Worcestershire Health and Wellbeing Board Joint Strategic Needs Assessment (JSNA)

Hoarding Disorder Rapid Needs Assessment

[Epidemiological]

February 2024

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1. Introduction

This report has been produced in response to a recognition of those working locally in Health and Adult Social Care that multiagency working is necessary to support individuals with Hoarding Disorder and concern that the underlying problem is not being addressed adequately.

This document only reports on the epidemiology of HD. There is ongoing work to identify best practice, to understand existing pathways and services, and finally to identify gaps in services and improvements that can be made within the resources that are currently available, and beyond.

What has become clear during the preparation of this report is that there is relatively limited research into HD, and what is available is generally not robust. This may be, in part, due to the disorder only recently being identified as a distinct mental health condition.

2. Definition of hoarding disorder

International classification

Hoarding Disorder was previously considered a form of Obsessive-Compulsive Disorder (OCD). OCD belongs to the anxiety family of mental health conditions.

There are two internationally recognised classifications of health conditions in common use. The first is the Diagnostic and Statistical Manual of Mental Disorders (DSM) which is an American classification system purely focusing on mental health problems. In 2010, when the latest version of the manual was issued, HD was moved from the overarching anxiety disorder group to the obsessive-compulsive sub-group of disorders and given a distinct code (**300.3 (F42)**).

The other classification system, the International Classification of Disease, which is used in the NHS, did not give HD a distinct code until very recently but classified it under the OCD group using the 'OCD - Other' code.

While it is the case that those with hoarding tendencies can share similar traits with those with OCD, and the two disorders can and do co-exist in some individuals, HD is now thought to be a distinct health problem. This is because most individuals with HD do not exhibit the key features of OCD, and the natural histories of the two conditions are different, as is the response to current treatments.

Hoarding Disorder has now been given its own distinct code in the international classification of disease.[1] This addition was only made to the current operating ICD-10 - CM (the American version) in October 2017 as an 'emergency code'. The classification is F40-F48 - *Anxiety, dissociative, stress-related, somatoform and other nonpsychotic mental disorders* / F42 *Obsessive-compulsive disorder* / **F42.3 Hoarding disorder.**

A new version of the classification system (ICD-11) will not routinely be used in the NHS until 2026. In this classification, HD has been given the code **6B24**.

[1] Hoarding | Royal College of Psychiatrists (rcpsych.ac.uk)

All the above has relevance on two counts. First, because the disorder has not been seen as being distinct from OCD for so many decades, much of the research on HD has been dominated by OCD research with many case series including a mix of patients with both disorders. Second, is that it is difficult to get a true picture of how and when individuals present because individuals are not being 'counted' in the system. For example, the NHS uses the ICD system. Data for all of England has been checked for the years 2021/22 and 2022/23 and there is not one use of the code of F42.3 in either inpatient or outpatient records. This is despite the fact that individuals may need to be admitted because of HD because it is not possible to provide treatment in their own home, or individuals cannot be discharged from hospital because of their HD. 46 patients with the code *F42.8 OCD-Other* were identified some of which could have hoarding disorder.

Morein-Zamir and Ahluwalia reasonably state: '*the classification history [of HD] has hindered research, clinical understanding, and treatment development*'. [2]

ICD-11 Description

The latest International Classification of Disease book (ICD-11) defines the condition as follows:

Hoarding disorder is characterised by an accumulation of possessions that results in living spaces becoming cluttered to the point that their use or safety is compromised. Accumulation occurs due to both repetitive urges or behaviours related to amassing items and difficulty discarding possessions due to a perceived need to save items and distress associated with discarding them. If living areas are uncluttered this is only due to the intervention of third parties (e.g., family members, cleaners, authorities). Amassment may be passive (e.g., accumulation of incoming flyers or mail) or active (e.g., excessive acquisition of free, purchased, or stolen items). The symptoms result in significant distress or significant impairment in personal, family, social, educational, occupational, or other important areas of functioning.[3]

The key features of the definition are:

- There is a pervasive and sustained pattern of thinking / behaviour
- Accumulation can be passive or active
- Accumulation is the result of either a need to keep items or distressed in throwing them away
- The accumulation impacts on their quality of life to a significant degree

Individuals can have good insight or lack insight and that is classified also:

- *Hoarding disorder with fair to good insight (ICD 11 6B24.0)*
- *Hoarding disorder with poor to absent insight (ICD 11 6B24.1)*
- *Hoarding disorder, unspecified (ICD 11 6B24.Z)*

In addition:

- The hoarding should not be attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi Syndrome).

- The hoarding should not be better accounted for by the symptoms of another disorder (e.g., obsessions in Obsessive-Compulsive Disorder, decreased energy in Major Depressive Disorder,

[2] S Morein-Zamir and S Ahluwalia, Hoarding disorder: evidence and best practice in primary care. British Journal of General Practice, 2023, 73(729), pp.182–183.
[3] ICD-11 for Mortality and Morbidity Statistics (who.int)

delusions in Schizophrenia or another Psychotic Disorder, cognitive deficits in Dementia, restricted interests in Autism Spectrum Disorder).

Other aspects of the condition

Hoarding arises results because of the accumulation of objects either through increased acquisition or/or an inability to discard. Many individuals with a HD have a pattern of behaviour of Compulsive Acquisition although this varies person to person: [4]

- Compulsive Buying: Retail/discount, E-bay, Home shopping network
- Acquisition of Free Things: Advertising flyers/handouts, Give-aways, Trash - dumpster diving
- Stealing/Kleptomania

Animal hoarding

Animal hoarding is a distinct form of HD which is more likely to be come to the attention of animal welfare organisations. There is no distinct classification or code for this variation.

The Hoarding of Animals Research Consortium (HARC) (USA)[5] identifies the following characteristics of this group:

- Accumulation of numerous animals, which has overwhelmed that person's ability to provide even minimal standards of nutrition, sanitation, and veterinary care.
- Failure to acknowledge the deteriorating condition of the animals (including disease, starvation, and even death) and the household environment (severe overcrowding, very unsanitary conditions).
- Failure to recognize the negative effect of the collection on their own health and well-being, and on that of other household members.

This group appears to be dealt with largely through animal welfare and regulatory services rather than the health or social services.

Those that hoard inanimate objects may, however, own one or two animals whose welfare still needs to be considered because of the conditions of the house and neglect.

Data hoarding

The Avon Fire Service have identified a new phenomenon related to the storage of data collection equipment such as computers, electronic storage devices or paper copies. [6]

Chronic disorganisation

Chronic disorganisation is not a recognised medical condition, nor does it appear that the condition has been subject to clinical research. However, it is a term that is widely used by those working in the professional organisation industry – many of which also deal with HD.

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[4] G Steketee and CR Ayers, Challenges in Treating Hoarding in Midlife and Older Adults, Slide deck from a presentation, Undated.

[5] V Hayes, a (May 2010), The Animal Legal and Historical Center, Michigan State University College of Law, *Detailed Discussion of Animal Hoarding*, May 2010 in Wikipedia: Animal Hoarding

[6] Avon Fire and Rescue, Working with Hoarders, A multi-agency approach https://bristolsafeguarding.org/media/1289/hoarding-cirs-working-document-final-draft-v2.pdf

It is a term that has been coined by the Institute for Challenging Disorganization and it is terms used by professionals for persons who cannot arrange time and space elements in their lives. [7]

Individuals may:

- Accumulates large quantities of objects, documents, papers or possessions beyond apparent necessity or pleasure
- Have difficulty parting with things and letting go
- Have a wide range of interests and many uncompleted projects
- Need visual "clues" as reminders to take action
- Tend to be easily distracted or lose concentration
- Often have weak time management skills

Interestingly, it is reported that that individuals exhibiting these symptoms do not have the same attached to items. They can discard items without the anxiety experienced in individuals with HD. The issue is that they find the process of organising all their possession and task of discarding overwhelming.

It has also been stated that there may be a strong association or an expression of Attention Deficit Hyperactivity Disorder ADHD. Indeed, a recent UK study found that 20% of adults with ADHD had clinically significant hoarding, with a higher percentage exhibiting lower levels of cluttering. Inattention was a predictor of hoarding while individuals who had predominantly features of impulsivity and hyperactivity were more likely to only clutter mildly. [8]

It is not possible to determine the status of chronic disorganisation as a distinct entity although it be of significance if that were the case.

The association of HD (or cluttering) with ADHD is likely to be an area of research in the future, particularly in relation to treatment.

Collectors versus hoarders

Collectors are more specific in what they acquire, usually confining this to a narrow range of items, and planning purchases, usually of predetermined items. They are also more likely to organise their items and less likely to be excessive in the number of items they accumulate. Collectors do not, therefore, fulfil the ICD or DSM criteria for diagnosis HD.

3. Diagnosis of hoarding disorder

The diagnosis of HD is made using the ICD 10/11 criteria. However, more often than not, non-specialist health care, social care and other professionals have to deal with individuals in the absence of a formal diagnosis.

It is important to note that significant clutter can also arise in other conditions, particularly when an individual has lost some executive functioning, as in the case of dementia. Depression may also lead

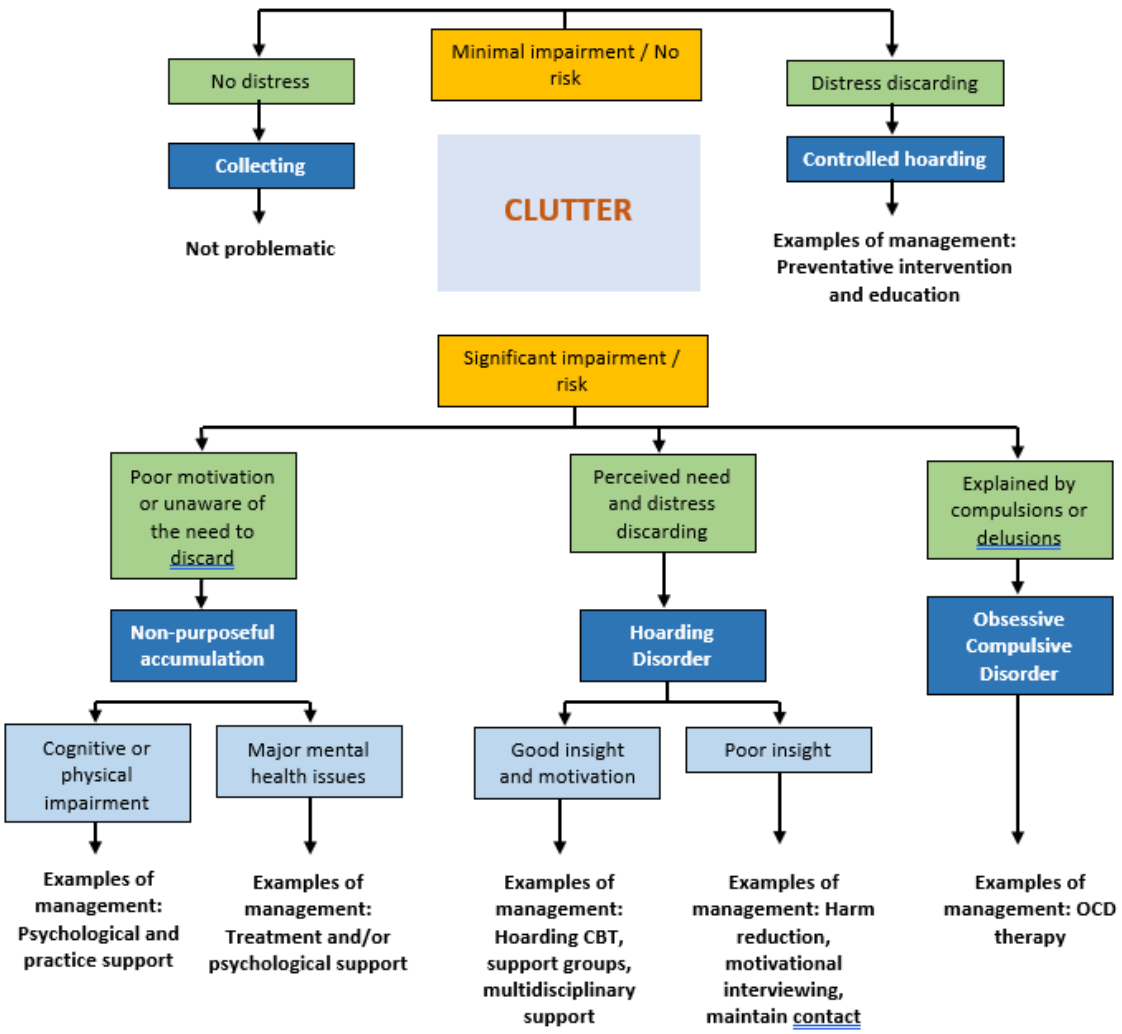
[7] The Institute for Challenging Disorganization

[8] S Morein-Zamir, M Kasese, SR Chamberlain and E Trachtenberg, Elevated levels of hoarding in ADHD: A special link with inattention, J Psychiatr Res, 2021, Dec 13:145:167-174.

to individuals failing to take care of themselves and their home. In those situations, where the clutter arises from another diagnosis the individual should not be considered as having HD. Dealing with the clutter in the absence of HD should be more straight forward.

Canterbury Health Board, in their document, Enabling Spaces, providers a useful flow diagram to help with the diagnosis of HD. This is shown in Figure 1. This does not present the definitive process of diagnosis.

Figure 1: Flow diagram to understand common presentations
Modified from original [9]



[9] Canterbury Health Board, Enabling spaces, supporting elderly people with hoarding, 2020

4. Epidemiology

Prevalence

The prevalence of HD is difficult to ascertain. There is a paucity of community-based studies, and it is not clear what criteria are being used to count individuals. Hoarding behaviour, in its early stages, may not at that point have a significant impact on the individual. Does this therefore constitute a behaviour or a disorder? As has already been illustrated above, clutter and hoarding are the same thing.

A significant problem is identifying the epidemiology of HD is that the majority of those that hoard do not recognise that they have a problem. They will not volunteer that they have a problem with clutter or admit to the impact that their clutter may have on them and others around them. As the condition worsens, individuals can also become reclusive. Surveys that depend on self-completed information or interviews away from the home are likely to underestimate the prevalence and severity. Studies based on home visits are difficult and expensive to conduct and so are the least likely to be used.

The issue is compounded by the fact that clutter can be associated with other mental health disorders such as dementia and so HD should not be diagnosed unless these other disorders have been ruled out.

The most cited prevalence is 2.5% of the population which is the best estimate obtained from a recent systematic review of all prevalence studies in 2019. [10] However, the range given across different studies is 1.5% to 6%.

A community-based study that was incorporated onto the back of the Hopkins Epidemiology of Personality Disorder Study found a prevalence of 4% which, when adjusted for the age profile of the Baltimore (USA) population community, gave a prevalence of 5.3%. [11]

A UK study, which had the same difficulties as the Baltimore study with high dropout rates from the study sample arrived at an unweighted prevalence of 1.3%. [12]

Applying the more commonly quoted prevalence of 2.5% to Worcestershire gives a figure of 15,342 individuals with HD is using the total population, or 12,820 for the 15+ population only. [13]

[10] Postlethwaite, A., Kellett, S., & Mataix-Cols, D. (2019). Prevalence of hoarding disorder: A systematic review and meta-analysis. Journal of Affective Disorders, 256, 309-316.
[11] JF Samuels, OJ Bienvenu, MA Grados et al, Prevalence and Correlates of Hoarding Behavior in a Community-Based Sample, Behav Res Ther. 2008, Jul: 46(7): 836–844.
[12] AE Nordsletten, A Reichenberg, SL Hatch et al, Epidemiology of hoarding disorder, BJ Psychiatry, 2013, 206(6): 445-452.
[13] Worcestershire County Council, Population statistics and projections [Accessed 12.1.24]

Demographics [14] [15] [16] [17] [18] [19]

- The behaviours associated with HD begin in early life (childhood/adolescence) and increase in severity with age. Steketee and Ayers report that amongst their patients 68% of hoarding has an onset before the age of 20 years. The current view is that the common age at which hoarding starts is between 15 and 19 but younger children have been reported as exhibiting the features of HD.

- Those working in the field report that it is rare for hoarding to start for the first time in middle and old age.

- The average age at which individuals become known to services is around 50, at which point the HD is usually well-established and impacting on lives of individuals and those around them.

- A similar prevalence has been observed between men and women in several studies, however women are more likely to be in contact with services. [20]

- Hoarding disorder is associated with reduced occupational and social functioning. This is illustrated by the fact that individuals with HD are more likely to have financial difficulties, be unemployed and unmarried. Of those that have at some point been married, a higher percentage of those with HD are divorced when compared with the general population.

- A higher percentage of individuals with HD are widowed than the general population.

- Negative health behaviours such as smoking or excessive drinking were *not* increased in individuals with HD.

- The prevalence of HD across cultures and western/developed countries have been reported with the range given above, and the features consistent.

[14] Royal College of Psychiatrists (2019) Hoarding. Available at: https://www.rcpsych.ac.uk/mental-health/mental-illnesses-and-mental-health-problems/hoarding (Accessed: September 2023)
[15] Morein-Zamir, S. and Ahluwalia, S. (2023). Hoarding disorder: evidence and best practice in primary care. British Journal of General Practice, 73(729), pp.182–183. doi:https://doi.org/10.3399/bjgp23x732513.
[16] Hoarding UK. [Accessed: September 2023]
[17] Slough Borough Council (2021) Hoarding Protocol. [Accessed: September 2023]
[18] G Steketee and CR Ayers, Challenges in Treating Hoarding in Midlife and Older Adults, Slide deck from a presentation, Undated.
[19] AE Nordsletten, A Reichenberg, SL Hatch et al, Epidemiology of hoarding disorder, BJ Psychiatry, 2013, 206(6): 445-452.
[20] Brakoulias, V., & Milicevic, D. (2015). Assessment and treatment of hoarding disorder. Australasian Psychiatry, 23(4), 358-360 ***in*** Canterbury Health Board, Enabling spaces, supporting elderly people with hoarding, 2020.

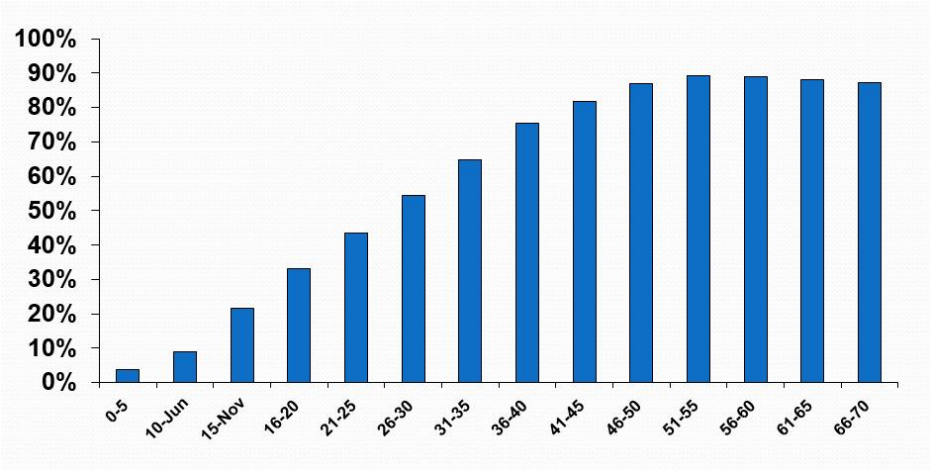
Natural history

Hoarding disorder and its natural history has been poorly studied. However, its course tends to be chronic with very few reports of spontaneous remission. [21]

Tolin et al conducted a survey of HD. They had 751 self-reporting adults with hoarding behaviours who were asked to complete a survey of how their behaviours had worsened over time and in relation to life events. They report that *most respondents described a chronic course of illness, with a significant minority describing an increasing or relapsing/remitting course. Stressful and traumatic events were common in this sample; changes in relationships and interpersonal violence were disproportionately associated temporally with periods of symptom onset or exacerbation*.

Figure 2 is taken from their paper and shows the progression to moderate and severe hoarding, with a rise to about 85% to 90% by the age of 50. Thereafter, the proportion of individuals stabilises.

Figure 2: Percentage of individuals with moderate to severe hoarding disorder



Taken from Tolin et al [22]

Steketee and Ayers cite other studies which indicate high rates of hoarding behaviours (as opposed to HD) amongst the elderly:

- 15% of nursing home residents and 25% of community day care elder participants hoarded small items (Marx & Cohen- Mansfield, 2003)

- Rates of hoarding in specific USA institutions or programmes:
  - Elders at Risk Program, Boston 15%
  - Visiting Nurses Association, New York City 10-15%
  - Community Guardianship, North Carolina 30-35%

[21] G Steketee and CR Ayers, Challenges in Treating Hoarding in Midlife and Older Adults, Slide deck from a presentation, Undated.

[22] DF Tolin, SA Meunier, RO Frost & G Steketee, Course of compulsive hoarding and its relationship to life events, Depress Anxiety, 2010, Sep;27(9):829-38

It is frequently observed that hoarding behaviour deteriorates following stressful life events.

One of the challenges of understanding HD is that individuals and their families often do not seek help until later in life due in part as a result of the insidious nature of the condition but also because affected individuals often as a lack of insight or the stigma and shame that individuals and families experience. Individuals are more likely to come to the attention of authorities as a consequence of the hoarding and by that time the disorder is moderate to severe. This may be one reason why HD is perceived to be a condition of older age.

Co-morbidities

Individuals with HD have high rates of other mental health problems depression or anxiety, somatic symptoms, personality disorder and psychotic features.

The relationship with obsessive compulsive disorder is complex and has yet to be fully explained. Currently it is thought about 12-17% of individuals with HD have both conditions.

This is also true of ADHD.

Again, there is considerable difficulty in ascertaining good quality data concerning co-morbidities because many studies focus on those already known to the system, and HD is largely a hidden problem. One team recruited individuals with hoarding behaviours from a range of settings including health and mental health clinic settings, newspapers, and informational websites, as well as through investigator media appearances. Of those that participated, 217 were diagnosed with HD and the prevalence of other conditions in this group is shown in Table 1. [23]

Table 1: Counts of co-morbidities amongst 217 individuals seen in a Boston Clinic

Condition	Count	Prevalence (%)
Major depression	50	23.04
Obsessive compulsive disorder	39	17.97
Generalised anxiety disorder	24	11.06
Social phobia	23	10.60
Post traumatic distress syndrome	7	3.23
Substance misuse	2	0.92
Attention deficit disorder	28	12.90

[23] RO Frost, G Steketee and DF Tolin, Comorbidity in Hoarding Disorder, Depress Anxiety, 2011, Oct 3, 28(10): 876–884.

Cause [24] [25] [26] [27]

The cause of HD is not known and is likely to be multifactorial. Several factors are thought to play a part either as a primary cause or as a factor that is likely to worsen hoarding behaviours. Research interest in this disorder has grown.

Trauma and loss

- In some individuals a link has been identified between the start of hoarding and a traumatic life event/period. Examples include abuse, relationship breakdown, loss of a loved one, prolonged stress, extreme loneliness.
- In those with already established hoarding, major stresses can exacerbate the hoarding.

Family history

- It is common for family members to also display hoarding disorder.
- Some studies suggest a genetic vulnerability to hoarding. Twin studies indicate that up to 50% of variance may be explained by genetics.

Neurocognitive Functioning

- Individuals with HD have been found to have certain cognitive impairments, particularly in relation to executive functioning and decision making. This may explain the progression that is often observed in older age, as cognitive function declines. Those with HD in older age demonstrate more cognitive impairment than non-HD controls.
- When compared with age- and education-matched controls, individuals with HD have an increased incidence of impairment in visual memory, visual detection, and visual categorisation.

Personality

- It is thought that there is a link to certain personality traits such as perfectionistic and indecisiveness.
- Those with HD have a higher prevalence of personality disorders.

Childhood experiences

- A deprived childhood may be associated with hoarding disorder. Examples include living in poverty or emotional abuse/neglect.

Education

- Hoarding disorder is more prevalent in lower SES groups.

[24] Royal College of Psychiatrists (2019) Hoarding. [Accessed: September 2023]
[25] Gilliam, C.M., Norberg, M.M., Villavicencio, A., Morrison, S., Hannan, S.E. and Tolin, D.F. (2011). Group cognitive-behavioral therapy for hoarding disorder: An open trial. Behaviour Research and Therapy, [online] 49(11), pp.802–807.
[26] G Steketee and CR Ayers, Challenges in Treating Hoarding in Midlife and Older Adults, Slide deck from a presentation, Undated.
[27] ME Doziera and CR Ayers, The Etiology of Hoarding Disorder: A Review, Psychopathology, 2017, 50(5): 291–296.

5. Activity data

Hoarding disorder is an issue that has been highlighted by a number of individuals but tracking and quantifying contact with services is impossible at present.

Health Service Data

It is known that HD is a reason for delayed discharges. However, the Public Health Intelligence Team have not been able to identify any activity that is coded for HD in either hospital or outpatient activity data (both locally and nationally). They have confirmed locally that the dedicated emergency WHO ICD10 code for HD is not being used, and it is not anticipated that HD will be coded for before 2025.

Secondary care services report virtually no referrals for HD and associated mental health co-morbidities.

The Talking Therapy service do not currently accept patients with HD.

EMIS, the data management system used by primary care has hoarding codes under the SNOWMED classification system. Currently, the relevant codes have only been used for 6 patients in Worcestershire.

Adult social care data

There are a number of different points where those with HD may come into contact with social services. In each case, cluttering or hoarding will be recorded in the individuals file when identified as an issue, but this cannot be routinely extracted.

Individuals with HD will be referred to into the Safeguarding Pathway either because of concerns about the individual themselves or for children living in the household of a parent with HD. Again, this is not easy to extract to determine the percentage of case load that involves HD.

Those with HD are also more likely to be placed into a care home. However, we do not know the figures for those directly placed because they are no longer able to live in their home as a result of HD (either because the clutter cannot be cleared, or because the house is no longer safe in other ways).

Housing data

Public housing is likely to record hoarding issues, but again it is not readily extractable. Work to quantify this issue is currently ongoing.

The Fire Service

The Fire Service provide Home Fire Safety Visits (HFSVs) as part of their prevention services. Assessments can be made either as a result of a call out, a referral from an agency, a request from the public or direct offer from the service itself (for example in a house where a fire has occurred). Properties that have clutter are marked on their system as they present an increased fire risk to individuals living in the house, those fighting a fire and the property.

Between 1 April 2022 – 30 December 2023 the service undertook 5,478 assessments. Of these 153 were found to be considered has having clutter that might be compatible with hoarding (**2.8%** of total visits).

Generally, clutter ratings above 4 are likely to impinge on daily life and could represent hoarding.

Where the clutter ratings reach 6 and above it is very likely that there is a moderate to severe hoarder in the household and the problem presents escalating risk to fire fighters.

48 properties had a clutter rating of above 6.

Table 2: Distribution of clutter ratings for those household with clutter rating above 6
1 April 2022 – 30 December 2023

Clutter rating	No. Households	Percentage of all those identified as 'hoarders'	Percentage of all household visited
6	28	18.50 %	0.51 %
7	7	4.58 %	0.13 %
8	5	3.27 %	0.09 %
9	8	5.23 %	0.15 %

Source: Hereford & Worcester Fire and Rescue Service

Of these 48 households:

- 31% were in housing association properties, 69% were owner occupiers and non were living in private rental properties.
- 75% lived alone.
- Of the 70 residents in these properties: 63% were over 65 years, 33% were adults between 18 and 64 and 4% were between 6 and 17 years of age. There were no very young children in this sample.
- 96% came from White British or Irish origin, 2% were from White – Other background and 2% did not wish to share their ethnicity.
- There was a 50:50 gender split between men and women.

Without fully understanding the routes to referral in detail and the characteristics of all households visited, it is difficult to interpret these results. It is also likely to be sample that does not represent the whole population. Nevertheless, this is the only dataset that is routinely recording clutter and so it is worthy of further examination.

Environmental Health - Enforcement

Environmental Health Services have powers to act to enforce clearance of houses under The Environmental Protection Act 1990, The Prevention of Damage by Pests Act 1949 and The Housing Act 2004.

Data awaited.

6. Impact of hoarding [28]

The *Enabling Spaces* document (New Zealand 2020) states that the 5 year mortality rates for elderly people that hoard is 50% compared to 26% for the general population. [29]

Hoarding behaviours can lead to the following problems:

- Social isolation
- Strained relationships with family, friends, landlords and neighbours.
- Legal and financial problems such as credit card debt, storage fees, dealing with property damage
- Eviction

In older age hoarding can:

- Complicate chronic and age-related medical illnesses
- Increase medication mismanagement
- Impair the activities of daily living such as self-care including eating well
- Impact on the ability to move within the home, find important items, eat at a table, use the kitchen sink, prepare food, and sleep in a bed. The inability to move properly around the home increases the risk of falls.

Hoarding increases both the risk of fire and the dangers posed by a fire (individuals not able to quickly leave the property or the fire service less able to control the fire).

Hoarding increases other environmental risks such as contamination by rotting foods, allergies due to contact with dust pollen and infestations of rats and cockroaches.

Hoarding increases the likelihood of moving into a care home either as a result of eviction from the private sector or the inability of provide a safe environment to vulnerable individuals. In addition, those with HD are at higher risk of falling. About 30% of individuals who experience a fracture neck of femur as a result of a fall cannot return to their own home.

Hoarding impacts on the mental health of family and friends, particularly those also living in the home (children and spouses), although there is little research in this area. [30]

For those organisations providing services, particularly the health service and housing departments, working with people with HD can be resource intense.

[28] G Steketee and CR Ayers, Challenges in Treating Hoarding in Midlife and Older Adults, Slide deck from a presentation, Undated.
[29] Canterbury Health Board, Enabling spaces, supporting elderly people with hoarding, 2020, Page 11
[30] AK Sekhon & L Leontieva, The Impact of Hoarding Disorder on Family Members, Especially the Significant Other, Cureus. 2023 Sep; 15(9): e45871

7. Treatment / Management [31] [32] [33] [34] [35] [36]

One of the challenges of managing HD is that individuals rarely present for help themselves. This may be because of either lack of insight, shame or social isolation that has developed over the years.

Individuals are much more likely to come to the attention of the authorities as the result of a consequence of their hoarding behaviour such as threatened eviction, a fall, a referral to safeguarding etc. By this time the hoarding behaviour often is moderate to severe. However, the focus on HD by the Canterbury Health Board as a consequence of the 2010 earthquake identified that individuals with HD had often been in contact with a number of agencies, but that this information had not been shared.

The current status of the evidence for its management is limited and of poor quality.

Historically, much of the treatment that has been tested in HD was tried in the belief that HD was an expression of OCD. This view has now changed. Historical studies often included a mix of patients with a range of conditions that then fell under the banner of OCD.

Most studies have focused on treating older individuals who have come to the attention of services and there is nothing on early intervention in the course of the disorder or at potential early intervention points such as major life events when the hoarding behaviour may worsen in response to the increased anxiety experienced. However, one clinical view is that age appears to be a predictor of outcome from treatment. Younger people generally respond better than older people.

Treatment response overall is poor. At the end of most trials (all of which are small case series) many individuals had not respond to treatment. Of those that did, most patients still met the clutter criteria for HD at the end of the course of treatment. However, the gains that were made, however small, were often retained.

The experience of Steketee is that the reduction in clutter can be relatively quick with patients who compulsively acquire items, while for others it took one or more years to see a significant improvement in the reduction in clutter. It is likely therefore, that within the group of individuals with HD there are variables that make treatment more or less successful. To date the following have been reported:

- Insight (more responsive)
- Lower age (more responsive)
- Presence of cognitive impairment (less responsive)
- Compulsive acquisition (more responsive)

[31] G Steketee and CR Ayers, Challenges in Treating Hoarding in Midlife and Older Adults, Slide deck from a presentation, Undated.
[32] Canterbury Health Board, Enabling spaces, supporting elderly people with hoarding, 2020.
[33] Evidence Exchange Network (EENet), Ontario, Canada, Rapid Review: What are the effective treatments for hoarding? 2016
[34] J Muroff, C Bratiotis and G Steketee, Treatment for Hoarding Behaviors: A Review of the Evidence, Clin Social Work J, 2011, 39: 406-423
[35] DF Tolin, RO Frost, G Steketee and J Muroff, Cognitive behavioral therapy for hoarding disorder: a meta-analysis, Depression and Anxiety, 2015m 32:158-166.
[36] Morein-Zamir, S. and Ahluwalia, S. (2023). Hoarding disorder: evidence and best practice in primary care. British Journal of General Practice, 73(729), pp.182–183.

The National Institute of Health and Care Excellence has not issued any guidance relating to HD.

The International OCD Foundation report that there is no gold standard for the management of HD as treatment is still being researched.

Currently there are a small number of clinical trials looking at the effectiveness of different treatments for HD.

A summary of current approaches to management is as follows:

1. Individuals that have co-morbidities such as depression and generalised anxiety should have these conditions treated.

2. Given that there is a suggestion that HD might involve faulty neuroprocessing the use of drugs for attention deficit hyperactivity disorder in combination with CBT has been proposed. However, good quality evidence is needed as many of the older studies focused on OCD rather than hoarding per se. Currently there is no single drug that can be recommended as part of treatment of the HD itself.

3. A multicomponent treatment protocol based on cognitive behavioural therapy appears to be the current preferred management. There is a wide range in the ways that this can be delivered. However, the management protocol developed by Steketee and Frost appears to have gained international support. [37]

4. Outcomes are improved when more of the intervention is delivered in the home.

5. There is strong consensus that 'one time forced clear ups' should be avoided as they lead to poor outcomes. This is because these 'quick fix' approaches don't address the emotional state of the patient, may in fact worsen their mental health and results in lack of trust. The latter can then lead the patient to reject further support meaning that the improvement cannot be sustained. If clearance of clutter is required, it should be conducted with patient participation.

6. A multiagency approach is needed, with a single agreed set of pathways and high levels of co-ordination. Simplifying information sharing improves communication.

The Canadian rapid review of the evidence concluded: *Although mental health treatments such as cognitive behavioural therapy are highly recommended, they are used in the minority of cases (20%). Ultimately, the best evidence-informed approach is to use a collaborative, multi-disciplinary, community hoarding taskforce that includes mental health support. Delivering some intervention in the home is particularly useful.*

Other things that need to be considered:

- Treatment can take a long time and is more complex in those with mental health co-morbidities and those who are in the older age group.

- Establishing trust is crucial before any progress can be made but this, of itself, can take a long time.

[37] G Steketee and RO Frost, Compulsive Hoarding and Acquiring: Therapist Guide, 0-19-530025-4, Oct 2006. G Steketee and RO Frost, Compulsive Hoarding and Acquiring: Workbook, 0-19-531055-1, Oct 2006.

- Ongoing light touch support is often needed after intensive treatment has finished.

- There needs to be flexibility and stepped care, and this will require flexible funding mechanisms.

- Professionals who are not experts in treatment HD but who find themselves involved in care and support need resources on which to draw to help them support individuals with HD.

- More can be done to signpost to lower-level support, particularly for younger individuals with insight.

- Family, particularly those living in the same home as the individuals with the HD, need support both to understand how to best support the individual who is hoarding, and also to address their own mental health difficulties many of which arise directly as a result of living in such adverse conditions.

8. Implications and recommendations

1. Not all clutter is a Hoarding Disorder.

2. It is possible that not all individuals currently diagnosed with HD may belong to a single clinical group. Hoarding may be a sign of a range of conditions.

3. Hoarding Disorder is a complex disorder that is poorly understood. Currently we lack information about its prevalence, cause, or natural history. Clinically distinct subgroups that are more or less amenable to current treatment may exist but are not well described, although some have been proposed – most notably; those with insight, those with compulsive acquisition and younger individuals. In addition, the evidence base for treatment is poor. This makes designing care pathways difficult.

4. Hoarding Disorder presents challenges for many agencies. Dealing with hoarding as an underlying problem to other issues can be resource intense for agencies. Currently there are no specialist mental health services to refer to in Worcestershire, leaving front line workers with an overall feeling that it is not possible to make any significant impact on the individual's situation and mental health. As a result, HD is experienced as an intractable problem by agencies with professionals feeling they cannot help the individual in the way they would wish to.

5. While all agencies cite HD as a challenge, the level of contact those with HD have with and the resources they use are poorly documented. As a system, Worcestershire should attempt to capture that contact in a way that enables cases to be counted and case records easily retrieved. Systemwide agreement is needed on how to best do this.

   For example:
   - Use of the ICD-10/11 codes for Hoarding Disorder – including community nursing notes.
   - Primary care putting on a HD flag to patient records.
   - Adult Social Care putting on a HD flag to records.

It would also be useful to understand how many individuals move into care homes as a direct or indirect results their hoarding disorder.

6. Hoarding Disorder is reported as being established at a relatively young age. The diagnosis of HD specifically includes significant impact on the individual's quality of life or functioning. Yet, in this younger age group, the negative impact is not described. Does an individual demonstrating hoarding behaviours be automatically classified as an individual with HD – or does HD only become apparent with time? It is not therefore clear what is actually being counted when prevalence figures are given.

7. Clutter is often labelled as hoarding by front line workers or lay people. But not all clutter is indicative of hoarding. Advice is needed for front line workers to help them identify those individuals that are likely to have HD and those that do not.

8. Linked to above is the need for systemwide consistency approach to language and appreciation that the term hoarding should be restricted to those that have HD.

9. Figure 1 suggests a range of care pathways that depend heavily on the correct diagnosis. A clinical assessment of those suspected of having a HD and other existing mental health disorders is needed for three reasons:

    i. To identify individuals with significant mental health co-morbidities, particularly major depression as they should be treated, probably through secondary care.

    ii. To ensure that the clutter within a dwelling is not due to some other condition, such as depression. In these instances, the management pathway will be different. For example, doing a one-time house clearance will not have the same negative impact on this group, compared to those with HD.

    iii. Identify those individuals who appear to be more likely to respond to treatment (those with insight and those where compulsive acquisition is the main feature.

10. Management is currently based on multiagency working, combined with cognitive behavioural therapy. What evidence there is points to HD being more resistant to (existing) treatment than other anxiety disorders. Treatment is expected to take much longer than for other anxiety disorders and requires some element of home-based therapy. More research is needed for public bodies to confidently invest in resource intense treatment services, whose outcomes, at present at least, appear to be poor. That is not the same as saying no support or treatment should at this point be offered.

    Most areas do not have specialist mental health services to offer treatment programmes for this group. However, services which provide support to individuals to improve their living conditions do exist. These may be viewed as alternatives to treatment for many individuals who are unlikely to engage in therapy or as a supplement to treatment-based services.

11. Drug treatments specifically targeted at the HD should only be used in the context of robust clinical trials.

12. There is very little focus within the research on the younger age group and how to prevent progression which may be associated with adverse and traumatic life events.

13. HD is largely a hidden disorder, particularly under the age of 50 years. There should be local support for National Hoarding Awareness Week to raise awareness of HD with signposting to information, advice, and services. The Adult Front Door and other agencies should also be encouraged to signpost individuals to these resources. However, awareness raising of this mental disorder raises some issues as currently there are no dedicated services locally for this group.

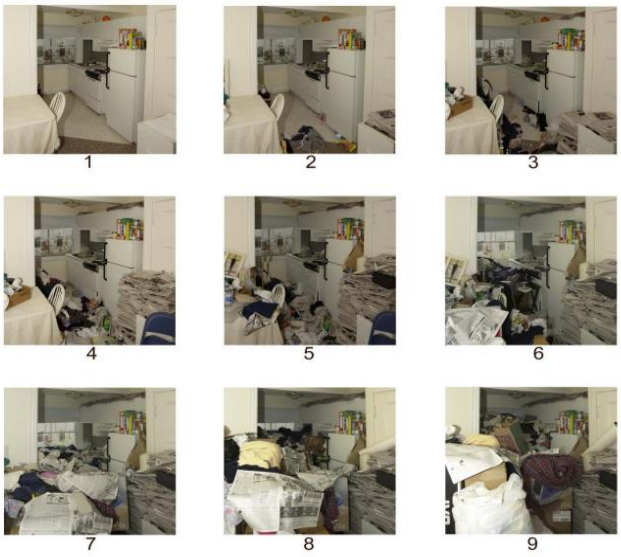
14. Those who live with an individual with HD are likely to experience mental health problems, and as such it important to open up conversations with household members and offer support and treatment if needed, as appropriate.

Appendix 1: Clutter Image Rating (CIR) [38]

In general, a picture scoring more than 4 is likely to impede individuals lives sufficient to seek help. Although the images focus on the kitchen, living room and bedrooms, all areas should be rated including hallways, the garage, and the individual's car if relevant.

Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.



Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.

[38] The International OCD Foundation and were originally from a study by Frost RO, Steketee G, Tolin DF, Renaud S. Development and validation of the Clutter Image Rating. Journal of Psychopathology and Behavioral Assessment, 2008, 32:401–417

Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room.


1


2


3


4


5


6


7


8


9

Appendix 2: Savings Inventory - Revised (SI-R) [39]

For each question below, circle the number that corresponds most closely to your experience **DURING THE PAST WEEK**.

0	1	2	3	4
None	A little	A moderate amount	Most/ Much	Almost All/ Complete

1.	How much of the living area in your home is cluttered with possessions? (Consider the amount of clutter in your kitchen, living room, dining room, hallways, bedrooms, bathrooms, or other rooms).	0	1	2	3	4
2.	How much control do you have over your urges to acquire possessions?	0	1	2	3	4
3.	How much of your home does clutter prevent you from using?	0	1	2	3	4
4.	How much control do you have over your urges to save possessions?	0	1	2	3	4
5.	How much of your home is difficult to walk through because of clutter?	0	1	2	3	4

For each question below, circle the number that corresponds most closely to your experience **DURING THE PAST WEEK**.

0	1	2	3	4
Not at all	Mild	Moderate	Considerable/ Severe	Extreme

6.	To what extent do you have difficulty throwing things away?	0	1	2	3	4
7.	How distressing do you find the task of throwing things away?	0	1	2	3	4
8.	To what extent do you have so many things that your room(s) are cluttered?	0	1	2	3	4
9.	How distressed or uncomfortable would you feel if you could not acquire something you wanted?	0	1	2	3	4
10.	How much does clutter in your home interfere with your social, work or everyday functioning? Think about things that you don't do because of clutter.	0	1	2	3	4
11.	How strong is your urge to buy or acquire free things for which you have no immediate use?	0	1	2	3	4

[39] Savings Inventory – Revised (modified version produced by Philadelphia Hoarding Organisation)

DURING THE PAST WEEK:

0	1	2	3	4
Not at all	Mild	Moderate	Considerable/ Severe	Extreme

12. To what extent does clutter in your home cause you distress?	0	1	2	3	4
13. How strong is your urge to save something you know you may never use?	0	1	2	3	4
14. How upset or distressed do you feel about your acquiring habits?	0	1	2	3	4
15. To what extent do you feel unable to control the clutter in your home?	0	1	2	3	4
16. To what extent has your saving or compulsive buying resulted in financial difficulties for you?	0	1	2	3	4

For each question below, circle the number that corresponds most closely to your experience

DURING THE PAST WEEK.

0	1	2	3	4
Never	Rarely	Sometimes/Occasionally	Frequently/ Often	Very Often

17. How often do you avoid trying to discard possessions because it is too stressful or time consuming?	0	1	2	3	4
18. How often do you feel compelled to acquire something you see? e.g., when shopping or offered free things?	0	1	2	3	4
19. How often do you decide to keep things you do not need and have little space for?	0	1	2	3	4
20. How frequently does clutter in your home prevent you from inviting people to visit?	0	1	2	3	4
21. How often do you actually buy (or acquire for free) things for which you have no immediate use or need?	0	1	2	3	4
22. To what extent does the clutter in your home prevent you from using parts of your home for their intended purpose? For example, cooking, using furniture, washing dishes, cleaning, etc.	0	1	2	3	4
23. How often are you unable to discard a possession you would like to get rid of?	0	1	2	3	4

SI-R (Modified) Scoring Subscales:

Clutter Subscale (9 Items):

Sum items: 1, 3, 5, 8, 10, 12, 15, 20, 22

Difficulty Discarding/ Saving Subscale (7 items):

Sum items: 4 (reverse score), 6, 7, 13, 17, 19, 23

Acquisition Subscale (7 items):

Sum items: 2 (reverse score), 9, 11, 14, 16, 18, 21

Total Score = sum of all items

Interpretation of Scores

Means for Nonclinical samples:

Acquisition	Mean = 8.1; standard deviation = 4.1
Difficulty Discarding	Mean = 7.8; standard deviation = 4.5
Clutter	Mean = 8.1; standard deviation = 7.1
Total Score	Mean = 24; standard deviation = 12.0

Typical scores for people with hoarding problems:

Acquisition	Score greater than 13
Difficulty Discarding	Score greater than 13
Clutter	Score greater than 15
Total	Score greater than 40

Appendix 3: Christchurch City Council Hoarding Assessment Tool [40]

CHRISTCHUCH CITY COUNCIL
HOARDING ASSESSMENT TOOL

SOURCE INFORMATION

Date Referral Received: **Time:**

Referrer's Name: **Agency:**

Referrers Phone: **Email:**

Relationship to Client:

Client's Name: **Age:** **DOB:**

Address:

Phone/Other contact:

Will clients allow access: ☐Yes ☐ No

HOUSEHOLD INFORMATION

Type of dwelling: ☐ Own ☐Rent £ per week

Household members:

Pets/Animals:

Other Agencies involved:

Has the person been helped in the past? By whom? When?

[40] Canterbury Health Board, Enabling spaces, supporting elderly people with hoarding, 2020

ASSESSMENT OF CLIENT

Physical or mental health problems of client:

☐ Does not seem to understand seriousness of problem
☐ Does not seem to accept likely health consequences of problem
☐ Defensive or angry
☐ Anxious or apprehensive
☐ Unaware, not alert, or confused

Client's attitude towards hoarding / living conditions:

Are basic needs being met? (food/shelter) ☐ **Yes** ☐ **No** _____

Is client's safety compromised? ☐ **Yes** ☐ **No** _____

Is clients wellbeing compromised? ☒ **Yes** ☐ **No** _____

Other issues / Problems / Needs (medication, mobility etc.):

Other agencies etc involved in initial assessment:

Sketch of dwelling:

ACTIVITIES AFFECTED BY CLUTTER OR HOARDING

	Can do it easily	Can do it with a little difficulty	Can do it with moderate difficulty	Can do it with great difficulty	Unable to do it
1. Food preparation	1	2	3	4	5
2. Use refrigerator	1	2	3	4	5
3. Use stove	1	2	3	4	5
4. Use kitchen sink	1	2	3	4	5
5. Eat at table	1	2	3	4	5
6. Move about house	1	2	3	4	5
7. Use toilet	1	2	3	4	5
8. Use bath/shower	1	2	3	4	5

LIVING CONDITIONS – PROBLEMS IN THE HOME

	None	Few	Moderate	Substantial	Severe
9. Structural damage	1	2	3	4	5
10. Water not working	1	2	3	4	5
11. Heating not working	1	2	3	4	5
12. Power not working	1	2	3	4	5
13. Presence of waste/ rotten food	1	2	3	4	5
14. Presence human faeces	1	2	3	4	5
15. Animal welfare issues	1	2	3	4	5
16. Animal urine/faeces present	1	2	3	4	5
17. Vermin infestation	1	2	3	4	5
18. Insect infestation	1	2	3	4	5

SAFETY ISSUES

	None	Few	Moderate	Substantial	Severe
19. Fire hazards	**1**	**2**	**3**	**4**	**5**
20. Unsanitary areas	**1**	**2**	**3**	**4**	**5**
21. Presence of mould / mildew	**1**	**2**	**3**	**4**	**5**
22. Visitors / services moving around the home	**1**	**2**	**3**	**4**	**5**
23. Clutter outside the house Garden, path, common areas etc.	**1**	**2**	**3**	**4**	**5**

Additional information or comments (including health issues etc):

Clutter Image Rating Score:

Living room ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9**
Kitchen ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9**
Bedroom ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9**
Score:

Photos taken? ☐ **Yes** ☐ **No** **By:**

RECOMMENDSATION FOLLOW-UP ACTION/S:

Officer:

Position:

Inspection Date and Time: