Thesis submitted in partial fulfilment of the degree of Doctor of Clinical Psychology (DClinPsych)



Fahreen Walji

Oxford Institute of Clinical Psychology Training and Research

Harris Manchester College

University of Oxford

August 2023

Word Counts

Systematic Review of the Literature	7019
Service Improvement Project	5008
Theoretically Driven Research Project	5295
Executive Summary	708
Reflective Connecting Narrative	559
Total	18,589

Contents

Word counts	2
Contents	3
Abstracts	6
Systematic Review of the Literature	9
Abstract and keywords	10
Introduction	11
Method	12
Results	15
Narrative synthesis	88
Discussion	103
References	107
Service Improvement Project	119
Abstract and keywords	120
Introduction	121
Methods	124
Results	127
Discussion	136
References	144
Theoretically Driven Research Project	148
Abstract and keywords	149
Introduction	150
Method and design	153
Results	158
Discussion	170

References 176

Executive Summary 181

Reflective Connecting Narrative 184

Acknowledgements 186

Appendices

Appendix A: SRL and TDRP Journal submission guide 187

Appendix B: SIP Journal submission guide 197

Appendix C: SRL Further explanation of the inclusion/exclusion criteria 205

Appendix D: SRL Search strategies 210

Appendix E: SRL Quality assessment tool 212

Appendix F: SRL Quality assessment scores 224

Appendix G: SRL Division of studies into sample-types 225

Appendix H: SIP Lay abstract 226

Appendix I: SIP NDC service ASD assessment process 227

Appendix J: SIP Initial approval correspondence 228

Appendix K: SIP Recruitment process 231

Appendix L: SIP Participant information sheet and consent form 234

Appendix M: SIP Interview schedule 237

Appendix N: SIP Introduction given to participants 239

Appendix O: SIP Assessment-related and demographic information 240

Appendix P: SIP Support services document 242

Appendix Q: SIP Interviewee information 243

Appendix R: SIP Reflexive statement 247

Appendix S: SIP Detail on service assessment data collected 249

Appendix T: SIP Further detail on recommendation 250

Appendix U: TDRP Initial study approval 251

Appendix V: TDRP Participant information sheet and consent form 252

Appendix W: TDRP Example of the recruitment materials 257

Appendix X: TDRP Allocation questions 258

Appendix Y: TDRP Questions relating to demographics and mental health 260

Appendix Z: TDRP Follow-up letter 261

Abstracts

Systematic Review of the Literature

The risks associated with living in hoarded spaces; a systematic review

Background and review question: This review addresses the question "What is the extent of the risks (for humans) associated with the physical conditions of the living spaces of adults with hoarding difficulties?" **Method:** Embase, PsycINFO, MEDLINE and Social Services Abstracts databases were searched for English-language articles dated from 2013 onward. The review criteria included that studies focus on adults, contain quantitative data and meet pre-defined requirements around hoarding and risk identification. For all included studies, citation-tracking was conducted, reference lists were reviewed, and authors were contacted for unpublished work. Pre-defined data were extracted, and papers quality assessed using an amended version of the Kmet et al. (2004) tool. A narrative synthesis of the findings was conducted. **Findings:** Nineteen studies (totalling 3,986 hoarders, including overlap across studies) were included. Quality assessment scores spanned 14 to 20, out of 28. Evidence of elevated risks relating to fire, squalor, falling, impaired utilities, landslip, and properties' structure/composition was found. Within this, some of the relative risks regarding hoarded environments were extremely high: data on fire-related deaths provide a key illustration of this. **Discussion:** Limitations of the available literature are identified. The findings' implications, and related recommendations for research and practice, are discussed. **Funding:** None. **Study registration number:** CRD42022293840 (PROSPERO).

Service Improvement Project

Improving the Autism Spectrum Disorder diagnostic process in the Oxford Health NHS Foundation Trust Child and Adolescent Mental Health Service Neurodevelopmental Conditions Service

Background: This study's overall aim was to investigate parent/carer experiences of the feedback session and assessment report forming part of the target service's Autism Spectrum Disorder (ASD) assessment process, consider how these reflect adherence to the National Institute for Health and Care Excellence (NICE) guidelines, and identify potential improvements. **Method:** A mixed-methods, cross-sectional design was used, consisting of: semi-structured interviews (analysed using thematic analysis) with parents/carers; and collecting service data (analysed using descriptive statistics) on referrals and assessments to provide context to the interviews. **Results:** Four themes were developed from the interview data (finally – a diagnosis; the varied influence of wider factors; variable gains made; competent and caring professionals), which indicated variation in experiences and variable accordance with the NICE guidelines. The service data revealed a high ASD diagnostic rate. **Discussion:** Key clinical implications of the results are: parent/carer needs appear to be variably met, the incremental validity of the diagnostic process is called into question; and the possibility of false negatives at triage and false positives at assessment is raised. Improvement recommendations (including future research), dissemination of the results and study limitations (including the potential impact of the Covid-19 pandemic) are discussed.

Theoretically Driven Research Project

Hoarding Disorder – investigating the development of beliefs about possessions

Background and aims: Hoarding Disorder (HD) presents in individuals with varied background experiences, suggesting there are multiple avenues to hoarding. One suggested pathway is that early material deprivation leads to hoarding primarily driven by a fear of further material deprivation: this study aimed to investigate this. **Method:** A cross-sectional design dividing participants into three groups was used: hoarders with early material deprivation experience (HWD); hoarders without early material deprivation experience (HND); and community controls (CC). All groups completed quantitative measures assessing descriptives, demographics, psychopathology, and three hoarding-related beliefs (fear of material deprivation, harm avoidance, attachment disturbance). **Results:** There was no significant difference between the HWD and HND groups in terms of fear of material deprivation beliefs, nor for the other two hoarding-related beliefs. All three beliefs were raised in the HND and HWD groups relative to the CC group. **Discussion:** Fear of material deprivation beliefs can motivate hoarding irrespective of any perceived experience of early material deprivation, and future research should investigate what might contribute to the development of these beliefs.

Systematic Review of the Literature

Trainee: Fahreen Walji

Contact details: fahreen.walji@hmc.ox.ac.uk

Title: The risks associated with living in hoarded spaces; a systematic review

Word count: 7019 words (excluding references and appendices, and allowing 100 words for each table and figure in the main text)

Date: 1st February 2023

Supervisor: Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk)

Proposed journal: The Journal of Obsessive-Compulsive and Related Disorders – this journal was chosen as it welcomes studies on hoarding, including systematic reviews

Abstract

Background and review question: This review addresses the question “What is the extent of the risks (for humans) associated with the physical conditions of the living spaces of adults with hoarding difficulties?” **Method:** Embase, PsycINFO, MEDLINE and Social Services Abstracts databases were searched for English-language articles dated from 2013 onward. The review criteria included that studies focus on adults, contain quantitative data and meet pre-defined requirements around hoarding and risk identification. For all included studies, citation-tracking was conducted, reference lists were reviewed, and authors were contacted for unpublished work. Pre-defined data were extracted, and papers quality assessed using an amended version of the Kmet et al. (2004) tool. A narrative synthesis of the findings was conducted. **Findings:** Nineteen studies (totalling 3,986 hoarders, including overlap across studies) were included. Quality assessment scores spanned 14 to 20, out of 28. Evidence of elevated risks relating to fire, squalor, falling, impaired utilities, landslip, and properties’ structure/composition was found. Within this, some of the relative risks regarding hoarded environments were extremely high: data on fire-related deaths provide a key illustration of this. **Discussion:** Limitations of the available literature are identified. The findings’ implications, and related recommendations for research and practice, are discussed. **Funding:** None. **Study registration number:** CRD42022293840 (PROSPERO).

Keywords: risks, hoarding, systematic review.

Introduction

Hoarding Disorder (HD)

HD is defined around a “difficulty discarding or parting with possessions… due to a perceived need to save the items and to distress associated with discarding them” that results – unless others have acted – in living spaces being unsuitable for their original functions (American Psychiatric Association (APA), 2013). It occurs in approximately 2.5% of individuals in developed countries (Postlethwaite et al., 2019); information on prevalence across developing countries is sparse (Jaisoorya et al., 2021). Hoarding symptoms can also present in other conditions. For instance, object accretion can result from conditions such as major depressive disorder (where accumulation might result from extreme tiredness), Obsessive-Compulsive disorder (OCD; where hoarding symptoms can result from obsessions or compulsions), or neurocognitive disorders (APA, 2013).

Rationale and review question

Almost by definition, hoarding is likely to result in increased risk by virtue of impairment of the living space. The risks can affect both the individual and those around them, including neighbours and service personnel. They include risks of items falling on individuals or damaging buildings’ structural integrity due to their weight (The British Psychological Society, 2015). Additionally, piles of flammable materials near ignition sources, combined with hoarded items impeding evacuation and blocking doors from closing, increases fire risks (Devon and Somerset Fire and Rescue Service (FRS), Undated). The risks can pose a threat to life, and require preventative and/or remedial action by services, such as fire departments (Devon and Somerset FRS, Undated). Further, clutter hindering access to fix facilities, for example those for heating, can add the presence of

impaired utilities (see Piacentino et al., 2019's discussion of Bratiotis et al., 2011a).

Although the risks are generally recognised by clinicians/agencies involved in hoarding support, and despite the limited mental health help available for targeting factors underpinning the hoarding itself (French et al., 2002), a better understanding of these risks should support targeted mitigation measures. Accordingly, this systematic review of the literature (SRL) sought to answer the question “What is the extent of the risks (for humans) associated with the physical conditions of the living spaces of adults with hoarding difficulties?” This SRL was guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA; Page, McKenzie, et al., 2021; Page, Moher, et al., 2021) and pre-registered in PROSPERO (registration number CRD42022293840). Note some information in this SRL is taken verbatim (this is not noted where it is done) from its PROSPERO registration (Walji et al., 2022).

Method

Inclusion and exclusion criteria

Study types

All types of English-language peer-reviewed quantitative studies (bar case studies/series) dated from 2013 onward were eligible for inclusion. Exclusion criteria were: qualitative studies; theoretical/review studies; publications such as editorials, comments, books, dissertations; and publications from conferences, symposiums, congresses.

Participants/population

Studies were required to report on adults (aged 18 years or over) who hoard (or hoarded, if deceased), where the hoarding did not exclusively involve

animals. A flexible approach to identifying hoarding was taken: meeting HD (APA, 2013) diagnostic criteria was not required, and identification of hoarding could be based on the individual's surroundings.

Main outcome(s)

The main outcome was the extent of the risks for humans associated with the physical conditions of the living spaces of adults with hoarding difficulties; a measure of this was required. Broadly, "risks" was defined to include hazards, safety risks and health risks.

Summary

The above criteria (detailed further in appendix C) were defined flexibly for pragmatic reasons: to not completely exclude studies reporting on agencies' work with hoarders (for which strict criteria for identifying hoarding and risk are typically neither practicable nor helpful), whilst ensuring the review was not so all-encompassing as to lose focus.

Procedure

Sources and searches

On 30th May 2022 the trainee (FW) ran searches in four databases: Embase, PsycINFO and MEDLINE (all using the Ovid platform); and Social Services Abstracts. See appendix D for the search strategies.

1. Selection process

Removing duplicates. FW saved search results onto Endnote (The EndNote Team, 2013) and removed duplicates first using the relevant Endnote function (though checking each duplicate identified), and then manually.

Abstract screening. FW saved the remaining results onto an Excel spreadsheet (Microsoft Corporation, 2018). FW and a second rater (EK) screened,

blindly to one another, the first 20% of results' (ordered alphabetically) titles and abstracts against the exclusion criteria. “Substantial” agreement was achieved (Landis & Koch, 1977), Cohen’s κ=0.77, p<.001. Differences were resolved through discussion. FW screened all remaining abstracts.

Full text screening. FW and EK screened, blindly to one another, the full texts of 25% of the remaining results (ordered alphabetically) against the inclusion/exclusion criteria. “Almost perfect” agreement was achieved (Landis & Koch, 1977), Cohen’s κ=0.90, p<.001. Differences were resolved through discussion. FW screened all remaining texts.

Reviewing reference lists, citation-tracking, contacting authors and addition of a further article. For all remaining texts, FW: reviewed their reference lists; conducted citation-tracking in Scopus (in July/August 2022); and contacted authors for any unpublished work (in August/September 2022). This process was repeated for any article then identified as meeting this SRL’s inclusion/exclusion criteria. At this stage an article in FW’s personal files meeting this SRL’s inclusion/exclusion criteria was included, as it had not been identified through the processes conducted so far.

2. Data extraction

FW and EK, blindly to one another, extracted data for 50% of articles (ordered alphabetically). Where available, data were extracted around: research aims; study design; data collection setting/dates; hoarder selection strategy or source of information/input variables; hoarder characteristics; information on others reporting on hoarders; methodology; interventional/random allocation; interventional and blinding of investigators/subjects; risk type(s); risk measure(s); hoarding group size; analytic methods and/or descriptive statistics regarding risk;

study results/conclusions regarding risk. The agreement rate was approximately 90%; differences were resolved through discussion. FW extracted the data for the remaining papers and identified overlapping data.

3. Risk of bias (quality) assessment

Papers' were quality assessed using Kmet et al. (2004)'s tool for quantitative studies, modified to place greater focus on hoarders and risk (appendix E). FW and EK quality assessed eight papers (approximately 45% of total papers) blindly to one another. For all but five items on the tool, there was at most one point of disagreement. FW and EK therefore quality assessed two further articles (approximately 10% of total papers) on these five items, achieving full agreement. FW completed all remaining quality assessment.

4. Synthesis

Due to papers' expected heterogeneity, a narrative synthesis of the results was planned and conducted (focusing on risk type, measurement and outcome data).

Results

Eighteen studies initially met this SRL's inclusion/exclusion criteria: see the PRISMA flowchart (Boers, 2018; Mayo-Wilson et al., 2018; Page, McKenzie, et al., 2021; Stovold et al., 2014) in figure one. A further article was identified through FW conducting updated searches on 2nd March 2023. Tables one to five summarise studies' characteristics.

Figure 1

PRISMA Flowchart

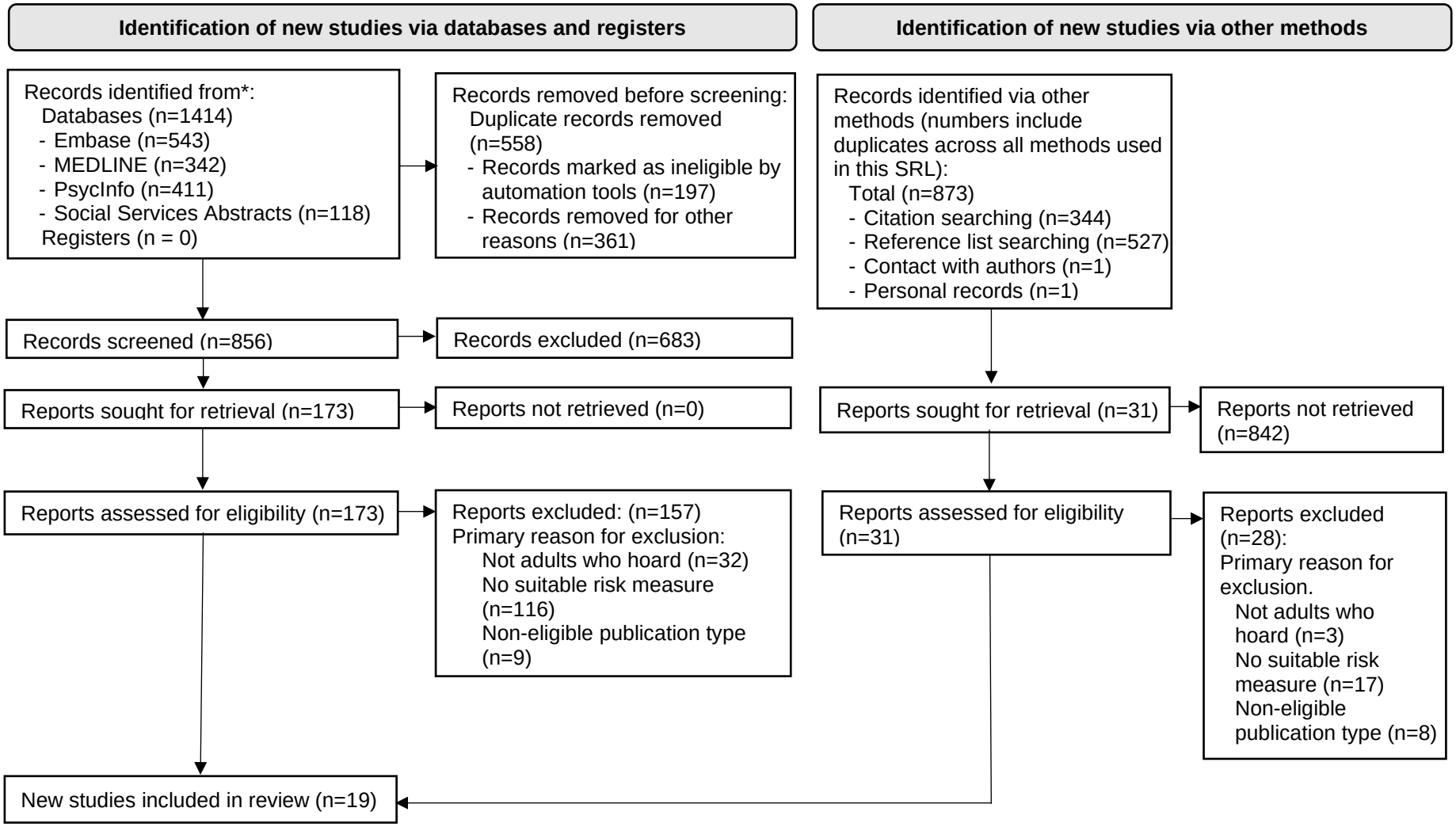


Table 1

Study design, research aims, data collection dates

Study	Study design	Research aims	Data collection dates
Ayers and Dozier (2015)	Cross-sectional	To identify "possible predictors… of hoarding symptom severity in older adults with HD."	Data collection: January 2010 to January 2014.
Bratiotis et al. (2013)	Cross-sectional	To "characterise the types of services used in two samples: a large Internet sample of self-identified people who hoard and a sample of diagnosed hoarding participants…"	Not reported (though the internet sample had previously approached the hoarding researchers from 2006 to 2007).
Da Cunha et al. (2021)	Cross-sectional	To "describe the characteristics of people with hoarding behavior in Curitiba, Brazil."	The study occurred between September 2013 and April 2015.
Darke and Duflou (2017)	Cross-sectional	To "determine the characteristics and circumstances of cases sudden or unnatural death... with evidence of pathological	The cases reviewed were amongst those received by the Department of Forensic Medicine (DOFM) from 1 January 2001 to September 2015

		hoarding, their major organ pathology and toxicology."	
Diefenbach et al. (2013)	Cross-sectional	To "determine the clinical characteristics of late-life HD".	Not reported.
Dimauro et al. (2013)	Cross-sectional	Two studies were conducted, only one is relevant to this SRL and is reported on here; its aim was "to compare hoarding severity and functional impact reported by HD participants versus their loved ones (friends, family members)."	Not reported (though recruitment included contacting individuals who had approached the researchers between January 2004 and January 2007).
Drury et al. (2014)	Cross-sectional	To "quantify and directly compare the level of functional impairment, health and well-being for individuals with HD compared to HD relatives and the nonclinical comparison group", and to investigate family accommodation.	Not reported.

Drury et al. (2015)	Cross-sectional	To investigate the "reliability of self- and informant-ratings of hoarding severity and insight, and whether individuals who self-identify with HD differ from those who do not".	See Drury et al. (2014).
Hall et al. (2013)	Cross-sectional	To "identify potential patterns of comorbidity and related clinical correlates of hoarding in a community sample."	Data collection: 15 September 2009 to 19 October 2009.
Luu et al. (2018)	Cross-sectional	To “identify correlates and unique predictors of squalor in the context of hoarded homes based on archival data”	Data collection: 2012 to 2014 for Metropolitan Boston Housing Partnership (MBHP); January 2011 to April 2014 for the Hoarding Action Response Team (HART); 2010 to 2014 for Gatekeepers.
McGuire et al. (2013)	Survey	To "[examine] the frequency, characteristics, and outcomes of cases involving hoarding	Not reported.

		encountered by code enforcement officials and social service staff."	
Nordsletten et al. (2018)	Cross-sectional	To "describe and directly compare the features of individuals meeting diagnostic criteria for HD across four cultural settings".	Recruitment/assessment: October 2010 to December 2011 for the London sample; March and June 2015 for the Rio de Janeiro sample.
Nordsletten, Fernández de la Cruz, et al. (2013)	Cross-sectional	To examine “the features that differentiate pathological hoarding from normative collecting”.	Recruitment: October 2010 to December 2011.
Nordsletten, Reichenberg, et al. (2013)	Cross-sectional	"To provide a prevalence estimate specific to DSM-5 hoarding disorder and to delineate the demographic, behavioural and health features that characterise individuals with the disorder."	Recruitment for the South East London Community Health (SELCoH) study (Hatch et al., 2011) was as follows: • recruitment for part 1 (SELCoH-I): 2008 to 2010. • recruitment for part 2 (SELCoH-II) began in September 2011.

Nutley et al. (2022)	Cross-sectional	“to explore global and hoarding-specific disability in a large sample of individuals with clinically relevant and subclinical hoarding symptoms…”.	The study reports data collected between January 2019 and August 2020.
Snowdon et al. (2013)	Cross-sectional	"to examine the utility of the [Environmental Cleanliness and Clutter Scale (Halliday & Snowdon, 2009)] in rating a cross-age series of cases of hoarding and/or squalor referred to a service developed specifically to organize and coordinate interventions to deal with these problems."	The cases were amongst those referred from August 2008 to November 2011.
Tesauro et al. (2021)	Cross-sectional	For survey one: "… to apply the … (ECCS) in order to assess domestic squalor in dwellings of hoarders, prevent sanitary risks, and intervene in solving the problem.”	The first survey occurred from May to September 2016. The second survey occurred from May to September 2019.

		For survey two: “to evaluate the reliability of the ECCS method between two raters with different amounts of experience”.	
Waters et al. (2022)	Cross-sectional	"To characterize deaths reported to occur in “hoarding conditions,” within a medicolegal context, in a large urban setting."	The cases were amongst those reviewed by the Cook County Medical Examiner's office (CCMEO) from 1 January 2017 to 31 December 2018.
Woody et al. (2020)	Cross-sectional	To “explore differences between research samples and hoarding that [occur] in the community at large.”	Information is only provided for one research sample (Tolin et al., 2012): this study occurred between 9 November 2006 and 13 August 2010. For the three community agencies, data collection was from: April 2010 to February 2014 (Gatekeepers/Hamilton); February 2011 to January 2015 (“Vancouver 1”- HART), and March 2015 to April 2017 (“Vancouver 2”- HART); and

June 2011 to June 2014 (MBHP/Boston).

Table 2

Selection criteria, methodology

Study	For hoarders / those reporting on them: sampling / recruitment criteria / referral criteria; geographical location	Criteria for hoarding	Methodology
Ayers and Dozier (2015)	Hoarders were recruited mainly from fliers in San Diego County (United States; US). Participants were taking part in one of two (unspecified, but it appears treatment-focused) hoarding studies.	Inclusion criteria: to meet the HD criteria under consideration for the Diagnostic and Statistical Manual of Mental Disorders DSM-5; American Psychiatric Association (2013), decided upon by a consensus diagnosis approach. Hoarding was assessed by: self-	One sample (of 71 hoarders) self-reported on measures including a questionnaire based on one by Diefenbach et al. (2013) covering topics including health and safety.

	report on the Clutter Image Rating (CIR; Frost et al., 2008) and Saving Inventory-Revised (SI-R; Frost et al., 2004); and being administered the UCLA Hoarding Severity Scale (UHSS; Saxena et al., 2007). Exclusion criteria: scoring under 23 on the Montreal Cognitive Assessment (MCA; Nasreddine et al., 2005); meeting Mini-International Neuropsychiatric Interview (MINI; Sheehan et al., 1998) criteria for bipolar disorder, schizophrenia, psychosis, suicidal ideation, or substance dependence.

Bratiotis et al. (2013)	Two hoarding samples were recruited. The “internet survey” sample was recruited from a database of individuals (their location is unspecified, but the researchers are based in the US) who had previously approached the researchers about hoarding after seeing them in the media. The “interview study” sample were recruited across the US through hoarding self-help/support groups, referrals from clinicians, and a university website. Recruitment for both samples also occurred through participants telling others of the	Inclusion criteria: scores of at least moderate on the “clutter”, “difficulty discarding” and “distress” or impairment” items on the Hoarding Rating Scale (HRS; Tolin et al., 2010) - competed by self-report in the “internet survey” sample, and administered by an “independent assessor” at interview with the “interview study” sample. The paper refers to the latter sample as “people diagnosed with hoarding”.	The ”interview survey” sample (426 participants) and the “interview study” sample (53 participants) completed measures (the former sample self-reported, the latter sample were administered them by an “independent assessor” at interview) including a Service Utilization Questionnaire relevant to this SRL.

	research. Both samples appeared to also be partaking in a wider study.		
Da Cunha et al. (2021)	Cases came from complaints about hoarding made by individuals living in Curitiba, Brazil to Curitiba City Hall (the latter can receive complaints “regarding any problem… including issues related to animals, public health, environment, and social vulnerability”).	Inclusion criteria: this took into account HD (APA, 2013) criteria but did not require diagnosis, and was the presence of any of these elements at a home visit: a) For "probable" object hoarding: "a large number of items that had been accumulated without an apparent purpose, the obstruction of living spaces in the household, and a reported reluctance to dispose of objects". b) For "probable" animal hoarding: "animal accumulation, a lack of	In 69 cases, an “official inspector” applied a “standardized questionnaire” measure developed from the HOMES Multidisciplinary Hoarding Risk Assessment (Bratiotis et al., 2011) which used “objective questions” to gather information about the hoarder, and “observational questions” in a home visit to assess the environment/home. Investigation also involved the input of a “hoarding [behaviour] workgroup” including “physicians, nurses, psychologists, veterinarians, biologists, and social

		health standards, space, nutrition, or veterinary care, and a refusal to surrender the animals".	services personnel" (aided by university researchers). 44 cases concerned object hoarding (14 of these also entailed animal hoarding): these are reported on in this SRL.
Darke and Duflou (2017)	Cases were those concerning hoarding assessed by the coroner at the DOFM (they review deaths that are "violent or unnatural" death, or where there is a "[sudden] and [unexpected] of unknown cause" Referrers are not specified.	Inclusion criteria: if the autopsy file recorded "compulsive hoarding" (where mentioned by the forensic pathologist and/or police/witness reports).	61 hoarding cases were identified: the researchers examined their case files (which could include information on autopsies, toxicology, "case histories" and "circumstances of death" – and as part of which a forensic pathologist tried to establish the reason for the death).
Diefenbach et al. (2013)	All participants were recruited through Frost, Steketee, et al. (2011)'s study. Recruitment was at	Inclusion criteria: to meet the HD criteria under consideration for the DSM-5 (APA, 2013), as assessed	210 hoarders (within whom 55 older hoarders were identified), and 39 older adults with no psychiatric

	university/hospital locations (in Boston, Massachusetts and Hartford, Connecticut) and it appears through health / mental health clinics, newspapers and other media, and websites.	by scores of at least moderate on the clutter, difficulty discarding and distress/impairment items on the HRS-Interview (Tolin et al., 2010), and for the clutter/discarding to not be due to another Obsessive-Compulsive (OCD) symptom. Exclusion criteria: “high risk of suicide or other risk factor requiring immediate attention”; “current psychotic symptoms”; “substance abuse or dependence in the last 3 months”.	diagnoses, completed measures (both through self-report and these being administered to them) including questions on health risks (relevant to this SRL) – it appears using an unnamed health measure. Home visits were conducted in about three quarters of cases.
Dimauro et al. (2013)	Study one recruitment: (the location is unspecified, though the researchers are based in the US)	Inclusion criteria: scores of at least moderate on the “clutter”, “difficulty discarding” and “distress” or	Study one: 22 pairs of hoarders and their friends/family completed (the former about themselves, the latter

	was through advertising in a newsletter and contacting individuals who had previously approached the researchers about hoarding.	impairment" items on the HRS self-report (Tolin, Frost, Steketee, Gray, et al., 2008).	about the former) measures including the 20-item Home Environment Index (HEI; Rasmussen et al., 2014). Family/friends only completed the Patient Rejection Scale (Kreisman et al., 1979) to measure their own frustration with the hoarder.
Drury et al. (2014)	Hoarders were largely recruited from support groups in London. Hoarders already known to the researchers were also approached.	Inclusion criteria: hoarders, and the individuals hoarder relatives were reporting on (see column to the right) were required to meet HD criteria (APA, 2013) using the Structured Interview for Hoarding Disorder (SIHD; Nordsletten, Fernandez de la Cruz, et al., 2013), with diagnosis decided	37 hoarders, 55 relatives of hoarders, 51 self-identified collectors, and 25 relatives of self-identified collectors completed measures including the HEI-revised (Rasmussen et al., 2014) – hoarders and collectors gave ratings for themselves, and the relatives for their family member.

		upon by “best estimate procedure” (Leckman et al., 1982) after all study measures were finished.	
Drury et al. (2015)	See Drury et al. (2014) above, which Drury et al. (2015) describe as “the initial study publication”.	See column to the left.	Participants were: 24 pairs of hoarders and their relatives (22 hoarders; 24 relatives), and 40 relatives of individuals not wanting to participate but probably meeting HD (APA, 2013) criteria. See Drury et al. (2014) above for study methodology.
Hall et al. (2013)	Participants were recruited (location not specified, though the authors are from the US) from a database of people who had approached the researchers about hoarding in the previous five years.	Inclusion criteria: to meet study criteria for “clinically significant hoarding”, designated as a score of at least moderate on “clutter”, “difficulty discarding”, and the “distress” or “impairment” items on	363 hoarders self-reported on measures including the 15-item HEI (Rasmussen et al., 2014). They were split into three groups as part of analysis: depressed; inattentive-depressed, and non-comorbid.

		the HRS-Self Report (Tolin, Frost, Steketee, Gray, et al., 2008).	
Luu et al. (2018)	“Archival” data from three community agencies assisting individuals who hoard were used: • MBHP (Boston, Massachusetts, the US): a housing advocacy body. Data are from their first "Hoarding Intervention and Tenancy Preservation Project". Referrals are from services, families, or the individual themselves. • HART (Vancouver, British Columbia, Canada): this seeks to create "domestic safety" for	Inclusion criteria: see column to the left, and note all agencies “accepted referrals for clients whose homes had an excessive accumulation of clutter that had developed over a period of time”, and that all homes had “hoarded conditions”.	Total sample size was 381: 137 (HART); 129 (Gatekeepers); 115 (MBHP). Each agency applied different measures to assess clients and their surroundings: • MBHP personnel (case managers) used HOMES (Bratiotis et al., 2011) and a “structured intake form”; • HART personnel (healthcare workers, a fire inspector, a property use inspector) used HOMES (Bratiotis et al., 2011); and

	individuals / their neighbours, and is focused on fire risks. Referrals are through “a central general hotline”. • Gatekeepers (Hamilton, Ontario, Canada): this helps older adults (including hoarders) at “risk of self-neglect”. It locates clients with the help of other community bodies.		• Gatekeepers personnel (case managers, support workers) used a “structured intake assessment”.
McGuire et al. (2013)	Social service staff and code enforcement officials from Florida (the US) were asked to take part in the study just before a hoarding training session. The 191 cases (see column to the right) were the result of complaints from the	Inclusion criteria: to meet the Frost and Hartl (1996) definition of “compulsive hoarding”, described by McGuire et al. (2013) as being: “1) the acquisition of a large number of possessions that appear to be useless or of limited	39 adult social service staff and 197 code enforcement officials completed a survey based on one by Frost et al. (2000) asking about hoarding cases in the last year. This included focused questions on their latest case: 191 respondents reported on this.

	following categories: “Neighbor or fellow tenant”, “Stranger”, “Fireman or policeman”, “Social service agency”, “Relative”, “Service person visiting home (e.g., nurse)”, “Friend or acquaintance”, “Anonymous or unknown”, “Family member or roommate”.	value; 2) the inability and/or subsequent failure to discard these acquired sessions; 3) living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and 4) significant distress or impairment in functioning caused by hoarding behaviors”.	
Nordsletten et al. (2018)	London (United Kingdom; UK) sample: all participants were partaking in the London field trial for HD (Mataix-Cols et al., 2012), which is described as having recruited hoarders through “community	Inclusion criteria: to meet DSM-5 HD (APA, 2013) criteria. London sample: a consensus diagnosis approach (Leckman et al., 1982) was taken. The SIHD (Nordsletten, Fernandez de la Cruz, et al., 2013) was	There were 82 hoarders across four geographical locations, but only the London (29 hoarders) and Rio de Janeiro (15 hoarders) samples are relevant to this SRL and so reported on here. Amongst other measures, both samples self-reported on the HEI

	advertisements" and hoarding support groups in London. The Rio de Janeiro (Brazil) sample were recruited from a university institute with a clinic for anxiety and related conditions, in Rio de Janeiro.	administered, aided by the CIR (Frost et al., 2008 through a home visit, photographs or self-report depending on what was possible). Rio de Janeiro sample: the SIHD (Nordsletten, Fernandez de la Cruz, et al., 2013) was administered, comorbidities assessed for, and clutter was assessed using photographs/self-report.	(Rasmussen, Steketee, Frost, Tolin, & Brown, 2014).
Nordsletten, Fernández de la Cruz, et al. (2013)	All participants were partaking in the London field trial for HD (Mataix-Cols et al., 2012), which recruited hoarders through advertising on the	HD diagnosis was decided upon by a consensus diagnosis approach using a "best estimate procedure" (Leckman et al., 1982) as follows. The MINI (Lecrubier et	29 hoarders and 20 self-identified collectors completed semi-structured interviews (one by telephone; the others in-person – at home in about half of cases), and self-report

	internet and a hoarding support group in London.	al., 1997; Sheehan et al., 1998) assessed for “major DSM-IV Axis I diagnoses”. The SIHD (Nordsletten, Fernandez de la Cruz, et al., 2013) was administered, aided by the CIR (Frost et al., 2008, mainly through researcher assessment at home visits, though otherwise photographs / self-report).	measures including the HEI (Rasmussen, Steketee, Frost, Tolin, & Brown, 2014).
Nordsletten, Reichenberg, et al. (2013)	All participants were “initially recruited… as part of… SELCoH-I” (Hatch et al., 2011). SELCoH-I recruited by randomly selecting homes (approaching residents in-person) in two London boroughs.	HD diagnosis was decided upon by a consensus diagnosis approach using a “best estimate procedure” (Leckman et al., 1982) as follows. Using in-person (typically at home) interviews,	19 individuals with HD (APA, 2013) and 80 “non-cases” (8 “subclinical” individuals, and 72 without HD) completed self-report measures including the HEI (Rasmussen et al., 2014). Measures completed in

	The current research (that by Nordsletten, Reichenberg, et al., 2013) used data from a “Hoarding Study” undertaken under the umbrella of SELCoH-II. SELCoH-I participants who answered a clutter screening question affirmatively during SELCoH-I were asked to partake in the “Hoarding Study”.	OCD was first screened for using part of the MINI (Lecrubier et al., 1997; Sheehan et al., 1998), and the SIHD (Nordsletten, Fernandez de la Cruz, et al., 2013) was administered**.** Diagnosis was aided by the CIR (Frost et al., 2008) and using other study information.	SELCoH-1 (Hatch et al., 2011) were also used, as was information informally gained from home visits in SELCoH-I.
Nutley et al. (2022)	All participants were part of the Brain Health Registry (BHR), “an online research registry” of participants (aged 18 years plus) from across the US States, through which individuals are asked to complete measures twice a year.	Participants were divided into three groups according to HRS (Tolin et al., 2010) self-report scores: at least 14 (“clinically relevant hoarding symptoms” (CHS)); between 10 and 13 (“subclinical hoarding symptoms”	Participants completed an online version of the self-reported HRS (Tolin et al., 2010), the 12-item World Health Organization Disability Assessment Scale 2.0 (Ustun et al., 2010), an amended version of the Activities of Daily Living in Hoarding

	Recruitment occurred through various means, including ones that were “owned (e.g., BHR website and press-releases), paid (e.g., online advertising, direct mail), and earned (e.g., word of mouth, publicity) media.” Recruitment did not target/seek hoarders specifically.	(SCHS); and 9 and under (no hoarding symptoms (NHS)).	Scale (ADL-H; Frost et al., 2013), questions on safety, and questions on psychiatric and medical issues including the PHQ-9 (Kroenke et al., 2001). Participants were divided into three groups according to HRS (Tolin et al., 2010) scores: CHS (923 participants); SCHS (937 participants); and NHS (14,452 participants). Note supplementary analyses are not considered in this SRL.
Snowdon et al. (2013)	Cases were referred to the Severe Domestic Squalor (SDS) Project, operated by an agency in Sydney, Australia, which helps individuals in	Inclusion criteria: factor analysis conducted as part of the study identified Factor 2 on the ECCS (Halliday & Snowdon, 2009) as the	The researchers reviewed 203 cases referred to the SDS Project, for which the ECCS (Halliday & Snowdon, 2009) was completed by the referrers (who

	“unacceptable living conditions” including those with hoarding difficulties and/or squalor. Referrers are varied individuals/bodies in Sydney (“government and community services”, clients and their families, and others).	“hoarding factor” (composed of two ECCS items, “accumulation of items of little obvious value” and “reduced accessibility”): scores of 5 or 6 on this were required for hoarding to be identified.	were “untrained” in this but many had attended ”education sessions” on it, and some received help from the SDS Project with completion), and cases with limited squalor/hoarding were excluded. This SRL extracts data on the 63 hoarding cases.
Tesauro et al. (2021)	Cases were amongst those referred to the Local Health Protection Agency (LHPA) in North Milan, Italy, which focuses on “the prevention and promotion of public health, promoting health education, veterinary public health, food, medical and veterinary safety, and controlling hygienic conditions in	On the ECCS (Halliday & Snowdon, 2009), hoarding severity is judged in terms of accessibility, and accumulation of objects, however the specific criteria used to identify a case as hoarding in Tesauro et al. (2021) is not provided.	The researchers conducted two “surveys” of hoarders’ homes that included the LHPA using the ECCS (Halliday & Snowdon, 2009). Twenty home visits were conducted for each survey (it appears these were all those conducted during each survey’s time-frame), though for survey two, five were not completed due to

	domestic and working environments". Cases are referred to it by "Private citizens, administrators of buildings, or community services personnel". The referrals relevant to this SRL were of hoarding/squalor, for the LHPA to address uncleanliness.		access difficulties. The first survey considered both object and animal hoarding. The second survey only considered object hoarding. Survey 1 used one assessor, survey 2 used two assessors.
Waters et al. (2022)	Cases were those reviewed by the Cook County Medical Examiner's office (CCMEO) in Chicago, Illinois, to which "violent or unnatural" and "unattended" deaths, or deaths that occur "suddenly and unexpectedly without a known cause" are referred (referrers are not specified).	Inclusion criteria: for "hoard" to be in cases' electronic records (one case found was excluded as it stated "not hoarded").	138 hoarding cases were identified: the researchers examined their case files ("all vital records, investigations records, autopsy reports (final, histology, toxicology, etc), medical records, police reports, fire reports, and photos", including the reason for the death if established by the forensic

			pathologist), and conducted “case mapping” (to assess socioeconomics). Note a “qualitative scene analysis” by the researchers is not reported on in this SRL as it did not meet this SRL’s inclusion/exclusion criteria.
Woody et al. (2020)	“Archival” data were used from three hoarding university research studies: Frost, Steketee, et al. (2011 - see Diefenbach et al, 2013, for details); Tolin et al. (2012 - for which recruitment entailed advertising in a hoarding clinic in Hartford, Connecticut); and Woody et al. (2019 - for which recruitment was in Vancouver through advertising in	For Frost see Diefenbach et al. (2013) above. For Tolin the inclusion criteria appear to be an HD diagnosis using the HRS-Interview and home visits/photographs if needed; the exclusion criteria were “current serious suicidal ideation or history of psychotic, neurological, or substance use disorders [and]	The final was composed of 824 hoarders: 337 from research samples (217 from Frost; 46 from Tolin; 74 from Woody), 487 from community agencies (132 from MBHP/Boston; 108 from Gatekeepers/Hamilton; 138 from “Vancouver 1”; 109 from “Vancouver 2”). In some samples, hoarding/clutter measures were used. “Functional

the community and contacting individuals who had previously partaken in hoarding research). These samples will be referred to in the remaining tables as “Frost”, “Tolin” and “Woody” respectively. “Archival” data were used from the three community agencies used in Luu et al. (2018), which Woody et al. (2020) refer to for further information. The samples were labelled as follows: “Hamilton” (one sample from Gatekeepers); “Vancouver 1” and “Vancouver 2” (two samples from HART); “Boston” (from MBHP’s “Hoarding ...factors that would contraindicate fMRI.” For Woody the inclusion criteria appear to be an HD diagnosis (using the MINI with a hoarding module added, home photographs, and assessment of insight); the exclusion criteria were “neurological conditions or current substance use disorders.”

For the community samples see the information for Luu et al. (2018).

impairment” was assessed differently across samples:

- The ADL-H was used by Frost, Steketee, et al. (2011 - the researcher completed the 29-item version), Tolin et al. (2012 - participants self-reported on the 29-item version) and Woody et al. (2019 - participants self-reported on the 15-item version).
- Community agency staff are described in Luu et al. (2018) above. Hamilton/Gatekeepers personnel completed an unnamed structured assessment tool; Boston/MBHP and Vancouver 1/HART personnel

	Intervention and Tenancy Preservation Project").			completed the HOMES Multidisciplinary Hoarding Risk Assessment (Bratiotis et al., 2011).

Table 3

Hoarder characteristics

Study	Hoarding severity (focusing on the SI-R (Frost et al., 2004), HRS (Tolin et al., 2010; Tolin, Frost, Steketee, Gray, et al., 2008) and CIR (Frost et al., 2008) where available). If animal hoarding is mentioned this is noted.	Age (years)	Race/ethnicity	Sex/gender
Ayers and Dozier (2015)	Mean, sd, minimum, and maximum: • SI-R (Frost et al., 2004) total: 58.9; 11.7; 35; 89.	67 (mean); 5.8 (SD); 60 to 86 (range).	85% White; "no significant other minority percentage".	69% female.

	• CIR (Frost et al., 2008): 4.1; 1.9; 1; 8.			
Bratiotis et al. (2013)	Mean, sd: • HRS (Tolin et al., 2010) total: 24.15. 4.94 (internet survey); 24.13, 6.84 (interview study). • SI-R (Frost et al., 2004) total: 57.42, 12.35 (internet survey); 54.98,15.17 (interview sample). • CIR (Frost et al., 2008) total: 3.69, 1.45 (internet survey); 3.42, 1.48 (interview study). The samples were not significantly different on the measures.	Internet survey: 53 (mean); 26 to 89 (range). Interview study: 55 (mean); 24 to 75 (range). Samples were not significantly different.	Internet survey: 94.9% White; 2.8% Indian; 2.6% Black; 1.9% Asian; 0.2% native Hawaiian; 2.1% other. Interview study: 84.9% White; 7.5% African American, 3.8% Hispanic, 3.8% other. Samples were	% female: 95.1 (internet survey); 88.7 (interview study). Samples were not significantly different.

			significantly different.	
Da Cunha et al. (2021)	Of the 69 cases: 30 (43.47%) concerned object hoarding only; 25 (36.23%) concerned animal hoarding only; 14 (20.28%) concerned both animal and object hoarding. So, 44 cases (63.76%) involved object hoarding.	For the 44 object hoarding cases: Mean, sd: 62.52, 10.61. n, % age category: 6, 13.63% (0 to 49); 12, 27.27% (50 to 59); 14, 31.81% (60 to 69); 12, 27.27% (70 or over).	Not reported.	For the 44 cases object hoarding cases: n, % gender: 24, 54.54% (female); 20, 45.45% (male).
Darke and Duflou (2017)	The authors note “In all cases there was evidence of extensive hoarding in the decedent’s residence, with hoarded objects restricting mobility throughout the residence, and hampering access by police and emergency personnel”.	Mean, sd, range at death: 65.8; 13.8; 36 to 88.	Not reported.	62.3% male (n=38).

Diefenbach et al. (2013)	Mean, sd of the 55 older adults: • HRS-I (Tolin et al., 2010): 25.49, 5.82. • SI-R (Frost et al., 2004): 60.74, 14.89.	For the 210 hoarders: 52.84 (mean); 9.99 (SD); 20 to 78 (range). For 55 older adult hoarders: 64.07 (mean); 4.06 (SD); 60 (minimum).	N, % for the 55 older adult hoarders: 2, 3.6% (non-White); 53, 96.4% (White).	Not reported.
Dimauro et al. (2013)	Mean, sd: • CIR (Frost et al., 2008): 3.52, 1.55 (self-report); 4.29, 2.02 (family/friend report). • SI-R (Frost et al., 2004) total: 52.86, 18.05 (self-report); 58.64, 2.66 (family/friend report).	Mean: 58.6.	100% White.	77.3% female.
Drury et al. (2014)	Mean, sd: • HRS (Tolin, Frost, Steketee, & Fitch, 2008): 25.92, 5.97 (self-	Mean: 54.08. Note it is not explicitly stated that	Not reported.	15.8% male

	report); 7.00, 6.72 (hoarder relatives informant-report). • CIR (Frost et al., 2008) self-report, per room: 4.54, 1.80 (bedroom); 3.51, 1.50 (kitchen); 4.49, 1.61 (living room).	participants are aged over 18 years.		
Drury et al. (2015)	Mean, sd: • HRS (Tolin, Frost, Steketee, & Fitch, 2008) total: 25.42, 5.83 (hoarder self-report); 25.50, 6.57 (hoarder (paired) relatives report); 30.03, 5.74 (hoarder unpaired relatives report). • CIR (Frost et al., 2008):	Mean, SD: 54.55, 12.07 (hoarder group); 67.98, no sd provided (hoarders the unpaired relatives reported on). This difference was significant. It is not explicitly stated that participants are aged over 18 years.	No reported.	% male: 13.6% or 16.7% (this appears unclear) – (hoarder group); 15% (hoarders the unpaired group reported on). The difference was non-significant.

	• Hoarder self-report: 4.04, 1.76 (bedroom); 3.08, 1.28 (kitchen); 4.04, 1.52 (living room). • (Paired) relatives report: 4.79, 2.41 (bedroom); 3.50, 2.00 (kitchen); 4.46, 1.69 (living room). • Unpaired relatives report: 7.03, 1.72 (bedroom); 5.48, 1.91 (kitchen); 6.03, 1.98 (living room).			
Hall et al. (2013)	SI-R (Frost et al., 2004): • clutter: 27.43 (depressed hoarders); 28.48 (inattentive-depressed hoarders); 25.46 (non-comorbid	Mean, sd, range: 52.8; 10.3; 26 to 80. The three hoarder groups did not differ significantly.	98% White.	95% female.

	hoarders – for whom the sd is also given as 5.5). • difficulty discarding: 20.24 (depressed hoarders); 20.67 (inattentive-depressed hoarders); 18.92 (non-comorbid hoarders – for whom the sd is also given as 4.1). • acquiring: 17.67 (depressed hoarders); 17.16 (inattentive-depressed hoarders); 14.27 (non-comorbid hoarders – for whom the sd is also given as 4.68).			
Luu et al. (2018)	The researchers conceptualised clutter differently across samples: • For Gatekeepers the assessor scored general “hoarding severity”	Mean, sd: 70.03, 8.93 (Gatekeepers); 64.67, 12.64 (HART); 56.62, 13.05 (MBHP).	Not reported.	% male: approximately 40% (MBHP and Gatekeeper); 53% (HART). There was a

from 1 (none/little) to 4 (severe) after completing certain HRS (Tolin et al., 2010) items (for which the sample mean and sd were 2.76 and 0.79 respectively). • For HART the “cannot sleep in bed” item of HOMES (Bratiotis et al., 2011) was used to indicate *high* clutter (found in 25 of 137 cases (18%)). • For MBHP the CIR (Frost et al., 2008) was used (for which the sample mean and sd were 4.16 and 1.63 respectively). Participants are said not to engage in animal hoarding.	There was a significant difference between HART and Gatekeepers/MBHP. There was a significant difference between Gatekeepers and MBHP.	significant difference between HART and MBHP/Gatekeepers.

McGuire et al. (2013)	n, % Level of clutter across the 191 cases: 1, <1% (not at all); 9, 4% (somewhat); 23, 12% (moderately); 156, 82% (extremely); 2, 1% (no information). Animal hoarding was reported in 129 of the 191 cases: 47% involved object hoarding only; 2% involved animal hoarding only; 51% involved object and animal hoarding occurring together).	%, n of the 191 cases: 7, 4% (younger than 30 years); 12, 6% (31 to 45 years); 66, 34% (45 to 60 years); 73, 38% (61 to 75 years); 22, 12% (75 years or older); 11, 6% (no information).	N, % race in the 191 cases: 165, 86% (White/Caucasian); 9, 5% (Black); 1, 0.5% (Asian); 1, 0.5% (Hispanic/Latino); 2, 1% (other); 13, 7% (no information).	N, % gender in the 191 cases: 96, 50% (female); 76, 40% (male); 19, 10% (no information).
Nordsletten et al. (2018)	Mean, sd: • HRS self-report (Tolin et al., 2010) total: 27.36, 7.05 (London); 25.13, 8.37 (Rio de Janeiro). This difference was non-significant.	Mean, sd: 56.62, 13.55 (London); 55.00, 11.06 (Rio de Janeiro). The two samples were not significantly different.	Not reported.	N, % female gender: 16, 55.17% (London); 6, 40% (Rio de Janeiro). The two samples were not significantly different.

	• SI-R (Frost et al., 2004) total: 58.85, 15.59 (London); 55.67, 16.51 (Rio de Janeiro). This difference was non-significant. • CIR (Frost et al., 2008) clinician-report: 5.31, 1.87 (London); 2.13, 1.23 (Rio de Janeiro). This difference was significant. • CIR (Frost et al., 2008) self-report total: 5.58, 1.82/1.83 (it is unclear; London); 3.11, 1.21/4.25 (it is unclear; Rio de Janeiro). This difference was significant.			
Nordsletten, Fernández	Mean, sd: • HRS-Self Reported (Tolin et al., 2010) total: 27.36, 7.95.	Mean, sd: 56.62, 13.55.	Not reported.	N, % male gender: 13, 44.8%

de la Cruz, et al. (2013)	• SI-R (Frost et al., 2004): 58.85, 15.60. • CIR (Frost et al., 2008) mean across 3 rooms: 5.58, 1.83.			
Nordsletten, Reichenberg, et al. (2013)	Mean, sd: • HRS-Self-report (Tolin et al., 2010): 17.89, 7.32 • CIR (Frost et al., 2008) mean across 3 rooms: 3.67, 1.71	Mean, sd: 48.8, 14.89. Note the minimum age for the SELCoH-I (Hatch et al., 2011) was 16 years, however in light of the above sample mean and sd, for this SRL it has been judged that participants are likely aged 18 years plus.	n, %: 15, 78.9% (white); 4, 21.1% (other)	n, % gender: 9, 4% (male); 10, 52.6% (female).

Nutley et al. (2022)	No specific HRS (Tolin et al., 2010) scores are provided for the CHS group.	The CHS group median age was 63 years, and the interquartile range was from 54 to 70 years.	CHS race (N, %): African-American (23, 2.5%); Asian (34, 3.7%); other / more than one race – “includes Native American, Pacific Islander, other, and individuals who identified with more than one race” – (58, 6.3%); White (808, 87.5%).	CHS group: 200 male (21.7%), 723 female (78.3%).

			CHS ethnicity (N, %): Hispanic/Latinx (25, 2.7%); Not Hispanic/Latinx (884, 95.8%), “Prefer Not to Say” (14, 1.5%).	
Snowdon et al. (2013)	63 cases met the study criteria for hoarding.	No information provided separately for the 63 hoarders.	No information provided separately for the 63 hoarders.	No information provided separately for the 63 hoarders.
Tesauro et al. (2021)	All cases across both surveys are stated as regarding “hoarders”, however severity ratings are not provided (a comment on this in the	Survey one: 64 (mean for males); 56 (mean for females); 34 to 80 (age	Not reported for either survey.	Survey one: 6 males; 14 females. Survey two: no information.

	paper appears to be a typographical error). Though scores on the ECCS items (Halliday & Snowdon, 2009) are given, as above it is unclear which items come together to identify/measure hoarding (but it is noteworthy that in both surveys "reduced accessibility" spans scores of 0 to 3, and "accumulation of items of little value" scores span 1 to 3). In 55% of survey one cases (n=11) there was at least one animal.	range). Survey two: no information.		
Waters et al. (2022)	138 deaths occurred in "hoarding environments". (Note that a subsequent qualitative scene analysis in the paper finds one of these to not	Mean, range at death for the 138 cases: 67; 35 to 94.	N, % of the 138 cases: 105, 76% (White); 30, 22% (Black); 2, 1.5%	N, % male of the 138 cases: 77, 56%.

	be a “true” hoard”, yet the authors do not remove it from this sample of 138 – and so it is included in this SRL).		(Asian); 1, <0.5% (Native American).	
Woody et al. (2020)	Mean, SD: • SI-R self-report (Frost et al., 2004): 61.7, 13.6 (Frost); 63.6, 12.6 (Tolin); 54.9, 13.4 (Woody). • CIR (Frost et al., 2008): 3.8, 1.6 (research samples); 5.3; 1.7 (community samples); 3.8, 1.6 (Frost – using self or experimenter report); 3.8, 1.7 (Tolin – self-report); 3.9, 1.4 (Woody – experimenter report); 4.4, 1.7 (Boston – it appears using assessor-report); 6.3, 1.2 (Vancouver 2 – assessor-	Mean, sd: 52, 10.6 (research samples overall); 64.4, 13.0 (community samples overall); 52.6, 10.3 (Frost); 50.5, 8.9 (Tolin); 51.2, 12.3 (Woody); 56.9, 12.8 (MBHP/Boston); 71.0, 8.5 (Gatekeepers/Hamilton); 63.9, 13.1 (HART/Vancouver 1); 67.7, 12	n, % non-white: 53, 17% (research samples overall); 53, 40% (community samples overall); 24, 12% (Frost); 4, 9% (Tolin); 25, 34% (Woody); 53, 40% (Boston). Community and research samples were not	n, % male gender: 78, 23% (research samples overall); 215, 45% (community samples overall); 50, 23% (Frost); 12, 26% (Tolin); 16, 22% (Woody); 53, 40% (MBHP/Boston); 44, 42% (Gatekeepers/Hamilton); 71, 54% (HART/Vancouver 1); 47, 44% (HART/Vancouver 2).

	report). There was a significant difference between community and research samples on clutter.	(HART/Vancouver 2). Community and research samples were significantly different.	significantly different.	Community and research samples were significantly different.

Table 4

Hoarder characteristics continued

Study	Employment	Socioeconomic data	Education	Marital/relationship status and/or living circumstances
Ayers and Dozier (2015)	Employment status: 58.73% retired; 20.63% employed full-time; 9.52% employed part-time; 4.76% unemployed;	Not reported.	High School graduate: 70 yes; 1 no. Education in years – mean, SD, range: 16; 2.16; 10 to 20.	Marital status: 21.54% married; 33.85% divorced; 4.62% separated; 6.15% living with partner; 29.23% single; 4.62% widow. Type of home: 66.15% single family; 32.31% apartment; 1.54% single room.

	4.76% disability; 1.59% other.			Living alone / with others: 61.82% living alone; 27.27% living with one other person; 0% living with five or more people.
Bratiotis et al. (2013)	Not reported.	Not reported.	Not reported.	Marital status: married/cohabiting (47.7% of the internet survey, 17% of the interview study); widowed/divorced (25.1% of the internet survey, 49% of the interview study); 26.5% of the internet survey were single / never married; and 34% of the interview study were single. The samples were significantly different.
Da Cunha et al. (2021)	Not reported.	Monthly income in relation to the	n, % education level (completed or not): for	n, % number of people living in the household for the 44 object

		minimum wage (MW) for the 44 object hoarding cases: 27, 61.36% (≤1 MW); 10, 22.72% (>1≤3 MW); 5; 11.36% (>3 MW); 2; 4.54% (no answer).	the 44 object cases: 5; 11.36% (illiterate); 17; 38.63% (elementary school); 10; 22.72% (middle school); 7, 15.90% (high school); 4; 9.09% (college); 1; 2.27% (no answer).	hoarding cases: 1, 2.27% (none); 16; 36.36% (hoarder only); 15, 34.09% (the hoarder and one other person); 3; 6.81% (the hoarder and two other people); 9; 20.45% (the hoarder and three other people).
Darke and Duflou (2017)	n, % employment status: 3, 4.9% (employed); 20, 32.8% (unemployed); 38, 62.3% (retired).	Not reported.	Not reported.	n, % marital status: 59, 96.7% (single); 2, 3.3% (married/cohabiting). N, % living circumstances: 58, 95.1% (lived alone); 3, 4.9% (lived with others).

Dimauro et al. (2013)	Not reported.	Not reported.	Not reported.	n, % in friends/family group: 10, 45.5% (spouses/partners); 7, 31.8% (adult children); 2, 9.1% (siblings); 2, 9.1% friends; 1, 4.5% (parent). 11 (50%) of the friends/family group lived with the hoarder: 8 (72.7%) were their “significant other”; 3 (27.3%) were the hoarder’s parent.
Diefenbach et al. (2013)	For older adult hoarders: 20, 38.5% (employed/student); unemployed: 32, 61.5%.	Income for older adult hoarders: 24, 61.5% ($10-39K); 9, 23.1% ($40-69K); 6, 15.4% ($70+ K).	For older adult hoarders: 35, 66.0% (college graduate); 18, 34.0% (non-college graduate).	For older adult hoarders: • n, % marital status: 41, 77.4% (not married); 12, 22.6% (married). • n, % type of home: 23, 44.2% (single family); 17, 32.7% (apartment); 12, 23.1% (other).

Drury et al. (2014)	Not reported.	Not reported.	Not reported.	60% of hoarders' relatives were the hoarders' children, and 21.8% of the hoarders' relatives were cohabiting with the hoarder.
Drury et al. (2015)	Not reported.	Not reported.	Not reported.	The type of relatives in each group were: • Paired relatives group: 58.3% (children); 25% (spouses), siblings (8.3%), 8.3% (friends). • Unpaired relatives group: 92.5% (children); 2.5% (one sibling); 2.5% (one friend); 2.5% (one niece).
Hall et al. (2013)	Not reported.	Not reported.	Not reported.	Not reported.

Luu et al. (2018)	Not reported.	Mean, SD monthly income ($): 1524; 1451 (MBHP); 1417, 625 (Gatekeepers). Both means were “substantially below the local median household income”	Not reported.	Living alone: approximately 75% of MHBP and Gatekeepers clients. n, % living in multifamily building: 81, 72% (MBHP); 77, 65% (HART); 77, 62% (Gatekeepers). n, % renting property: 95, 85% (MBHP); 77, 62% (Gatekeepers); 66, 51% (HART). MBHP was significantly different to both Gatekeepers and HART:
McGuire et al. (2013)	n, % employment status of the 191 cases: 31, 16% (employed); 45, 24% (unemployed); 60, 31% (retired); 27,	Not reported.	Not reported.	N, % marital status of the 191 cases: 60, 31% (single); 37, 19% (married / significant other); 26, 14% (divorced); 36, 19% (widowed); 32, 17% (unknown / no response / missing).

	14% (on disability); 1, 0.5% (student); 27, 14% (no information).			N, % type of residence of the 191 cases: 131, 69% (single-family home); 5, 2% (duplex); 14, 7% (apartment/condo); 34, 18% (mobile home); 5, 3% (other housing); 2, 1% (no response / missing)
Nordsletten et al. (2018)	Not reported.	Not reported.	Mean, SD education (years): 13.38, 2.73 (London); 14.00, 4.04 (Rio de Janeiro). The samples were not significantly different.	n, % married: 4, 13.79% (London); 7, 46.67% (Rio de Janeiro). n, % living alone: 21, 72.41% (London); 3, 20% (Rio de Janeiro). The samples were significantly different on both of the above.
Nordsletten, Fernández de la Cruz, et al. (2013)	Not reported.	Not reported.	Mean, SD education in years: 13.38, 2.73.	n, % living alone: 21, 72.4%. n, % married/partner: 4, 13.8%.

Nordsletten, Reichenberg, et al. (2013)	n, % employed/studying: 12, 63.2% (yes); 7, 36.8% (no).	n, % financial debt: 9, 47.4% (yes); 10, 52.6% (no). n, % receiving benefits: 9, 47.4% (yes); 10, 52.6% (no).	n, % educational attainment: 2, 10.5% (no qualification); 5, 26.3% (GCSE); 4, 21.1% (A-levels); 8, 42.1% (degree level – at least a university diploma). See also first column.	N, % marital status: 5, 26.3% (single); 6, 31.6% (married/cohabiting); 6, 31.6% (divorced); 2, 10.5% widowed.
Nutley et al. (2022)	Not reported.	Not reported.	Education (N, %) for CHS group (note further breakdown is not provided here): Graduate/professional degree (319, 34.6%); College degree (404,	Not reported.

			43.8%); less than college (200, 21.7%).	
Snowdon et al. (2013)	No information provided separately for the 63 hoarders.	No information provided separately for the 63 hoarders.	No information provided separately for the 63 hoarders.	No information provided separately for the 63 hoarders.
Tesauro et al. (2021)	Not reported for either survey.	Not reported for either survey.	Not reported for either survey.	For survey one: 60% (12) were single and 40% (8) lived with a "family member or cohabitant". Survey two: no information.
Waters et al. (2022)	n, % employment data (available for 59% (n=82) of the 138 cases): 7, 8.5% (educator); 10 (health care professions); other ("ranged from	The authors suggest data collected around employment, and "case mapping", indicate that hoarders came from	The authors suggest their employment data indicate that hoarders having differing educational experiences.	N, % marital status (available for 85% (117) of the 138 cases): 4, 3% (married); 36, 26% (divorced); 19, 14% (widowed); 58, 42% (never married); 21, 15% (unknown). n, % living situation: 119, 86%

	homemakers to laborers, to lawyers").	all socioeconomic levels.		(living alone); 19, 14% (living with others).
Woody et al. (2020)	n, % Not Employed: 140, 43% (research samples overall); 117, 89% (community samples overall); 102, 50% (Frost); 23, 43% (Tolin); 18, 24% (Woody); 119, 89% (Boston). Community and research samples were significantly different from each another.	N, % of sample with yearly income under $20K: 96, 33% (research samples overall); 144, 78% (community samples overall); 58, 33% (Frost); 10, 22% (Tolin); 28, 39% (Woody); 92, 76% (Boston); 52, 83% (Hamilton). Community and research samples	N, % No College: 36, 11% (research samples overall); 25, 27% (community samples overall); 23, 11% (Frost); 1, 2% (Tolin); 12, 16% (Woody); 25, 27% (Boston). Community and research samples were significantly different from each another.	N, % of sample with a partner: 157, 62% (Research Samples); 213, 92% (Community Samples); 126, 61% (Frost); 31, 67% (Tolin); 120, 94% (Boston); 93, 89% (Hamilton). Community and research samples were significantly different from each another.

		were significantly different from each another.

Table 5

Risk information

Study	Risk type(s) and measure(s)	Regarding risk: relevant analytic methods and/or descriptive statistics; relevant study results/conclusions
Ayers and Dozier (2015)	The self-report questionnaire based on one by Diefenbach et al. (2013) included asking "whether they or others think that clutter has caused any problems for their health and safety" (including regarding falling, fire hazard, mould,	**Analyses/descriptives:** descriptive statistics; group differences in SI-R (Frost et al., 2004), CIR (Frost et al., 2008), UHSS (Saxena et al., 2007) for categorical variables. **Results/conclusions:** • Health/safety issues they/others think clutter has caused problems for (% of participants): falling (63.24%); fire hazard (58.21%); mould (30.3%); insect infestation (25.37%); animal infestation (9.09%). All these risks, bar insect

insect infestation, animal infestation); “whether other people or agencies have tried to intervene because of home clutter” (including fire services); and “how concerned are they about falling and how much they avoid certain activities because they think they might fall”. It appears participants were also asked about the presence of certain items in their home.	and animal infestation, had a significant relationship with higher scores on the SI-R, CIR and UHSS – respectively, these relationships are as follows: • Falling: t=−2.56 (p<0.01); t=−3.11 (p<0.01); t=−2.22 (p<0.05). • Fire hazard: t =−2.12 (p<0.05); t= −2.18 (p<0.05); t = −0.95 ($p \geq 0.05$). • Mould: t=−1.98 (p<0.05); t=−2.05 (p<0.05); t=−1.76, p<0.05). • Insect infestation: t=−1.43 (p≥0.05); t=−0.88 (p≥0.05); t=−0.55 (p≥0.05). • Animal infestation: t=−0.17 (p≥0.05); t=−0.47 (p≥0.05); t=0.39, (p≥0.05). • Falls in the past three years: 69.35% had at least one fall; mean falls was 2.24 (SD=2.76); total falls in this time had a non-significant relationship to the SI-R, CIR, and UHSS (p-values>0.05). • % of participants avoiding activities due to concern about falling: “not at all” (40.62%); “quite a bit” (4.69%); “a little bit” (35.94%); “somewhat” (18.75%). Avoidance was insignificantly related to SI-R, CIR, and UHSS (p-values > 0.05). • % of participants concerned about falling: “not at all” (21.54%); “a little bit” (35.38%); “somewhat” (21.54%); “quite a bit” (21.54%). Concern regarding

		falling had a: significant relationship with number of falls in the previous three years (*r*= approximately 0.5 (it appears unclear if it was 0.50 or 0.53), *p*<0.0001); significant relationship with avoiding activities because of falling (*r*=0.55, *p*<0.0001); non-significant relationship with SI-R, CIR, or UHSS (*p*-values>0.05). • Fire service "intervention attempt": 4.48% of participants; non-significant relationship with SI-R, CIR, and UHSS (*p*-values>0.05). • Participants are also noted to have reported the presence of certain items in their homes including old paint (43.28%) and asbestos (5.97%).

Bratiotis et al. (2013)	The Service Utilization Questionnaire included questions on social service use including fire and sanitation services. The internet sample did this by self-report, and it	**Analyses/descriptives:** Summary descriptives and chi squared tests.
		Results/conclusions:
		• Social service use:
		  • n, % fire service: 11, 2.6% (internet sample); 3, 5.7% (interview sample). This difference was non-significant (χ^2: 0.68, *p*=.194).
		  • n, % sanitation: 5, 1.2% (internet sample); 1, 1.9% (interview sample). This difference was non-significant difference (χ^2: 0.19, *p*=.507).

	was administered to the interview sample.	
Da Cunha et al. (2021)	The questionnaire developed from the HOMES Multidisciplinary Hoarding Risk Assessment (Bratiotis et al., 2011) included inspectors observing if there was: "unpleasant odor, vector proliferation, the evidence of pest infestation (such as standing water, garbage accumulation or pest infestation itself, that is, rats, cockroaches, and mosquitoes), the possibility of fire risk (e.g.,	**Analyses/descriptives:** • "Data were initially grouped into object accumulation… and animal accumulation… Dichotomous variables were used to classify the data… All variables were evaluated using descriptive and univariate analyses with frequencies (simple and cross-tables), 95% confidence intervals (CI) for frequencies, odds ratio estimates and their corresponding 95% Cis, and Chi-square test…" • "Multiple correspondence analysis (MCA) was performed… (The main variable was the accumulation of animals and objects and the association with the following variables: Gender, categorized age, categorized income, categorized education, presence of health problems, family assistance, odor, risk of fire, risk of landslip, or risk of vector proliferation)"

no electricity was available, usage of candles, or the house electrical system was compromised), or the risk of landslip (e.g., when the accumulation of objects was so extreme that they could fall on the individual or the animals)." The authors note "an odor indicates unsanitary environmental conditions."	**Results/conclusions regarding the 44 cases involving object hoarding (n, %):** • Unpleasant odour: 23 yes (52%); 21 no; *p*=0.03; OR 0.14 [95% CI: 0.04-0.57]. • Vectors proliferation risk (it appears this includes pest infestation): 38 yes (88%), 5 no; *p*=.482; OR 0.55 [95% CI: 0.10-2.96]. • Fire risk: 20 yes (45%), 24 no; *p*=0.014; OR 4.37 [95% CI: 1.29-14.86]. ▪ Landslip risk: 9 yes (21%), 34 no; *p*=.015; OR 1.71 [95% CI: 1.38-2.12). ▪ The authors also write that "unpleasant perceptible odor… was higher in the case of… animal hoarding (*p*=0.001)" and "fire (p=0.018) and landslip (p=0.021) risks were significantly higher in object hoarding cases". ▪ MCA analysis revealed that object hoarding had a significant relationship with: fire risk; landslip risk; no unpleasant odour. **Some results regarding the cases involving animal hoarding (n, %) are presented here as they add context to the above data:** • Unpleasant odour: 37 yes; 7 no; *p*=0.01; OR 5.98 [95% CI: 2.01-17.79].

		• Vectors proliferation risk (it appears this includes pest infestation): 36 yes, 3 no; *p*=.449; OR 2.40 [95% CI: 0.52-10.97]. • Fire risk: 10 yes, 29 no; *p*=0.08; OR 0.39 [95% CI: 0.14-1.08]. ▪ Landslip risk: 3 yes, 36 no; *p*=.156; OR 0.33 [95% CI: 0.07-1.50). ▪ MCA analysis revealed that animal hoarding had a significant relationship with: unpleasant odour; no landslip risk.
Darke and Duflou (2017)	The measure consists of reviewing the case files as described previously.	**Analyses/descriptives:** Descriptive statistics. **Results/conclusions:** 2 (3.3%) “deaths directly related to hoarding” were identified (which are noted as being accidental): one death (1.6% of the sample) was due to “burns sustained during a house fire directly linked to the hoarding behaviour”; one death (1.6% of the sample) was due to “[sustaining] fatal injuries from falling hoarded objects”.
Diefenbach et al. (2013)	All participants completed an unnamed measure that asked “do you or other people think the clutter presents a problem	**Analyses/descriptives:** Descriptive statistics, Pearson correlation. **Results/conclusions:** • Prevalence of risks in the older adult hoarders: falling (59.6%); fire (53.8%); insect infestations (21.2%). These risks were prevalent in non-

	for your health or safety?" about "health risks" including falling, fire hazard and insect infestation.	hoarding individuals from between 0 to 2.6%. The former are stated as being "more likely to endorse health risks" than the latter. • Pearson correlation coefficients between age and risks in the sample of 210 hoarders showed the relationships were non-significant in all cases (*r* ranged from -0.04 to 0.11; *p*>0.05).
Dimauro et al. (2013)	The HEI (Rasmussen et al., 2014 - the authors say this is a 20-item measure), to assess squalor, was completed by the hoarder group and the family/friends group.	**Analyses/descriptives:** descriptive statistics; repeated-measures ANOVAs. **Results/conclusions:** • HEI (Rasmussen et al., 2014) scores (mean, sd): hoarders (26.21, 8.14); family friend (29.94, 10.38). • Repeated-measures ANOVA showed the comparison of the two HEI (Rasmussen et al., 2014) scores: without Patient Rejection Scale (PRS; Kreisman et al., 1979) as a covariate was significant (*F*=5.08, *p*<0.05); with PRS as a covariate was not significant (*F*= 2.84. *p*>0.05).
Drury et al. (2014)	All four groups provided self or informant-reports on the HEI (Rasmussen et al., 2014 - the	**Analyses/descriptives:** Student *t*-tests.

	authors refer to this as the revised version, suggesting it is the 15-item version), to assess squalor.	**Results/conclusions:** HEI (Rasmussen et al., 2014) scores (mean, sd, α): 13.46, 6.39, 0.88 (hoarder self-report); 4.92, 3.27, 0.72 (collector self-report). This difference was significant: t=7.45; p<.001; Cohen's d: 1.68. Means and standard deviations are not provided separately for the relatives groups' informant-reports.
Drury et al. (2015)	To assess squalor, the HEI (Rasmussen et al., 2014 - the authors refer to this as the revised version, suggesting it is the 15-item version) was self-reported on by the HD group, and the HD relatives group provided informant reports on it.	**Analyses/descriptives:** Student's t-tests. **Results/conclusions:** • HEI scores (mean, SD): 10.71, 6.01 (hoarder report); 13.71, 8.12 (hoarder (paired) relatives report); 23.30, 8.86 (unpaired hoarder relatives report). • The hoarder group and hoarder paired relatives group's HEI ratings were significantly different: (α (0.90); t=2.31; p=0.030; Cohen's d=.42). • Paired and unpaired hoarder relatives groups' HEI ratings were significantly different: (α (0.92); t=4.32; p<0.001; Cohen's d=1.13). • The difference in HEI scores of two subgroups in the paired relatives group (14 children of hoarders; 10 spouses/siblings/friends) was non-significant (p>0.1).

Hall et al. (2013)	Hoarders self-reported on the 15-item HEI (Rasmussen et al., 2014) as a means of assessing squalor.	**Analyses/descriptives:** Multinomial logistic regressions using the non-comorbid group as the reference group – the relevant model for this SRL is on “hoarding topography”. **Results/conclusions:** Mean HEI (Rasmussen et al., 2014) scores: 32.99 (depressed hoarders); 36.47 (inattentive-depressed hoarders); 31.59 (non-comorbid hoarders). The multinomial logistic regression found significantly more squalor in the inattentive-depressed hoarding group compared to the reference group (OR=1.07, *p*<.001, 95% CI [1.03, 1.11]), but not in the depressed hoarding group compared to the reference group (OR=1.02, *p*>.05, 95% CI [0.99, 1.05]).
Luu et al. (2018)	Data were extracted on squalor from the measures noted in table 2. The researchers conceptualised squalor differently across samples:	**Analyses/descriptives:** Descriptive statistics; regression, and follow-up within-site bivariate analyses. **Results/conclusions:** Incidence of squalor (%, n): Gatekeepers (72%, 75); HART (50%, 68); MBHP (35%, 39). Squalor was of a “significantly higher proportion” in Gatekeepers

- For MBHP this was rated “at face value” (no threshold stated);
- For Gatekeepers, this was where “unhygienic conditions” were rated as either a 2 (moderate) or 3 (severe), on a scale from 1 to 3.
- For HART this was the presence of one or more of: “spoiled food, feces/urine, insects/rodents, mold or chronic dampness, or garbage overflow”.

compared to HART, and significantly higher in MBHP than HART ($\chi^2 \geq 12.38$, $p \leq .02$).

Regression results:

- MBPH (this was a logistic regression analysis with the predictors being “CIR average score, poor access to kitchen or bathroom, number of pets, poor insight, social isolation, and HOMES mental state items”): χ^2 (8) = 43.48, $p < .001$, $R^2 = .50$
  - The only unique predictors of squalor were clutter volume (OR= 2.06, *p<.05,* [CI: 1.39, 3.02]), and “poor access to kitchen/bathroom” (OR=4.94, $p < 0.05$, [CI: 1.51, 16.21]).
- HART (this was a logistic regression analysis with the predictors being “being unable to sleep in the bed, poor access to kitchen or bathroom, number of pets, poor insight, and HOMES mental state items”): χ^2 (7) = 32.30, $p < .001$, $R^2 = .29$.

- The only unique predictors of squalor were poor access to a kitchen/bathroom (OR=4.78, p<.05. [CI: [2.11, 10.87]), and clutter (OR=5.91, p<.05, [CI: 1.78, 19.64]).

- Gatekeepers (this was a multiple regression analysis with the predictors being “hoarding severity, poor access to kitchen or bathroom, number of pets, poor insight, and social isolation”): $F(5, 79) = 5.54$, p<.001, adjusted R^2 =.21.
  - The only unique predictors of squalor were “poor access to kitchen/bathroom” (β=0.32. p<.05, [CI: 0.10, 0. 53]) and low insight (β= 0.25, p<.05; [CI: 0.06, 0.45]).
- Within-site analysis between age and squalor showed the relationships were not significant ($-0.18 \geq r \geq 0.10$).
- Follow-up within-site bivariate analyses regarding living alone established that this was not related to squalor, $\chi^2 \leq 2.69$, $p \geq .10$.

		Note “poor access to bathroom or kitchen” was conceptualised differently across sites.
McGuire et al. (2013)	The survey (based on one by Frost et al., 2000) completed by code enforcement officials and social services staff included asking the following about their most recent hoarding case: which “hazards and risks of hoarding” were present (see the column on the right); and if a fire service (amongst other services) was involved in “resolving the case”.	**Analyses/descriptives:** Descriptive statistics. **Results/conclusions:** • n, % hazards and risks of hoarding: 4, 2% (“No risk present”); and 140, 73% (“Fire risk”). • In 53 cases (28%), the fire department had a role in “case resolution”.

Nordsletten et al. (2018)	The 15-item HEI (Rasmussen et al., 2014), to assess squalor, was self-reported by on the London and Rio de Janeiro samples.	**Analyses/descriptives:** Non-parametric Kruskal-Wallis test, χ^2 adjusted for ties (significance was assessed using Fisher's Exact tests). **Results/conclusions:** Mean, SD of HEI (Rasmussen et al., 2014) scores: 13.61, 8.48 (London); Rio de Janeiro (11, 7.63). This difference was non-significant (χ^2=0.943, p>0.05).
Nordsletten, Fernández de la Cruz, et al. (2013)	The HEI (Rasmussen et al., 2014 - suggesting the 15-item version was used), to assess squalor was self-reported on by the hoarder and collector groups.	**Analyses/descriptives:** Descriptive statistics, Student's t-tests. **Results/conclusions:** Mean, SD on the HEI (Rasmussen et al., 2014): 13.61, 8.48 (hoarders); 5.53, 3.82 (collectors). The two groups' scores were significantly different from one another (t=−3.885, p=<.001)
Nordsletten, Reichenberg, et al. (2013)	The HEI (Rasmussen et al., 2014 - suggesting the 15-item version was used) was self-reported on by the HD group	**Analyses/descriptives:** Descriptive statistics, Wilcoxon rank sum tests. **Results/conclusions:** Mean, sd HEI score (Rasmussen et al., 2014): 9.47, 4.53 (hoarders); 7.03, 5.08 (non-cases). The groups' HEI scores were significantly different (z=-2.27; p=0.023).

	and “non-cases” group to assess squalor.	
Nutley et al. (2022)	An amended version of the ADL-H (Frost et al., 2013) was used. This covered “the presence and severity of hoarding-related safety concerns”, and points relevant to this SRL concerned: “Fire hazard in the home”; “EMS ability to move through home” – referring to “emergency medical personnel’s ability to move equipment through their home”; “Exits from home	**Analyses/descriptives for CHS, SCHS and NHS groups:** Pearson’s Chi-squared test comparing the CHS, SCHS and NHS groups, using dichotomised scores (scores 2 and below on the one hand, scores 3 and above on the other hand – indicating at least moderate difficulties.) on the ADL-H (Frost et al., 2013). **Results/conclusions:** • Fire hazard: CHS group (n=93, 10.1%); SCHS group (n=20, 2.1%); NHS group (n=32, 0.2%), χ^2= 973.8, p <0.001, Cramer’s V=0.24. • EMS moveability: CHS group (n=200, 21.7%); SHS group (n=57, 6.1%); NHS group (n=50, 0.4%), χ^2=2231.1, p <0.001, Cramer’s V=0.37 • Blocked exits: CSH group (n=59, 6.4%); SHS group (n=16, 1.7%); NHS group (n=20, 0.1%), χ^2=607.8, p <0.001, Cramer’s V=0.19

	blocked"; each rated from 1 to 5 (representing "no problem" to "severe problem" respectively), or N/A.	For each of the above three safety aspects, pairwise chi-square tests showed that: CHS scores were significantly different from SHS and NHS scores; and SHS scores were different from NHS scores. In all cases $p<0.01$. The authors state these findings "remained when examining variability between hoarding groups when ADL-H items were measured using a 5-point Likert scale; for all single-item measures, individuals with CHS endorsed the highest levels of impairment, followed by those with SCHS, and those with no HS (data not shown)".
Snowdon et al. (2013)	Factor analysis identified Factor 1 as the squalor factor, this was composed of eight ECCS (Halliday & Snowdon, 2009) items (E3 to E10, regarding: "accumulation of garbage or refuse", "floors and carpets", "walls and surfaces",	**Analyses/descriptives:** Descriptive statistics. Principal Component analysis. **Results/conclusions:** Of the 63 hoarding cases: 28 (44%) had high squalor; 35 (55.6%) had low squalor. Within the 28 former cases, there were 8 where the hoarding ECCS (Halliday & Snowdon, 2009) items (E1 and E2) were rated as 6, and the squalor rating was at least 20.

	“bathroom and toilet”; “kitchen”, “odor”; “vermin” and “sleeping area”). Low and high squalor were identified respectively by total scores of under 16, and 16 and over. Note each item is scored from 0 to 3 (a higher scores means worse conditions).	
Tesauro et al. (2021)	The total ECCS score (Halliday & Snowdon, 2009) was used to identify mild (a score of under 13), moderate (a score of between 13 and 17) and severe (a score of 18 to 30) squalor.	**Analyses/descriptives:** Descriptive statistics. For survey 1 only, two scores were produced – one including a “correction” for animal hoarding, and the other not. **Results/conclusions:** • For survey 1, squalor levels without the correction are reported both as consisting of six mild, seven moderate and seven severe cases, and as consisting of six mild, six moderate, and eight severe cases; it is unclear

		which of these results is correct. With the correction factor applied, the results were: six mild; four moderate; and ten severe cases of squalor. In each of these findings, however, 14 out of 20 cases showed moderate/severe squalor. • For survey 2, the authors report that in 14 of the 15 cases, the two assessors' overall categorisation regarding squalor was the same. However, the breakdown of the data provided appear to show that there was agreement in 13 cases, as follows: three mild, one moderate, and nine severe, cases of squalor.
Waters et al. (2022)	The measure consists of reviewing the case files as described above.	**Analyses/descriptives:** Descriptive statistics. **Results/conclusions:** Four of five cases in which the "hoarding environment" was a "contributory factor" in death met this SRL's criteria. These four cases (3% of 138) were fire-related (the fire service considered the hoarding and "increased amount(s) of combustible materials" as fostering the fire).
Woody et al. (2020)	The researchers used items from the "functional	**Analyses/descriptives:**

assessments” noted above to create classifications of impairment, whereby the presence of a single item in a classification would lead to impairment being recorded: a) structural: this regarded “structural damage” in Frost and Tolin; “roof, walls, unstable floorboards/stairs/porch” in Boston and Vancouver 1; “structural damage” in Hamilton. b) Utilities: this regarded “water, heat” in Frost, Steketee, et al. (2011) and	The authors used: 1) “Linear mixed-effect regression for continuous variables and logistic mixed-effect regression for binary categorical variables. Sample type (research vs. community) was modelled as a fixed effect, and the individual participant within sample as a nested random effect.” 2) “Hierarchical logistic mixed effect regression with demographic variables included in the first step, clutter volume in the second step, and sample type in the third step, with individual within sample as the random effect for each step.” Within both models, chi-square likelihood ratio tests were completed to assess parameters’ significance. **Results/conclusions** Results of the logistic mixed-effect regressions: • n, % structural: 19, 12% (Frost); 5, 13% (Tolin); 9, 8% (Boston); 30, 38% (Hamilton); 5, 4% (Vancouver 1). The difference between the research (n=24, 12%) and community samples (n=44, 13%) was non-significant: χ^2= 0.002, p=.97 OR = 1.03, [95% CI: 0.14, 8.41].

Tolin et al. (2012); “plumbing, heat/electricity in Boston and Vancouver 1; and “hot water, heat, electricity” in Hamilton. c) Squalor: “rotten food, insects, urine/feces” in Frost and Tolin; “Spoiled food, pests, urine/feces, mould, garbage overflow” in Boston and Vancouver 1; “Rotten food, pest infestation, urine/feces, mould” in Hamilton. d) Fire hazards (defined as “conditions that could start or accelerate a fire”): this regarded “fire hazards” in

- Utilities (n, %): Frost (n=5, 3%); Tolin (n=1; 3%); Boston (n=8, 7%); Hamilton (n=3, 3%); Vancouver (n=14, 10%). The difference between the research (n=6, 3%) and community samples (n=25, 7%) was non-significant: χ^2=3.2, p=.08, OR=2.44 [95% CI: 0.77, 7.85].
- n, % squalor: 29, 18% (Frost); 4, 10% (Tolin); 58, 50% (Boston); 61, 57% (Hamilton); 68, 49% (Vancouver 1). Community participants had significantly higher squalor levels than research participants (Comparison: Research (n=33, 16%) vs. Community (n=187, 52%) [χ^2=61.5, p=<.001, OR=5.50, [95% CI: 3.64, 8.80]]
- n, % fire hazards: 51, 32% (Frost); 7, 18% (Tolin); 52, 45% (Boston); 38, 44% (Hamilton); 67, 49% (Vancouver 1). Community participants had significantly more fire hazards than research participants (Research (n=58, 29%) vs. Community (n=157, 46%) [χ^2=16.1, p<.001, OR=2.14 [95% CI:1.48, 3.33]].
- n, % fire safety: 63, 39% (Frost); 14, 35% (Tolin); Woody (14, 19%); 71, 62% (Boston); 96, 90% (Hamilton); 80, 58% (Vancouver 1). Community

Frost, Tolin and Hamilton, and "Flammable items, blocked/unsafe heater, hazardous materials, exposed wire" in Boston and Vancouver 1. e) Fire Safety (defined as "threats to safe evacuation of occupants or first responders in the event of a fire"): this regarded "exit quickly, exits blocked" in Frost and Tolin; "exit quickly" in Woody; "exits/vents blocked" in Boston and Vancouver 1; and "exit home, exits blocked, smoke detectors" in Hamilton.

participants had significantly more fire safety issues than research participants (Comparison: Research (n=91, 33%) vs. Community (n=247, 69%) [χ^2=11.0, *p*=<.001, OR = 5.96, [95% CI:1.75, 21.74]].

Results of the hierarchical mixed-effect logistic regressions**:**

- No demographics significantly predicted squalor, fire hazards or fire safety.
- Clutter volume significantly predicted squalor [R^2=.25; $\chi^2(1)$=27.9; *p*<0.05; OR 1.79 [95% CI: 1.41, 2.31], fire hazards [R^2=.29; $\chi^2(1)$=38.5; *p*<0.05; OR 1.88 [95% CI: 1.51, 2.39] and fire safety [R^2=.50; $\chi^2(1)$=81.8; *p*<0.05; OR 2.91 [95% CI: 2.18, 4.04]. When CIR and demographics were controlled for, the difference between community and research samples became non-significant regarding fire hazards [R^2=.30; $\chi^2(1)$=0.3; *p* value not provided; OR 1.88 [95% CI: 1.51, 2.39] and fire safety [R^2=.51; $\chi^2(1)$=1.8; *p*>0.05; OR 1.73 [95% CI: 0.78, 3.95], but remained significant for squalor: R^2=.39; $\chi^2(1)$=6.6; *p*<0.05; OR 4.69 [95% CI: 2.00, 15.12].

Overlapping samples

Three instances of overlapping samples (table 6) are commented on as relevant within the narrative synthesis.

Table 6

Overlapping samples

Studies	Detail
Woody et al. (2020), Diefenbach et al. (2013)	One of Woody et al. (2020)'s research samples is that from Frost, Steketee, et al. (2011) – the former report on all 217 participants used in the latter paper. Diefenbach et al. (2013)'s state that "[all] participants were recruited as part of a larger study…"; they cite Frost, Steketee, et al. (2011) for this – it therefore appears that their sample of hoarders also derive from this study, but they only drew 210 participants from it.
Nordsletten et al. (2018), Nordsletten, Fernández de la Cruz, et al. (2013)	Nordsletten et al. (2018) and Nordsletten, Fernández de la Cruz, et al. (2013) appear to report on the same data from Mataix-Cols et al. (2013) – both state their samples participated in this study. This is further suggested by the data they report on for their (London) hoarding samples being very nearly the same (minor differences appear to be typographical errors / rounding differences).
Drury et al. (2015), Drury et al. (2014)	Drury et al. (2015) note that their sample is from Drury et al. (2014); there is therefore an overlap between these samples (it appears the former study uses 22 of the latter's 37 hoarders).

Narrative synthesis

This synthesis divides the risks identified from the data into several categories: fire, squalor, falling, impaired utilities, landslip, and properties' structure/composition. Key aspects of studies' results are discussed below, and both living and deceased samples are reported on.

Note quality assessment scores ranged from 14 to 20 (appendix F). Only Darke and Duflou (2017) and Waters et al. (2022) scored 14 and should be considered accordingly, though their scores likely reflect the difficulties of conducting hoarding research with deceased samples. Scores spanned 15 to 20 across other studies; due to this narrow range it was not considered useful to further unpick the data according to quality. However, of note is that insufficient description of the statistical analyses in Da Cunha et al. (2021) in particular mean their results should be given reduced weight.

To aid understanding of the data, within living samples (bar Nutley et al., 2022) a separation is made between *research* and *community* samples (see appendix G), adopting Luu et al. (2018) and Woody et al. (2020)'s differentiation between individuals putting themselves forward for participation in hoarding research, and those identified through their contact with community agencies. This division is based on these sample-types appearing to show broad differences (such as typically less pronounced hoarding-related difficulties in the former group), likely stemming from their distinct ways of identifying hoarders (Woody et al., 2020). Of note, however, is that even when considering these sample-types separately, studies differed broadly from one another (despite also having similarities), so limiting their comparability and generalisability. "General considerations" below outlines some key themes regarding these differences.

Nutley et al. (2022) was not included in the above division as it concerns a large sample of convenience not recruited specifically for hoarding research (it reports on individuals completing measures on an online research database, within whom it measures hoarding symptomology). Note however that the content of “general considerations” – bar that relating to recruitment strategies and to community data specifically – can also be read as including Nutley et al. (2022) within its scope.

Note two studies of deceased hoarders (Darke & Duflou, 2017; Waters et al., 2022) are considered sufficiently similar to be comparable (having similar approaches to hoarder and risk identification, for example).

General considerations

Recruitment/referral criteria and sampling

Research samples’ varied recruitment strategies entailed various sampling biases – including in Nordsletten, Reichenberg, et al. (2013), an epidemiological study – these relied considerably on hoarders recognising their difficulties, so perhaps skewing samples towards those with better insight (as discussed in reviewed articles such as Drury et al., 2015). Research samples’ differing inclusion/exclusion criteria (where reported) add further variability. Community agencies’ referral criteria varied widely according to their particular remits.

Geographical location

Studies spanned different regions (mainly Western countries), adding cultural variation (for instance see Da Cunha et al., 2021's discussion of this issue). Due to studies’ existing differences, however, results are further disaggregated by region only when considered particularly pertinent.

Hoarding criteria and demographics

Across research samples, hoarders were identified using varying clinical tools, adding further variation. Hoarders in community samples were largely identified by hoarded surroundings, except in McGuire et al. (2013), which applied Frost and Hartl (1996)'s hoarding definition. Studies differed regarding who reported on hoarding, raising similar issues to those discussed under "risk" below.

Community samples showed particular breadth (and some ambiguity) regarding the level of hoarding reported on. In some cases, the thresholds for hoarding appear unspecific or unclear (such as in Luu et al., 2018; McGuire et al., 2013; Tesauro et al., 2021). This likely reflects the complicated reality of community hoarding cases (discussed in reviewed papers such as Luu et al., 2018), added to by some community samples also hoarding animals (Da Cunha et al., 2021; McGuire et al., 2013; Tesauro et al., 2021 - see the data extraction tables for how these effect the results reported).

Studies also show variation in hoarder demographics (where reported), though some similarities (such as regarding race/ethnicity) indicate that on some variables a narrow range of hoarders are being reported on. This issue is discussed in several papers, such as Hall et al. (2013).

Risk

Variability regarding risk included: risk definition/conceptualisation (including if this captured the occurrence of, or a potential, risk); the measure and threshold used; and who reported. Such information is not always provided, adding further difficulty. These disparities raise multiple issues. For example, regarding who reports, self-report data can be subjective and impacted by insight, whilst reports from agency personnel, though more unbiased, can be impacted by job-role (as discussed in papers such as Dimauro et al., 2013; Woody et al.,

2020). Note the typically higher risk rates in community samples should be understood in their context; these regard hoarders whose situations have already been identified as problematic in some way (how exactly is typically not detailed within the discussion of each risk).

Risks identified

Fire

Fire risks/hazards/safety in living samples, bar Nutley et al. (2022). Some studies report on “fire risk”, “fire hazard” and “fire safety”. Aside from samples reported on in the same article (Woody et al., 2020), it is difficult to ascertain if these concern similar constructs across papers. Only two studies define terms. Woody et al. (2020) helpfully define two terms – “fire hazards” (“conditions that could start or accelerate a fire”) and “fire safety” issues (“threats to safe evacuation of occupants or first responders in the event of a fire”) – and they provide some criteria regarding each of these for their different samples. Da Cunha et al. (2021) refer to “fire risk”; however their discussions of this (referring for example to using candles, and to clutter “[obstructing] fire exits”) suggest it encompasses both constructs outlined by Woody et al. (2020) and perhaps more (it also includes “no electricity [being] available”). The absence of definitions in other studies exacerbates the difficulty of amalgamating results.

Despite this, the research provides *some* sense of this issue. Fire risks/hazards were identified for approximately 20% to 60% of hoarders from four research samples (Ayers & Dozier, 2015; Diefenbach et al., 2013; and two samples from Woody et al., 2020) and 45% to 75% of hoarders in five community samples (Da Cunha et al., 2021; McGuire et al., 2013; and three samples from Woody et al., 2020). Further, Woody et al. (2020) found fire safety issues overall in

33% of their three research samples and 69% of their three community samples. Compared to under 3% of Diefenbach et al. (2013)'s non-hoarding sample reporting a "fire hazard", this suggests fire-related risk issues are very elevated in hoarders.

Variation across studies in other areas discussed under "general considerations" above further reduces their comparability. This includes the use of different risk measurements (with little overlap between studies) and reporters. Across both sample-types, measures used span ones devised by the authors, unnamed tools, to more established measures or tools based on these, with limited explanation of the questions used. Further, research samples used a mixture of hoarders self-reporting and third-party reports, whilst community sample data – with the exception of Snowdon et al. (2013) possibly using some self-report data, though this appears unlikely – were provided by varying third parties (for example agency/service staff). Arguably illustrating how different approaches to assessing risk can yield different results is that despite the Frost, Steketee, et al. (2011) sample reported on by Woody et al. (2020) also largely being used by Diefenbach et al. (2013; see table 6), these two studies' findings differ greatly (they identify fire-related risks in 32% and 53.8% of their samples respectively).

Overall, the research paints a picture of highly elevated fire-related risks in hoarded environments. However, variation in studies' approaches to risk renders drawing further conclusions difficult. Uniformity of approach – including in risk definitions, measurement tools and reporters used – is required to gain further knowledge to support the provision of targeted support.

Other considerations. Demographics including age, gender, income, employment, education, and relationship status were not found to be significantly

related to risks around fire in research or community samples (Diefenbach et al., 2013; Woody et al., 2020). However, Diefenbach et al. (2013) comment that their study's findings more broadly – which include a nonsignificant relationship between age and fire hazards – may be due to their sample's particular composition (mobile older adults without cognitive difficulties).

The literature supports clutter being significantly related to increased risks around fire (Ayers & Dozier, 2015; Da Cunha et al., 2021; Woody et al., 2020). This includes Woody et al. (2020) finding that significant differences in fire hazards/safety between research and community samples lost significance once clutter (and demographics) were considered.

Together, these data highlight the need for research across broader populations of hoarders to understand some of the nuances (for instance regarding demographics) of fire-related risks. However, in some respects, there appears to be more clarity: as would be expected, increased clutter likely raises fire risks (Cheshire FRS, 2021).

Nutley et al. (2022). Nutley et al. (2022)'s findings are consistent with the above findings indicating that hoarding is associated with increased fire-related risks. Using the ADL-H (Frost et al., 2013), Nutley et al. (2022) found that the prevalence of risks in three groups of individuals with clinically relevant hoarding symptoms (CHS), subclinical hoarding symptoms (SCHS) and no hoarding symptoms (NHS) was, respectively: 10.1%, 2.1% and 0.2% (fire hazards present); 21.7%, 6.1% and 0.4% ("concerns regarding emergency medical personnel's ability to move equipment through their home"); and 6.4%, 1.7% and 0.1% (blocked exits). For each risk, the differences between the CHS group and the SCHS/NHS groups, and between the SCHS group and NHS group, were

significant – suggesting that as hoarding symptoms increased, so did risk (Nutley et al., 2022).

So, this not only further shows that fire-related risks can be very heightened in hoarding environments, but it also appears to indicate that these risks can rise with increasing hoarding symptoms (Nutley et al., 2022).

Deceased samples. The data also show that the relative risk of fire-related death in hoarders is extremely high. In Darke and Duflou (2017) one of 61 hoarders, and in Waters et al. (2022) four of 138 hoarders, were found to have died in hoarding-linked fires. Darke and Duflou (2017)'s sample was formed of deaths investigated by the Sydney Department of Forensic Medicine that took place in hoarding environments in New South Wales from around 2001 to 2015 (during which time this department conducted approximately 29,500 to 36,875 autopsies overall). Waters et al. (2022)'s sample was comprised of deaths in Cook County in 2017 and 2018 investigated by the Cook County Medical Examiner's office that took place in hoarding environments (this office reviewed 12,531 deaths overall in this period). Note the 138 hoarding deaths constituted 0.16% of total deaths in County Cook in this period (Waters et al., 2022). Compared to deaths from avoidable house fires in 0.29 out of 100,000 people in Australia over 14 years (from around 2003 to 2017; Coates et al., 2019), and 5,485 deaths from residential building fires in the US overall in 2017 and 2018 (US Fire Administration, Undated), death from fire in hoarders is extremely raised.

Fire service/department use in living samples. Fire service/department use involvement spanned: 2 to 6% in three research samples (Ayers & Dozier, 2015; Bratiotis et al., 2013), to nearly a quarter of a community sample (McGuire et al., 2013). However, studies use differing terms for service use ("utilization",

"intervention attempt", and involvement in "case resolution") and different data collection methods (Ayers & Dozier, 2015; Bratiotis et al., 2013; McGuire et al., 2013). Further, usage-type is not described – it is unclear if it even concerned fire-related issues. This renders it untenable to draw conclusions about risk presentation from these data other than to state that in some instances, it appears likely that risk-related issues gained service input. It is notable that Ayers and Dozier (2015) found fire service use to be unrelated to hoarding severity: this potentially suggests the relevance of this service to hoarders regardless of the extent of their difficulties. This highlights the need to consider risk across different presentations of hoarding severity.

Summary. Together, all the data indicate much higher fire-related risks in hoarders than non-hoarders, sometimes leading to death. As would be expected, clutter is associated with higher risk, however the relationship with demographics appears less straight-forward. Data on fire service use likely indicate that risk requires service input in some cases; future research would benefit in particular from identifying what service-input consists of. Overall, the data indicate that fire-related risks can pose a serious threat in hoarding environments: high quality data to increase understanding of this is therefore vital.

Squalor

Many studies measured squalor, or its components. Squalor concerns "filthy, unhygienic living conditions" that can vary in severity to the extent that they are "unhealthy, unsafe, and potentially harmful" (see Norberg & Snowdon, 2014; including their discussion of Snowdon et al., 2012). Again, variation across studies limits comparability but overall the data point to increased risk in hoarders' homes.

Squalor in research samples. Studies with research samples measuring squalor using the total HEI score (Rasmussen et al., 2014 - each item is scored from 0 to 3; higher scores mean worse squalor) all used the 15-item version bar Dimauro et al. (2013; they used the 20-item version). Two American studies found mean hoarder self-reported scores of 26 (Dimauro et al., 2013), and 32 to 37 (three samples in Hall et al., 2013). Mean self-report scores were 11 in a Rio de Janeiro sample, and about 9 to 14 in four London samples (Drury et al., 2014; Drury et al., 2015; Nordsletten et al., 2018 - who found no significant difference between their Rio de Janeiro and London samples; Nordsletten, Fernández de la Cruz, et al., 2013; Nordsletten, Reichenberg, et al., 2013). Studies comparing hoarder scores to collectors' and non-hoarders' scores found the former significantly higher (Drury et al., 2014; Nordsletten, Fernández de la Cruz, et al., 2013; Nordsletten, Reichenberg, et al., 2013).This all points to greater squalor in hoarders.

This picture is added to by Woody et al. (2020) finding squalor in 18% and 10% of two research samples, albeit using the ADL-H, by experimenter-report in one sample and self-report in the other – the issues around differing reporters have been noted above. This issue is well-illustrated by Dimauro et al. (2013) and Drury et al. (2015) reporting that family/friend informant-HEI (Rasmussen et al., 2014) scores were significantly higher than hoarders' self-reported scores, and Dimauro et al. (2013) finding that this significance ceased when family/friend frustrations were taken into consideration. This highlights the importance of considering who reports risk information (Dimauro et al., 2013).

The data also raise other points. Firstly, Drury et al. (2015) compared family/friend mean HEI (Rasmussen et al., 2014) scores of hoarders partaking in

their research to third-party ratings of hoarders not taking part, finding the latter significantly higher. In light of this and other aspects of their results, Drury et al. (2015) suggest research is not capturing the full spectrum of hoarders and their associated difficulties. Secondly, Hall et al. (2013) report significantly higher self-reported HEI (Rasmussen et al., 2014) scores in hoarders with both depression and inattention difficulties, than those with neither or just depression; as they note, this suggests squalor can be exacerbated in hoarders with other complexities. This emphasises the need to research how different factors can contribute to risk presentation.

Despite variation in studies' approaches, the data on squalor are – like those on fire – consistent in demonstrating significantly raised levels of squalor in research samples of hoarders. However, the variation in studies' approaches limits further understanding: again, this highlights the importance of studies taking a uniform approach to risk assessment (considering who reports as part of this), and researching a broader range of hoarders.

Squalor in community samples. Squalor appears elevated in community samples too. In Snowdon et al. (2013) and Tesauro et al. (2021), concerning Australian and Italian samples respectively, the ECCS (Halliday & Snowdon, 2009) helped identify medium and/or high squalor in about 45% to 75% of cases where concerns around cleanliness had already been raised. Further, Woody et al. (2020) and Luu et al. (2018) respectively report the following rates of squalor for data from three community agencies: 50% and 35% for MBHP; 57% and 72% for Gatekeepers; and 49% and 50% for HART.

It is noteworthy that despite Luu et al. (2018) and Woody et al. (2020) using similar measures and having overlapping data collection periods, their results are

only similar for HART. This could be due to differences between the samples assessed; if so, this would caution against relying on single studies to garner risk information in particular populations. This could also be due to differing risk conceptualisations across the two studies (these appear similar for HART only, not MBHP or Gatekeepers); if so, this would highlight further the need for uniform risk conceptualisation across studies.

So, the data on community samples also show a higher risk of squalor in hoarded homes. The data, again, present difficulties in generalisability, arising from differing approaches to assessing risk, stressing further the need for consistency in approach.

Comparison of research and community samples. Woody et al. (2020) found, across both sample-types, that no demographics (age, gender, relationship status, income, employment and education) significantly predicted squalor, but clutter did. Further, Woody et al. (2020) also found that squalor remained significantly higher overall in their community compared to their research samples, even after demographics and clutter were controlled for – they suggest that whilst this could be attributed to “methodological" differences, research and community samples likely capture different hoarding groups.

Luu et al. (2018) also found age not to be significantly related to squalor, and that pets, “social isolation”, and “mental state” did not predict squalor – but insight did, though for the Gatekeepers sample only. Luu et al. (2018) also found that clutter predicted squalor only in MBHP and HART (not Gatekeepers) – though limited access to the kitchen/bathroom predicted squalor in all samples. Luu et al. (2018) suggest clutter stops hoarders from reaching areas requiring cleaning and

that certain areas in the home are central to enabling hygiene, such that risk reduction should include a focus on addressing this.

Overall, this data suggest that hoarder characteristics are largely unpredictive of squalor, indicating that squalor can present across different populations of hoarders (possibly being more pronounced in community samples). However, the finding that insight was predictive of squalor in one community sample (Luu et al., 2018) cautions against drawing conclusions from this limited data. This adds further impetus to conducting research unpicking the presentation of squalor across differing hoarders, to support the provision of tailored support. Very practically, however, the data do support focusing intervention on removing obstacles to cleaning (Luu et al., 2018).

Components of squalor in research and community samples. Some studies measured specific components of squalor. About 30%, 25% and 9% of Ayers and Dozier (2015)'s hoarding research sample reported that they/others "think that clutter has caused any problems for" mould, insect infestation and animal infestation respectively. Approximately 21% of Diefenbach et al. (2013)'s hoarding research sample reported that they/others "think the clutter presents a problem for" insect infestation (under 3% of their non-hoarders reported this). In Da Cunha et al. (2021), inspectors found "unpleasant [odour]" and the risk of vector/pest "proliferation" (which appears to include this risk's manifestation and circumstances increasing its likelihood) in 52% and 88% respectively in this community sample's object hoarders. A US Census Bureau (2021) survey indicates that in 128,504 "occupied units", in the last year, about 12% had "signs of mice or rats inside [the] home", 11% "signs of cockroaches", and 3% mould. Whilst these categories do not fit exactly with those in the above three studies,

they nevertheless indicate that sub-types of squalor can be elevated in hoarding environments.

Of note is that Diefenbach et al. (2013) found that insect infestation had a non-significant relationship with age – as with fire risks they query if such results reflect their particular sample. Further, Ayers and Dozier (2015) found that insect and animal infestation were not significantly related to hoarding severity (including clutter) but mould was, adding to the need for research unpicking the relationship between squalor and different variables.

These investigations of sub-categories of squalor fit with the studies of overall squalor: they show that aspects of squalor can be a risk for hoarders of different presentations, and that the relationship of these with different factors requires investigation.

Summary. As with the fire data, studies' variability emphasises the need for homogeneity in approach across studies, and to consider a wider spectrum of hoarders. The importance of this is demonstrated by 21.2% of Diefenbach et al. (2013)'s sample reporting insect infestation, and Woody et al. (2020) finding squalor in 18% of its Frost, Steketee, et al. (2011) sample – similar rates despite the latter category being broader.

Again, despite studies' heterogeneity, there is clear evidence of raised risks of squalor (including its components) in hoarded homes, and there is evidence for focusing intervention on practical steps to enable cleaning (Luu et al., 2018). It is noteworthy that Bratiotis et al. (2013) report that under 2% of both their research samples used sanitation services; this appears low compared to squalor rates in some of the above research samples. This suggests hoarders may not be coming

to service attention or perhaps that their difficulties are not so severe as to require such input: further research is needed to explore this.

Falling

Approximately 60% of participants in Diefenbach et al. (2013) and in Ayers and Dozier (2015) stated they/others thought clutter “presents” or “has caused” (respectively) a problem around falling, and under 3% of the former study’s non-hoarders reported this. Ayers and Dozier (2015) found that this had a significant relationship with clutter, and that nearly three-quarters of hoarders had fallen a minimum of once in the last three years (average falls in that time was around two). Ayers and Dozier (2015) also found that hoarders worried about falling and eschewed activities due to this, suggesting they can be aware of risks but manage them through changing behaviour. Diefenbach et al. (2013) found age and falls not to be significantly related (as above, they query if their results reflect their particular sample).

Though the data are limited, it appears risks around falling can also be highly elevated in hoarders’ homes. Again, the questions raised by the data highlight the need for further research, including on how different variables might impact risk presentation.

Impaired utilities

The data on impaired utilities also indicate heightened risk in hoarding environments. Woody et al. (2020) found impaired utilities in 3% overall of two research samples and 7% overall of three community samples (sample-types were not significantly different), with individual sample rates spanning 3% to 10%. US Census Bureau (2021) survey data on the “housing adequacy” of 128,504 “occupied units” shows that around: 1.4% were “severely inadequate” regarding

plumbing, heating, electricity/wiring and/or “upkeep”; 3.8% were “moderately inadequate” regarding “upkeep” and/or “other”; and 95% were “adequate”.

Again, this adds to the potential risks in hoarders’ homes requiring targeted intervention. As noted previously, Da Cunha et al. (2021)’s “fire risk” definition included where “no electricity was available”, raising questions about the possible overlap of different risk constructs across studies and illustrating the importance of consistency across research.

Landslip

Da Cunha et al. (2021) found a risk of landslip in 20% of object hoarding cases, and that this was significantly related with object rather than animal hoarding. Further, Darke and Duflou (2017) identified that falling objects led to death for one of their 61 hoarders. Even without comparative data, this appears very elevated, indicating a higher possibility of injury, or even death, in hoarders’ living spaces.

Structure and composition of properties

Woody et al. (2020) found structural issues in 12% overall of two research samples, and 13% overall of three community samples (the latter’s individual rates spanned 4% to 38%), with no significant difference between sample-types. US Census Bureau (2021) survey data show a range of problems regarding properties’ exteriors each feature in about 1% to 6% of just under 90,000 single-unit “housing properties”. Although how many households have at least one of these issues is unknown, this benchmark data indicate that structural risks can also be higher in hoarding environments.

Further, approximately 6% and 43% of Ayers and Dozier (2015)’s hoarders stated that they had asbestos and old paint in their household, respectively. The

latter likely has lead in it (US Government Accountability Office, 2018). Approximately 35% of US homes have “lead-based paint” and about 22% have “one or more lead-based paint hazards” (US Department of Housing and Urban Development, 2011): both rates are lower than that in Ayers and Dozier (2015). Clear benchmark data on asbestos is lacking (though it is known that over half of American homes were constructed using asbestos; Mesothelioma Guide, 2022), rendering comparison with hoarders’ homes difficult. However, arguably, the presence of old paint and asbestos in hoarders’ homes is concerning: both become hazardous through damage (US Consumer Product Safety Commission, Undated; US Environmental Protection Agency, 2022), and the overall risk data in Ayers and Dozier (2015) cast doubt on whether hoarders’ homes would be sufficiently well-maintained to avert these risks.

These data add to the picture of risk in hoarded living conditions, with implications for hoarders and those around them: targeted intervention addressing these concerns too is therefore vital.

Discussion

This SRL aimed to answer the question “What is the extent of the risks (for humans) associated with the physical conditions of the living spaces of adults with hoarding difficulties?” Studies’ heterogeneity reduces their comparability and the ability to draw conclusions, and this is compounded by limited data. Nevertheless, there is evidence of elevated risks linked to hoarding in all areas identified: fire, squalor, falling, impaired utilities, landslip, and structure/composition of properties. Within this, though absolute risk of serious harm can be low, the relative risks can be very high: this is well illustrated by the findings on fire-related deaths, which are

very elevated in hoarders. Also of note is that some risks are additive and some may interact, so potentially augmenting possible dangers.

Key implications

Early effective hoarding treatment should be the “go to” strategy for all the issues described here, however this can be lacking (French et al., 2002). Nevertheless, all the identified risks are mutable, and so targetable by harm reduction strategies. However, high quality data on the risks presenting in varied populations of hoarders are needed to help develop tailored support for differing needs (see helpful discussions of support provision in papers such as Bratiotis et al., 2013). The data also raise questions about how much hoarders are coming to services’ attention.

Recommendations

The findings arguably point to the importance of certain approaches in research and practice, detailed below – note these are matters discussed in many of the reviewed papers, for example Bratiotis et al. (2013), Drury et al. (2015), Luu et al. (2018), Nordsletten et al. (2018), Tesauro et al. (2021) and Woody et al. (2020). Firstly, designating a uniform way of identifying hoarding could increase studies’ comparability. For research samples, this could include a clinician-administered HD (APA, 2013) diagnostic measure, and for community bodies a specific clutter measure. Ideally, both approaches would involve the researcher / agency worker conducting a home visit, or otherwise viewing photographs of the household. A uniform way of identifying risk would also be ideal, encompassing how risks are defined/conceptualised and measured (ideally research/community personnel would report, undertaking home visits or using photographs). These approaches could be used alongside others, to ensure they are not considered

restrictive. Standardised training on these measures and inter-reliability checks would help achieve uniformity. Foundational work such as validating measures across different settings might also be required. Collaboration between researchers and services to involve a broader range of hoarders in research on all risks identified in this SRL is also vital to expand knowledge. The importance of different agencies addressing risks in individual hoarding cases liaising to achieve harm reduction is also underlined by the findings.

Supplementing this SRL with information from sources that were beyond its parameters might also help develop a wider (albeit more nebulous) picture of the risks. This might include: non-peer-reviewed documentation (including reports by organisations/services working with hoarders); peer-reviewed research studies not meeting this SRL's inclusion/exclusion criteria including case studies (for example, Cappelletti et al., 2019; Neave et al., 2017; Porter & Hanson, 2022); or additional data from studies included in this SRL not meeting its inclusion requirements (such as for McGuire et al., 2013).

Limitations

Including only English-language results may have omitted relevant research, and may explain the identified papers' narrow geographical scope. Additionally, that one paper came from FW's personal files rather than the search strategies raises questions about the identifiability of the data: it may be that studies in which the risk data are more peripheral were not always captured by the search strategies. However, the strategies used likely captured all key data.

Conclusion

Various elevated risks for humans associated with the physical conditions of the living spaces of adults with hoarding difficulties have been identified. The

findings' implications, and this SRL's limitations, have been considered. Building on the results will help further identify and address risks, and recommendations have accordingly been identified.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (Fifth ed.). American Psychiatric Publishing.

Ayers, C. R., & Dozier, M. E. (2015). Predictors of hoarding severity in older adults with hoarding disorder. *International psychogeriatrics*, *27*(7), 1147-1156. https://doi.org/10.1017/S1041610214001677

Boers, M. (2018). Graphics and statistics for cardiology: designing effective tables for presentation and publication. *Heart*, *104*, 192-200. https://doi.org/10.1136/heartjnl-2017-311581

Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The Hoarding Handbook: A Guide for Human Service Professionals* (1st Edition ed.). Oxford University Press.

Bratiotis, C., Steketee, G., Davidow, J., Samuels, J., Tolin, D. F., & Frost, R. (2013). Use of services by people who hoard objects. *Best Practices in Mental Health: An International Journal*, *9*(2), 39-51.

Cappelletti, S., Cipolloni, L., Piacentino, D., & Aromatario, M. (2019). A lethal case of hoarding due to the combination of traumatic and confined space asphyxia. *Forensic Science, Medicine and Pathology volume*, *15*, 114–118. https://doi.org/10.1007/s12024-018-0056-x

Cheshire Fire & Rescue Service. (2021). *Hoarding - fire safety information*. Retrieved 26th March from https://www.cheshirefire.gov.uk/public-safety/campaigns/awareness-campaigns/hoarding-awareness-week/hoarding-awareness-week

Coates, L., Kaandorp, G., Harris, J., Van Leeuwen, J., Avci, A., Evans, J., George, S., Gissing, A., van den Honert, R., & Haynes, K. (2019). *Preventable*

residential fire fatalities in Australia July 2003 to June 2017. https://www.bnhcrc.com.au/publications/biblio/bnh-5807

Da Cunha, G., Marinelli Martins, C., Pellizzaro, M., Pettan-Brewer, C., & Biondo, A. (2021). Sociodemographic, income, and environmental characteristics of individuals displaying animal and object hoarding behavior in a major city in South Brazil: A cross-sectional study. *Veterinary World*, *14*. https://doi.org/10.14202/vetworld.2021.3111-3118

Darke, S., & Duflou, J. (2017). Characteristics, circumstances and pathology of sudden or unnatural deaths of cases with evidence of pathological hoarding. *Journal of forensic and legal medicine*, *45*, 36-40. https://doi.org/10.1016/j.jflm.2016.11.004

Devon and Somerset Fire and Rescue Service. (Undated). *Hoarding*. Devon and Somerset Fire and Rescue Service. Retrieved 6th March from https://www.dsfire.gov.uk/safety/home/hoarding#:~:text=If%20you%20know%20a%20friend%2C%20family%20member%2C%20or,get%20rid%20of%20items%2C%20professional%20help%20is%20available

Diefenbach, G. J., DiMauro, J., Frost, R., Steketee, G., & Tolin, D. F. (2013). Characteristics of hoarding in older adults. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, *21*(10), 1043-1047. https://doi.org/10.1016/j.jagp.2013.01.028

Dimauro, J., Tolin, D. F., Frost, R. O., & Steketee, G. (2013). Do People with Hoarding Disorder Under-Report Their Symptoms? *Journal of Obsessive-Compulsive and Related Disorders*, *2*(2), 130-136. https://doi.org/10.1016/j.jocrd.2013.01.002

Drury, H., Ajmi, S., Fernández de la Cruz, L., Nordsletten, A. E., & Mataix-Cols, D. (2014). Caregiver burden, family accommodation, health, and well-being in relatives of individuals with hoarding disorder. *Journal of Affective Disorders*, *159*, 7-14. https://doi.org/10.1016/j.jad.2014.01.023

Drury, H., Nordsletten, A., Sana, A., Fernández de la Cruz, L., & Mataix-Cols, D. (2015). Accuracy of self and informant reports of symptom severity and insight in Hoarding Disorder *Journal of Obsessive-Compulsive and Related Disorders*, *5*(1), 37-42. https://doi.org/10.1016/j.jocrd.2015.01.005

French, S., Lock, K., Zortea, T., Hassall, E., Bream, V., Webb, K., & Salkovskis, P. (2002). Working together when the problem is multi-faceted: Understanding inter-agency working for the benefit of people with hoarding problems. *The Cognitive Behaviour Therapist*, *15*. https://doi.org/10.1017/S1754470X22000575

Frost, R. O., & Hartl, T. L. (1996). A cognitive-behavioral model of compulsive hoarding. *Behaviour Research and Therapy*, *34*(4), 341-350. https://doi.org/10.1016/0005-7967(95)00071-2

Frost, R. O., Hristova, V., Steketee, G., & Tolin, D. F. (2013). Activities of Daily Living Scale in Hoarding Disorder. *Journal of Obsessive-Compulsive and Related Disorders*, *2*(2), 85-90. https://doi.org/10.1016/j.jocrd.2012.12.004

Frost, R. O., Patronek, G., & Rosenfield, E. (2011). Comparison of object and animal hoarding. *Depression and anxiety*, *28*, 885-891. https://doi.org/10.1002/da.20826

Frost, R. O., Steketee, G., & Grisham, J. (2004). Measurement of compulsive hoarding: saving inventory-revised. *Behaviour Research and Therapy*, *42*, 1163–1182. https://doi.org/10.1016/j.brat.2003.07.00

Frost, R. O., Steketee, G., & Tolin, D. F. (2011). Comorbidity in hoarding disorder. *Depression and anxiety*, *28*, 876–884. https://doi.org/10.1002/da.20861

Frost, R. O., Steketee, G., Tolin, D. F., & Renaud, S. (2008). Development and validation of the clutter image rating *Journal of Psychopathology and Behavioral Assessment*, *30*, 193–203. https://doi.org/10.1007/s10862-007-9068-7

Frost, R. O., Steketee, G., & Williams, L. (2000). Hoarding: a community health problem. *Health and social care in the community*, *8*(4), 229–234. https://doi.org/10.1046/j.1365-2524.2000.00245.x

Hall, B. J., Tolin, D. F., Frost, R. O., & Steketee, G. (2013). An exploration of comorbid symptoms and clinical correlates of clinically significant hoarding symptoms. *Depression and anxiety*, *30*(1), 67-76. https://doi.org/10.1002/da.22015

Halliday, G., & Snowdon, J. (2009). The Environmental Cleanliness and Clutter Scale. *International psychogeriatrics*, *21*, 1041–1050. https://doi.org/10.1017/S1041610209990135

Hatch, S. L., Frissa, S., Verdecchia, M., Stewart, R., Fear, N. T., Reichenberg, A., Morgan, C., Kankulu, B., Clark, J., Gazard, B., Medcalf, R., SELCoH study team, & Hotopf, M. (2011). Identifying socio-demographic and socioeconomic determinants of health inequalities in a diverse London community: the South East London Community Health (SELCoH) study. *BMC public health*, *11*. https://doi.org/10.1186/1471-2458-11-861

Jaisoorya, T. S., Thamby, A., Manoj, G., Kumar, S., Gokul, G. R., Narayanaswamy, J. C., Arumugham, S., S, Thennarassu, K., & Reddy, Y. C. J. (2021). Prevalence of hoarding disorder among primary care patients.

Brazilian Journal of Psychiatry, *43*(2), 168-173. https://doi.org/10.1590/1516-4446-2020-0846

Kmet, L. M., Cook, L. S., & Lee, R. C. (2004). Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields. *HTA Initiative*, *13*. https://doi.org/10.7939/R37M04F16

Kreisman, D. E., Simmens, S. J., & Joy, V. D. (1979). Rejecting the patient: Preliminary validation of a self-report scale. *Schizophrenia Bulletin*, *5*, 220–222.

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*, 606–613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x.

Landis, J. R., & Koch, G. G. (1977). The Measurement of Observer Agreement for Categorical Data. *International Biometric Society*, *33*(1), 159-174. https://doi.org/10.2307/2529310

Leckman, J. F., Sholomskas, D., Thompson, W. D., Belanger, A., & Weissman, M. M. (1982). Best estimate of lifetime psychiatric diagnosis: a methodological study. *Archives of General Psychiatry*, *39*(3), 879-883. https://doi.org/10.1001/archpsyc.1982.04290080001001

Lecrubier, Y., Sheehan, D. V., Weiller, E., Amorim, P., Bonora, I., Sheehan, K. H., Janavs, J., Dunbar, G. C., & Dunbar, G. C. (1997). The Mini International Neuropsychiatric Interview (MINI). A short diagnostic structured interview: Reliability and validity according to the CIDI. *European Psychiatry*, *12*(5), 224–231. https://doi.org/10.1016/S0924-9338(97)83296-8

Luu, M., Lauster, N., Bratiotis, C., Edsell-Vetter, J., & Woody, S. R. (2018). Squalor in community-referred hoarded homes. *Journal of Obsessive-*

Compulsive and Related Disorders, *19*, 66-71. https://doi.org/10.1016/j.jocrd.2018.08.005

Mataix-Cols, D., Billotti, D., Fernández de la Cruz, L., & Nordsletten, A. E. (2013). The London field trial for hoarding disorder. *Psychological medicine*, *43*, 837-847. https://doi.org/10.1017/S0033291712001560

Mayo-Wilson, E., Li, T., Fusco, N., & investigators, D. K. (2018). Practical guidance for using multiple data sources in systematic reviews and meta-analyses (with examples from the MUDS study). *Research Synthesis Methods*, *9*, 2-12. https://doi.org/10.1002/jrsm.1277

McGuire, J. F., Kaercher, L., Park, J. M., & Storch, E. A. (2013). Hoarding in the Community: A Code Enforcement and Social Service Perspective. *Journal of Social Service Research*, *39*(3), 335-344. https://doi.org/10.1080/01488376.2013.770813

Mesothelioma Guide. (2022). *Asbestos in Homes: Number of Homes, How Exposure Happens*. Mesothelioma Guide. Retrieved 21st January from https://www.mesotheliomaguide.com/community/asbestos-in-homes-how-many-homes-still-contain-asbestos/

Microsoft Corporation. (2018). *Microsoft Excel*. In https://office.microsoft.com/excel

Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J. L., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A Brief Screening Tool For Mild Cognitive Impairment. *Journal of the American Geriatrics Society*, *53*, 695-699. https://doi.org/10.1111/j.1532-5415.2005.53221.x

Neave, N., Caiazza, R., Hamilton, C., McInnes, L., Saxton, T. K., Deary, V., & Wood, M. (2017). The economic costs of hoarding behaviours in local

authority/housing association tenants and private home owners in the north-east of England. *Public health*, *148*, 137–139. https://doi.org/10.1016/j.puhe.2017.04.010

Norberg, M. M., & Snowdon, J. (2014). Severe Domestic Squalor', in (eds), , Oxford Library of Psychology. In R. O. Frost & G. Steketee (Eds.), *The Oxford Handbook of Hoarding and Acquiring*. Oxford University Press. https://doi.org/10.1093/oxfordhb/9780199937783.013.005

Nordsletten, A. E., Fernández de la Cruz, L., Aluco, E., Alonso, P., López-Solà, C., Menchón, J. M., Nakao, T., Kuwano, M., Yamada, S., Fontenelle, L. F., Campos-Lima, A. L., & Mataix-Cols, D. (2018). A transcultural study of hoarding disorder: Insights from the United Kingdom, Spain, Japan, and Brazil. *Journal of psychiatric research*, *55*(2), 261-285. https://doi.org/10.1177/1363461518759203

Nordsletten, A. E., Fernández de la Cruz, L., Billotti, D., & Mataix-Cols, D. (2013). Finders keepers: the features differentiating hoarding disorder from normative collecting. *Comprehensive psychiatry*, *54*(3), 229-237. https://doi.org/10.1016/j.comppsych.2012.07.063

Nordsletten, A. E., Fernandez de la Cruz, L., Pertusa, A., Reichenberg, A., Hatch, S. L., & Mataix-Cols, D. (2013). The Structured Interview for Hoarding Disorder (SIHD): Development, usage and further validation. *Journal of Obsessive-Compulsive and Related Disorders*, *2*(3), 346–350. https://doi.org/10.1016/j.jocrd.2013.06.003

Nordsletten, A. E., Reichenberg, A., Hatch, S. L., Fernández de la Cruz, L., Pertusa, A., Hotopf, M., & Mataix-Cols, D. (2013). Epidemiology of hoarding

disorder. *The British journal of psychiatry: the journal of mental science*, *203*(6), 445-452. https://doi.org/10.1192/bjp.bp.113.130195

Nutley, S. K., Read, M., Martinez, S., Eichenbaum, J., Nosheny, R. L., Weiner, M., Mackin, R., & Mathews, C. A. (2022). Hoarding symptoms are associated with higher rates of disability than other medical and psychiatric disorders across multiple domains of functioning. *BMC Psychiatry*, *22*. https://doi.org/10.1186/s12888-022-04287-2

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., . . . Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, *372*(n71). https://doi.org/doi:10.1136/bmj.n71

Page, M. J., Moher, D., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., . . . McKenzie, J. E. (2021). PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. *BMJ*, *372*(n160). https://doi.org/10.1136/bmj.n160

Piacentino, D., Pasquini, M., Cappelletti, S., Chetoni, C., Sani, G., & Kotzalidis, G. D. (2019). Pharmacotherapy for Hoarding Disorder: How did the Picture Change since its Excision from OCD? *Current Neuropharmacology*, *17*(8), 808-815. https://doi.org/10.2174/1570159X17666190124153048

Porter, B., & Hanson, S. (2022). Council tenancies and hoarding behaviours: A study with a large social landlord in England. *Health & Social Care in the Community*, *30*, 2292– 2299. https://doi.org/10.1111/hsc.13779

Postlethwaite, A., Kelletta, S., & Mataix-Cols, D. (2019). Prevalence of Hoarding Disorder: A systematic review and meta-analysis. *Journal of affective disorders*, *256*, 309-316. https://doi.org/https://doi.org/10.1016/j.jad.2019.06.004

Rasmussen, J. L., Steketee, G., Frost, R. O., Tolin, D. F., & Brown, T. A. (2014). Assessing squalor in hoarding: the Home Environment Index. *Community mental health journal*, *50*(5), 591–596. https://doi.org/10.1007/s10597-013-9665-8

Saxena, S., Brody, A. L., Maidment, K. M., & Baxter, L. R. (2007). Paroxetine treatment of compulsive hoarding *Journal of psychiatric research*, *41*, 481–487. https://doi.org/10.1016/j.jpsychires.2006.05.001

Sheehan, D. V., Lecrubier, Y., Sheehan, K. H., Amorim, P., Janavs, J., Weiller, E., Hergueta, T., Baker, R., & Dunbar, G. C. (1998). The mini-international neuropsychiatric interview (M.I.N.I): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *The Journal of Clinical Psychiatry*, *59*, 22–33. https://doi.org/10.1016/S0924-9338(99)80239-9

Snowdon, J., Halliday, G., & Banerjee, S. (2012). *Severe Domestic Squalor*. Cambridge University Press.

Snowdon, J., Halliday, G., & Hunt, G. (2013). Two types of squalor: Findings from a factor analysis of the Environmental Cleanliness and Clutter Scale

(ECCS). *International Psychogeriatrics*, *25*(7), 1191-1198. https://doi.org/10.1017/S104161021300032X

Stovold, E., Beecher, D., Foxlee, R., & Noel-Storr, A. (2014). Study flow diagrams in Cochrane systematic review updates: an adapted PRISMA flow diagram. *Systematic Reviews*, *3*. https://doi.org/10.1186/2046-4053-3-54

Tesauro, M., Nunno, L., Grappasonni, I., Scuri, S., Costa, G. A., Ciconali, G., Sozzi, G., & Consonni, M. (2021). The Environmental Cleanliness and Clutter Scale (ECCS) in the management of sanitary risks in dwellings of hoarders in North Italy. *Journal of Public Health*. https://doi.org/10.1007/s10389-020-01429-2

The British Psychological Society. (2015). *A Psychological Perspective on Hoarding - DCP Good Practice Guidelines*. The British Psychological Society.

The EndNote Team. (2013). *EndNote*. In (Version EndNote 20) [64 bit]. Clarivate.

Tolin, D. F., Frost, R., & Steketee, G. (2010). A brief interview for assessing compulsive hoarding: The Hoarding Rating Scale-Interview. *Psychiatry Research*, *178*(1), 147-152.

Tolin, D. F., Frost, R. O., Steketee, G., & Fitch, K. E. (2008). Family burden of compulsive hoarding: results of an internet survey. *Behaviour Research and Therapy*, *46*(3), 334-344. https://doi.org/10.1016/j.brat.2007.12.008

Tolin, D. F., Frost, R. O., Steketee, G., Gray, K. D., & Fitch, K. E. (2008). The economic and social burden of compulsive hoarding. *Psychiatry Research*, *160*, 200–211. https://doi.org/10.1016/j.psychres.2007.08.008

Tolin, D. F., Stevens, M. C., Villavicencio, A. L., Norberg, M. M., Calhoun, V. D., Frost, R. O., Steketee, G., Rauch, S. L., & Pearlson, G. D. (2012). Neural

mechanisms of decision making in hoarding disorder. *Archives of General Psychiatry*, *69*, 832–841. https://doi.org/10.1001/archgenpsychiatry.2011.1980

United States Census Bureau. (2021). *American Housing Survey for the United States 2021 (Table Creator)*. US Government. Retrieved 22nd January 2023 from https://www.census.gov/programs-surveys/ahs/data/interactive/ahstablecreator.html?s_areas=00000&s_year=2021&s_tablename=TABLE1&s_bygroup1=1&s_bygroup2=1&s_filtergroup1=1&s_filtergroup2=1

United States Consumer Product Safety Commission. (Undated). *Asbestos In The Home*. United States government. https://www.cpsc.gov/safety-education/safety-guides/home/asbestos-home

United States Department of Housing and Urban Development. (2011). *American Healthy Homes Survey: Lead and Arsenic Findings*. https://www.gao.gov/assets/gao-18-394.pdf

United States Environmental Protection Agency. (2022). *Protect Your Family from Sources of Lead*. United States government. Retrieved 21st January 2023 from https://www.epa.gov/lead/protect-your-family-sources-lead

United States Fire Administration. (Undated, 21st September 2022). *Residential Fire Estimate Summaries*. Retrieved February 22nd 2022 from https://www.usfa.fema.gov/statistics/residential-fires/index.html

United States Government Accountability Office. (2018). *Lead Paint in Housing*. United States. Retrieved 21st January 2023 from https://www.gao.gov/blog/2018/06/20/lead-paint-in-housing

Ustun, T., Kostanjesek, N., Chatterji, S., Rehm, J., & World Health Organization. (2010). Measuring health and disability: manual for WHO Disability Assessment Schedule (WHODAS 2.0). In. https://apps.who.int/iris/handle/10665/43974: World Health Organization.

Walji, F., Kerry, E., & Salkovskis, P. (2022). *The risks associated with living in hoarded spaces; a systematic review*. PROSPERO: International prospective register of systematic reviews. https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42022293840

Waters, D. M., Eckhardt, M., & Eason, E. A. (2022). Characteristics of Deaths With Evidence of Pathological Hoarding in Cook County 2017 to 2018. *The American Journal of Forensic Medicine and Pathology*, *43*(1), 2-6. https://doi.org/10.1097/PAF.0000000000000702

Woody, S. R., Lenkic, P., Bratiotis, C., Kysowa, K., Luu, M., J, E.-V., Frost, R. O., Lauster, N., Steketee, G., & Tolin, D. F. (2020). How well do hoarding research samples represent cases that rise to community attention? *Behaviour Research and Therapy*, *126*. https://doi.org/10.1016/j.brat.2020.103555

Woody, S. R., Lenkic, P., Edsell-Vetter, J., Frost, R., Steketee, G., & Tolin, D. (2019). *Neuropsychological functioning in hoarding disorder* 9th world congress of behavioural and cognitive therapies, Berlin, Germany.

Service Improvement Project

Trainee: Fahreen Walji

Contact details: fahreen.walji@hmc.ox.ac.uk

Title: Improving the Autism Spectrum Disorder diagnostic process in the Oxford Health NHS Foundation Trust Child and Adolescent Mental Health Service Neurodevelopmental Conditions Service

Word count: 5008 words (excluding references and appendices, and allowing 100 words maximum for each table and figure in the main text)

Date: 23rd September 2022

Internal supervisors: Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk),

Dr Matthew Hotton (matthew.hotton@hmc.ox.ac.uk)

(Initially: Dr Brynjar Halldorsson, brynjar.halldorsson@psych.ox.ac.uk)

External supervisor: Dr James Stacey (james.stacey@oxfordhealth.nhs.uk)

(Initially: Dr Jennifer Chapman, jennifer.chapman@oxfordhealth.nhs.uk)

Proposed journal: Autism – this journal was chosen as it welcomes articles on topics related to Autism Spectrum Disorder, included around diagnosis

Abstract

Background: This study's overall aim was to investigate parent/carer experiences of the feedback session and assessment report forming part of the target service's Autism Spectrum Disorder (ASD) assessment process, consider how these reflect adherence to the National Institute for Health and Care Excellence (NICE) guidelines, and identify potential improvements. **Method:** A mixed-methods, cross-sectional design was used, consisting of: semi-structured interviews (analysed using thematic analysis) with parents/carers; and collecting service data (analysed using descriptive statistics) on referrals and assessments to provide context to the interviews. **Results:** Four themes were developed from the interview data (finally – a diagnosis; the varied influence of wider factors; variable gains made; competent and caring professionals), which indicated variation in experiences and variable accordance with the NICE guidelines. The service data revealed a high ASD diagnostic rate. **Discussion:** Key clinical implications of the results are: parent/carer needs appear to be variably met, the incremental validity of the diagnostic process is called into question; and the possibility of false negatives at triage and false positives at assessment is raised. Improvement recommendations (including future research), dissemination of the results and study limitations (including the potential impact of the Covid-19 pandemic) are discussed.

Keywords: Autism Spectrum Disorder assessment, parent/carer experiences, service improvement.

Lay abstract: appendix H.

Introduction

Autism Spectrum Disorder (ASD)

ASD is a neurodevelopmental condition entailing difficulties with “social communication and social interaction”, and “restricted, repetitive patterns of behavior, interests, or activities” (American Psychatric Assocation; APA, 2013). Current estimates are that in England about 1.76% of children have ASD (Roman-Urrestarazu et al., 2021).

Guidelines and literature

The National Institute for Health and Care Excellence (NICE, 2011) guidelines delineate the gold-standard (though not compulsory) approach to assessment. Regarding feeding back assessment results to service users, recommendations include sharing if a diagnosis has been reached, providing a written assessment report, and providing relevant information (such as on post-diagnostic support; NICE, 2011). Research shows that various factors can influence the satisfaction levels of parents/carers whose children receive a diagnosis with these aspects of the assessment process. A recent systematic review identified these parents/carers as having “emotional, informational and relational needs” at these stages that include: continuing relationships with professionals; being given information on ASD to foster understanding of how to meet their child’s needs; and being informed of, and having extended support in accessing, post-diagnostic support (Legg & Tickle, 2019). Legg and Tickle (2019) also note the breadth of emotions diagnosis can engender and highlight the importance to parents/carers of how diagnosis is conveyed. Other studies have similar findings, and indeed research shows that parents can therefore experience these stages of the diagnostic process as unsatisfactory and stressful, and be left

feeling ill-equipped and unsupported regarding helping their child (Crane et al., 2018; Crane et al., 2016; Howlin & Moore, 1997; Legg & Tickle, 2019; Mansell & Morris, 2004; Potter, 2016). Where the NICE (2011) guidelines are considered in research, they are typically found not to be fully adhered to (Abbott et al., 2012; Legg & Tickle, 2019).

Theory

Bandura (1995) holds that "[perceived] self-efficacy refers to beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations". Parental self-efficacy can be understood as concerning parents' belief in their ability to raise their child (Jones & Prinz, 2005). As discussed under "literature" above, research suggests that parents/carers can experience their needs around how to care for their child as being unfulfilled when a diagnosis is given. Legg et al. (2022) – albeit in the context of their study on the experiences of parents of *adults* diagnosed with ASD – note that this could reduce a parent's capacity to help their child, and accordingly they suggest focusing post-diagnostic support on increasing parental self-efficacy by fostering parents' grasp of how the diagnosis impacts their child and how they might manage this. Of note is that this is in keeping with Legg and Tickle (2019 - who draw on Jones & Prinz, 1995) finding that some parents reported that learning about ASD helped them to manage the implications of diagnosis, which the authors suggest was partly because this greater understanding improved their sense of self-efficacy. Applied to this Service Improvement Project (SIP), self-efficacy theory will be used to assist consideration of how parents'/carers' experiences of the latter parts of the diagnostic process may impact their self-efficacy levels.

Rationale and aims

The Oxford Health NHS Foundation Trust (OX NHS FT) Child and Adolescent Mental Health Service Neurodevelopmental Conditions Service ("NDC service") primarily conducts neurodevelopmental assessments for five to 17-year-olds. Its ASD assessment process (appendix I) concludes with a feedback session (occasionally two sessions take place) at which assessment results and related matters are discussed with families. The session is usually attended by parents/carers, and sometimes the child depending on family preferences. A written assessment report (accompanied by a booklet on ASD) are also given to families at this time. The service reports that only individuals who have been through a very thorough triage/screening process are seen for ASD assessment.

In recognition of the research findings and the absence of parent/carer views on the feedback session and assessment report in cases where a diagnosis is given, the NDC service identified exploring parents'/carers' experiences of these, and related improvements, as a clinical priority. In collaboration with the trainee's supervisors and NDC service staff members, this SIP was therefore developed to address the following improvement question: "What are parents'/carers' experiences of the ASD diagnostic process feedback session and the written assessment report, and how can these be improved?" Within this, specific aims were identified to:

1. Identify the context of such sessions including in terms of the base rates for those undergoing assessment.
2. Explore parents'/carers' experiences of the feedback session and the written assessment report.
3. Explore the extent to which the NDC service is meeting the relevant NICE (2011) guidelines.

4. Identify recommendations for service improvements based on parents'/carers' experiences of the feedback session and written assessment report.

Methods

Procedure

Plan, Do, Study, Act Quality Improvement methodology – see Deming (1986) as discussed in Taylor et al. (2014) – was used as follows:

- Plan: development of the study aims and design
- Do: interviewing parents and collecting service data
- Study: analysing the interviews (including how they reflect adherence to the NICE (2011) guidelines), summarising the service data, identifying the clinical implications and recommendations for improvements
- Act: preliminary dissemination of the results, including considering implementation of the recommendations.

Governance issues and ethical approval

The Quality and Audit team at OX NHS FT provided study approval (note they do not provide approval numbers; appendix J). As aspects of the study developed, amendments were submitted and approved.

Data Management Strategy

Data was collected and managed in line with OX NHS FT Information Governance requirements. This included that electronic and audio material was stored on Trust encrypted devices, and participants' anonymity was maintained.

Method and design

A two-part, mixed-methods, cross-sectional design was used.

Part 1 - Interviews

Nine semi-structured interviews were conducted digitally with parents regarding their experiences of, and suggestions of improvements to, the feedback session and assessment report. Parents' involvement with the service overlapped with the Covid-19 pandemic. During the pandemic, feedback sessions took place monthly, usually digitally or by telephone.

Inclusion and exclusion criteria.

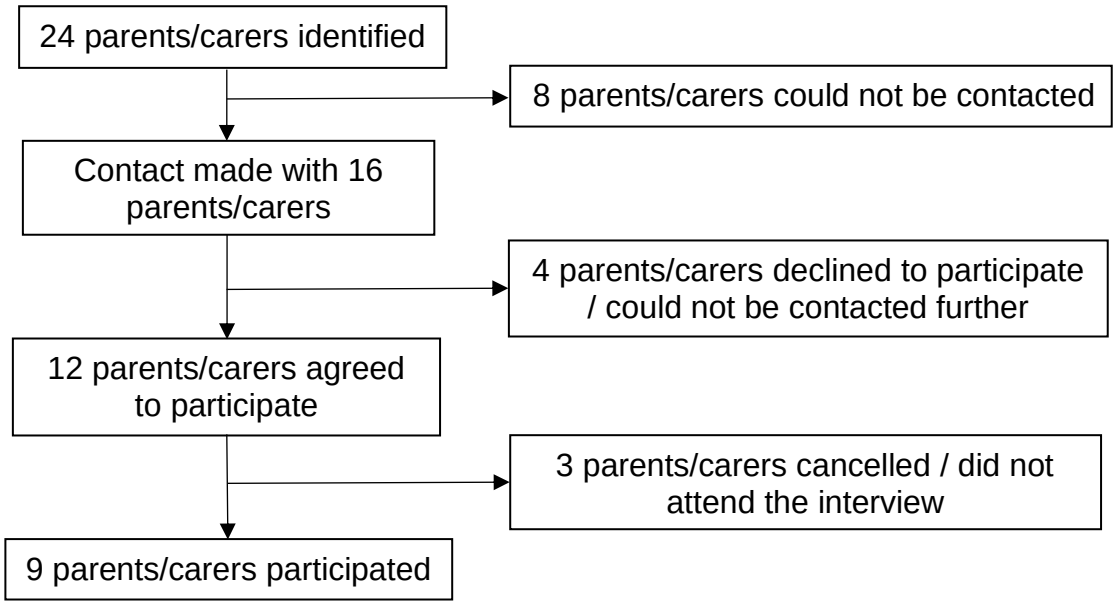
- Initial inclusion criteria: an ASD diagnosis; the parent/carer attended the feedback session in the previous three months, has the capacity to consent to participate and speaks English.
- Initial exclusion criteria: the ASD assessment was to get a second opinion on diagnosis; the child also had a diagnosis of, or was undergoing assessment for, Attention-Deficit/Hyperactivity Disorder (ADHD) or a tic disorder.

Due to recruitment difficulties, a contingency plan allowing parents/carers who attended the feedback session in the previous six months to be approached (including where the child was also assessed for ADHD but only received an ASD diagnosis) was implemented.

Selection and recruitment of participants. Recruitment occurred between July 2021 and April 2022; potential participants were approached by NDC service staff and/or the trainee (appendix K). Interviewees were provided with a participant information sheet and a consent form (appendix L), and provided written informed consent. Figure 2 below shows the participant flow diagram.

Figure 2

Participant Flow



Interview schedule and process. The interview schedule was developed with the input of NDC service staff, a service user (the parent of a child diagnosed with ASD in the NDC service) and the trainee's supervisors. It was briefly amended after the first interview, and subsequently for parents whose children also had an ADHD assessment. See appendix M for the interview schedule. Before interviews, an introduction was given to participants (appendix N), and assessment-related and demographic information was collected (appendix O). Details of support services were provided post-interview (appendix P).

Description of participants. Interviewees were White British parents (six females) in their forties and fifties, eight of whom were employed (three in graduate, and five in non-graduate employment, providing some indication of possible socioeconomic status). Of the nine children (five females at birth, all White British), two were aged between 10 to 14 years, and seven between 15 to 18 years. Six families had the feedback session digitally, one by telephone, one in-person, and one partly digitally and partly by telephone. Eight interviewees had

received a hard and/or electronic copy of the assessment report (though two stated they had not yet read it fully) and three of these eight parents recalled receiving an additional document with it (the booklet on autism). See appendix Q for further details.

Data analysis. The trainee transcribed and anonymised the interviews. Reflexive thematic analysis was used – within this, a more inductive and semantic stance was taken, and analysis leant towards an experiential and realist position (Braun & Clarke, 2022). It was considered that this approach would support the identification of improvement recommendations whilst recognising the trainee's bias in doing this (Braun & Clarke, 2022). Reflexivity was facilitated by reflexive journalling (Braun & Clarke, 2022). See appendix R for a reflexive statement.

Part 2 – Service data

Service data was collected on referrals and assessments to provide contextual information on ASD assessments, including in terms of base rates for those undergoing assessment. Data on all referrals, and ASD diagnostic assessments (whether or not alongside ADHD), between July and September 2021 were collated (appendix S). These data were analysed using descriptive statistics.

Community Involvement Statement. As above, the parent of an autistic child helped develop the interview schedule.

Results

Part 1 – Interviews – Thematic Analysis

Four themes were developed. How many participants comments apply to is indicated as follows: "a few" means one to three, "some" means four to six, and

"many" means seven to nine participants (taking a similar approach to that of Terry, 2010 - discussed in Braun & Clarke, 2022).

Theme one: Finally – a diagnosis!

Theme one reflects the fact that many parents appeared to experience the session/report as the culmination of a long journey to obtain an ASD diagnosis. It encompasses the extent to which parents wanted and expected a diagnosis, and their emotional reactions to it.

Wanting a diagnosis. Many parents expressed wanting a diagnosis; key reasons were thinking this would lead to support and help make sense of their child's presentation. Many parents described wanting a diagnosis for many years; in cases they described this period as entailing emotional and practical burdens on their family.

Expecting a diagnosis. Many parents felt so certain that their child had ASD that they expected a diagnosis – in instances parents stated that *not* receiving a diagnosis would have been difficult.

Emotional reaction. Many parents described their emotional reactions to diagnosis; the types and strength of emotions varied, and included happiness, relief, shock (even where diagnosis was expected) and receiving the news more matter-of-factly. It appeared that knowing others with ASD (such as family members) or the child receiving the diagnosis being older appeared to make it easier for certain parents to accept diagnosis.

As an illustration of some of the above points, participant nine stated that waiting for diagnosis took years of their child "having a terrible time", and that both they and their child wanted the diagnosis (the parent becoming "absolutely

desperate" for it) – in particular to help make sense of the child's presentation and difficulties – they described diagnosis as "validating" for them both.

Theme two: The varied influence of wider factors

Parents' experiences of the session/report appeared to be influenced by their perspectives on wider factors *around* these: the diagnostic procedures; the logistics of the feedback session; and broader communication with the NDC service.

Diagnostic procedures. Some parents expressed contentment around the diagnostic procedures (their speed, logistics and/or the professionals themselves); this appeared to improve their experiences of the session/report. A few parents reported dissatisfaction with the diagnostic procedures (including that: the scope of assessment included ADHD but not other conditions, provided limited opportunity for rapport-building between child and clinician, and occurred digitally; the standardised ASD assessment felt age-inappropriate; and there were inaccuracies in the report attributed to clinician error at assessment). One other parent was not dissatisfied but would have preferred face-to-face assessment.

Feedback session logistics. Some parents identified positive aspects of the feedback session's duration and/or format. Whilst a few of these parents, and a few others, identified some disadvantages of having it digitally / by telephone, this did not necessarily engender dissatisfaction. In cases, parents stated they appreciated that Covid-19 limited what the service could provide.

Communication. A few parents identified aspects of good communication regarding wider factors (who the report is shared with and how to access it, and the organisation of the feedback session), and some described instances of a lack of communication (including who the report is shared with, who is informed of

diagnosis, who the feedback session attendees were, and when the feedback session would occur). Two participants described not knowing the feedback session's purpose when informed of it – however only one considered this problematic; for the other having a session compared positively to their experience of other services. This illustrates a broader finding across interviews whereby some parents' views of the session/report were informed by their experiences with other services.

Theme three: Variable gains made

Parents' perspectives on the information the service provided in the session/report varied: many indicated gaining skills/knowledge of *some* value, but the skills/knowledge were not necessarily considered *fully* suitable.

Understanding diagnosis. Many families reported developing their understanding of how their child's presentation fit ASD, such as through learning about the diagnostic procedures and criteria. In instances it appeared parents wanted little more from the service as they already felt largely equipped to support their child – including due to pre-existing familiarity with ASD (through family members or their employment), feeling they already knew how to help their child, or having support in the pipeline. One parent specified wanting further information on the diagnostic procedures.

Advice on strategies/support. Many parents found some value in the service's advice on strategies/support (including their content, their format/volume in the report, and the discussion with the clinician of them), however some of these parents nevertheless considered the advice lacking, as did one other parent. Reasons included limited topics being covered, a lack of child-friendly

materials (such as the report), the format the information was presented in, and already knowing some of the advice (through other services or their employment).

Barriers to accessing support. A few parents identified barriers to accessing support sources including: emotional and practical demands of their daily lives; not knowing if other services had been informed of the assessment outcome; finding the NDC service's written guidance on accessing support (including the service's post-diagnostic group) confusing; and feeling insufficiently supported in contacting services (including lacking an onward referral). Accordingly, a few families also described feeling insufficiently supported by external services post-diagnosis.

Feeling cut-off. Some families expressed feeling cut-off by the NDC service post-diagnosis, and appeared to want ongoing support (such as a follow-up meeting).

Perspectives on limitations. Families' perspectives on the above limitations differed. They appeared to find them more challenging where they had pronounced difficulties in supporting their child combined with unmet expectations for support, in such situations describing feeling unskilled in helping their child and low parental self-efficacy. For example, both participants one and six considered the advice on strategies/support lacking, but only the former considered this problematic: they described difficulty managing their child and a strong expectation of help, whilst participant six did not. Indeed, participant one described "[feeling] like … [child] and I are on a desert island… people know that we're here, but no-one's sending any…kind of ship or something to try and get us off it", stating "I've got no idea how to… do anything".

Of note is participant nine, who appeared to want support but stated that the service had informed them pre-feedback that they would not provide this due to the child's age; being forewarned appeared to make this *somewhat* easier to accept.

Theme four: Competent and caring professionals

Many parents appeared to experience the clinicians themselves as *largely* competent and caring; where parents felt their needs were not met within other themes, this was typically not in the context of a difficult encounter with the clinician themselves.

Many parents expressed appreciation for characteristics shown by clinicians, including their communication skills, kindness and approachability. A few parents appeared to appreciate the clinician's understanding of their child, and many appeared to value the feedback session discussion being tailored to their needs. Many parents praised how diagnosis was delivered: for instance participant four appreciated being told immediately ("she come up straight away and say that (child) is autistic… it wasn't this big build up") and participant five valued the opposite approach ("we kind of didn't get straight into the diagnosis, we kind of had that little bit of a, a chat first…").

A few parents expressed some dissatisfaction. Participant six felt the clinician could have spoken differently to them and their child (including around diagnosis) due to their child's age. Participant two felt their reaction to diagnosis could have been acknowledged more – they felt this could have helped their child during the session; this illustrates that parents' experiences of the session could be impacted by that of their child.

Adherence to the (2011) guidelines

The issues raised in the interviews speak to various items of the NICE (2011) guidelines; these are summarised in table 7 below, which also includes ratings of adherence to the guidelines (none; partial; complete; and a note if the rating is unclear) made by the trainee, with the reasoning for this. It is acknowledged that the NDC service may consider that they practice some of the below (as some of the disparities between parents might suggest), and that these ratings are based on limited data (the nine interviews).

Table 7

Adherence to the NICE (2011) guidelines

Issue, NICE (2011) guidelines item(s), rating	Reasoning for rating
Issue: The conditions assessed for. **Items:** 1.5.5, 1.5.7, 1.5.15. **Rating:** Partial/Unclear.	One parent reported dissatisfaction that assessment included ADHD but not other conditions, however there is insufficient information to assess if other conditions should have been assessed for.
Issue: Communication around the feedback session. **Items:** 1.5.2, 1.5.3, 1.8.1. **Rating:** Partial/Unclear.	Certain parents expressed not knowing the feedback session's purpose, when it would occur or attendees, suggesting they may not have been told this. It is unclear if the guidance on assigning a case coordinator (who would provide updates on appointments) was followed.
Issue: Communication about sharing the report/diagnosis with	Whilst one parent specifically praised the service for informing them of who the assessment report would be shared with, another felt unclear on this and on who the diagnosis was shared with.

others **Items:** 1.1.7, 1.8.5, 1.8.6. **Rating:** Partial.	
Issue: Gaining an understanding of the diagnosis. **Items:** 1.8.1, 1.8.3, 1.8.4. **Rating:** Partial.	Many families reported developing understanding of how their child fits the presentation of ASD, and in cases this included gaining knowledge of the diagnostic process and criteria. However, one parent noted that they would have liked more information on the diagnostic process.
Issue: Advice on strategies / support. **Items:** 1.1.7, 1.5.2, 1.5.3, 1.5.15, 1.9.1. **Rating:** Partial/unclear.	Parents' assessment of the advice on services/support varied. One parent noted the absence of a referral from the NDC service (suggesting guidance on referrals may not have been met) and some families' comments on the lack of appropriate advice suggests a case coordinator may not have arranged this for them – however there is insufficient information to assess both of these points.
Issue: Ongoing support. **Item:** 1.5.5, 1.5.8, 1.8.7, 1.8.8. **Rating:** Partial.	Some families expressed feeling cut-off by the service and appeared to want ongoing support, suggesting a follow-up appointment was not offered. Further, parents' comments on the lack of ongoing support suggests a profile of their child had not been developed (or developed sufficiently).
Issue: Sharing the diagnosis. **Items:** 1.1.6, 1.1.7, 1.5.4, 1.5.5, 1.8.1,	Many parents praised how clinicians discussed the diagnosis, though a few identified difficulties. Further,

1.8.2. **Rating:** Partial/unclear. **Issue:** Provision of assessment report **Item:** 1.8.4. **Rating:** Unclear.	parents' discussions of diagnosis suggested they did not know how diagnosis would be delivered to them. Though one interviewee had not received their report, there is no guidance on time-limits for providing the report, and their interview was only ten days after their feedback session.

Part 2 – Audit

Referrals data

In total, 103 referrals were made: 90 (87%) were for ASD either alone or alongside ADHD. Regarding these 90 children and young people: 35 (39%) were aged between 5 to 9 years, 31 (34%) between 10 to 14 years, and 24 (27%) between 15 to 18 years. The majority (72; 80%) were White British/English and most (89; 99%) spoke English as their first/primary language (though note data were missing on these demographics for some children), and approximately half were female (42; 47%). At least one main contact was marked for 79 (88%) of these children. Of the 83 main contacts (one contact for 75 children and two contacts for four children), most were (though again note there were missing data): female (69; 83%); the child's parent (81; 98%). All spoke English as their first/primary language. Contacts for whom age data were available ranged in age from their twenties to their fifties.

Diagnostic assessments

Sixty-three assessments were conducted: 20 (32%) for ASD; 39 (62%) for ASD and ADHD; and 4 (6%) for ADHD. Nineteen of the 20 ASD-only assessments were found to have been completed; 18 (95% of 19) resulted in an ASD diagnosis. Thirty-six of the 39 ASD and ADHD assessments have been completed so far:

one resulted in no diagnoses, and 35 (97% of 36) resulted in a diagnosis (9 in ASD only, 22 in ASD and ADHD/ADD, and 4 in ADHD) – so 31 (86% of the completed assessments) resulted in at least an ASD diagnosis.

For the 20 ASD-only, and 39 ASD and ADHD, assessments together, 17 (29%) of the children were aged between 5 to 9 years, 22 (37%) between 10 to 14 years, and 20 (34%) between 15 to 18 years. Most were White British/English (39 children; 66% - but note this demographical information was lacking for 13 children), spoke English as their first/primary language (57; 97% children), and 23 (39%) were female. Further, 23 (39%) of children had an immediate/wider family member with ASD (information on this was unavailable for seven children). Of children's main contact(s) (62 in total as three children had two contacts marked for them), most were parents (58; 94% of 62) who were aged between their twenties to sixties, and most children had a main contact whose first language appeared to be English (53 main contacts; 90% of 59).

Discussion

Summary of findings

In this study, a review of the service's referral and assessment activity, and an in-depth examination of parent/carer experiences of the ASD feedback session and assessment report (including in relation to the NICE (2011) guidelines), was conducted. The service data showed that the majority of individuals undergoing an ASD-only assessment, and those undergoing a combined ASD and ADHD assessment, received an ASD diagnosis. The interviews revealed broad experiences of the session and report; a notable finding was the differences in the amount and type of information and support wanted, and some parents found the service's offerings in this regard lacking. Families' differing needs, aims and expectations around

diagnosis appeared to influence their varied perspectives. Further, the interview data indicates variable adherence to the NICE (2011) guidelines.

Literature

The high ASD diagnostic rate found is at the upper end of the diagnostic rates given by other services, which appear to span between 50 to 90% (City of York Council, 2016; Merton Council, 2018). We are not aware of any peer-review reports of diagnostic rates in such services, but note that these are very high rates.

A key finding from interviews that parents can feel dissatisfied with the support offered post-diagnostically – including because their expectations are not met in this regard – corresponds with existing literature (Crane et al., 2018; Potter, 2016). That parents' views of the session/report were shaped by the perspectives on wider factors around the diagnostic process is also reflective of research (for example see Crane et al., 2018). Other findings from the interviews also fit with the literature, such as that parents can find a diagnosis helpful in making sense of their child's presentation (Abbott et al., 2012; Potter, 2016). As with previous research, interviewees attached high value to the manner of the diagnosing clinician (Abbott et al., 2012; Crane et al., 2016). The variable adherence to the NICE (2011) guidelines found also accords with previous research (Abbott et al., 2012; Legg & Tickle, 2019).

Clinical implications for the service

The high ASD diagnostic rate raises various issues. Firstly, it raises the question of potential false positives (children receiving a diagnosis without meeting the diagnostic criteria) at the diagnostic stage. However, if the diagnostic assessment process is accurate, this means the base rate of ASD is between 86 and 95%, severely limiting the ASD diagnostic assessment's incremental validity (how much it

adds to the triage process/criteria; Hunsley & Meyer, 2004) and calling into question its predictive value in this population. If the diagnostic assessment were 100% accurate, the incremental validity could not exceed 3% (Anastasi, 1976). Further, the service have indicated that their triage process/criteria for their ASD assessment waiting list has a very high threshold; this also raises the possibility of potential false negatives at this stage (that is, children for whom diagnosis is not clear-cut will not progress to full assessment).

The clinical implications of the interview data are that parents can feel that they lack the support and information required to manage the diagnosis. So, it appears that families can end the assessment process feeling that their aims and expectations around diagnosis are not fully met.

Theory

Overall, levels of parental self-efficacy appeared to be influenced by the extent to which they felt skilled in understanding and supporting their child. In keeping with the predictions of self-efficacy theory discussed above (Legg & Tickle, 2019; Legg et al., 2022), the interview data suggest that where parents' needs regarding how to help their child were unmet by the NDC service, they had a reduced belief in their ability to support their child, and so had low parental self-efficacy. This seemed particularly pronounced when they had high expectations of support.

Recommendations for improvement (including future research)

Regarding the service data, key recommendations are to research the possibility of false positives at the assessment stage, and the potential for false negatives at triage (by assessing who does and does not pass the triage criteria/process).

Table 8 contains recommendations relating to the interview data. These focus in particular on clarifying families' aims and expectations around diagnosis, and tailoring provisions to their needs. Where the service is not able to implement any recommendation, it would be important to manage families' expectations of these.

Table 8

Recommendations relating to the interview data

Issue(s)	Recommendation and when to implement it
	For all families (regardless of if a diagnosis is given):
The conditions assessed for and communication around the feedback session	1. Discuss the content and time-frame of the assessment process with families, covering: the conditions assessed for; that assessment may not feel age-appropriate; the amount of opportunity for rapport-building; the purpose, time-frame, format and attendees for the feedback session; and what to expect regarding support if a diagnosis is given.
Communication about sharing the report/diagnosis with others	2. At the feedback session, discuss who the report and diagnosis will/can be shared with, and share accordingly. Revisit this after the feedback session if needed.
Sharing of the diagnosis	3. Discuss with families how they feel about diagnosis and how they would like the result to be discussed with them.
	If a diagnosis is given:

Gaining an understanding of the diagnosis	4. Explore with families how much information they would like about ASD and the assessment process. One parent recommended an additional sheet containing information on: acronyms; scores; the rationale for testing; the methodology; and how the outcome is ascertained.
Advice on strategies / support	5. At the feedback session, explore families' current (and hoped for) knowledge and support, and the format they would like this in (see appendix T for further detail). 6. Regarding the NDC service's post-diagnostic course: provide clearer instructions on how to access it; make it more accessible to parents if possible; and emphasise the importance of joining it. 7. Bring families' attention to the ASD booklet.
Ongoing support	8. If possible, provide: onward referrals (and follow these up) or explain why a referral is not possible; information on how to pursue other diagnoses; greater support with contacting other services (by the NDC service doing this and/or providing clearer instructions on how parents/carers can do this); information on what to expect from other services (including whether parents/carers should expect services to be in contact with them). 9. Offer a follow-up appointment. One family suggested that this could include discussion of: what the family has done so far; how suitable they have found the NDC service's advice so far; and how the service could help them going forward. This might

	also be a suitable time for families to raise any errors in the assessment report.
	10. Develop a profile of the child if this is not currently being done.
	11. Identifying the case coordinator to families.
Provision of assessment report	12. Review the time-frame in which reports are usually provided to families to assess how timely this usually is. Provide an age-appropriate report / information pack for the child if required.

Preliminary dissemination and response to recommendations

The recommendations have been shared with the external supervisor, and arrangements have been made for them to be shared with the wider NDC service staff and service manager.

Regarding the recommendations from the service data, the external supervisor has indicated that the service will be undertaking research to investigate the possibility of false negatives, and peer review work to address the question of false positives.

With regard to the recommendations stemming from the interview data, the external supervisor has noted that the service already practices some of these (producing an assessment report for children; making referrals when there is a clinical need; sharing the assessment report with key members of the child's network; assigning case coordinators; and assessing for co-occurring conditions) and so it will take steps to ensure these aspects of its practice are clearer to parents/carers. Regarding other recommendations, the external supervisor has indicated that the service will conduct further research to explore parent/carer needs (focusing on experiences of the diagnostic procedures and feedback session, and post-diagnostic support), take steps to further develop profiles for

children, and consider how to implement other recommendations into everyday practice.

The results have been provided to the Quality and Audit Specialist team at OX NHS FT. The interview findings have been shared with interviewees and the parent who helped develop the interview schedule.

Limitations

Limitations to this SIP include that all interviewees were from a limited demographic (all were White British, parents, and in their forties and fifties), and so in this respect only a narrow range of participants were interviewed. Secondly, at the recruitment stage, at least one parent/carer declined to participate because they found the feedback session too emotionally difficult, suggesting the interview format may have presented a barrier to certain individuals partaking in this research (so potentially limiting the range of views explored). Additionally, most interviewees' children had an ADHD assessment alongside their ASD assessment, which may have impacted their feedback. Additionally, Covid-19 may have influenced the care provided by the service (see Spain et al., 2022 for how the pandemic impacted ASD assessments more broadly), potentially limiting the findings' applicability post-pandemic.

Conclusion

Various issues have arisen from the interview data and service data; the clinical implications and recommendations (including future research) arising from them have been discussed with the external supervisor and disseminated more widely, and study limitations have been identified. Continuing to develop clinical practice in this area will be important to ongoing improvement of the quality of care

provided in the NDC service, and in keeping with wider policy to improve the lives of those with autism (HM Government, 2021).

References

Abbott, M., Bernard, P., & Forge, J. (2012). Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences. *Clinical Child Psychology and Psychiatry*, *28*(3), 370-382. https://doi.org/DOI: 10.1177/1359104512455813

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5.* (Fifth ed.). American Psychiatric Publishing.

Anastasi, A. (1976). *Psychological testing*. Collier Macmillan.

Bandura, A. (1995). *Self-efficacy in changing societies*. Cambridge University Press. https://doi.org/10.1017/CBO9780511527692

Braun, V., & Clarke, V. (2022). *Thematic Analysis - A Practical Guide*. Sage.

City of York Council. (2016). *Annex C - Needs Assessment for All Age Autism*. City of York Council. Retrieved 4.6.22 from https://democracy.york.gov.uk/documents/s113199/Annex%20C%20-%20All%20Age%20autism%20needs%20assessment%20FINAL%20DRAFT.pdf

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *Journal of Autism and Developmental Disorders*, *48*, 3761–3772 https://doi.org/10.1007/s10803-018-3639-1

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. L. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*, 153-162. https://doi.org/10.1177/1362361315573636

Deming, W. E. (1986). *Out of the crisis*. MIT Press.

HM Government. (2021). *The national strategy for autistic children, young people and adults: 2021 to 2026* https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026

Howlin, P., & Moore, A. (1997). Diagnosis in autism: a survey of over 1200 patients in the UK. *Autism*, *1*(2), 135-162. https://doi.org/10.1177/1362361397012003

Hunsley, J., & Meyer, G. (2004). The Incremental Validity of Psychological Testing and Assessment: Conceptual, Methodological, and Statistical Issues. *Psychological assessment*, *15*(4), 446-455. https://doi.org/10.1037/1040-3590.15.4.446

Jones, T. L., & Prinz, R. J. (2005). Potential roles of parental self-efficacy in parent and child adjustment: a review. *Clinical psychology review*, *25*(3), 341–363. https://doi.org/10.1016/j.cpr.2004.12.004

Legg, H., & Tickle, A. (2019). UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. *Autism*, *23*(8), 1897-1910. https://doi.org/10.1177/1362361319841488

Legg, H., Tickle, A., Gillott, A., & Wilde, S. (2022). Exploring the Experiences of Parents Whose Child has Received a Diagnosis of Autistic Spectrum Disorder in Adulthood. *Journal of Autism and Developmental Disorders*. https://doi.org/https://doi.org/10.1007/s10803-021-05296-y

Lord, C., Rutter, M., Dilavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism diagnostic observation schedule, second edition (ADOS-2) manual (Part 1) modules 1-4*. Western Psychological Services.

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: access to information and use of services. *Autism*, *8*(4), 387-407. https://doi.org/10.1177/1362361304045213

Merton Council. (2018). *Merton Autism Profile 2018*. Retrieved 4.6.22 from https://www.merton.gov.uk/system/files?file=merton20autism20profile.pdf

National Institute for Health and Care Excellence. (2011). Autism spectrum disorder in under 19s: recognition, referral and diagnosis (CG128). https://www.nice.org.uk/guidance/cg128

Potter, C. A. (2016). “I received a leaflet and that is all”: Father experiences of a diagnosis of autism. *British Journal of Learning Disabilities*, *45*(2), 95-105. https://doi.org/10.1111/bld.12179

Roman-Urrestarazu, A., van Kessel, R., Carrie Allison, C., Matthews, F. E., Brayne, C., & Simon Baron-Cohen, S. (2021). Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. *JAMA Pediatrics*, *175*(6). https://doi.org/10.1001/jamapediatrics.2021.0054

Spain, D., Stewart, G. R., Mason, D., Robinson, J., Capp, S. J., Gillan, N., Ensum, I., & Happé, F. (2022). Autism Diagnostic Assessments With Children, Adolescents, and Adults Prior to and During the COVID-19 Pandemic: A Cross-Sectional Survey of Professionals [Original Research]. *Frontiers in Psychiatry*, *13*. https://doi.org/10.3389/fpsyt.2022.789449

Taylor, M. J., McNicholas, C., Nicolay, C., Darzi, A., Bell, D., & Reed, J. E. (2014). Systematic review of the application of the plan–do–study–act method to

improve quality in healthcare. *BMJ Quality & Safety*, *23*(4), 290-298. https://doi.org/10.1136/bmjqs-2013-001862

Terry, G. (2010). *Men, masculinity and vasectomy in New Zealand* The University of Auckland]. New Zealand.

Ulberstad, F. (2012). *QbTest technical manual.* . Qbtech AB.

Theoretically Driven Research Project

Trainee: Fahreen Walji

Contact details: fahreen.walji@hmc.ox.ac.uk

Title: Hoarding Disorder – investigating the development of beliefs about possessions

Word count: 5295 words (excluding references and appendices, and allowing 100 words maximum for each table and figure in the main text)

Date: 23rd May 2023

Supervisor: Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk)

Proposed journal: The Journal of Obsessive-Compulsive and Related Disorders – this journal was chosen because it welcomes a range of studies on hoarding, including on psychopathology

Abstract

Background and aims: Hoarding Disorder (HD) presents in individuals with varied background experiences, suggesting there are multiple avenues to hoarding. One suggested pathway is that early material deprivation leads to hoarding primarily driven by a fear of further material deprivation: this study aimed to investigate this. **Method:** A cross-sectional design dividing participants into three groups was used: hoarders with early material deprivation experience (HWD); hoarders without early material deprivation experience (HND); and community controls (CC). All groups completed quantitative measures assessing descriptives, demographics, psychopathology, and three hoarding-related beliefs (fear of material deprivation, harm avoidance, attachment disturbance). **Results:** There was no significant difference between the HWD and HND groups in terms of fear of material deprivation beliefs, nor for the other two hoarding-related beliefs. All three beliefs were raised in the HND and HWD groups relative to the CC group. **Discussion:** Fear of material deprivation beliefs can motivate hoarding irrespective of any perceived experience of early material deprivation, and future research should investigate what might contribute to the development of these beliefs.

Keywords: hoarding, beliefs, material deprivation.

Introduction

Hoarding Disorder (HD) is a “difficulty discarding or parting with possessions… due to a perceived need to save the items and to distress associated with discarding them”, and typically also involves an “excessive acquisition” of items (American Psychiatric Association, APA, 2013). The ensuing build-up of items impedes the use of spaces for their conventional purposes, and the individual experiences “distress” or reduced “functioning” (APA, 2013).

Hoarding affects around two to six per cent of individuals, with symptoms usually beginning in childhood and increasing over the life course (The British Psychological Society (BPS), 2016). It can entail wide-ranging difficulties for the individual and those around them, including their carers/families and communities. For example, it is associated with greater unemployment, being unmarried, divorced or separated (Archer et al., 2019). It can also lead to health and safety risks stemming from poor home maintenance (BPS, 2015), and discord with family members (Büscher et al., 2014).

Regarding the development of hoarding behaviour, it may best be described as resulting from *convergent pathways* – that is, it can arise from varied experiences, such that hoarders’ life paths can look very different from one another (Gordon et al., 2013; Thew & Salkovskis, 2016). One such pathway to hoarding appears to be experiencing material deprivation.

Indeed, some studies report experiences preceding hoarding that appear to entail *sudden* and *substantial* material deprivation. Marx and Cohen-Mansfield (2003) comment that Greenberg et al. (1990) discuss hoarding behaviour in survivors of the Holocaust and an individual who fled Europe during World War Two (WW2), and that Hogstel (1993) states that hoarding behaviour has been

seen in immigrants who left Europe after WW2. Schroepfer and Ingersoll-Dayton (2001) report on hoarding by an individual subsequent to all her possessions and home being set ablaze during WW2. Grisham et al. (2006) report on hoarding starting around the time of an individual's belongings being destroyed in a fire. Note the ages of the individuals at the time of their material deprivation experiences are unclear (Greenberg et al, 1990, and Hogstel, 1993, as discussed in Grisham et al., 2006; Marx & Cohen-Mansfield, 2003), aside from in Schroepfer and Ingersoll-Dayton (2001) where the deprivation occurred in adulthood. Note other research also reports on possession loss (in childhood) but the extent of loss and/or its timing in relation to hoarding symptom onset is unclear (for example see Kellett et al., 2010; and Samuels et al., 2008).

There are also reports of hoarders experiencing *general* material deprivation during childhood, though an association between this and hoarding is not supported by the research. Frost and Gross (1993) and Landau et al. (2011) found that some hoarders had experienced childhood material deprivation, but they also found that non-hoarders' experiences were no different in this respect. Similarly, Hezel and Hooley (2014) found no significant differences in early material deprivation between individuals with and without clinical hoarding symptoms. Of note is that Frost and Gross (1993), Landau et al. (2011) and Hezel and Hooley (2014) do not report on whether this deprivation experience preceded hoarding symptom onset. However, Shafran and Tallis (1996) do report on cases of hoarding starting after varied experiences that appear to include childhood material deprivation.

There is therefore some, albeit limited, evidence of hoarding behaviours developing after sudden substantial material deprivation, and developing in the context of childhood material deprivation.

Theoretical underpinning

Regarding underpinning psychological factors, there are two cognitive models on hoarding. One, outlined in Frost and Hartl (1996) and Steketee and Frost (2003), states that hoarding arises from three factors. The first factor concerns difficulties with information processing, namely “attention, categorization, memory, and the use of information to draw conclusions and make decisions” (Steketee & Frost, 2003). The second factor, “beliefs about and attachments to possessions”, spans hoarding items: to maintain memories; to secure control over them; because of “emotional attachment” to them; and due to feeling “responsibility” towards them (Steketee & Frost, 2003). The model’s third aspect is that the two previous factors give rise to "distress” when the individual contemplates not attaining items and dispensing of them, resulting in the “avoidance” of such behaviours (Steketee & Frost, 2003). There is increasing though incomplete evidence for this model (David et al., 2022).

A related model by Gordon et al. (2013) – which builds on Seaman et al. (2010)’s model – identifies three motivations for hoarding: “harm avoidance”, “fear of material deprivation”, and “attachment disturbance”. The former is where it is believed that not hoarding will harm the self or others, the second entails a desire to insure against a repeat of earlier sudden (and substantial) or chronic material deprivation, and the latter is where acute emotional attachment to items means parting from them feels extremely difficult (Gordon et al., 2013; Seaman et al.,

2010). Gordon et al. (2013) highlight the need for further research on the concepts underpinning the model.

A link between early material deprivation and fear of material deprivation as a driver for hoarding, as set out by Gordon et al. (2013), has yet to be evaluated. The current research sought to address this. Quantitative methods were used to compare two groups of individuals with HD (APA, 2013):

1. Hoarders with early material deprivation experience (HWD) – those reporting a childhood/adolescent history, that preceded hoarding symptom onset, of chronic material deprivation and/or sudden substantial material deprivation.
2. Hoarders without early material deprivation experience (HND) – those not reporting the above history

It was hypothesised that there would be significantly higher fears of material deprivation in the HWD group compared to the HND group, with the HND group scoring more highly than the HWD group on the other two beliefs. The basis for these predictions was that the two groups are likely to have developed different beliefs regarding possessions due to their differing pathways to hoarding.

Method and Design

Design

This study used a cross-sectional design with three groups. The HWD and HND groups have been defined above in terms of the presence or absence of significant early material deprivation. A third (benchmark) group was formed of individuals without HD (APA, 2013) from the community (Community Controls: CC).

Power analysis and sample size

There is no directly comparable study upon which to base a sample size calculation. However, using Gordon et al. (2013) and Lambe (2015) as a guide, G* power (Faul et al., 2007) was used to conduct an a priori power calculation (with effect size f = .2, alpha = .05, and power = .8) to detect an interaction in a mixed-model ANOVA, giving a total sample size of 75.

Ethical approval

The Oxford University Central University Research Ethics Committee (CUREC) provided study approval (number R77237). Appendix U contains the initial study approval letter.

Data Management and governance procedures

Data were collected by post, email, telephone/digital interviews, and using Qualtrics (2020) – the latter is an online platform for collecting data. The data were managed in accordance with Information Governance requirements, including that participants were allocated unique identification numbers to maintain their anonymity, paper documents were stored in a locked filing cabinet at Oxford University, and recorded postal delivery was used as needed.

Recruitment

Data collection

Data collection occurred between February 2022 and April 2023, in the United Kingdom.

Inclusion and exclusion criteria

- Inclusion criteria: aged over 18 years; able to read, write and speak English.
- Exclusion criteria: evidence of a lack of capacity to consent.

Process

The study was publicised through different means, including: social media; websites; posters/flyers; and in-person approaches. This involved using various networks, such as: libraries; charities; support groups; councils; housing agencies; fire services; and Oxford University. Recruitment also occurred through snowball sampling and approaching individuals who took part in previous research in the trainee's university department who had consented to such contact.

Interested individuals were directed to email the trainee, who provided further information – including the participant information sheet and consent form (appendix V) – and the opportunity to ask questions. Written informed consent was required to participate. See appendix W for an example of the recruitment materials.

Study procedure

Hoarding screening question and group allocation

Participants were asked the following question from the Structured Clinical Interview for DSM-5 – Research Version (SCID-RV; First et al., 2015): "Have you found it difficult to throw out, sell, or give away things?", which has a yes or no answer. Individuals who answered "no" were placed in the CC group. Individuals who answered "yes" were administered the SCID-RV hoarding module (First et al., 2015): those not meeting HD (APA, 2013) diagnostic criteria were assigned to the CC group, those who did meet the criteria were asked about early material deprivation (appendix X) to enable their allocation to the HWD or HND groups.

Questionnaires

Descriptives, demographics, psychopathology. All participants self-reported on descriptives, demographics and psychopathology using the measures

below. This information was used to characterise the sample and assess for potential confounding variables.

1. Questions on demographics and mental health (appendix Y).
2. The Patient Health Questionnaire-9 (PHQ-9), to measure depression symptoms: this has proven internal consistency (Cronbach's α = .86 to .89) and test-retest reliability (.84; Kroenke et al., 2001). In this sample, internal consistency was high (Cronbach's α = .92).
3. The Generalised Anxiety Disorder-7 (GAD-7), to assess anxiety symptoms: this has good internal consistency (Cronbach's α = .92) and test-retest reliability (intraclass correlation = .83; Spitzer et al., 2006). In this sample, internal consistency was high (Cronbach's α = .93).
4. The Work and Social Adjustment Scale (WASAS), to assess functional impairment: this has good internal scale consistency (Cronbach's α = .70 to .94) and test-rest reliability (test-retest correlation =.73; Mundt et al., 2002). In this sample, internal consistency was good (Cronbach's α = .87).
5. The Saving Inventory-Revised (SI-R), to measure hoarding symptoms; for the measure overall and its three subscales (*clutter*, *difficulty discarding*, and *excessive acquisition*), there is proven internal consistency (.80 to .94) and test-retest reliability (correlations span .78 to .90; Frost et al., 2004). In this sample, internal consistency for the whole scale and all subscales was high (Cronbach's α = .92 to .98).

Beliefs About Hoarding questionnaire (BAH; Gordon et al., 2013). To measure beliefs about hoarding and so answer the research question, all participants completed the BAH (Gordon et al., 2013). Gordon et al. (2013) found good internal consistency (.79 to .96) and test-retest reliability (*r* = .69 to .89) for

the scale as a whole and for its individual subscales (*harm avoidance, fear of material deprivation*, and *attachment disturbance*). In this sample, internal consistency for the whole scale and all subscales was high (Cronbach's α = .82 to .96).

Supplementary data. A questionnaire, informed by Hezel and Hooley (2014)'s Early Financial Hardship Scale and developed with Patient and Public Engagement input (an individual who hoards), was used to collect supplementary data on the hoarding groups' experiences of material deprivation more broadly, for future analysis. This is not reported on in the current paper.

Study end

Participants were sent a follow-up letter (appendix Z) after completion of, or withdrawal from, the study.

Data Analysis

Analyses were conducted using SPSS version 29 (IBM Corporation, 2021).

Main analyses

An alpha level of .05 was used for the main analyses. Histograms of the results for the continuous measures (displayed for the whole sample, and for each group individually) were first visually analysed to assess for normality.

Group differences were calculated for the descriptive, demographic and psychopathology measures, bar the SI-R (Frost et al., 2004), to assess for confounding variables between groups. For continuous data, one-way between-subjects ANOVAs were conducted and significant findings were followed by multiple comparisons (if Levene's test indicated homogeneity of variance then the LSD test was used, otherwise Dunnett T3 was used). An exception to this approach regards hoarding duration: an independent samples t-test was used to assess the difference

between the two hoarding groups. For categorical data, differences between groups were assessed using the chi-square test (or Fisher's Exact test, if the assumptions for the chi-square test were not met).

For the BAH (Gordon et al., 2013) and SI-R (Frost et al., 2004), mixed-model ANOVAS (with the between-subjects factor of group, and the within-subjects factor of subscale) were conducted. This allowed for the testing of the main effects of both subscale and group, and of the group x subscale interaction. For both ANOVAs, Mauchly's Test of Sphericity was not significant regarding the within-subjects effect, indicating that the assumption of homogeneity of variance was met. As an interaction effect was present for both measures, simple main effects analysis with planned comparisons across the three subscales for each measure were conducted (if Levene's test indicated homogeneity of variance then the LSD test was used, otherwise Dunnett T3 was used).

Conducting the above analyses for the BAH (Gordon et al., 2013) allowed for the testing of the hypothesis. An additional 2 (group) x 3 (subscale) mixed-model was conducted for the BAH (Gordon et al., 2013) for the two hoarding groups only, to further test the main effects of both subscale and group, and the group x subscale interaction. No follow-up analyses were required.

The above analyses used scaled BAH (Gordon et al., 2013) and SI-R (Frost et al., 2004) scores to adjust for the different numbers of items in each of their subscales.

Exploratory analyses

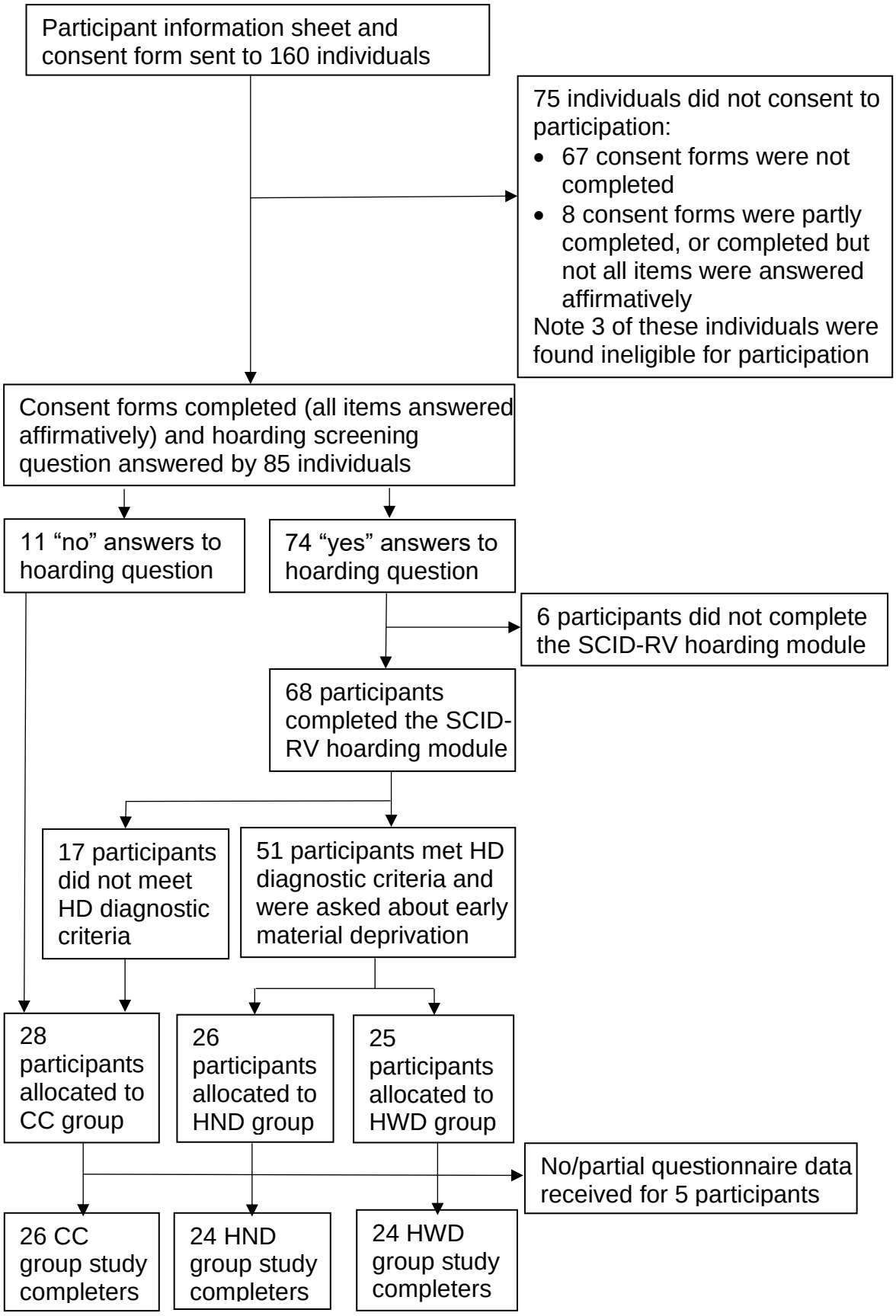
Exploratory analyses conducted following the main analyses are explained below.

Results

Complete data were received for 74 participants: 24 in the HWD group; 24 in the HND group; and 26 in the CC group. Data collection was incomplete for two other participants, who were therefore excluded from analysis. Figure 3 below shows the participant flow diagram.

Figure 3

Participant flow



Descriptives, demographics, psychopathology

Age

Age data were available for 73 participants: ages ranged from 19 to 78 years (M=55.36, SD=14.67). A one-way between-subjects ANOVA found no significant main effect of group on age ($F_{(2,70)}$=2.56, p=.084; table 9).

Gender

81.8% of participants (n = 60) were female. A Fisher's Exact test showed groups were not significantly different on gender (p=.364; table 9).

Ethnicity

The majority of participants (85.1%, n = 63) were white. A Fisher's Exact test showed groups were not significantly different on ethnicity (p=.264; table 9).

Education

Most participants had completed education beyond secondary/high school (74.3%, n = 55). A Chi-square test showed groups were not significantly different on education ($\chi^2_{(2)}$=1.12, p=.570; table 9).

Work

50% of participants (n = 37) undertook paid labour, 6.8% (n = 5) unpaid labour, and 43.2% (n = 32) no labour: a Fisher's Exact test showed groups were not significantly different on work status (p=.436; table 9).

Relationship status

29.7% of participants (n = 22) were married or living as a couple, and just under 60% (n = 43) had ever been married. Chi-squared tests found no significant differences between groups in either of these respects: $\chi^2_{(2)}$=.02, p=.990 for the former; $\chi^2_{(2)}$=2.12, p=.346 for the latter (table 9).

Mental health status

56.8% participants (n = 42) reported having had mental health difficulties in the last year that they had sought help for at least to the level of their GP. A chi-squared test found no significant differences between groups in this respect ($\chi^2_{(2)}$=5.81, p=.055; table 9).

Duration of problematic hoarding symptoms

Mean duration of problematic hoarding symptoms in the HWD and HND groups was 18.13 and 15.58 years respectively; an independent-samples t-test established no significant difference in this respect ($t_{(46)}$=.88, df=46, p=.384; table 9).

Table 9

Demographics and descriptives

Item	Group			Statistic
	HWD group (n=24)	HND group (n=24)	CC group (n=26)	
	Mean (SD)	Mean (SD)	Mean (SD)	*Main effect*
Age (years)	60.50 (10.21)	54.38 (12.18)	51.36 (18.97)	$F_{(2,70)}$=2.56, p>.084
	N (%)	*N* (%)	*N* (%)	*Chi-square or Fisher's Exact*
Gender				Fisher's exact test (p=.364)
Female	21 (87)	17 (70.8)	22 (84.6)	
Male	2 (8.3)	6 (25.0)	3 (11.5)	
Other	1 (4.2)	1 (4.2)	0 (0)	
Prefer not to say	0 (0)	0 (0)	1 (3.8)	
Ethnicity				Fisher's exact test (p=.264)
White	21 (87.5)	21 (87.5)	21 (80.8)	
Not white	1 (4.2)	0 (0)	4 (15.4)	
Unknown/unclear	2 (8.3)	3 (12.5)	1 (3.8)	
Education				$\chi^2_{(2)}$=1.12, p=.570
Not beyond secondary/high school	5 (20.8)	8 (33.3)	6 (23.1)	
Beyond secondary/high school	19 (79.2)	16 (66.7)	20 (76.9)	

Work				Fisher's exact test (p=.436)
Paid labour (employed / self-employed)	10 (41.7)	13 (54.2)	14 (53.8)	
Unpaid labour (unpaid work / homemaker)	3 (12.5)	2 (8.3)	0 (0)	
No labour (retired / student / unemployed)	11 (45.8)	9 (37.5)	12 (46.2)	
Relationship status – civic status				$\chi^2_{(2)}$=.02, p=.990
Married / Living as a couple	7 (29.2)	7 (29.2)	8 (30.8)	
Other (widowed, single, divorced/separated, prefer not to say)	17 (70.8)	17 (70.8)	18 (69.2)	
Relationship status – if ever married				$\chi^2_{(2)}$=2.12, p=.346
Yes	12 (50)	13 (54.2)	18 (69.2)	
No	12 (50)	11 (45.8)	8 (30.8)	
If sought help for mental health difficulties in the last year at least to the level of a GP				$\chi^2_{(2)}$=5.81, p=.055
Yes	17 (70.8)	15 (62.5)	10 (38.5)	
No	7 (29.2)	9 (37.5)	16 (61.5)	
	Mean (SD)	Mean (SD)		*t-test*
Duration of problematic hoarding symptoms (years)	18.13 (9.89)	15.58 (10.15)		$t_{(46)}$=.88, df=46, p=.384

Note. Categories above are the ones used in analysis.

Psychopathology (table 10)

PHQ-9, GAD-7, WASAS. One-way ANOVAs were carried out for total PHQ-9 (Kroenke et al., 2001), total GAD-7 (Spitzer et al., 2006), and total WASAS (Mundt et al., 2002) scores. For each ANOVA, a significant main effect of group on total score was found: $F_{(2, 71)}$=16.57, p<.001, Dunnett T3 (PHQ-9); $F_{(2, 71)}$=11.71, p<.001, Dunnett T3 (GAD-7); and $F_{(2, 71)}$=25.63, p<.001 (WASAS). Multiple comparisons for each ANOVA showed that for each measure, the two hoarding groups were not significantly different from one another: PHQ-9 (p=.684; Dunnett T3); GAD-7 (p=.956; Dunnett T3); WASAS (p=.202). Multiple comparisons also showed that, both had significantly higher scores than the CC group (p<.001).

SI-R. A 3 (group) x 3 (subscale) mixed-model ANOVA was conducted for the SI-R (Frost et al., 2004). Significant main effects were found of subscale ($F_{(2,142)}$=14.44, p<.001) and of group ($F_{(2,71)}$=85.75, p<.001). This was modified by a group x subscale interaction ($F_{(4,142)}$=6.45, p<.001). Simple main effects showed that across each of the subscales, there was consistently a significant main effect of group. Multiple comparisons showed no significant differences between the HWD and HND groups on any of the scores: clutter subscale (p=.391); difficulty discarding subscale (p=.999; Dunnett T3); excessive acquisition subscale (p=.709). . Multiple Comparisons also showed that these groups' scores were all significantly higher than the respective CC scores (p<.001).

Paired t-tests were done for the three within subject variables for each group, giving nine comparisons in total. The acceptable significance level was set to 0.0056 on the basis of Bonferroni correction.

Comparing HWD group scores on the different subscales showed that: the difference between the clutter and difficulty discarding subscales was non-significant

($t_{(23)}$=1.23, df=23, *p*=.230); the difference between the excessive acquisition subscale and the clutter subscale was significant ($t_{(23)}$=3.53, df=23, *p*=.002); and the difference between the excessive acquisition subscale and the difficulty discarding subscale was significant ($t_{(23)}$=4.19, df=23, *p*<.001).

Paired *t*-tests comparing HND group scores on the different subscales showed that: the difference between the clutter and difficulty discarding subscales was non-significant ($t_{(23)}$=.32, df=23, *p*=.749); the difference between the excessive acquisition subscale and the clutter subscale was significant ($t_{(23)}$=3.33, df=23, *p*=.003); and the difference between the excessive acquisition subscale and the difficulty discarding subscale was non-significant ($t_{(23)}$=2.65, df=23, *p*=.014).

Paired *t*-tests comparing CC group scores on the different subscales showed that: the difference between the clutter and difficulty discarding subscales was significant ($t_{(25)}$=-4.26, df=25, *p*<.001); the difference between the excessive acquisition subscale and the clutter subscale was non-significant ($t_{(25)}$=-1.66, df=25, *p*=.111); and the difference between the excessive acquisition subscale and the difficulty discarding subscale was significant ($t_{(25)}$=3.30, df=25, *p*=.003).

Hypothesis (table 10)

A 3 (group) x 3 (subscale) mixed-model ANOVA was conducted for the BAH (Gordon et al., 2013). Significant main effects were found of subscale ($F_{(2,142)}$=61.01, *p*<.001) and of group ($F_{(2,71)}$=11.88, *p*<.001). These were modified by a group x subscale interaction ($F_{(4,142)}$=3.06, *p*=.019), shown in figure 4 below. Simple main effects showed that across each of the subscales, there was a consistent significant main effect of group. Multiple comparisons shown no significant differences between the HWD and HND on any of the scores: harm avoidance (*p*=.651); fear of material deprivation (*p*=.682); attachment disturbance (*p*=.644). Multiple comparisons also

showed that the HWD and the HND scores were all significantly higher than the respective CC scores: harm avoidance (HWD and CC: p=.009; HND and CC: p=.002); fear of material deprivation (HWD and CC: p<001; HND and CC: p<.001); and attachment disturbance (HWD and CC: p<.001; HND and CC: p<.001). . Therefore, there were not significantly higher fears of material deprivation in the HWD group compared to the HND group, and these groups were also similar in terms of scores on the harm avoidance and attachment disturbance subscales.

The above analysis was repeated for the two hoarding groups only, to verify the above analyses (so a 2 (group) x 3 (subscale) mixed-model ANOVA was conducted). Significant main effects were found of subscale ($F_{(2,92)}$=52.10, p<.001) but not of group ($F_{(1,46)}$=.20, p=.654). There was no group x subscale interaction ($F_{(2,92)}$=.01, p=.994), indicating consistent responses across the BAH (Gordon et al., 2013) subscales when only the two hoarding groups were included in the analysis.

Table 10

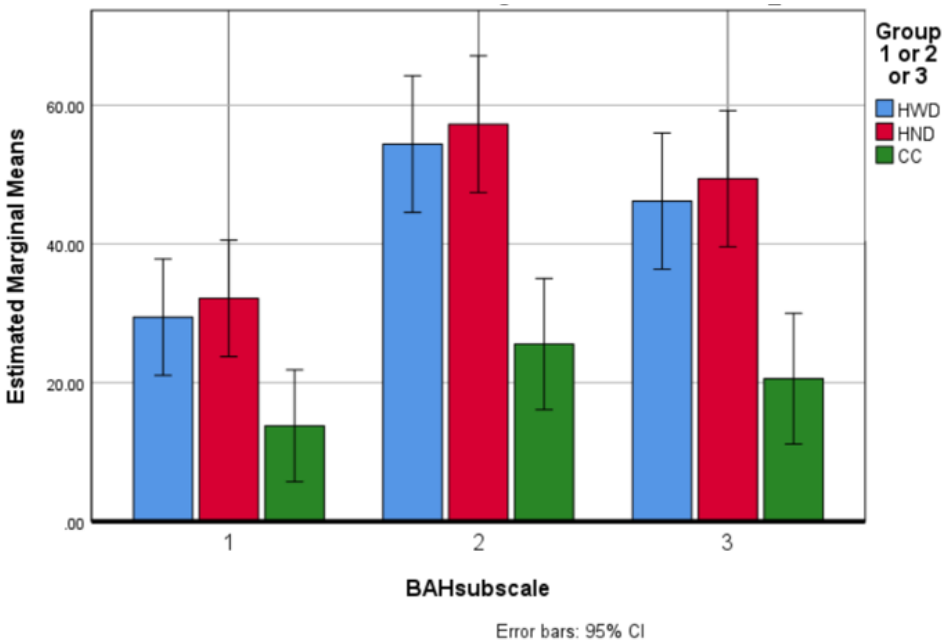
Psychopathology and BAH

Measure	Group			Statistic
	HWD group (n=24)	HND group (n=24)	CC group (n=26)	
	Mean (SD)	Mean (SD)	Mean (SD)	
PHQ-9 total score	13.75 (6.85)[a]	11.75 (7.00)[a]	4.62 (3.37)[b]	$F_{(2,71)}$=16.57, p<.001, Dunnett T3
GAD-7 total score	9.33 (6.13)[a]	10.13 (5.92)[a]	3.38 (4.04)[b]	$F_{(2,71)}$=11.71, p<.001, Dunnett T3
WASAS total score	23.12 (9.67)[a]	20.04 (8.09)[a]	7.35 (7.03) [b]	$F_{(2,71)}$=25.63, p<.001
SI-R scaled scores				
Clutter subscale	3.16 (.66)[a]	2.99 (.71)[a]	.71 (.63)[b]	$F_{(2,71)}$=106.12, p<.001*
Difficulty discarding subscale	2.97 (.54)[a]	2.95 (.63)[a]	1.26 (.98)[b]	$F_{(2,71)}$=43.32, p<.001*, Dunnett T3
Excessive acquisition subscale	2.49 (.64)[a]	2.57 (.80)[a]	.89 (.70)[b]	$F_{(2,71)}$=44.38, p<.001*
BAH scaled scores				
Harm avoidance subscale	29.44 (21.17)[a]	32.15 (24.59)[a]	13.78 (15.51)[b]	$F_{(2,71)}$=5.84, p<.01*
Fear of Material deprivation subscale	54.40 (24.24)[a]	57.27 (27.05)[a]	25.56 (21.22)[b]	$F_{(2,71)}$=13.28, p<.001*
Attachment disturbance subscale	46.18 (23.89)[a]	49.41 (26.50)[a]	20.58 (21.94)[b]	$F_{(2,71)}$=10.85, p<.001*

Note. PHQ-9 = Patient Health Questionnaire-9; GAD-7 = Generalised Anxiety Disorder-7; WASAS = Work and Social Adjustment Scale; SI-R = Saving Inventory-Revised; BAH = Beliefs About Hoarding questionnaire.
Note. Different lettered superscripts indicate significant differences between groups (p<.01); having the same superscript indicates a non-significant difference.
*This is the effect of group for simple main analyses.

Figure 4

Graph of group x subscale interaction for the BAH



Exploratory analyses (table 11)

Correlational analyses. Correlations between the three BAH (Gordon et al., 2013) subscales and three SI-R (Frost et al., 2004) subscales across the HWD and HND groups were conducted. As nine correlations were computed, significance level was subject to a Bonferroni correction; therefore a significance level of $p<.0056$ was required. The strongest correlations were found between a fear of material deprivation and: difficulty discarding ($r = .54$, $N = 48$, $p<.001$); and excessive acquisition ($r = .59$, $N = 48$, $p<.001$). There was no significant correlation between a fear of material deprivation and clutter ($r = .24$, $N = 48$, $p=.104$.

Table 11

Correlational analyses

	SI-R Clutter subscale	SI-R Difficulty discarding subscale	SI-R Excessive acquisition subscale
BAH Harm avoidance subscale	r = .29, N = 48, p=.042	r = .38, N = 48, p=.009	r = .48*, N = 48, ***p*<.001**
BAH Fear of material deprivation subscale	r = .24, N = 48, p=.104	r = .54*, N = 48, ***p*<.001**	r = .59*, N = 48, ***p*<.001**
BAH Attachment disturbance subscale	r = .20, N = 48, p=.165	r = .39, N = 48, p=.007	r = .51*, N = 48, ***p*<.001**

Note. All tests are two-tailed.
* Correlation is significant at the Bonferroni corrected level of p<.0056

Material deprivation experience in hoarders HWD group and HND group participants were divided into three groups according to material deprivation experience: chronic (n = 15); sudden and substantial (whether or not in addition to chronic; n = 9); and none (n = 24). A Kruskal-Wallis test using these groups as the between-subject variable, and the fear of material deprivation BAH (Gordon et al., 2013) subscale as the dependent variable, found no significant difference in subscale scores between these three groups, $\chi^2_{(2)}$=4.25, p=.120

Discussion

The current study examined the historical basis of fear of material deprivation beliefs in hoarding by comparing hoarders reporting early experience of material deprivation (the HWD group), hoarders not reporting this (the HND group) and a benchmark group of community controls (the CC group). It was anticipated that the HWD group would have significantly elevated fear of material deprivation beliefs relative to the HND group; the findings do not support this

hypothesis. Further, the HWD group was also similar to the HND group in terms of harm avoidance and attachment disturbance beliefs; that is, the HND group did not score more highly than the HWD group on these other two beliefs. Overall, however, the findings indicate that a fear of material deprivation may be a driver of hoarding behaviours but most likely this does not arise as a direct result of early material deprivation experience. Correlational analyses found a moderate positive correlation between material deprivation beliefs and both difficulty discarding and excessive acquisition. That there was no significant difference in fear of material deprivation beliefs between HWD participants with early sudden substantial material deprivation experience, and HWD participants with early chronic material deprivation experience, suggests distinguishing between these types of material deprivation may also not be important.

Literature

This was the first study directly examining the strength of fear of material deprivation beliefs in hoarders with and without early material deprivation experience. Previous evidence of hoarding following sudden substantial material deprivation (Greenberg et al, 1990, and Hogstel, 1993, as discussed in Grisham et al., 2006; Marx & Cohen-Mansfield, 2003; Schroepfer & Ingersoll-Dayton, 2001), and of hoarding in the context of childhood material deprivation, is very limited – and further the latter has not been found to be associated with hoarding (Frost & Gross, 1993; Hezel & Hooley, 2014; Landau et al., 2011). Previous research therefore indicates a limited role only for material deprivation experience in the development of hoarding: the results of the current research are consistent with this. That is, the findings do not suggest that early material deprivation experience

is key in the development of fear of material deprivation beliefs: these beliefs may motivate hoarding irrespective of such experience.

Limitations

There are several limitations to this study. One pertains to selection bias, meaning that this study's hoarders may not be representative of the general hoarding population. In particular, there was likely a response bias regarding the recruitment strategies used – for example, as discussed in previous hoarding studies (for instance Woody et al., 2020), hoarders coming forward to participate in research are likely those with more insight into their difficulties. Additionally, participating in the current study required hoarders to discuss any early experiences of material deprivation, so potentially excluding those for whom this felt too difficult. Combined with the limited variation in hoarder demographics in this study, this limits the generalisability of the results. However, a key advantage of the study is that the application of the SCID-RV hoarding module (First et al., 2015) means a clinical sample was used.

A further limitation is the use of retrospective reporting of material deprivation. The reliability of such reports can be reduced by difficulty remembering due to the passing of time, and subjectivity in the memories recalled (Grisham et al., 2006). Research with younger hoarders or a longitudinal and prospective study design may help target this issue.

Theoretical implications

The hoarding model by Gordon et al. (2013), which builds on that by Seaman et al. (2010), suggests that a fear of material deprivation can be an important driver in hoarding. The results of the current study are consistent with this. However, the suggestion that hoarding driven by a fear of material deprivation

stems from early experience of material deprivation is not supported: the results suggest these beliefs can be important in hoarders regardless of any recalled early experience of material deprivation. Whilst this result does not exclude a role for early material deprivation experiences in the development of these beliefs, it indicates that they are not the only (potential) influence. Other (as yet unidentified) experiences may lead to these beliefs. For example, this might include (based on comments made to the trainee by some participants in the current study) communication from previous generations of family members about the possibility of future deprivation and the benefits of parsimony.

Research implications

Following on from the above, future research might consider investigating hoarders' relatives' experiences of material deprivation, and their and hoarders' beliefs around a fear of material deprivation. Correlational analyses could assess the association between relatives' and hoarders' beliefs, with these results also considered in the context of the relatives' deprivation experiences.

As commented above, a longitudinal and prospective study could reduce reliance on retrospective reporting. This could assess, over a series of timepoints, hoarding behaviours and beliefs driving hoarding in individuals alongside any experiences of material deprivation. It is acknowledged that the practicalities of this would pose challenges, particularly ensuring sustained participation for the study duration. The addition of measures to an existing and ongoing online research database similar to the Brain Health Registry (used in Nutley et al., 2022's hoarding study) is one option, though this would mean less rigorous means of identifying hoarding and material deprivation experiences.

As also noted, research with younger hoarders may improve the reliability of reports of material deprivation. Furthermore, this could reduce the possibility of later experiences modifying the initial motivators for hoarding. For example, a study by Tolin et al. (2010) found that hoarders can suffer deprivation / harm to possessions (though that paper's operationalisation of such experience is broader than that in the current paper) post-hoarding symptom onset. Indeed, it may be that the beliefs driving hoarding may change, or change in relative strength, in relation to such later experiences. So, research on pathways *to* hoarding may benefit from considering how journeys *during* hoarding might impact study results.

As part of any future studies, it might be helpful to measure multiple material deprivation experiences (whether pre or post hoarding symptom onset), to assess any additive effect of such experiences on the strength of fear of material deprivation beliefs. It could also be informative to measure the occurrence of specific material deprivation experiences, such as homelessness. Finally, considering how non-material deprivation experiences may impact the strength of material deprivation beliefs relative to other beliefs potentially driving hoarding could also be helpful.

Clinical implications

The results emphasise the importance of a comprehensive and wide-ranging assessment. That is, of not making assumptions about possible experiences influencing the development of fear of material deprivation beliefs that may be a driver for hoarding in an individual, but rather to explore this fully. The results do not point to more concrete clinical implications; further research is required.

Conclusions

This study found that beliefs around a fear of material deprivation can be an important driver for hoarding, but this is likely irrespective of any actual experience of early material deprivation. Theoretical and clinical implications of the study, and its limitations, have been discussed, and studies to explore the findings further have been suggested.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5.* (Fifth ed.). American Psychiatric Publishing.

Archer, C. A., Moran, K., Garza, K., Zakrzewski, J. J., Martin, A., Chou, C.-Y., Uhm, S. Y., Chan, J., Gause, M., Salazar, M., Plumadore, J., Smith, L. C., Komaiko, K., Howell, G., Vigil, O., Bain, D., Stark, S., Mackin, R. S., Eckfield, M., . . . Mathews, C. A. (2019). Relationship between symptom severity, psychiatric comorbidity, social/occupational impairment, and suicidality in hoarding disorder. *Journal of obsessive-compulsive and related disorders*, *21*, 158-164. https://doi.org/10.1016/j.jocrd.2018.11.001

Büscher, T. P., Dyson, J., & Cowdell, F. (2014). The effects of hoarding disorder on families: an integrative review. *Journal of Psychiatric and Mental Health Nursing*, *21*, 491–498. https://doi.org/10.1111/jpm.12098

David, J., Crone, C., & Norberg, M. M. (2022). A critical review of cognitive behavioural therapy for hoarding disorder: How can we improve outcomes? *Clinical psychology and psychotherapy*, *29*(2), 469–488. https://doi.org/10.1002/cpp.2660

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*, 175-191. https://doi.org/10.3758/bf03193146

First, M. B., Williams, J. B., Karg, R. S., & Spitzer, R. L. (2015). *The Structured clinical interview for DSM-5—Research version* American Psychiatric Association.

Frost, R. O., & Gross, R. C. (1993). The hoarding of possessions. *Behaviour Research and Therapy*, *31*(4), 367-381. https://doi.org/10.1016/0005-7967(93)90094-b

Frost, R. O., & Hartl, T. L. (1996). A cognitive-behavioral model of compulsive hoarding. *Behaviour Research and Therapy*, *34*(4), 341-350. https://doi.org/10.1016/0005-7967(95)00071-2

Frost, R. O., Steketee, G., & Grisham, J. (2004). Measurement of compulsive hoarding: saving inventory-revised. *Behaviour Research and Therapy*, *42*, 1163–1182. https://doi.org/10.1016/j.brat.2003.07.00

Gordon, O. M., Salkovskis, P. M., & Oldfield, V. B. (2013). Beliefs and experiences in hoarding. *journal of Anxiety Disorders*, *27*, 328-339. https://doi.org/10.1016/j.janxdis.2013.02.009

Greenberg, D., Witztum, E., & Levy, A. (1990). Hoarding as a psychiatric symptom. *The Journal of Clinical Psychiatry*, *51*(10), 417-421.

Grisham, J. R., Frost, R. O., Steketee, G., Kim, H. J., & Hood, S. (2006). Age of onset of compulsive hoarding. *journal of Anxiety Disorders*, *20*(5), 675–686. https://doi.org/10.1016/j.janxdis.2005.07.004

Hezel, D. M., & Hooley, J. M. (2014). Creativity, personality, and hoarding behavior. *Psychiatry Research*, *220*, 322-327. https://doi.org/10.1016/j.psychres.2014.07.037

Hogstel, M. E. (1993). Understanding hoarding behaviours in the elderly. *Amerrican Journal of Nursing*, *93*(7), 42-45.

IBM Corporation. (2021). *IBM SPSS Statistics for Windows*. In (Version 29.0) IBM Corp.

Kellett, S., Greenhalgh, R., Beail, N., & Ridgway, N. (2010). Compulsive Hoarding: An Interpretative Phenomenological Analysis. *Behavioural and Cognitive Psychotherapy*, *38*, 141–155. https://doi.org/10.1017/S1352465809990622

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: validity of a brief depression severity measure. . *Journal of General Internal Medicine*, *16*, 606–613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x.

Lambe, S. (2015). *Beliefs in Compulsive Hoarding: An examination of their development of time* University of Bath]. Unpublished.

Landau, D., Iervolino, A. C., Pertusa, A., Santo, S., Singh, S., & Mataix-Cols, D. (2011). Stressful life events and material deprivation in hoarding disorder. *journal of Anxiety Disorders*, *25*(2), 192-202. https://doi.org/10.1016/j.janxdis.2010.09.002

Marx, M. S., & Cohen-Mansfield, J. (2003). Hoarding Behavior in the Elderly: A Comparison Between Community-Dwelling Persons and Nursing Home Residents. *International psychogeriatrics*, *15*(3), 289-306. https://doi.org/10.1017/S1041610203009542

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British journal of psychiatry: the journal of mental science*, *180*, 461-464. https://doi.org/10.1192/bjp.180.5.461

Nutley, S. K., Read, M., Martinez, S., Eichenbaum, J., Nosheny, R. L., Weiner, M., Mackin, R., & Mathews, C. A. (2022). Hoarding symptoms are associated with higher rates of disability than other medical and psychiatric disorders across multiple domains of functioning. *BMC Psychiatry*, *22*. https://doi.org/10.1186/s12888-022-04287-2

Qualtrics. (2020). *Qualtrics XM*. In Qualtrics XM. https://www.qualtrics.com

Samuels, J. F., Bienvenu, O. J., Grados, M. A., Cullen, B., Riddle, M. A., Liang, K.-y., Eaton, W. W., & Nestadt, G. (2008). Prevalence and correlates of hoarding behavior in a community-based sample. *Behaviour Research and Therapy*, *46*(7), 836-844. https://doi.org/10.1016/j.brat.2008.04.004

Schroepfer, T., & Ingersoll-Dayton, B. (2001). Caregiver Mastery of Hoarding Behavior in a Patient with Dementia. *Clinical Gerontologist*, *22*(3-4), 109-135. https://doi.org/10.1300/J018v22n03_10

Seaman, C., Oldfield, V. B., Gordon, O., Forrester, E., & Salkovskis, P. M. (2010). The Impact of Symptomatic Hoarding in OCD and its Treatment. Behavioural and Cognitive Psychotherapy. *38*(2), 157-171. https://doi.org/10.1017/S1352465809990695

Shafran, R., & Tallis, F. (1996). Obsessive-Compulsive Hoarding: A Cognitive-Behavioural Approach. *Behavioural and Cognitive Psychotherapy*, *24*(3), 209-221. https://doi.org/10.1017/S1352465800015071

Spitzer, R. L., Kroenke, K., Williams, J. B., & Lowe, B. (2006). A brief measure for assessing generalised anxiety disorder: the GAD-7. *Archives of Internal Medicine*, *22*, 1092–1097. https://doi.org/10.1001/archinte.166.10.1092

Steketee, G., & Frost, R. (2003). Compulsive hoarding: current status of the research. *Clinical psychology review*, *23*(7), 905–927. https://doi.org/10.1016/j.cpr.2003.08.002

The British Psychological Society. (2015). *A Psychological Perspective on Hoarding - DCP Good Practice Guidelines*. The British Psychological Society.

The British Psychological Society. (2016). *Understanding Hoarding - When our relationship with possessions goes wrong*. The British Psychological Society.

Thew, G. R., & Salkovskis, P. M. (2016). Hoarding among older people: an evaluative review. *The Cognitive Behaviour Therapist*, *9*(e32). https://doi.org/10.1017/S1754470X16000180

Tolin, D. F., Meunier, S. A., Frost, R. O., & Steketee, G. (2010). Course of compulsive hoarding and its relationship to life events. *Depression and anxiety*, *27*(9), 829-838. https://doi.org/10.1002/da.20684

Woody, S. R., Lenkic, P., Bratiotis, C., Kysowa, K., Luu, M., J, E.-V., Frost, R. O., Lauster, N., Steketee, G., & Tolin, D. F. (2020). How well do hoarding research samples represent cases that rise to community attention? *Behaviour Research and Therapy*, *126*. https://doi.org/10.1016/j.brat.2020.103555

Executive Summary

Hoarding Disorder – investigating the development of beliefs about possessions

What did the study address and why?

- Individuals with Hoarding Disorder (HD) have varied background experiences, suggesting there may be differing pathways to this condition. This includes that there are a few examples of people who have developed hoarding behaviours in the context of sudden substantial material deprivation, and childhood chronic material deprivation (though research has not found a relationship between the latter and hoarding).
- Gordon et al., 2013's hoarding model (which builds on Seaman et al., 2010's model) suggests there are three motivators for hoarding. One of these, *fear of material deprivation*, is posited in the model to result from early experience of material deprivation. The current study sought to test this proposal.

What did the study involve?

- Beliefs about hoarding were measured in three groups of adult participants: 1) 24 hoarders with experience of early material deprivation (the HWD group); 2) 24 hoarders with no experience of early material deprivation (the HND group); and 3) a community control (CC) group of 26 non-hoarders.
- Due to their differing background experiences, it was expected that the HWD group would have stronger *fear of material deprivation* beliefs than the HND group, and that the other types of beliefs (*harm avoidance* and *attachment disturbance*) driving hoarding would be stronger in the HND group than the HWD group.

What were the key results?

- The HWD and HND groups did not differ in how much they endorsed *fear of material deprivation* beliefs, nor the other two beliefs driving hoarding. Further, all the hoarding-related beliefs in the HWD and HND groups were elevated compared to the CC group.
- It was also found that *fear of material deprivation* beliefs did not differ in strength between hoarders with sudden substantial material deprivation experience, and hoarders with chronic material deprivation experience.

What do the results mean?

- The results indicate that whilst *fear of material deprivation* beliefs can motivate hoarding, this is likely irrespective of early material deprivation experience. This reduced role for early material deprivation is in keeping with previous studies suggesting a limited role for early material deprivation in hoarding.
- Differentiating between sudden substantial, and chronic, early material deprivation might not be necessary.

What are the findings' implications?

- The findings' theoretical implications are that Gordon et al. (2013)'s proposal that early material deprivation experience leads to hoarding driven by a *fear of material deprivation* is not substantiated – though the results do not exclude early material deprivation leading to these beliefs in some individuals. However, the model appears to be correct in holding that *fear of material deprivation* can be an important motivator for hoarding. This raises the question of what other experiences might lead to the development of *fear of material deprivation* beliefs.

- The results' clinical implications are to stress the need for thorough assessment to investigate any experiences potentially leading to the development of *fear of material deprivation* beliefs motivating hoarding.

What are limitations of the study?

- Limitations include that the hoarders in this study may not be representative of hoarders more generally, for instance regarding their insight levels (which may be raised). It is also possible that some individuals did not wish to take part in the research because reporting on their past material deprivation felt too hard. Though these issues limit the results' generalisability, a strength of the study is that it used a clinical sample of hoarders.
- The use of retrospective reporting (on material deprivation) also raises potential questions around the reliability of the information provided.

What research might be helpful in future?

- It would be helpful to investigate what else might lead to developing *fear of material deprivation* beliefs. One approach could be to assess how hoarders' relatives' experiences and beliefs around material deprivation might impact hoarders' beliefs. Another would be a longitudinal and prospective study assessing the development of hoarding behaviours and beliefs, and tracking how this relates to any experiences of material deprivation.
- Studies with younger hoarders would help mitigate the shortcomings of retrospective reports, and also limit the opportunity for later experiences to potentially modify the beliefs driving hoarding.
- Future research might also investigate multiple and/or specific material deprivation experiences, and how non-material deprivation experiences might impact the relative strengths of the different beliefs motivating hoarding.

Reflective Connecting Narrative

Research

The research I have conducted during the doctorate has been guided by my desire to help develop understanding of important issues in clinical psychology, with the hope of supporting the provision of care in these areas. As part of this, I also wished to expand my own research skills, including by conducting both quantitative and qualitative studies.

TDRP and SRL

I had learnt a little about hoarding prior to the doctorate, and I recall being struck by the devastating impact hoarding can have on individuals and those around them. I was therefore keen to conduct research in this area, and also learn about an issue that was largely new to me.

My TDRP and SRL took shape over what felt like a long period of exploring and scrutinizing research ideas, with the support of my supervisor. I found this process very helpful in teaching me how to manage the challenges of translating research ideas into practice. Further, undertaking these studies from start to finish taught me to manage the complex issues that can arise over the course of the research process. For example, for my SRL, producing a narrative synthesis of the breadth of findings I identified in the reviewed papers was a long and at times an arduous process. Regarding my TDRP, recruitment for participants who hoard was challenging, and took over a year. The support I had from different individuals and organisations with this was invaluable, and I am very grateful to everyone who participated and who helped me recruit. My impression when speaking to some (not all) hoarders was that feeling shame regarding their difficulties made taking part hard; I wondered if this was one reason recruitment was so difficult.

SIP

Much of my pre-doctoral experience involved working with children and young people (CYP), their families and carers, and the systems around them. This had involved working with CYP with Autism Spectrum Disorder (ASD), through which I had seen different ways in which CYP and families/carers experienced and managed this diagnosis. Completing my SIP on the ASD diagnostic procedure felt important: looking at how this diagnosis can come about, and how service users are – and wish to be – supported with this.

Collaborating with different individuals to develop and undertake this research taught me how a breadth of clinical, research, academic, and first-hand experience can be brought together to develop a study that feels worthwhile to different individuals. Recruitment was again challenging – I greatly appreciated the support I received with this, and I am very grateful to the participants for sharing their views with me. That the results of the project have identified meaningful ways of supporting the service to help its service users feels very worthwhile.

Overview and looking forward

I am excited about sharing the results of my research with broad audiences, so contributing to the expansion of knowledge on these issues. I hope that the findings will be helpful to many others.

Going forward, I would like to use the skills and knowledge I have developed during the doctorate to expand the remit of care available for others. My experiences across the doctorate have impressed upon me the importance of doing this thoughtfully and respectfully with others, and ensuring as best I can that I am providing input tailored to the specific needs of those who I am working with.

Acknowledgements

I would first like to thank Prof Paul Salkovskis, my main research supervisor for my research studies. I have greatly appreciated Paul's support, encouragement and understanding throughout the doctorate.

Thank you also to my other supervisors and my course tutors for their support (in alphabetical order): Dr Jennifer Chapman; Dr Sarah Coles; Dr Brynjar Halldorsson; Dr Matthew Hotton; Dr Fiona McFarlane; and Dr James Stacey. I am also thankful to the Oxford Health NHS Foundation Trust Child and Adolescent Mental Health Service Neurodevelopmental Conditions Service, within which I conducted my SIP. I additionally wish to thank Ellie Kerry, with whom I worked on my SRL – I really appreciated Ellie's hard work and her commitment to my SRL.

I am also very grateful to all the individuals/organisations who gave their time to support my research – including through participating, and helping with study development and recruitment. My research could not have been completed without their help.

Finally, I would like to thank my loving family, and also my friends and all others who have supported me before and during the doctorate.

Appendix A

SRL and TDRP Journal submission guide

Journal of Obsessive-Compulsive and Related Disorders submission guideline extracts (please note only parts considered relevant have been extracted)

Your Paper Your Way

We now differentiate between the requirements for new and revised submissions. You may choose to submit your manuscript as a single Word or PDF file to be used in the refereeing process. Only when your paper is at the revision stage, will you be requested to put your paper in to a 'correct format' for acceptance and provide the items required for the publication of your article.
To find out more, please visit the Preparation section below.

SUBMISSION TYPES

Research paper: Clinical and non-clinical research dealing with all aspects of obsessive-compulsive disorder (OCD) and related conditions (OC spectrum disorders; e.g., trichotillomania, hoarding, body dysmorphic disorder)

Review: The journal welcomes systematic reviews and meta-analysis that make valuable contributions on all aspects of OCD-related disorders.

Short communication: A condensed paper with a brief scientific message.

Correspondence: Letters in response to papers published in journal.

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:
- E-mail address
- Full postal address

All necessary files have been uploaded:
Manuscript:
- Include keywords
- All figures (include relevant captions)
- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided
- Indicate clearly if color should be used for any figures in print

Graphical Abstracts / Highlights files (where applicable)
Supplemental files (where applicable)

Further considerations
- Manuscript has been 'spell checked' and 'grammar checked'
- All references mentioned in the Reference List are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet)
- A competing interests statement is provided, even if the authors have no competing interests to declare
- Journal policies detailed in this guide have been reviewed
- Referee suggestions and contact details provided, based on journal requirements

Studies in humans and animals

If the work involves the use of human subjects, the author should ensure that the work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. The manuscript should be in line with the Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals and aim for the inclusion of representative human populations (sex, age and ethnicity) as per those recommendations. The terms sex and gender should be used correctly.

Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed.

All animal experiments should comply with the ARRIVE guidelines and should be carried out in accordance with the U.K. Animals (Scientific Procedures) Act, 1986 and associated guidelines, EU Directive 2010/63/EU for animal experiments, or the National Research Council's Guide for the Care and Use of Laboratory Animals and the authors should clearly indicate in the manuscript that such guidelines have been followed. The sex of animals must be indicated, and where appropriate, the influence (or association) of sex on the results of the study.

Informed consent and patient details

Studies on patients or volunteers require ethics committee approval and informed consent, which should be documented in the paper. Appropriate consents, permissions and releases must be obtained where an author wishes to include case details or other personal information or images of patients and any other individuals in an Elsevier publication. Written consents must be retained by the author but copies should not be provided to the journal. Only if specifically requested by the journal in exceptional circumstances (for example if a legal issue arises) the author must provide copies of the consents or evidence that such consents have been obtained. For more information, please review the Elsevier Policy on the Use of Images or Personal Information of Patients or other Individuals. Unless you have written permission from the patient (or, where applicable, the next of kin), the personal details of any patient included in any part of the article and in any supplementary materials (including all illustrations and videos) must be removed before submission.

Declaration of Interest

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential conflicts of interest include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. If no such conflict of interest exists, please include the statement 'The authors declare no conflict of interest.' Authors should upload this statement as a separate file to the submission system at the Attach/Upload Files step.

Editors for JOCRD must disclose this position and how it was handled within the review process as part of their conflict of interest statement. We recommend using the following text: Given their role as Editor/Associate Editor/Guest Editor, [NAME] had no involvement in the peer-review of this article and has no access to information regarding its peer-review. Full responsibility for the editorial process for this article was delegated to [NAME of delegated editor].

Declaration of generative AI in scientific writing

The below guidance only refers to the writing process, and not to the use of AI tools to analyse and draw insights from data as part of the research process.

Where authors use generative artificial intelligence (AI) and AI-assisted technologies in the writing process, authors should only use these technologies to improve readability and language. Applying the technology should be done with human oversight and control, and authors should carefully review and edit the result, as AI can generate authoritative-sounding output that can be incorrect, incomplete or biased. AI and AI-assisted technologies should not be listed as an author or co-author, or be cited as an author. Authorship implies responsibilities and tasks that can only be attributed to and performed by humans, as outlined in Elsevier's AI policy for authors.

Authors should disclose in their manuscript the use of AI and AI-assisted technologies in the writing process by following the instructions below. A statement will appear in the published work. Please note that authors are ultimately responsible and accountable for the contents of the work.

Disclosure Instructions

Authors must disclose the use of generative AI and AI-assisted technologies in the writing process by adding a statement at the end of their manuscript in the core manuscript file, before the References list. The statement should be placed in a new section entitled 'Declaration of Generative AI and AI-assisted technologies in the writing process'.

Statement: During the preparation of this work the author(s) used [NAME TOOL / SERVICE] in order to [REASON]. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

This declaration does not apply to the use of basic tools for checking grammar, spelling, references etc. If there is nothing to disclose, there is no need to add a statement.

Submission declaration and verification

Submission of an article implies that the work described has not been published previously (except in the form of an abstract, a published lecture or academic thesis, see 'Multiple, redundant or concurrent publication' for more information), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder. To verify compliance, your article may be checked by Crossref Similarity Check and other originality or duplicate checking software.

Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Content should make no assumptions about the beliefs or commitments of any reader; contain nothing which might imply that one individual is superior to another on the grounds of age, gender, race, ethnicity, culture, sexual orientation, disability or health condition; and use inclusive language throughout. Authors should ensure that writing is free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions. We advise to seek gender neutrality by using plural nouns ("clinicians, patients/clients") as default/wherever possible to avoid using "he, she," or "he/she." We recommend avoiding the use of descriptors that refer to personal attributes such as age, gender, race, ethnicity, culture, sexual orientation, disability or health condition unless they are relevant and valid. When coding terminology is used, we recommend to avoid offensive or exclusionary terms such as "master", "slave", "blacklist" and "whitelist". We suggest using alternatives that are more appropriate and (self-) explanatory such as "primary", "secondary", "blocklist" and "allowlist". These guidelines are meant as a point of reference to help identify appropriate language but are by no means exhaustive or definitive.

Author contributions

For transparency, we encourage authors to submit an author statement file outlining their individual contributions to the paper using the relevant CRediT roles: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualization; Roles/Writing - original draft; Writing - review & editing. Authorship statements should be formatted with the names of authors first and CRediT role(s) following. More details and an example.

Role of the funding source

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement, it is recommended to state this.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service ↗ available from Elsevier's Author Services.

Systematic Review or Meta-analysis

For systematic reviews and meta-analysis the journal recommends following the PRISMA guidelines (http://www.prisma-statement.org/)(http://www.prisma-statement.org/).

NEW SUBMISSIONS

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process.
As part of the Your Paper Your Way service, you may choose to submit your manuscript as a single file to be used in the refereeing process. This can be a PDF file or a Word document, in any format or lay-out that can be used by referees to evaluate your manuscript. It should contain high enough quality figures for refereeing. If you prefer to do so, you may still provide all or some of the source files at the initial submission. Please note that individual figure files larger than 10 MB must be uploaded separately.

References

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the article number or pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

Formatting requirements

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.
If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.
Divide the article into clearly defined sections.

Please ensure the text of your paper is double-spaced—this is an essential peer review requirement.

Figures and tables embedded in text

Please ensure the figures and the tables included in the single file are placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file. The corresponding caption should be placed directly below the figure or table.

REVISED SUBMISSIONS

Use of word processing software

Regardless of the file format of the original submission, at revision you must provide us with an editable file of the entire article. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier). See also the section on Electronic artwork. To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results. If the focus of the paper is on a disorder other than OCD (as defined in DSM-IV.TR), provide a rationale for including the disorder as an obsessive-compulsive related disorder (see Editorial Guidance section).

Methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

Results

Results should be clear and concise.

Discussion

This should explore the significance of the results of the work, not repeat them. Avoid extensive citations and discussion of published literature. Be sure to include limitations of the present study and suggestions for future research.

Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

- ***Title.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- ***Author names and affiliations.*** Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. You can add your name between parentheses in your own script behind the English transliteration. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
- ***Corresponding author.*** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about Methodology and Materials. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**
- ***Present/permanent address.*** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Highlights

Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Graphical abstract

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, it is recommended to include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

Reference formatting

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the article number or pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct. If you do wish to format the references yourself they should be arranged according to the following examples:

Reference style

Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Seventh Edition, ISBN 978-1-4338-3215-4, copies of which may be ordered online ↗ .

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

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*, Article 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.). 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). E-Publishing Inc.

Reference to a website:

Powertech Systems. (2015). *Lithium-ion vs lead-acid cost analysis.* Retrieved from http://www.powertechsystems.eu/home/tech-corner/lithium-ion-vs-lead-acid-cost-analysis/. Accessed January 6, 2016

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.

Reference to software:

Coon, E., Berndt, M., Jan, A., Svyatsky, D., Atchley, A., Kikinzon, E., Harp, D., Manzini, G., Shelef, E., Lipnikov, K., Garimella, R., Xu, C., Moulton, D., Karra, S., Painter, S., Jafarov, E., & Molins, S. (2020, March 25). *Advanced Terrestrial Simulator (ATS) v0.88 (Version 0.88).* Zenodo. https://doi.org/10.5281/zenodo.3727209.

Journal abbreviations source

Journal names should be abbreviated according to the List of Title Word Abbreviations ↗ .

Appendix B

SIP Journal submission guide

Relevant extracts of submission guidelines of Autism

DESCRIPTION | AIMS AND SCOPE | EDITORIAL BOARD | ABSTRACTING / INDEXING | SUBMISSION GUIDELINES

This Journal is a member of the Committee on Publication Ethics

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/autism to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Autism will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. What do we publish?
   - 1.1 Aims & Scope
   - 1.2 Article types
   - 1.3 Writing your paper
2. Editorial policies
   - 2.1 Peer review policy
   - 2.2 Authorship
   - 2.3 Acknowledgements
   - 2.4 Funding
   - 2.5 Declaration of conflicting interests
   - 2.6 Research ethics and patient consent
   - 2.7 Clinical trials
   - 2.8 Reporting guidelines
   - 2.9 Data
3. Publishing policies
   - 3.1 Publication ethics
   - 3.2 Contributor's publishing agreement
   - 3.3 Open access and author archiving
4. Preparing your manuscript
   - 4.1 Formatting
   - 4.2 Artwork, figures and other graphics
   - 4.3 Supplementary material
   - 4.4 Terminology
   - 4.5 Reference style
   - 4.6 English language editing services
5. Submitting your manuscript
   - 5.1 ORCID
   - 5.2 Information required for completing your submission
   - 5.3 Lay Abstracts
   - 5.4 Permissions
6. On acceptance and publication
   - 6.1 SAGE Production
   - 6.2 Online First publication
   - 6.3 Access to your published article
   - 6.4 Promoting your article
7. Further information

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the Aims & Scope.

1.2 Article Types

The Journal considers the following kinds of article for publication:

1. Research Reports. Full papers describing new empirical findings;
2. Review Articles

   (a) general reviews that provide a synthesis of an area of autism research;

   (b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.

   Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [**200 words maximum**], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

3. Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.
4. Letters to the Editors. Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

Back to top

2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

2.4.1 National Institutes of Health (NIH) funded articles

If you have received NIH funding for your research, please state this in your submission and if your paper is accepted by *Autism* an electronic version of the paper will automatically be sent to be indexed with the National Library of Medicine's PubMed Central as stipulated in the NIH policy .

2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the SAGE Journal Author Gateway. In particular, for working reporting on the development or evaluation of interventions the ICJME Conflict of Interest form provides an excellent template for considering a range of potential sources of conflict, and this can be uploaded and submitted with your manuscript if relevant.

Where an Editor of Autism is a lead or contributing author to a paper submitted to publication, the paper is always handled through the peer review process by another member of the Editor team and three reviews are obtained in each case. A statement is also published on each article where this occurs.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals , and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

2.8.1 Transparent reporting of trials

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

The What Works Clearinghouse (WWC) guidelines should be followed when submitting in single-case design (SCD) and meet the standards outlined for internal validity of the SCD.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

2.8.2 Sample selection and demographic characteristics

Autism now requires authors to report the following information for all Research Reports (including systematic reviews):

i. procedures for sample selection and recruitment; and
ii. major demographic characteristics, including age, gender, race/ethnicity and socioeconomic status.

Including this information will provide greater clarity regarding sample characteristics and generalisability of the findings, even when such characteristics are not used in the analysis (although we encourage investigation of subgroup differences, where possible). It should also encourage researchers to consider the way in which context and culture contribute to their findings.

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., "specific data on socioeconomic status and educational attainment levels were not recorded"). Manuscripts that contain neither the required information nor an appropriate statement will be returned prior to consideration by the editors.

2.8.3 Community involvement

Autism encourages research that is actively carried out 'with' or 'by' members of the Autistic and autism communities (rather than 'to', 'about', or 'for' them), often referred to as 'co-production', 'participatory research', 'patient and public involvement' or 'integrated knowledge translation'.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution. We recommend that authors follow the BMJ's editorial guidelines for documenting how community stakeholders were involved in their research.

If community members were not involved in the study, authors should state this.

For more details about the reasoning behind this journal requirement, and editorial expectations of authors, please download this FAQs document.

2.9 Data Policy Statement

Autism supports open research practices and FAIR principles . As such encourages authors to share their data wherever possible and submit their data (or a link to it) and where applicable, their syntax/command files for the analyses presented in the contribution. Authors can make data available through a third party data repository or on the journal website as a supplementary data file .

If cited data is restricted (e.g. classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors should notify the editor at the time of submission. The editor shall have full discretion to follow their journal's policy on restricted data, including declining to review the manuscript or granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

Where data is sensitive and cannot be shared in an open forum, authors are encouraged to share metadata and provide a contact for requesting access if the raw data itself cannot be made available.

Data can be submitted with your article and hosted on the SAGE *Autism* website where we work with Figshare to host data content. Authors can use a recognised third party data repository service to host their data such as Open Science framework . Authors may use their institution's data sharing repository.

Autism also encourages authors to delineate clearly the analytic procedures upon which their published claims rely, and where possible provide access to all relevant analytic materials. If such materials are not published with the article, we encourage authors to share to the greatest extent possible through a digital repository (above).

Autism encourages authors to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier. In sum, data should be referenced and cited, where possible, as an intellectual product of value.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Autism offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

4. Preparing your manuscript for submission

4.1 Formatting

Autism asks that authors use the APA style for formatting. The APA Guide for New Authors can be found on the APA website, as can more general advice for authors .

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Terminology

4.4.1 Terminology about autism and autistic people

Autism has researched and produced its own guidance on terminology and language used in autism research. Please consult the guide here: autism terminology guidelines.

4.4.2 Language used to discuss race and ethnicity

Likewise, *Autism* has also produced the following guidance to be considered when writing about race and ethnicity. Please consult the guide here: race and ethnicity language guidelines.

4.5 Reference style

Autism adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

Autism is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID . ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Lay Abstracts

As part of your submission you will be asked to provide a lay abstract of your article. Lay abstracts are a brief (max 250 words) description of the paper that is easily understandable. These abstracts will be made widely available (to the general public, and particularly to autistic people and their families). As such, lay abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

Authors may consider the following questions when composing their lay abstract.

a. What is already known about the topic?
b. What this paper adds?
c. Implications for practice, research or policy

Authors may also find the following resources helpful on this topic:

- How to write a summary paragraph
- Self Advocacy Resource and Technical Assistance Center (SARTAC): Plain Language
- Center for Plain Langauage: Five steps to Plain Language

5.4 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

Back to top

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Autism editorial office as follows:

Katie Maras
Department of Psychology
University of Bath, UK
Email: katiemaras.autism@gmail.com

Appendix C

SRL Further explanation of the inclusion/exclusion criteria

Issue	Explanation and/or clarifications
	Issue: study types
Definitions of study types	For the purposes of this SRL, articles were not automatically categorised as the study-type they described themselves as.
	Issue: participants/population
Further detail on specific inclusion/exclusion criteria	Further detail on the inclusion criteria: the human adults who hoard/hoarded need not form the sample (this could be formed of individuals/organisations reporting on individuals who hoard/hoarded). Exclusion criteria: human children (individuals aged under 18 years); samples composed of both children and adults who hoard/hoarded where the data relating to adults could not be separately identified; non-human animals who hoard/hoarded; adults who do not hoard (if they are alive) or did not hoard (if they are deceased); articles focusing exclusively on animal hoarding.
Age	Where the minimum age of individuals who hoard/hoarded was not stated specifically, the inclusion criteria regarding age could be considered as met if other data were not considered to contradict this.
Identification of hoarding	Hoarding could be identified using information from any source, though a means of identifying hoarding as a *difficulty*, *in and of itself*, was required. This meant the following did not

	suffice for inclusion in this SRL: the identification of some hoarding symptoms solely as part of another disorder; simply saying hoarding was present without further explanation (so simply using yes/no criteria to identify hoarding was insufficient) – in particular the hoarding was required to be at a level indicative of the individual having a *difficulty* (as defined by the authors) with hoarding. However, a clinical diagnosis of hoarding was not required. For living individuals, hoarding behaviour could be identified: i) by way of a clinical diagnosis of hoarding; ii) using an assessment/measure with the person themselves; iii) using an assessment/measure in the person's living environment (such as of clutter levels); and/or iv) by some other specified criteria/approach (for example, an individual meeting the criteria for hoarding difficulties set by an organisation providing support for this). For deceased individuals, some means by which the individual was identified (by any person/organisation) as having had (or likely to have had) difficulties with hoarding was required. Less stringent criteria were applied for deceased individuals due to it potentially being harder to identify hoarding in such situations.
Focus on object, rather than animal hoarding	Object hoarding was focused on due to the differences between object and animal hoarding meaning they potentially hold different risks (Frost, Patronek, et al., 2011).

	Concentrating this SRL on object hoarding allowed the risks associated with this to be focused upon. Articles addressing both object and animal hoarding were included if risk issues did not focus on the former. Where possible, only the data specific to object hoarding were extracted (unless it was relevant to do otherwise).
	Issue: main outcome
Information sources	The outcomes could be formed of information from any source within a paper (and if multiple sources contributed to the same/different outcome(s), all would be taken into account).
Identification of a risk	The main outcome was required to either identify the presence of risk or strongly indicate the presence of risk. Specifically: • Some criteria were required to have been applied to identify the risk (though the criteria need not have been set out in detail). • Simply describing the presence of a risk issue (such as just describing hoarded items) or providing a photograph of a risk issue without applying some criteria to this was not sufficient. • An example of what could be eligible is using all/part of a questionnaire, including one devised by the authors.

- In the case of deceased individuals, the main outcome could be the result of procedures to investigate deaths. This was permitted for pragmatic reasons.

Types of risk

- Pre-defined examples of eligible risks were: squalor; harmful environmental issues such as asbestos; problems with the living space's structural integrity; the risks of falls/slips/trips; the risk of items falling; fire risks; damaged utilities (inaccessible utilities were not included in the remit of risk).
- The involvement of a service/agency that deals with a relevant risk could suffice as indication of risk (such as fire or sanitation services). Examples of what this could not include are a cleaning service (as this does not necessarily indicate uncleanliness to the point of it constituting a risk), a de-cluttering service, a health service or involvement with the police (as such service input does not make clear if there was a qualifying type of risk).
- If it was unclear if a potential risk related to the living space, it would not be included (for example if "hygiene" difficulties were identified without stating if this referred to the person or property).
- Similarly, papers were required to provide more detail than just staying something was a hazard, safety risk or health risk, so that the specific issue was clear.

	• Excessive clutter by itself was not considered a risk for the purposes of this SRL, due to this being integral to the identification of hoarding. • The inability to use certain living spaces (or aspects of them – such as sinks, toilets, baths) was not included as a risk in itself.
“Associated with”	This meant a link between hoarding and risk(s) need not necessarily have been made in articles (so identifying a risk in hoarded conditions sufficed). However, in the case of articles reporting on deceased hoarders, information was extracted only on deaths directly attributed to hoarding (where other criteria in this SRL were met).
“Extent of”	This included (not exclusively): the number of individuals within a group of hoarders to whom a risk applies; the average rating for a risk amongst a group of hoarders; individual ratings of risk for individuals in a group of hoarders.

Appendix D

SRL Search strategies

Note:

- the search strategies were developed collaboratively by Fahreen Walji, Professor Paul Salkovskis and a university librarian; and
- the same search strategy (except for the MeSH terms) was used for PsycINFO, MEDLINE and Embase, and a different search strategy was used for Social Services Abstracts.

Search strategy on PsycINFO

1.	(hoarder* or hoarding).ti,ab.
2.	exp Hoarding Behavior/ or exp Hoarding Disorder/
3.	1 or 2
4.	(contaminat* or dirt* or filth* or neglect* or hygien* or unhygienic* or sanit* or unsanit* or squal* or unclean* or infest* or insect* or mice or rats or rodent* or vermin or pest* or mildew or mould* or mold* or rot or rotten* or rotting or odor* or odour* or smell* or fall* or fell or slip* or trip* or garbage or trash or rubbish or damag* or injur* or accident* or casualty or danger* or hazard* or impair* or risk* or endang* or expose* or exposure or harm* or threat* or safe* or unsafe or welfar* or death or dead* or decease* or fatal* or lethal* or asphyx* or fire* or flammable or inflammable or ignit* or combust*).ti,ab.
5.	3 and 4
6.	(bats or squirrels or market* or seed or "supply chain" or honeybee or bird* or fish or toad or zoology or "animal behaviour" or "animal behavior" or frog* or mammal* or bumblebee or bee or farm* or agricultur* or prehistoric or "bronze age" or "iron age" or "stone age" or medieval or roman* or engineering or "game theory" or microbes or ecology or diplomacy or "scatter hoarding" or "scatter-hoarding" or "scatter hoard" or "scatter-hoard" or "food storing" or hamster* or "female rat*" or "male rat*" or consumers or computing or literary or "computer science" or "pharmacy practice" or "knowledge hoarding" or "digital hoarding").ti,ab.
7.	exp Animal Behavior/ or exp Animal Research/
8.	6 or 7
9.	5 not 8
10.	limit 9 to english language
11.	limit 10 to yr="2013 -Current"

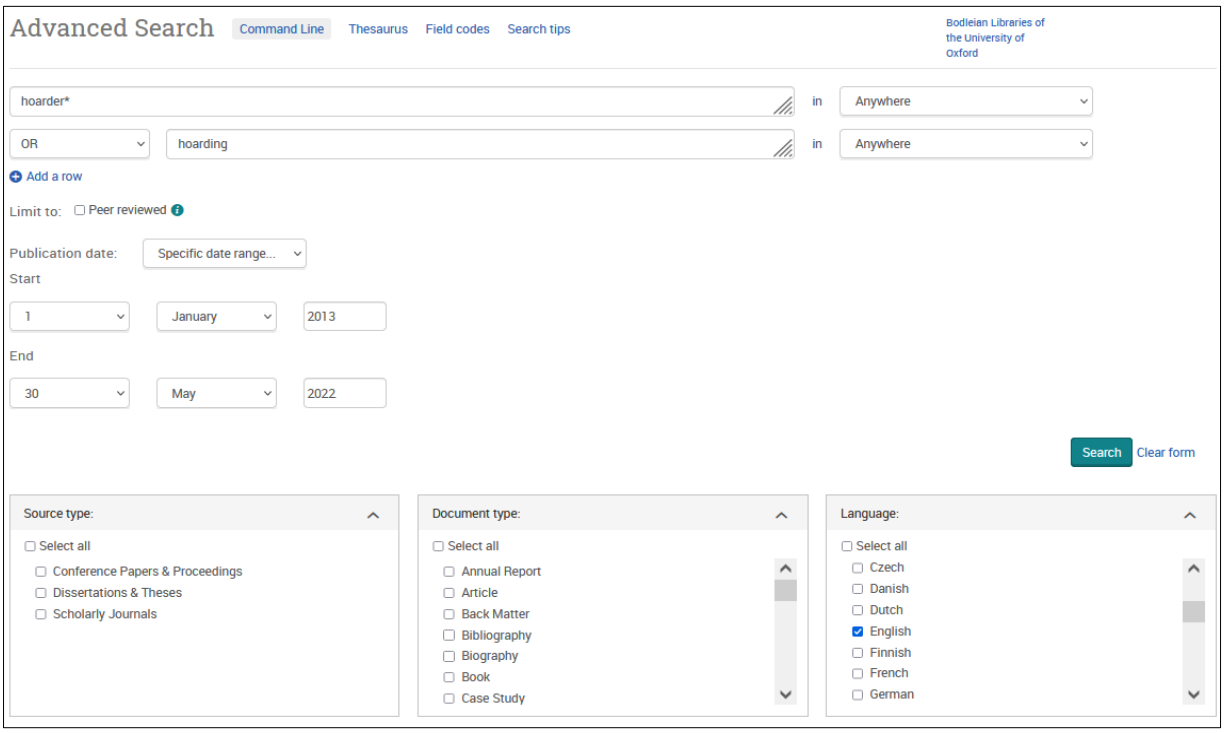
Search strategy on MEDLINE

1	(hoarder* or hoarding).ti,ab.
2	Hoarding/ or Hoarding Disorder/
3	1 or 2
4	(contaminat* or dirt* or filth* or neglect* or hygien* or unhygienic* or sanit* or unsanit* or squal* or unclean* or infest* or insect* or mice or rats or rodent* or vermin or pest* or mildew or mould* or mold* or rot or rotten* or rotting or odor* or odour* or smell* or fall* or fell or slip* or trip* or garbage or trash or rubbish or damag* or injur* or accident* or casualty or danger* or hazard* or impair* or risk* or endang* or expose* or exposure or harm* or threat* or safe* or unsafe or welfar* or death or dead* or decease* or fatal* or lethal* or asphyx* or fire* or flammable or inflammable or ignit* or combust*).ti,ab.
5	3 and 4
6	(bats or squirrels or market* or seed or "supply chain" or honeybee or bird* or fish or toad or zoology or "animal behaviour" or "animal behavior" or frog* or mammal* or bumblebee or bee or farm* or agricultur* or prehistoric or "bronze age" or "iron age" or "stone age" or medieval or roman* or engineering or "game theory" or microbes or ecology or diplomacy or "scatter hoarding" or "scatter-hoarding" or "scatter hoard" or "scatter-hoard" or "food storing" or hamster* or "female rat*" or "male rat*" or consumers or computing or literary or "computer science" or "pharmacy practice" or "knowledge hoarding" or "digital hoarding").ti,ab.
7	exp Animal Experimentation/ or exp Behavior, Animal/
8	6 or 7
9	5 not 8
10	limit 9 to english language
11	limit 10 to yr="2013 -Current"

Search strategy on Embase

(hoarder* or hoarding).ti,ab.
hoarding/ or hoarding disorder/ or obsessive hoarding/
1 or 2
(contaminat* or dirt* or filth* or neglect* or hygien* or unhygienic* or sanit* or unsanit* or squal* or unclean* or infest* or insect* or mice or rats or rodent* or vermin or pest* or mildew or mould* or mold* or rot or rotten* or rotting or odor* or odour* or smell* or fall* or fell or slip* or trip* or garbage or trash or rubbish or damag* or injur* or accident* or casualty or danger* or hazard* or impair* or risk* or endang* or expose* or exposure or harm* or threat* or safe* or unsafe or welfar* or death or dead* or decease* or fatal* or lethal* or asphyx* or fire* or flammable or inflammable or ignit* or combust*).ti,ab.
3 and 4
(bats or squirrels or market* or seed or "supply chain" or honeybee or bird* or fish or toad or zoology or "animal behaviour" or "animal behavior" or frog* or mammal* or bumblebee or bee or farm* or agricultur* or prehistoric or "bronze age" or "iron age" or "stone age" or medieval or roman* or engineering or "game theory" or microbes or ecology or diplomacy or "scatter hoarding" or "scatter-hoarding" or "scatter hoard" or "scatter-hoard" or "food storing" or hamster* or "female rat*" or "male rat*" or consumers or computing or literary or "computer science" or "pharmacy practice" or "knowledge hoarding" or "digital hoarding").ti,ab.
exp animal behavior/ or exp animal experiment/
6 or 7
5 not 8
limit 9 to english language
limit 10 to yr="2013 -Current"

Search strategy on Social Services Abstracts



Appendix E

SRL Quality assessment tool

Kmet et al. (2004) item as modified	Scoring
1. Question / objective sufficiently described	Scoring: Yes (2); Partial (1); No (0).
2. Study design evident and appropriate?	Scoring: Yes (2); Partial (1); No (0).
3. Method of hoarder group selection *or* source of information/input variables described and appropriate? This will include considering the appropriateness of any measures used to identify hoarding and/or its severity.	Scoring: Yes (2); Partial (1); No (0); N/A.
4. Hoarder (and comparison group, if applicable) characteristics sufficiently described?	Scoring: Yes (2); Partial (1); No (0).
5. If interventional and random allocation was possible, was it described?	Scoring: Yes (2); Partial (1); No (0); N/A.
6. If interventional and blinding of investigators was possible, was it reported?	Scoring: Yes (2); Partial (1); No (0); N/A.
7. If interventional and blinding of subjects was possible, was it reported?	Scoring: Yes (2); Partial (1); No (0); N/A.
8. Regarding risk outcome(s) only: outcome and (if applicable) exposure measure(s)	Scoring: Yes (2); Partial (1); No (0); N/A.

	well defined and robust to measurement / misclassification bias? Means of assessment reported?	
9.	Size of hoarding group appropriate?	Scoring: Yes (2); Partial (1); No (0); N/A.
10.	Regarding risk only, analytic methods and/or use of descriptive statistics described/justified and appropriate?	Scoring: Yes (2); Partial (1); No (0); N/A.
11.	Some estimate of variance is reported for the main results? *Note this item was focused on the risk information.*	Scoring: Yes (2); Partial (1); No (0); N/A.
12.	Controlled for confounding? *Note this item was focused on the risk information.*	Scoring: Yes (2); Partial (1); No (0); N/A.
13.	Results regarding risk reported in sufficient detail?	Scoring: Yes (2); Partial (1); No (0).
14.	Conclusions regarding risk supported by the results?	Scoring: Yes (2); Partial (1); No (0).

Operationalisation of the quality assessment tool (in its amended form) followed guidance in the manual provided by Kmet et al. (2014) – copied below:

1. "*Question or objective sufficiently described?*

Yes: Is easily identified in the introductory section (or first paragraph of methods section). Specifies (where applicable, depending on study design) all of the following: purpose, subjects/target population, and the specific

intervention(s) /association(s)/descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is *not* considered sufficiently described.

Partial: Vaguely/incompletely reported (e.g. “describe the effect of” or “examine the role of” or “assess opinion on many issues” or “explore the general attitudes”...); *or* some information has to be gathered from parts of the paper other than the introduction/background/objective section.

No: Question or objective is not reported, or is incomprehensible.

N/A: Should not be checked for this question.

2. *Design evident and appropriate to answer study question?*

   (If the study question is not given, infer from conclusions).

   Yes: Design is easily identified and is appropriate to address the study question / objective.

   Partial: Design and /or study question not clearly identified, but gross inappropriateness is not evident; *or* design is easily identified but only partially addresses the study question.

   No: Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); *or* design cannot be identified.

   N/A: Should not be checked for this question.

3. *Method of subject selection (and comparison group selection, if applicable) or source of information/input variables (e.g., for decision analysis) is described and appropriate.*

Yes: Described and appropriate. Selection strategy *designed* (i.e., consider sampling frame and strategy) to obtain an unbiased sample of the relevant target population or the entire target population of interest (e.g., consecutive patients for clinical trials, population-based random sample for case-control studies or surveys). Where applicable, inclusion/exclusion criteria are described and defined (e.g., “cancer” -- ICD code or equivalent should be provided). *Studies of volunteers:* methods and setting of recruitment reported. *Surveys:* sampling frame/ strategy clearly described and appropriate.

Partial: Selection methods (and inclusion/exclusion criteria, where applicable) are not completely described, but no obvious inappropriateness. Or selection strategy is not ideal (i.e., likely introduced bias) but did not likely seriously distort the results (e.g., telephone survey sampled from listed phone numbers only; hospital based case-control study identified all cases admitted during the study period, but recruited controls admitted during the day/evening only). Any study describing participants only as “volunteers” or “healthy volunteers”. *Surveys:* target population mentioned but sampling strategy unclear.

No: No information provided. *Or* obviously inappropriate selection procedures (e.g., inappropriate comparison group if intervention in women is compared to intervention in men). *Or* presence of selection bias which likely seriously distorted the results (e.g., obvious selection on “exposure” in a case-control study).

N/A: Descriptive case series/reports.

4. *Subject (and comparison group, if applicable) characteristics or input variables/information (e.g., for decision analyses) sufficiently described?*

Yes: Sufficient relevant baseline/demographic information clearly characterizing the participants is provided (or reference to previously published baseline data is provided). Where applicable, reproducible criteria used to describe/categorize the participants are clearly defined (e.g., ever-smokers, depression scores, systolic blood pressure > 140). If “healthy volunteers” are used, age and sex must be reported (at minimum). *Decision analyses:* baseline estimates for input variables are clearly specified.

Partial: Poorly defined criteria (e.g. “hypertension”, “healthy volunteers”, “smoking”). *Or* incomplete relevant baseline / demographic information (e.g., information on likely confounders not reported). *Decision analyses:* incomplete reporting of baseline estimates for input variables.

No: No baseline / demographic information provided. *Decision analyses:* baseline estimates of input variables not given.

N/A: Should not be checked for this question.

5. *If random allocation to treatment group was possible, is it described?*

Yes: *True randomization done - requires a description of the method used (e.g., use of random numbers).*

Partial: Randomization mentioned, but method is not (i.e. it may have been possible that randomization was not true).

No: Random allocation not mentioned although it would have been feasible and appropriate (and was possibly done).

N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.

6. *If interventional and blinding of investigators to intervention was possible, is it reported?*

   Yes: Blinding reported.

   Partial: Blinding reported but it is not clear who was blinded.

   No: Blinding would have been possible (and was possibly done) but is not reported.

   N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.

7. *If interventional and blinding of subjects to intervention was possible, is it reported?*

   Yes: Blinding reported.

   Partial: Blinding reported but it is not clear who was blinded.

   No: Blinding would have been possible (and was possibly done) but is not reported.

   N/A: Observational studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports.

8. *Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?*

   Yes: Defined (or reference to complete definitions is provided) and measured according to reproducible, “objective” criteria (e.g., death, test completion – yes/no, clinical scores). Little or minimal potential for measurement / misclassification errors. *Surveys:* clear description (or reference to clear

description) of questionnaire/interview content and response options. *Decision analyses:* sources of uncertainty are defined for all input variables.

Partial: Definition of measures leaves room for subjectivity, *or* not sure (i.e., not reported in detail, but probably acceptable). *Or* precise definition(s) are missing, but no evidence or problems in the paper that would lead one to assume major problems. *Or* instrument/mode of assessment(s) not reported. Or misclassification errors may have occurred, but they did not likely seriously distort the results (e.g., slight difficulty with recall of long-ago events; exposure is measured only at baseline in a long cohort study). *Surveys:* description of questionnaire/interview content incomplete; response options unclear. *Decision analyses:* sources of uncertainty are defi ned only for some input variables.

No: Measures not defined, or are inconsistent throughout the paper. Or measures employ only ill-defined, subjective assessments, e.g. “anxiety” or “pain.” *Or* obvious misclassification errors/measurement bias likely seriously distorted the results (e.g., a prospective cohort relies on self-reported outcomes among the “unexposed” but requires clinical assessment of the “exposed”). *Surveys:* no description of questionnaire/interview content or response options. *Decision analyses:* sources of uncertainty are not defined for input variables.

N/A: Descriptive case series / reports.

9. *Sample size appropriate?*

Yes: Seems reasonable with respect to the outcome under study and the study design. When statistically significant results are achieved for major outcomes, appropriate sample size can usually be assumed, unless large standard errors

(SE > ½ effect size) and/or problems with multiple testing are evident. *Decision analyses:* size of modeled cohort / number of iterations specified and justified.

Partial: Insufficient data to assess sample size (e.g., sample seems "small" and there is no mention of power/sample size/effect size of interest and/or variance estimates aren't provided). *Or* some statistically significant results with standard errors > ½ effect size (i.e., imprecise results). *Or* some statistically significant results in the absence of variance estimates. *Decision analyses:* incomplete description or justification of size of modeled cohort / number of iterations.

No: Obviously inadequate (e.g., statistically non-significant results and standard errors > ½ effect size; or standard deviations > _ of effect size; or statistically non-significant results with no variance estimates and obviously inadequate sample size). *Decision analyses:* size of modeled cohort / number of iterations not specified.

N/A: Most surveys (except surveys comparing responses between groups or change over time). Descriptive case series / reports.

10. *Analysis described and appropriate?*

Yes: Analytic methods are described (e.g. "chi square"/ "t-tests"/"Kaplan-Meier with log rank tests", etc.) and appropriate.

Partial: Analytic methods are not reported and have to be guessed at, but are probably appropriate. *Or* minor flaws or some tests appropriate, some not (e.g., parametric tests used, but unsure whether appropriate; control group exists but is not used for statistical analysis). *Or* multiple testing problems not addressed.

No: Analysis methods not described and cannot be determined. *Or* obviously inappropriate analysis methods (e.g., chi-square tests for continuous data, SE

given where normality is highly unlikely, etc.). *Or* a study with a descriptive goal / objective is over-analyzed.

N/A: Descriptive case series / reports.

11. *Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/ objective upon which the conclusions are based)?*

    Yes: Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). *Decision analyses:* sensitivity analysis includes all variables in the model.

    Partial: Undefined "+/-" expressions. *Or* no specific data given, but insufficient power acknowledged as a problem. *Or* variance estimates not provided for all main results/outcomes. *Or* inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at "time 1" or "time 2", but does not provide an estimate of the variance around the difference). *Decision analyses:* sensitivity analysis is limited, including only some variables in the model.

    No: No information regarding uncertainty of the estimates. *Decision analyses:* No sensitivity analysis.

    N/A: Descriptive case series / reports. Descriptive surveys collecting information using open-ended questions.

12. *Controlled for confounding?*

    Yes: Randomized study, with comparability of baseline characteristics reported (or non-comparability controlled for in the analysis). Or appropriate control at

the design or analysis stage (e.g., matching, subgroup analysis, multivariate models, etc*). Decision analyses:* dependencies between variables fully accounted for (e.g., joint variables are considered).

Partial: Incomplete control of confounding. *Or* control of confounding reportedly done but not completely described. *Or* randomized study without report of comparability of baseline characteristics. *Or* confounding not considered, but not likely to have seriously distorted the results. *Decision analyses:* incomplete consideration of dependencies between variables.

No: Confounding not considered, and may have seriously distorted the results. *Decision analyses:* dependencies between variables not considered.

N/A: Cross-sectional surveys of a single group (i.e., surveys examining change over time or surveys comparing different groups should address the potential for confounding). Descriptive studies. Studies explicitly stating the analysis is strictly descriptive/exploratory in nature.

13. *Results reported in sufficient detail?*

Yes: Results include major outcomes and all mentioned secondary outcomes.

Partial: Quantitative results reported only for some outcomes. *Or* difficult to assess as study question/objective not fully described (and is not made clear in the methods section), but results seem appropriate.

No: Quantitative results are reported for a subsample only, or “n” changes continually across the denominator (e.g., reported proportions do not account for the entire study sample, but are reported only for those with complete data -- i.e., the category of “unknown” is not used where needed). Or results for some major or mentioned secondary outcomes are only qualitatively reported when

quantitative reporting would have been possible (e.g., results include vague comments such as “more likely” without quantitative report of actual numbers).

N/A: Should not be checked for this question.

14. *Do the results support the conclusions?*

Yes: All the conclusions are supported by the data (even if analysis was inappropriate). Conclusions are based on all results relevant to the study question, negative as well as positive ones (e.g., they aren’t based on the sole significant finding while ignoring the negative results). Part of the conclusions may expand beyond the results, if made in *addition to* rather than instead of those strictly supported by data, and if including indicators of their interpretative nature (e.g., “suggesting,” “possibly”).

Partial: Some of the major conclusions are supported by the data, some are not. *Or* speculative interpretations are not indicated as such. *Or* low (or unreported) response rates call into question the validity of generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).

No: None or a very small minority of the major conclusions are supported by the data. *Or* negative findings clearly due to low power are reported as definitive evidence against the alternate hypothesis. *Or* conclusions are missing. *Or* extremely low response rates invalidate generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/ strategy).

N/A: Should not be checked for this question.”

Where necessary, FW and EK agreed upon further notes to interpret the guidance. A key clarification is that question four was identified as requiring age, sex/gender and ethnicity/race information for a “yes” score.

Appendix F

SRL Quality assessment scores

Study	Quality assessment score (out of 28)
Ayers and Dozier (2015)	16
Bratiotis et al. (2013)	17
Da Cunha et al. (2021)	15
Darke and Duflou (2017)	14
Diefenbach et al. (2013)	15
Dimauro et al. (2013)	17
Drury et al. (2014)	17
Drury et al. (2015)	17
Hall et al. (2013)	20
Luu et al. (2018)	19
McGuire et al. (2013)	16
Nordsletten et al. (2018)	19
Nordsletten, Fernández de la Cruz, et al. (2013)	18
Nordsletten, Reichenberg, et al. (2013)	18
Nutley et al. (2022)	20
Snowdon et al. (2013)	18
Tesauro et al. (2021)	16
Waters et al. (2022)	14
Woody et al. (2020)	18

Appendix G

SRL Division of studies into sample-types

Studies reporting on research samples only:

- Ayers and Dozier (2015)
- Bratiotis et al. (2013)
- Diefenbach et al. (2013)
- Dimauro et al. (2013)
- Drury et al. (2014)
- Drury et al. (2015)
- Hall et al. (2013) – note these authors describe their study as having a "community sample" but this is not in the way described in this SRL
- Nordsletten et al. (2018)
- Nordsletten, Fernández de la Cruz, et al. (2013)
- Nordsletten, Reichenberg, et al. (2013)

Studies reporting on community samples only:

- Da Cunha et al. (2021)
- Luu et al. (2018) – these authors report on three samples
- McGuire et al. (2013)
- Snowdon et al. (2013)
- Tesauro et al. (2021)

Study reporting on community samples and research samples:

- Woody et al. (2020) – these authors report on three community samples and three research samples

Appendix H

SIP Lay abstract

Background. Research suggests that parents/carers of children who are assessed for, and receive a diagnosis of, autism, can find the process around being informed of the diagnosis stressful. This can be for different reasons, for example around how much they feel they have been given helpful guidance on supporting their child. Although there are national guidelines advising services on how to manage this process, research shows these guidelines are not always followed. **Study aims.** The current study took place in a service that conducts autism assessments. It aimed to find out about the wider context around the assessments, parents'/carers' experiences of being informed of a diagnosis, how much the service is following the national guidelines, and how the service could be improved. **What was done.** Nine parents/carers were interviewed. Additionally, wider information was collected on families referred to the service and whose children underwent assessment, to find out more about them. **What was found.** The parents/carers interviewed had varied experiences; sometimes they did, and sometimes they did not, feel the service met their needs. The wider information collected on referrals and assessment showed in particular that most children who had an autism assessment received a diagnosis. **What was done with the findings.** The implications, and recommendations for improvement, stemming from the results were discussed (these focused on how to better meet parent/carer needs, and investigating the high diagnostic rate) and the findings were shared with others, including the service. Ways in which the current study is limited were identified.

Appendix I

SIP NDC service ASD assessment process

The NDC service's ASD assessment process consists of the following steps:

- Taking background information from parents/carers, including a developmental history; and
- Conducting a standardised assessment for ASD (either in-person using the Autism Diagnostic Observation Schedule, second edition (Lord et al., 2012), or digitally using the Oxford Virtual Assessment for Autism Tool (OVAT) to inform diagnosis). Note the OVAT is being developed by the NDC service and is currently going through an ethical approval process for formal research evaluation to take place; and
- A feedback session (sometimes two feedback sessions take place).

Appendix J

SIP Initial approvement correspondence

Below is an extract of correspondence from Oxford Health NHS Foundation Trust providing initial study approval

From: Rhodes Katie (RNU) Oxford Health <Katie.Rhodes@oxfordhealth.nhs.uk>
Sent: 21 June 2021 3:15 PM
To: Walji Fahreen (RNU) Oxford Health <Fahreen.Walji@oxfordhealth.nhs.uk>
Subject: FW: Form

Good afternoon fahreen,

Your audit has been approved.

Upon completion please complete a report. I have attached a template for your convenience.

Kind Regards,

Katie Rhodes
Senior Team Administrator
Buckinghamshire Mental Health Directorate
Oxford Health NHS Foundation Trust
The Whiteleaf Centre | Bierton Road | Aylesbury | HP20 1EG

Caring, Safe and Excellent. If you are interested in becoming a member of our Foundation Trust please join us online at www.oxfordhealth.nhs.uk

From: Bale Rob (RNU) Oxford Health <Rob.Bale@oxfordhealth.nhs.uk>
Sent: 14 June 2021 15:05
To: Rhodes Katie (RNU) Oxford Health <Katie.Rhodes@oxfordhealth.nhs.uk>
Subject: RE: Form

Thanks
approved

Regards

Rob
Dr Rob Bale
Clinical Director and Consultant Psychiatrist, Oxford Health NHS Foundation Trust

Clinical Director, Strategic Clinical Network (Mental Health), NHS England Thames Valley
Oxfordshire, BaNES, Swindon and Wiltshire Mental Health Directorate,
Oxfordhealth NHS Foundation Trust, John Sharich House, Slade Hospital,
Horsepath Driftway, Oxford
OX3 7JH
Email: rob.bale@oxfordhealth.nhs.uk
PA: Ian Horwood, Phone: 01865 902759,
Email: ian.horwood@oxfordhealth.nhs.uk

From: Rhodes Katie (RNU) Oxford Health <Katie.Rhodes@oxfordhealth.nhs.uk>
Sent: 14 June 2021 12:36
To: Bale Rob (RNU) Oxford Health <Rob.Bale@oxfordhealth.nhs.uk>
Subject: FW: Form

Please see attached for your approval

Katie Rhodes
Senior Team Administrator
Buckinghamshire Mental Health Directorate
Oxford Health NHS Foundation Trust
The Whiteleaf Centre | Bierton Road | Aylesbury | HP20 1EG

Caring, Safe and Excellent. If you are interested in becoming a member of our Foundation Trust please join us online at www.oxfordhealth.nhs.uk

From: Lofthouse Emma (RNU) Oxford Health <Emma.Lofthouse@oxfordhealth.nhs.uk>
Sent: 03 June 2021 08:33
To: Rhodes Katie (RNU) Oxford Health <Katie.Rhodes@oxfordhealth.nhs.uk>; Ampofo Jelena (RNU) Oxford Health <Jelena.Ampofo@oxfordhealth.nhs.uk>
Cc: Fahreen Walji <fahreen.walji@hmc.ox.ac.uk>
Subject: FW: Form

Hi both

For sign off, please note Fahreen is keen to start this as soon as possible so would be really grateful for sign off as soon as you can get it.

Best wishes

Emma

From: Fahreen Walji <fahreen.walji@hmc.ox.ac.uk>
Sent: 03 June 2021 08:29

To: Lofthouse Emma (RNU) Oxford Health <Emma.Lofthouse@oxfordhealth.nhs.uk>
Subject: Form

This email originated from outside of Oxford Health. Please consider carefully when choosing to open attachments, click links or deal with unexpected or unusual requests.

Dear Emma,

I hope you are well. Please find attached my completed form for my study.
Thanks again for all your help.
Best wishes,
Fahreen

Fahreen Walji
Trainee Clinical Psychologist | OXICPT |https://oxicptr.web.ox.ac.uk
Oxford Health NHS Foundation Trust | University of Oxford | Isis Education Centre | Warneford Hospital | Oxford | OX3 7JX

Appendix K

SIP Recruitment process

Recruitment initially took place through NDC service clinicians involved in ASD assessments first identifying potential participants, and the latter then either being approached by clinicians (including at feedback sessions) or administrative team members. A protocol for approaching families was written as follows:

Step 1

Clinicians or administrative team members were asked to say the following to families: *An audit is taking place in the service by a Trainee Clinical Psychologist to find out about the experiences of parents/carers of the feedback session and the written assessment report in the Autism Spectrum Disorder (ASD) diagnostic process in the service, and also about how parents/carers feel these can be improved. This will involve a 30 minute interview and collecting some further data (such as gender and ethnicity) about you and your child. Would you be happy for the Trainee Clinical Psychologist to get in touch with you about this and email you an information sheet and consent form for it so that you can consider if you would like to participate?*"

Step 2

After step 1:

1. if parents/carers indicated after being told the above that they were happy for the trainee to contact them, they were asked for their permission for their contact details to be given to the trainee;
2. if parents/carers were not sure if they wanted to be contacted by the trainee, they would be asked if they were happy to be sent the

Notification and *Consent to contact* documents (below) by the staff member; and

3. if parents/carers did not wish to be involved in the study, no further steps would be taken.

The *Notification* document is as follows:

Date and version of Notification: version 1, 2.8.21

Improving the Autism Spectrum Disorder diagnostic process in the Oxford Health NHS Foundation Trust CAMHS Neurodevelopmental Conditions (NDC) Service

Notification



Who am I?

My name is Fahreen Walji and I am a Trainee Clinical Psychologist working in the Oxford Health NHS Foundation Trust.

Why is this notification being sent to you?

I would like to find out about the experiences of parents/carers of the feedback session and the written assessment report that form part of the Autism Spectrum Disorder (ASD) diagnostic process in the Oxford Health NHS Foundation Trust CAMHS NDC Service, and also about how parents/carers feel these can be improved.

This notification is being sent to you because you have recently been through the feedback session that forms part of the ASD diagnostic process, and I am really keen to hear your views on it.

Taking part will involve meeting with me digitally, for approximately 30 minutes, to provide some details about yourself and your child (such as gender and ethnicity) and to answer some questions about the ASD diagnostic process.

I would like to know more. What's next?

Taking part is completely voluntary, however if you would like to know more please send an email to **fahreen.walji@oxfordhealth.nhs.uk** with your telephone number, and let me know if you would prefer me to initially contact you by telephone or email.

Thank you!

The *Consent to contact* document is as follows:

Date and version of Consent to contact form: version 1, 2.8.21

Improving the Autism Spectrum Disorder diagnostic process in the Oxford Health NHS Foundation Trust CAMHS Neurodevelopmental Conditions (NDC) Service

CONSENT TO CONTACT FORM

You are being invited to give consent for Fahreen Walji (a Trainee Clinical Psychologist working in the Oxford Health NHS Foundation Trust) to contact you about the audit entitled "Improving the Autism Spectrum Disorder diagnostic process in the Oxford Health NHS Foundation Trust CAMHS Neurodevelopmental Conditions (NDC) Service". If you do give your consent to be contacted about the audit, there is no obligation to take part in it.

If you do wish to be contacted, please either:

(1) email this form to **fahreen.walji@oxfordhealth.nhs.uk** with the following details completed:

Your name: .....

Your telephone number: .....

Your preferred way of being contacted for initial correspondence: .....

OR

(2) email **fahreen.walji@oxfordhealth.nhs.uk** to state your interest and provide your telephone number. Please also let me know if you would prefer me to initially contact you by telephone or email.

Thank you very much for your time.

If there was permission to do so, the trainee would then contact parents/carers and email them the participant information sheet and consent form, and answer any questions about participation. However, due to difficulties recruiting (due to the clinicians' and administrative team's workload rendering this recruitment process difficult for them), the trainee then additionally identified parents/carers herself for the administrative team to contact, and subsequently also made contact with parents/carers herself directly (approaching families using information similar to that in the protocol above).

Appendix L

SIP Participant information sheet and consent form

Participant information sheet

Parents/carers were provided with one of two versions (versions two or three) of the participant information sheet. The only difference between the two versions was that they named different supervisors. Version three is below:

Improving the Autism Spectrum Disorder diagnostic process in the Oxford Health NHS Foundation Trust CAMHS Neurodevelopmental Conditions (NDC) Service

PARTICIPANT INFORMATION SHEET



Who am I?
My name is Fahreen Walji and I am a Trainee Clinical Psychologist working in the Oxford Health NHS Foundation Trust.

What is the purpose of the study?
I would like to find out about the experiences of parents/carers of the feedback session and the written assessment report that form part of the Autism Spectrum Disorder (ASD) diagnostic process in the Oxford Health NHS Foundation Trust CAMHS NDC Service, and also how parents/carers feel these can be improved.

Do you have to take part?
No, taking part is completely voluntary. You have the right to withdraw from the project at any point while you are completing it without giving a reason, however as the data collected will be anonymised you will be unable to withdraw your data once you complete the project.



What will you be asked to do?
If you decide you wish to take part, after completing the consent form, you will be asked to provide some details about yourself and your child (such as gender and ethnicity) and complete an online interview with me that will last approximately 30 minutes.

What happens after the interview?
The interviews will be video/audio recorded and transcribed, either by me or a transcription company. I will then analyse the transcripts from the interviews to look for themes across participants.

I will write a report of my findings, which will be used for the development of the Oxford Health NHS Foundation Trust CAMHS NDC Service, submitted to The University of Oxford for partial fulfilment of a Doctoral Degree in Clinical Psychology, and published in a journal.

Study results will be disseminated anonymously (including that NDC staff, including Dr James Stacey, will not know what feedback particular parents/carers have provided) and no identifiable information will be included in the transcripts or the report, and your identifiable information will be stored separately to the recordings and transcripts. The care provide to you and your child will not be impacted in any way.

Are there any disadvantages/risks from taking part?
Some of the questions, inviting you to reflect on your experiences of the ASD diagnostic process, may be difficult to think about and be upsetting. You will be provided with contact details of services that will be able to offer support and guidance if you experience distress.

What are the possible benefits of taking part?
We hope that your participation in the study will help us to improve the experiences of parents/carers who go through the ASD diagnostic process in the future.

What if there is a problem?
If you have a concern about any aspect of this project, please contact Fahreen Walji (fahreen.walji@oxfordhealth.nhs.uk), or Dr James Stacey (james.stacey@oxfordhealth.nhs.uk) and we will do our best to answer your questions.

If you remain unhappy or wish to complain please contact my supervisor on the project Professor Paul Salkovskis at paul.salkovskis@oxfordhealth.nhs.uk, or to make a formal complaint please contact the NHS Patient Advice and Liaison Service (PALS) on 0800 328 7971 or email PALS@oxfordhealth.nhs.uk

I'm interested. What's next?
If you would like to participate, please return the completed consent form to fahreen.walji@oxfordhealth.nhs.uk. If you are not sure if you wish to participate and you have any questions about the study, please email this email address with any queries.

We are very aware that this is a difficult time for you and your family, and really appreciate your participation. We will be as flexible as possible with the interview, and fully understand if you would like to take a break, or decide not to continue.

Thank you for taking the time to read this information sheet and for your interest in the project.

Consent form

Parents/carers completed the consent form (versions two, three or four of the consent form). The only difference between version two and the latter versions was the addition of the phrase “that the audio recording of” in later versions to item two. The only difference between versions three and four is that they referred to the two different participant information sheets. Below is version four of the consent form:

Improving the Autism Spectrum Disorder diagnostic process in the Oxford Health NHS Foundation Trust CAMHS Neurodevelopmental Conditions (NDC) Service

CONSENT FORM

Participant Identification Number:

Please initial box

1. I confirm that I have read the participant information sheet dated 4.11.21 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason at any time while I am completing the project (but not once I complete the project) without my child's care or legal rights being affected. ☐
3. I understand that my interview will be video/audio recorded and transcribed verbatim, and that the audio recording of it may be sent to a transcription company to be transcribed. ☐
4. I agree for my quotes to be used anonymously in the report of the project. I understand that only a small number of my quotes will be used. ☐
5. I understand that if there is any indication of risk to myself, my child, or others, information about this may need to be shared with others. ☐
6. I agree to take part in the above project. ☐
7. I would like to receive a summary of the results of this study. ☐

_____ _____ _____

Name of Participant Date Signature

_____

Interviewer name and signature

Appendix M

SIP Interview schedule

The initial amendment made to the interview schedule is using the word "me" instead of "us" in the opening question below.

The amendments made to the schedule for parents whose children additionally had an ADHD assessment are specifying that the questions relate to the ASD assessment and diagnosis (these additions are shown in italics below).

Opening question:

- Please can you tell me about your experience of the feedback session and assessment report *regarding those aspects that related to your child's autism assessment and diagnosis*?"

Prompts to use as necessary:

- What did you find helpful and unhelpful about the session and report, *regarding those aspects that related to your child's autism assessment and diagnosis*?
- Do you have any suggestions for improvements to the session and report, *regarding those aspects that related to your child's autism assessment and diagnosis*?
- When thinking back to what you were originally hoping to get from the session and report *regarding those aspects that related to your child's autism assessment and diagnosis*, were your expectations met?
- What did you find helpful and unhelpful about how the *autism* diagnosis was discussed in the feedback session? What changes would you make to this?
- Did the clinician deliver the autism diagnosis sensitively in the feedback session?

- What did you find helpful and unhelpful about how the findings of the *autism* assessment and recommendations *related to this* were fed back to you in the feedback session? What changes, if any, would you make to this?"
- What did you find helpful and unhelpful about the assessment report regarding *your child's autism assessment and diagnosis*, and the accompanying booklet on autism? What changes would you make to this?

Appendix N

SIP Introduction given to participants

After the consent form was confirmed as completed, the trainee did as follows:

- Thanked the participant for taking part.
- Explained that the participant would first be asked some demographic questions and for some details around their feedback session, and that after this the interview would take place.
- Confirmed the scope of the interview (to find out about their experiences of the feedback session and the written assessment report that form part of the ASD diagnostic process in the service, and how they feel these can be improved).
- Confirmed that the estimated duration of the interview would be thirty minutes.
- Verified that parents/carers were happy for the interview to be recorded.
- Stated that the parent/carer did not have to answer any questions if they did not wish to, and that they could stop the interview at any point, and they should let the interviewer know if they feel upset at any point.
- Stated that after the interview they would be sent a document listing support services in case this is helpful, and that this was standard practice for all interviews.
- Asked the participant if they had any questions.

Appendix O

SIP Assessment-related and demographic information

Assessment-related information

1. The number of feedback sessions they had.
2. The date of the feedback session(s).
3. Who was present at their feedback session(s).
4. The format of their feedback session(s).

Demographic information

Question	Answer options
1. What is your gender?	Male; female; or other.
2. What is your relationship to the child?	Parent; grandparent; other relative; other carer type.
3. What is your age?	*Open text answer*
4. Who does your/the (as applicable) child live with?	*Open text answer*
5. If applicable, does your child have contact with their parents / other parent?	*Open text answer*
6. What is the highest level of education you have completed?	No formal schooling; Less than primary school; Primary school; Secondary school; Further Education College; University degree; or Post graduate degree
7. What is your employment status?	Unemployed; in paid work; retired; homeworker; student; non-paid work.

8. What is your employment (if applicable)?	*Open text answer*
9. What is your ethnicity and your/the (as applicable) child's ethnicity?	*Open text answer*
10. What is your first language and your/the (as applicable) child's first language?	*Open text answer*
11. What is your religion?	*Open text answer*
12. What is your child's gender?	Male; female; or other
13. What was your child's age at diagnosis?	*Open text answer*

Appendix P

SIP Support services document

Note this is the final version of this document, the only difference to the first version is that the latter referred to the initial external supervisor.

Support Services Sheet: version 2, dated 6.12.21

Support Services

Dear parent/carer,

Thank you for taking part in this interview.

This letter is intended for anyone who experienced distress following completion of the interview and wishes to access support for this.

There are several sources of advice or help which are free and readily available to you and which may prove useful. These include:

Name and contact details	Opening times
Your General Practitioner	Usually 9-5 Usually Monday-Friday
NHS 111, on 111	All day, every day
Samaritans, on 116 123	All day, every day
Saneline, on 0300 304 7000	4.30pm-10.30pm every day

If you would like additional information please contact Fahreen Walji (fahreen.walji@oxfordhealth.nhs.uk) or Dr James Stacey (james.stacey@oxfordhealth.nhs.uk).

Thank you,

Fahreen Walji
Trainee Clinical Psychologist

Appendix Q

SIP Interviewee information

Assessment-related information	*n*
Type of assessment	
ASD only	4
ASD and ADHD	5
Number of feedback sessions	
One	9
Time elapsed since feedback session	
Overall range	1-20 weeks
1-4 weeks	4
5-8 weeks	3
9-12 weeks	1
13-17 weeks	0
18-21 weeks	1
Format of the feedback session	
Digital	6
Telephone	1
In person	1
Half digitally, half by telephone (due to technical difficulties)	1
Present at feedback session	
Parent(s) only	5
Parent(s) and child	4
Assessment report	

Received	8
Not received	1
Recalled receiving ASD booklet (of those who had received the assessment report)	
Recalled	3
Not recalled/received	5

Demographic information

Demographic	*N*
Gender	
Female	6
Male	3
Other	0
Relationship to the child	
Parent	9
Parent age (years)	
20-29	0
30-39	0
40-49	6
50-59	3
Who the child lives with	
With or mainly with interviewed parent	5
Mainly with non-interviewed parent (including parent's partner if applicable)	3
With both parents	1

If applicable, does your child have contact with both their parents / other parent?	
Yes	4
No	1
Not applicable (child lives with both parents)	1
Sometimes / not currently	3
Highest level of education completed	
No formal schooling	0
Less than primary school	0
Primary school	0
Secondary school	1
Further Education College	5
University degree	1
Post graduate degree	2
Employment status	
Unemployed	0
In paid work	8
Retired	1
Homeworker	0
Student	0
Non-paid work	0
Employment (where applicable)	
Graduate employment	3
Non-graduate employment	5
Not applicable	1

Parent ethnicity/race	
White British	9
Parent first language	
English	9
Parent religion	
No religion	7
Christian	2
Child ethnicity/race	
White British	9
Child first language	
English	9
Child gender at birth	
Female	5
Male	4
Child age at diagnosis (years)	
5-9	0
10-14	2
15-18	7

Please note interviews took place on Microsoft Teams and lasted on average 24 minutes (and ranged from 16 to 36 minutes in length), and interviews concerned feedback sessions with five of the eleven clinicians in the NDC service.

Appendix R

SIP Reflexive statement

Reflexive journalling helped me to consider the potential influence of my background and experiences on the conduct of the study. Some of the issues I reflected on pertained to how my previous experience of engaging with others with neurodevelopmental difficulties may have affected my analysis.

Whilst I have no personal experience of neurodevelopmental issues within my family, I have significant experience outside of this sphere of engaging with individuals with neurodevelopmental difficulties, their families/carers and the broader systems around them. I gained this experience through my work during and prior to the doctorate. Before the doctorate, this consisted mainly of working in a school for autistic children. During the doctorate and at the time I conducted this SIP, I worked with autistic children – and their parents/carers and family members, and the systems/professionals around them – on clinical placements (not in the service where this SIP was conducted). This included assisting with neurodevelopmental assessments for ASD (and ADHD), and supporting with children's behavioural difficulties.

Together, the above experiences gave me the opportunity to learn broadly about ASD. I gained some understanding of different individuals' experiences of the process of gaining a diagnosis of ASD for themselves and or their child, as well as of the day-to-day lives of autistic children and their families/carers. I also learnt about the role that different systems and professionals – such as schools and health service clinicians – can play in this. I noticed differences in how families/carers perceived ASD, and in how it impacted their day-to-day lives. I also

observed differences in how much individuals felt they had the ability to manage on a daily basis.

As a result of my experiences, I felt a familiarity with some of the points raised by parents in the SIP interviews – and I was therefore aware that this pre-existing knowledge was influencing how I received the information shared by parents. Amongst the issues this raised in my mind, I wondered if this awareness of certain matters meant I noticed them more and gave them importance. I tried to challenge this to an extent, for instance through questioning the meanings I was making of the data. I held such a reflexive stance throughout analysis, in relation to this and other issues, remaining mindful that my particular positioning was influencing my work.

Appendix S

SIP Detail on service assessment data collected

As noted previously, the diagnostic process for ASD consists of various appointments. This is also the case for ADHD assessments (this entails the same steps as the ASD assessment, bar that the standardised assessment is the Quantified Behavioural Test (Ulberstad, 2012) for ADHD).

For the purposes of collecting assessment data, information on all assessments where the standardised assessment took place between July to September 2021 (regardless of when other parts of the assessment took place), were collated.

Appendix T

SIP Further detail on recommendation

Families' recommendations on this included providing separate information (including a separate report) to parents and children (tailored to their age and needs), and providing links to video/tutorial resources for both. They also suggested providing handouts, or paraphrased versions, of information contained in suggested resources for parents. Recommendations for children included framing ASD positively (as a gift) and providing information sensitively, creatively, accessibly (including by telephone) and in a fun manner, and providing: social media links about ASD; information on how people's lives have changed due to ASD; links and telephone numbers of organisations.

Appendix U

TDRP Initial study approval

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB
Tel: +44(0)1865 616575
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Ms Fahreen Walji
Oxford Institute of Clinical Psychology Training and Research (OCIPCTR)
Isis Education Centre
Warneford Hospital
Oxford

20 October 2021

Dear Fahreen,

Research Ethics Approval - CUREC 2

Ethics Approval Reference: R77237/RE001

Study title: Hoarding Disorder – investigating the development of beliefs about possessions

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) in accordance with the University's procedures for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **18 months**, commencing on **20th October 2021.**

You will be required to submit an annual progress report on each anniversary of study approval, until the study is completed, and your study may be selected for review during an annual audit.

Amendments

Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form.

Yours Sincerely

H. Barnby-Porritt

Dr Helen Barnby-Porritt
Research Ethics Manager

Appendix V

TDRP Participant information sheet and consent form

Participant information sheet

The below shows the text of version two of the participant information sheet.

Hoarding Disorder – investigating the development of beliefs about possessions

PARTICIPANT INFORMATION SHEET

Central University Research Ethics Committee Approval Reference: R77237/RE001

1. Introductory paragraph

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

2. Why is this research being conducted?

We would like your help in learning more about the link between past experiences of losing possessions and how people relate to things now.

We are interested in hearing from people who identify either as having problems with collecting and keeping clutter **or** those without such problems.

If you do have problems with collecting and keeping clutter, we are interested in hearing from you if before developing these problems, you had a childhood/adolescent experience of you (and/or family) losing possessions and/or being chronically materially deprived. We are also interested in hearing from you if you have problems with collecting and keeping clutter but have not had such experiences.

If you don't have problems with collecting and keeping clutter, we are interested in hearing from you whether or not you have any experience of material deprivation.

We hope that this research will help us to develop a deeper understanding of factors that may impact the relationship with possessions, and improve treatments for individuals having problems with collecting and keeping clutter.

3. Why have I been invited to take part?

We are keen to hear from a full range of people aged 18 years old and above (with no upper age limit) and who are able to read, write and speak English. We wish to include people from the following three groups in our study:

1. Individuals who consider themselves to have a **significant problem with collecting and keeping clutter and** who have a childhood/adolescence experience occurring before they developed difficulties with collecting and keeping clutter, of (i) sudden (occurring in under a

year) **material deprivation** resulting in the loss of all or nearly all of their and/or their family's possessions; and/or (ii) them and/or their family being **chronically material deprivation**.

2. Individuals who consider themselves to have a **significant problem with collecting and keeping clutter** but do not have a childhood/adolescent experience of losing possessions or of chronic material deprivation as described above.
3. Individuals **who do not consider** themselves to have a **significant problem with collecting and keeping clutter** (whether or not they have a childhood/adolescent experience of losing possessions or of chronic material deprivation as described above.

We aim to include the views of 75 individuals in this research project.

4. Do I have to take part?

No. It is up to you to decide whether or not to take part. You can withdraw yourself from the study at any time, without giving a reason, by advising us of this decision. Once you complete the study you will be unable to withdraw your data. If you decide to withdraw whilst your participation in the study is ongoing, your data will be destroyed.

5. What will happen to me if I take part in the research?

We would like you to email the researcher at fahreen.walji@hmc.ox.ac.uk so that you can be sent a unique identifying code and an online link to complete a consent form if you are happy to do this, and answer a question that asks you about hoarding behaviour. When you email the researcher please also provide your telephone number. This process can also take place largely by post.

If you complete the consent form and answer the question about hoarding behaviour, you may then be contacted by the researcher to undertake a telephone/digital interview in which you will be asked some questions around hoarding behaviours, and you will be asked about any experiences of sudden (occurring in under a year) material deprivation you may have. This will take about 10-15 minutes. Whether or not you complete the telephone/digital interview, you will be asked to complete an online or postal questionnaire pack containing some questions about your behaviours and beliefs around collecting and keeping clutter, demographic information and your mental health. This will involve being asked some detail about current and past psychological symptoms, including measures of psychological distress, and about your past experiences of material deprivation. This will take about 30-45 minutes.

In total, participation in the study will take about 30-60 minutes.

You can log in and log out of the program at your convenience if you would like to take a break from the questionnaires. If you would rather complete the online materials in hard copy, we will post them to you for you to complete.

As noted above, you can stop taking part in the research at any time or decline to answer any questions. Also, the information you provide will be kept strictly confidential except in rare circumstances in which it is judged that you or someone else is at risk of serious harm.

6. What are the possible disadvantages and risks in taking part?

Some of the questionnaire measures, inviting you to reflect on your mental health and your experiences of losing possessions, may be difficult to think about. The questions around experiences of losing possessions have been designed with feedback from people with personal experience of this,

in order to minimise the potential for distress. However, it is possible that you might find answering the questions upsetting.

As mentioned above, you can take a break from the study and return to it later.

At the end of the study, or if you withdraw at any point during completion, you will be provided with contact details of services and third-party organisations that will be able to offer support and guidance if you experience distress.

7. Are there any benefits in taking part?

While there are no immediate benefits for those people participating in the project, it is hoped that this research will lead to a better understanding of individuals who have a significant problem with collecting and keeping clutter, and the development of better treatment for this difficulty.

8. What information will be collected and why is the collection of this information relevant for achieving the research objectives?

During the study, you will be asked to provide the following information: your name, email address, telephone number, demographic information, information about your past and current psychological wellbeing, and your experiences of material deprivation of possessions.

The information you provide during the study is the **research data**. Any research data from which you can be identified (i.e. email address, telephone number and home address, should you request the consent form and questionnaires by post) is known as **personal data**.

Personal data (including consent forms) will be stored on a password protected Oxford University Computer, accessible only on University sites. Personal data will be stored for 3 months after the study has concluded and then permanently deleted. Once the research data has been checked your personal data will be detached from the research data, making it anonymous. This means that the data can no longer be withdrawn beyond this point as we will no longer know which is your data.

Other research data (including the questionnaire data that you fill in using a unique participant identifier) will be stored for at least 3 years after publication or public release of the work of the research. This information will then be shredded or permanently deleted and destroyed.

The researchers involved in this study will have access to the research data. Responsible members of the University of Oxford may be given access to the data for monitoring and and/or audit of the research. De-identified research data may be shared either directly with others or via a platform (so all personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public). Using the **research data**, we hope to report our findings in ways including writing in academic journals, and presenting to relevant charities and to health professionals at conferences. The findings will also contribute to Fahreen Walji's Doctorate in Clinical Psychology. You will not be identified in any reports or publications arising from the study.

9. Will the research be published? Could I be identified from any publications or other research outputs?

As above, the findings from the research will be written up as part of a thesis, and reported in other ways possibly including academic publications, presentations including conference presentations, and on websites. It will not be possible for participants to be identifiable from these outputs. Some of these outputs will include written comments made by you in the study, with your consent.

10. Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available from https://compliance.admin.ox.ac.uk/individual-rights.

11. Who has reviewed this study?

This study has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee (Ethics reference: R77237/RE001).

12. Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this study, please contact Fahreen Walji (fahreen.walji@hmc.ox.ac.uk) or Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk, (0)1865 226 369/431), and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Fahreen Walji
Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre, Warneford Hospital, Oxford OX3 7JX
fahreen.walji@hmc.ox.ac.uk

Or

Professor Paul Salkovskis
Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre, Warneford Hospital, Oxford OX3 7JX
paul.salkovskis@hmc.ox.ac.uk
+44 (0)1865 226 369/431

Consent form

The below shows the text of version two of the consent form.

PARTICIPANT CONSENT FORM

CUREC Approval Reference: R77237/RE001

Hoarding Disorder – investigating the development of beliefs about possessions

Study Summary: Learning more about the link between past experiences of losing possessions and how we relate to things now.

		Please initial each box
1	I confirm that I have read and understand the information sheet version_____dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I give my permission for written comments made by me in the study to be used in publications or other research outputs related to this study.	☐
3	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without penalty.	☐
4	I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to have access to this data.	☐
5	I understand who will have access to research data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
6	I understand that all information will be kept strictly confidential except in rare circumstances in which it is judged that I am, or someone else is, at risk of serious harm.	☐
7	I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.	☐
8	I understand how to raise a concern or make a complaint.	☐
9	I agree to take part in the above study.	☐

_____	dd / mm / yyyy	_____
Name of Volunteer	Date	Signature
_____	dd / mm / yyyy	_____
Name of person taking consent	Date	Signature

Appendix W

TDRP Example of the recruitment materials

Text from the study poster (version two):

We are interested in learning from you about your experiences relating to possessions.

We are looking for people who:

- have problems with collecting and keeping clutter and have a childhood/adolescent experience of them (and/or their family) losing possessions and/or being chronically materially deprived.
  OR
- have problems with collecting and keeping clutter and do not have a childhood/adolescent experience of them (and/or their family) losing possessions and/or being chronically materially deprived.
  OR
- do not have problems with collecting and keeping clutter (whether or not they have a childhood/adolescent experience of them (and/or their family) losing possession and/or being chronically materially deprived.

You will need to be aged at least 18 years to take part. Participating in the research will take 30-60 minutes, and involves completing a digital/telephone interview, and/or questionnaires (online or by post). Some questions will ask about your past and current psychological wellbeing, and about your past experiences of material deprivation.

Can you help us? Please contact me to find out more (I am also very happy to discuss any queries by telephone):
fahreen.walji@hmc.ox.ac.uk

Or go to: *[study website page]*

Appendix X

TDRP Allocation questions

Participants were asked both questions on sudden and chronic material deprivation:

1. Questions about sudden material deprivation

Note if participants provided all the answers marked in bold below, they were allocated to group one. Questions were therefore only asked as necessary.

i. Before you began hoarding, did you and your family (if you were with them) have an experience in which you lost your possessions? *Answer options:* ***yes****; no.*

ii. Were you under the age of eighteen when you had this experience? *Answer options:* ***yes****; no.*

iii. How much of your possessions did you and your family (if you were with them) lose? *Answer options: about half or under;* ***over half****.*

iv. Over what period of time did this loss occur? *Answer options:* ***it took place in under one year****; it took place over one year or longer.*

v. If applicable, participants were asked for further information.

2. Questions about chronic material deprivation

If participants provided all the answers marked in bold below, they were allocated to group one. Questions were therefore only asked as necessary.

i. Before you began hoarding, did you and your family (if you were with them) have an experience of material deprivation (this was defined as “struggling to obtain things that were important to your everyday life. This would include needing to rely on external help, such as welfare support, to obtain these things”). *Answer options:* ***yes****; no.*

ii. Were you under the age of eighteen when you had this experience? *Answer options: **yes**; no.*

iii. Does this experience include ongoing material deprivation that lasted for a continuous period of one year or longer? *Answer options: **yes**; no.*

iv. During this time of ongoing material deprivation, how much did you and/or your family struggle to obtain the things that were important to your everyday life, out of the following options: “rarely”, “sometimes”, “often”, “always”? *Answer options: “rarely”; “sometimes”; **“often”; “always”**.*

v. If applicable, participants were asked for further information.

Appendix Y

TDRP Questions relating to demographics and mental health

1. Gender. *Answer options: Male/Female/Other/Prefer not to say*
2. How old are you? *Answer option: free text.*
3. How would you describe your ethnicity? *Answer option: free text.*
4. What is the highest level of education you have completed? *Answer options: no formal schooling; less than primary school; primary school completed; secondary or high school completed; university degree completed; post graduate degree completed.*
5. Which of the following best describes your main work status over the past 12 months? *Answer options: unemployed; employed; retired; homemaker; student; non-paid work; self-employed.*
6. Employment (if applicable). *Answer option: free text.*
7. What is your civic status? *Answer options:* married; living as couple; divorced or separated; single; widowed; other; prefer not to say.
8. Have you ever been married? *Answer options: yes; no.*
9. Have you had any mental health difficulties in the last year that you have sought help for at least to the level of your GP? *Answer options: yes; no.*
10. If yes, what difficulty/difficulties has this been for? *Answer options: free text.*

Appendix Z

TDRP Follow-up letter

Hoarding Disorder – investigating the development of beliefs about possessions.

Ethics Approval Reference: R77237/RE001

Dear Volunteer,

Thank you for taking part in this research study. This letter is intended for anyone who indicated on their questionnaires that they may be feeling rather worried or in a low mood. Of course, our moods can change from day to day. However, for some people their mood may remain low for some time. If this applies to you, I would like to point out that there are several sources of advice or help which are free and readily available to you and which may prove useful. Specifically, these include:

1. Your General Practitioner
2. Your College nurse (if available)
3. Your University Counselling Service (if available).
   [http://www.brookes.ac.uk/students/wellbeing/counselling/,
   https://www.ox.ac.uk/students/welfare/counselling?wssl=1/]
4. NHS 111
5. Helplines,
   a. The Samaritans 116 123
   b. The Mental Health Crisis Line 01865 251152
   c. Listening Service (Oxford University Students) 01865 270270

If you would like additional information, or a confidential discussion with a senior member of the research team, please contact Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk).

If you would like to access guidance about hoarding behaviour, please see the following website: https://www.nhs.uk/mental-health/conditions/hoarding-disorder/

If you have any concerns, or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford: Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB

If you know anyone who may like to participate in this study, you are welcome to provide them with the details of our website here: *[Website address]* or ask them to email fahreen.walji@hmc.ox.ac.uk

Fahreen Walji

Working in collaboration with Professor Paul Salkovskis, Director at Oxford Centre for Psychological Health, Oxford Institute of Clinical Psychology Training and Research, and Oxford Cognitive Therapy Centre; (Oxford Health NHS Foundation Trust and University of Oxford)

Trainee Clinical Psychologist | The Oxford Institute of Clinical Psychology Training and Research (OXICPTR)