed.

Why have I been invited?
You have been invited to participate in this study because you are age 13 to 17 and you have been referred to Child and Adolescent Mental Health Service.

Do I have to take part?
No. You do not have to take part in this study, if you do not want to. If you decide not to take part, this will not affect your care. You will be given time to read this information sheet, discuss it with your family and consider your decision. You will also have the opportunity to ask any further questions that you have about the study to help you make this decision. If you agree to participate, you will be given a consent form to sign. You will have the right to leave the study at any time, even after signing the consent form and you will not have to give any reason for it.

What will happen if I agree to take part?
If you agree to take part, an appointment will be made with the researcher in your local clinic or at your home. At the beginning of this appointment you will be asked to sign the consent form, which confirms that you agree to take part in this study. You will then be asked to complete some questionnaires that measure various difficulties that people may experience, such as social withdrawal, loneliness, personal strengths and difficulties, and motivation. A member of your family will be asked to complete a few questionnaires too. For most people it does not take more than 60 minutes to complete these questionnaires. You can take breaks during this appointment as needed. The clinician who is the person that you usually see in your clinic will be asked to complete a questionnaire as well. You will have a choice, if you would like to receive the results of this study. If you chose to be informed of the results, we will send you the Summary by mail.

What are the possible risks and benefits of taking part?
It is unlikely that taking part in this study would make you feel upset. However, some people may become upset because of the questions included in the questionnaires. You do not have to answer any questions you do not want to, and you can stop the study at any point without giving a reason. If you become upset, the researcher will make arrangements for you to receive appropriate help for this.
If during the appointment you will express any thoughts or feelings that make the researcher concerned about your safety or the safety of somebody else, we may need to tell your doctor or the person that you usually see in the clinic about it. We will always try to inform you about this and explain the reasons why.
There are no personal benefits of taking part in the study, but you may be helping to increase the understanding of social withdrawal in young people. You may also help to develop a questionnaire that will allow clinicians to better recognise and help people who have difficulties with social withdrawal.

Will my taking part in the study be kept confidential?
Your personal information will be known to the researcher Kamila Dzik, Trainee Clinical Psychologist. In addition, representatives of the study sponsor, NHS Greater Glasgow and Clyde, may access your personal data to check if the study is being conducted correctly. Your GP and clinician will be also informed that you take part in the study. Your consent form and questionnaires that you complete will be stored separately in a locked filing cabinet on the NHS premises. Any electronic identifiable information will be stored on the password protected NHS computer. Once electronic information will be anonymised, it will be securely stored on the encrypted and password protected University of Glasgow computer. All data will be stored in accordance with the EU, UK, University of Glasgow and NHS policy for the duration of 10 years. After 10 years, the data will be destroyed. The results of this study will be written up and submitted to the University of Glasgow in the form of thesis. We hope that they will also be published in the relevant academic journals. They may also be presented at relevant conferences. Your personal information will not be used in any published results**.**

NHS Greater Glasgow and Clyde is the sponsor for this study based in Scotland. We will be using information from you and/or your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

NHS representatives may use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from NHS Greater Glasgow and Clyde and regulatory organisations may also look at your medical and research records to check the accuracy of the research study. The only people in NHS Greater Glasgow and Clyde who will have access to information that identifies you will be people who need to audit the data collection process.

You can find out more about how we use your information at http://www.nhsggc.org.uk/patients-and-visitors/faqs/data-protection-privacy and by contacting Data Protection Officer on 0141 2784774.

Who is organising and funding the research?
This study is being completed by Kamila Dzik as part of the Doctorate in Clinical Psychology programme. Her training costs are funded by NHS Education for Scotland.

What do I do now?
Please take time to consider the information provided in this sheet and discuss it with your family members and friends, if needed. You can contact the researcher on the email and telephone number below, if you have any further questions about this study. If you would like to take part in the study, please contact the researcher on the telephone number that you can find below to discuss the study. If you prefer, you can ask the family member of your choice to contact the researcher on your behalf.
You will be asked to sign a consent form before you complete the study questionnaires.

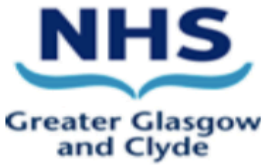
What if I want to make a complaint?
If you have any concerns regarding your participation in the study, please contact Professor Tom McMillan on the following number 0141 211 0354 or via email: thomas.mcmillan@glasgow.ac.uk. If you would like to make a complaint, please contact NHS Greater Glasgow and Clyde Complaints Department, West Glasgow Ambulatory Care Hospital, Dalnair Street, Glasgow, G3 8SJ on the telephone number 0141 201 4500 or via email: complaints@ggc.scot.nhs.uk.

What if I have any further questions about the study?
If you have any questions you would like to ask, please do not hesitate to get in contact.

Researcher:	Academic supervisor:
Kamila Dzik Institute of Health and Wellbeing University of Glasgow Gartnavel Royal Hospital 1055 Great Western Road Glasgow, G12 0XH E-mail: k.dzik.1@research.gla.ac.uk Telephone: 07933496451	Professor Hamish McLeod Institute of Health and Wellbeing University of Glasgow Gartnavel Royal Hospital 1055 Great Western Road Glasgow, G12 0XH E-mail: hamish.mcleod@glasgow.ac.uk Telephone: 0141 211 3922

Thank you for taking the time to read this information sheet and for any further involvement you may have with the study.

Appendix 2.12 Participant Consent Form



Doctorate in Clinical Psychology Research Project
Institute of Health and Wellbeing
University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Road, Glasgow
G12 0XH
T: 0141 211 3920

Participant Consent Form (Version 2, 14.03.2019)

Title of study: Social Withdrawal in Young People in Scotland

Name of Researcher: Kamila Dzik

Name of Participant:

Please read carefully and answer the following statements by initialling the appropriate box:

	YES	NO
I confirm that I have read and understand the Participant Information Sheet (Version 2, 14.03.2019) for the above study. I have had the opportunity to ask questions and have had these answered.	☐	☐
I understand that my participation is voluntary and that I can decide not to take part at any time without giving any reason, without my legal rights, or medical care being affected.	☐	☐

I agree that a family member of my choice will complete additional questionnaires to get a better understanding of my difficulties.	☐	☐
I agree that a clinician involved in my care will complete additional questionnaires to get a better understanding of my difficulties.	☐	☐
I agree to the research team writing to my GP/clinician who is involved in my care to inform them of my participation in the study.	☐	☐
I agree that representatives of the study sponsor, NHS Greater Glasgow and Clyde, may access my personal data to check if the study is being conducted correctly.	☐	☐
I agree to take part in the above study.	☐	☐

Name of Participant	Date	Signature
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Name of Person taking consent	Date	Signature
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Thank you for taking part in this study. Please note 1 copy of the form is for the participant and 1 for researcher.

Appendix 2.13 Study Flyer

Study title: Social Withdrawal in Young People in Scotland

University of Glasgow
Institute of Health & Wellbeing

NHS
Greater Glasgow and Clyde

Study Flyer

Social Withdrawal in Young People in Scotland

WHAT IS THE STUDY ABOUT

Social withdrawal affects many young people and can be associated with psychological distress and difficulties in various aspects of day to day live, such as social interactions and education. We are developing a questionnaire to measure social withdrawal in young people.

We want to invite people aged 13 to 17 who attend Child and Adolescent Mental Health Services (CAMHS) to take part in this study. Participation involves reading an information sheet, signing a consent form, and answering some questions about social withdrawal, loneliness, personal strengths and difficulties, and levels of motivation. We are asking for information from patients, a member of his/her family, and a clinician involved in their care (e.g. a nurse, doctor, or psychologist). The data is collected with a researcher at a CAMHS clinic or in the participant's home. The amount of time involved is about 60 minutes.

The development of the questionnaire will help to determine the impact of social withdrawal on young people in Scotland.

If you are willing to find out more about this study please contact the researcher, Kamila Dzik on the telephone number provided below. If it is more suitable for you, you can ask a family member of your choice to contact the researcher on your behalf.

Kamila Dzik
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Gartnavel Royal Hospital
1055 Great Western Road
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E-mail: k.dzik.1@research.gla.ac.uk
Telephone: 07933496451

Thank you for taking the time to read this information.