

Birmingham City Council: Research into Hoarding Final Report

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The Authors

RRR Consultancy Ltd was founded by Dr Alan Rust-Ryan and Dr Kate Rust-Ryan. They undertake research and consultancy in all areas of social policy from small-scale projects to long-term research studies.

The *RRR Consultancy* team has a proven successful track record in research and training relating to children, young people and adults, policy and practice, families and communities, housing, community development, hard to reach people and groups, education, multi-agency working, and service users and service provision.

RRR Consultancy also offer 'best practice' training courses to help ensure that public, voluntary and private organisations understand and successfully implement policies in areas such as domestic violence, children and families.

Executive Summary

- ES1. The Birmingham Community Safety Partnership's (BCSP) Vulnerable People Delivery Group seeks to gain a thorough understanding of the problem of hoarding in Birmingham, with the intention of devising a comprehensive strategy to address the problem in an informed and responsive manner. Accordingly, in December 2015 BCSP commissioned *RRR Consultancy Ltd.* to undertake research on the issue. To ensure that the aims and objectives of the research were met a range of research methods were adopted including a literature review, analysis of secondary data, online survey of service providers, and case studies with people experiencing hoarding difficulties.
- ES2. Since 2013 hoarding has been recognised as a distinct mental health difficulty on its own rather than solely an aspect of obsessional compulsive difficulties or as a 'lifestyle choice'. However, hoarding may be perceived as much a social as mental health issue and most people experiencing hoarding difficulties are never diagnosed by health professionals. As such, it is important not to perceive it solely as a mental health issue.
- ES3. It is estimated that between 2% and 5% of the population hoard equating to at least 1.2 million households across the UK and at least 22,000 people in Birmingham. Between April 2012 and February 2016 Birmingham City Council's Environmental Health Department recorded a total of 153 hoarding cases. Also, in 2014/15 the West Midlands Fire Service (WMFS) recorded 120 cases of severe hoarding and 321 cases of dangerous storage suggesting that much hoarding within the city remains 'hidden'.
- ES4. Although hoarding is commonly associated with socially isolated older people, the characteristics of hoarders vary widely. Hoarding difficulties are usually co-presented with a range of symptoms such as depression, anxiety, post-traumatic stress disorder, attention deficit/hyperactivity, intellectual or developmental difficulties, and autism. The impact of hoarding on hoarders, family and neighbours is well documented. Specific issues relating to hoarding include: the risk of fire and death, risk of crushing, loneliness and social isolation, poor sanitation, poor nutrition, damage to property, risk to staff safety, pests and vermin, and complaints from neighbours. Hoarding also impacts mentally and emotionally on family members and friends.
- ES5. Agencies have recourse to a wide range of legislation which can be used to resolve cases of domestic hoarding depending on the nature and severity of the case. This includes legislation relating to adult and child protection legislation, although the most extensive range of legislation relates to environmental health powers. It is particularly important that agencies intervene in hoarding cases when the safety of adults or children is undermined. However, it is important to recognise that enforcement action can lead to client disengagement with agencies, and that removing clutter is only addressing the symptom of hoarding, not the problem.

- ES6. There is extensive international and national good practice regarding dealing with hoarding. One key finding is that the most effective responses to hoarding are likely to be multi-agency in character. Relevant services could include mental health, housing, adult social care, community safety, environmental health, and animal welfare services. Similarly, agencies may want to consider community-based, multi-disciplinary approaches which both offers an approach that respects the individual living with hoarding behaviour and provides support to ensure successful intervention. The most successful interventions are based on partnership working, serious case reviews, raised awareness, and the training and support of staff.
- ES7. Some organisations such as Nottingham County Council and Liverpool Housing Trust have developed hoarding assessment forms and clutter image rating toolkits (Frost et al, 2008). Practitioners may also consider undertaking interviews with hoarders as part of an initial assessment and to determine motivation for change. The National Housing Federation (NHF) (2015) published guidance on hoarding which considers good practice. Examples included the Orbit 'Care and Repair' which works with people with hoarding tendencies from an occupational therapy perspective; the Pan-London Hoarding Task Force which is attended by over 20 different organisations from across London and meets around every 2 months; the Liverpool Housing Trust (LHT) 'Outside The Box' model which links practical support and therapeutic intervention together; and the London Borough of Hammersmith and Fulham which identified social work skills as being most effective when working with people who hoard.
- ES8. There is a wide range of therapeutic interventions that can be used to support people experiencing hoarding difficulties. In most larger cities such as Birmingham, Leeds, Manchester, Liverpool and Newcastle hoarding support groups have been established run by either volunteers or professionals. One therapy most commonly used by practitioners supporting hoarders is cognitive behaviour therapy (CBT). CBT is a talking therapy that can help people manage problems by changing the way they think and behave. During CBT, individuals gradually learn to discard unnecessary possessions with less distress, diminishing their exaggerated perceived need or desire to save for these possessions. They also learn to improve skills such as organisation, decision-making, and relaxation. Other therapeutic responses include group work, therapy groups, at-home sessions, family therapy, self-help groups, and motivational interviewing.
- ES9. Analysis of secondary data regarding these cases displays clear characteristics. In relation to tenure, a relatively large proportion of hoarding cases reside in the social rented sector. However, it is possible that this is due to social housing tenants or housing officers being more likely to report hoarding cases. Supporting this assumption, whilst a wide range of organisations referred hoarding cases to the Environmental Health Section, a fifth derived from the Birmingham City Council Housing Department. It is perhaps unsurprising, given its complexity, that a large number of agencies are involved in supporting hoarding cases. Whilst most hoarding cases usually involve around 2 hours support, a large proportion of cases required much more extensive support.

- ES10. Analysis of data from both Environmental Health and West Midlands Fire Service (WMFS) suggest that there are a range of health and social factors which contribute to hoarding. However, the three which are most evident are the age of the hoarder, whether living alone or with family, and whether the hoarder had mental health needs. It is apparent that many of the hoarding and dangerous storage cases involve older, single people living alone. Some hoarding cases involved older people who had been hospitalised due to mental health issues such as dementia. Other issues such as drug or alcohol misuse impact on the likelihood of hoarding. Ethnic identity appears to not substantially on the likelihood of hoarding. However, there is a geographic dimension to the data with hoarding more likely to occur in deprived areas of Birmingham.
- ES11. As well as the psychological, health, social and environmental impact that compulsive hoarding may have on hoarders, family and neighbours, there are also financial impacts. Estimates of responding to hoarding range from between £35,000 to £45,000 per case. The average 38 cases per annum supported by the Birmingham Environmental Health Section combined with the 120 severe hoarding cases supported by the West Midlands Fire Services (WMFS) during 2014/15 equates to potential costs of between £5.53m and £7.11m. However, a Social Return on Investment (SROI) analysis suggests that implementing a hoarding support scheme would lead to financial gains of between £2.70 and £3.50 for every £1 invested. Whilst it is not possible to undertake a similar analysis regarding charging for services in relation to hoarding, it is apparent that the disadvantages of charging outweigh the advantages. As such, it is recommended that generally, hoarders are only charged after alternative options have failed and after careful consideration of the impact of costs on the hoarder
- ES12. As part of the research an online survey was devised to determine the extent of hoarding in Birmingham, its impact on hoarders, families and neighbours, the effectiveness of multi-agency approaches to hoarding, and examples of good practice. There was agreement amongst respondents that hoarders tend to display complex issues, and that these may manifest themselves in terms of social, health or mental health issues. Such issues frequently lead to self-neglect and increasing social isolation. Some hoarders had recently experienced a traumatic experience such as bereavement meaning that they formed an emotional attachment to objects so were less willing to discard them. Respondents described the social isolation associated with hoarding. Hoarders are frequently socially isolated and have few close family or friends to turn to for support.
- ES13. Respondents stated a wide range of risks associated with hoarding although the main one cited was risk of fire. Hoarding of objects meant that in the event of fire escape routes were likely to be obstructed. Risk of fire also places neighbouring properties at risk. The impact of hoarding can be severe leading to mental and physical health issues, impacting on quality of life, and affecting family relationships and neighbours. In some instances, it can lead to relationship breakdown. For hoarders with children there may be safeguarding issues. Hoarding can also severely impact on neighbours in terms of fears about general health and safety, risk of fire, or insect and vermin infestation.

- ES14. Generally, respondents stated criteria for determining when organisations should provide support to people experiencing hoarding difficulties are not clear. This means it can be difficult for agencies to determine when they need to provide help and support to hoarders. Decisions as to which agency or internal department is responsible for dealing with a hoarding case may be hampered by financial costs. Most agencies have limited resources to support hoarders and some lack specialist staff. For some respondents there was a sense of frustration at being unable to secure the services of external organisations. Also, most respondents stated that they had not received sufficient training and support to help people with hoarding difficulties.
- ES15. Importantly, it was suggested that there needs to be a more 'joined-up' and ongoing approach to hoarding and a need for better integration and cooperation. It was clear from respondents that a multi-agency approach to support hoarders is essential. This is because hoarding encompasses many different health and social care factors and people will need different approaches depending on what is affecting them.
- ES16. Case studies were undertaken with 10 people experiencing hoarding issues. It is apparent that although some cases share similar characteristics such as being elderly and alone, they are complex and involve a range of different social, health factors. In many of the cases hoarding appears to be in response to life changing events such as relationship breakdown, bereavement or redundancy. In some instances, hoarding has led to life-changing events such as children being placed in foster care. Hoarding negatively impacts on relations with family, friends and neighbours. Mental health issues such as depression or anxiety also predominate irrespective of whether in response to events or some other underlying cause. In the case of bereavement people may place a strong emotional attachment to the deceased belongings. These are frequently combined with other types of health issues such as diabetes or epilepsy.
- ES17. There is extensive good practice regarding dealing with hoarding. One key finding is that the most effective responses to hoarding are likely to be multi-agency in character. Relevant services could include mental health, housing, adult social care, community safety, environmental health, and animal welfare services. Similarly, agencies may want to consider community-based, multi-disciplinary approaches which both offers an approach that respects the individual living with hoarding behaviour and provides support to ensure successful intervention.
- ES18. More specific suggestions included the use of visual image scales, adopting risk assessment tools such as HOMES (Health, Obstacles, Mental Health, Endangerment, Structure), and adopting Vulnerable Adult Risk Management (VARM) principles. Also, it is clear from respondents that there is a need to improve agency and public awareness of hoarding and the type of help and support available. This could take the form of public awareness campaigns which uses a wide range of traditional and social media.
- ES19. Chapter 6 provides recommendations based on the evidence discussed above including:

- To adopt the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) (2013) definition of hoarding
- To consider implementing a hoarding support programme.
- To adopt a multi-agency approach to hoarding cases to ensure a collaborative approach between relevant agencies and organisations.
- Improve information sharing between agencies regarding hoarding including the implementation of information-sharing protocols to facilitate the swift sharing of information.
- Agreeing data collecting protocols on hoarding to ensure consistency of data collection across agencies i.e. agree the type of information to be collected.
- Agencies should be proactive rather than reactive in response to hoarding cases i.e. offer early intervention where possible.
- Adopting the Liverpool Housing Trust 'Self-Assessment' form (in liaison with increasing public awareness of the issue) (see Appendix 1)
- Adopting the Liverpool Housing Trust 'Hoarding Disorder Impact Assessment form' (see Appendix 2)
- Adopting the Nottinghamshire County Council 'Hoarding Assessment Referral' form (see Appendix 3)
- Using the 'Clutter Image Rating' scale (Nottingham County Council) (see Appendix 4) to determine agency responses. Specific actions would include:
 - Adopting the Liverpool Housing Trust 'My Acquiring Rules' form (see Appendix 5)
 - Implement an awareness raising campaign using traditional and social media.
 - Implement training across agencies to ensure that both front-line staff and managers know best how to deal with hoarding cases.
- To consider adopting community approaches to hoarding
- Adopting a sympathetic approach to hoarders and awareness of the emotional difficulties involved in decluttering.
- Ensuring that help and support to people experiencing hoarding issues is ongoing e.g. to maintain support once a property has been decluttered.
- Charging hoarders only after alternative options have failed and after careful consideration of the impact of costs on the hoarder.
- For legal action against hoarders to be considered only as a last resort.

1. Background

- 1.1. The Birmingham Community Safety Partnership's (BCSP) Vulnerable People Delivery Group seeks to gain a thorough understanding of the problem of Hoarding in Birmingham, with the intention of devising a comprehensive strategy to address the problem in an informed and responsive manner. Accordingly, in December 2015 BCSP commissioned *RRR Consultancy Ltd.* to undertake research on the issue of hoarding in Birmingham. The main aims of the research were to enhance understanding and knowledge of the issue and enable a multi-agency response and present options for agencies seeking tackle the problem, including providing guidance for people concerned about the welfare of relatives or others (such as close neighbours) who are owner-occupiers.

- 1.2. To ensure that the aims and objectives of the research were met a range of research methods were adopted including a literature review, analysis of secondary data, online survey of service providers, and case studies with people experiencing hoarding difficulties. The following discusses the estimated extent of hoarding in Birmingham, the causes and key characteristics of hoarding, legal frameworks, good practice, the costs of implementing a hoarding support programme, the perspectives of agencies regarding hoarding, and the findings of hoarding cases. It makes an extensive number of recommendations as to how Birmingham agencies can best resolve the issue of hoarding.

2. Literature review

Background

2.1. According to the British Psychological Society (BPS) (2015) hoarding is recognised as a distinct mental health difficulty on its own rather than solely an aspect of obsessional compulsive difficulties or as a 'lifestyle choice'. Importantly, it is identified as a standalone mental disorder by the Diagnostic and Statistical Manual of Mental Disorders (DSM) (2013). Recent studies estimate that between 2-5 per cent of the population experience hoarding difficulties although a recent and well conducted study (Nordsletten 2013) estimated a prevalence of around 1.5 per cent. Key facts about hoarding include:

- It is estimated that between 2% and 5% of the population hoard
- This equates to at least 1.2 million households across the UK
- It is estimated that only 5% of hoarders come to the attention of statutory agencies
- Hoarding cases can cost anywhere from £1,000 to £60,000
- 20-30% of OCD sufferers are hoarders (Chartered Institute of Environmental Health)
- Often, people who hoard can stop landlords from meeting their statutory duties e.g. gas safety checks and other certification required for Registered Social Landlords

(Nottinghamshire County Council, 2015: 6)

2.2. Given that the population of Birmingham was 1.1m people in 2014 (NOMIS, 2016), it is estimated that between 22,000 and 55,000 people in the city display hoarding difficulties. Even applying the lower estimate of 1.5% (Nordsletten, 2013) would equate to around 16,500 people in Birmingham experiencing hoarding difficulties¹.

Definitions of hoarding

2.3. As stated above, since 2013 hoarding has been recognised as a distinct mental health difficulty on its own rather than solely an aspect of obsessional compulsive difficulties or as a 'lifestyle choice'. The Diagnostic and Statistical Manual of Mental Disorders (DSM 5) (2013) defines hoarding as:

“a pattern of behaviour that is characterized by the excessive acquisition of and inability or unwillingness to discard large quantities of objects that cover the living areas of the home and cause significant distress or impairment” (DSM-5, 2013).

2.4. According to Brown and Pain (2014), although the inclusion of hoarding in DSM-5 can be seen as positive in that it recognises its prevalence and impact, it has the potential to stigmatise and label those

¹ Please note that throughout this study the term people with 'hoarding difficulties' is used. This includes people who may display symptoms regarding hoarding but have not been diagnosed as displaying a mental health condition.

affected by hoarding and discourage people from engaging with support services. As such, there is concern that diagnostic labels are medicalising human problems and have the potential to cause harm to service users. Brown and Pain (2014) cite Kinderman et al. (2013) who suggest that introducing the language of 'disorder' undermines a human response by implying that these experiences indicate an underlying defect. They instead suggest that psychological distress should be acknowledged as a normal, not abnormal part of human life' (2013, p.3). Also, hoarding may be perceived as much a social as mental health issue and most people experiencing hoarding difficulties are never diagnosed by health professionals. As such, whilst the DSM-5 definition of hoarding is useful, it is important not to perceive it solely as a mental health issue.

- 2.5. It is important to distinguish hoarding with similar but non-problematic behaviours. For example, it is possible to compare and contrast hoarding and collecting (British Psychological Society (BPS), 2015). An interesting feature of collecting (like hoarding) is that it often entails building a collection of objects with relatively low economic value, with individual items being granted elevated, high personal value by the collector, due to their place and position in the collection. (BPS, 2015). Although hoarding is commonly associated with older people, many collectors begin collecting as young people. Similarly, the National Housing Federation (NHF) (2015) suggest a key difference is that hoarding impacts adversely on the individual and their environment, whereas it is possible to be an avid collector and for the collection of items to never congest or disrupt the home environment.
- 2.6. Further, whilst those who collect may have an attachment to their collected items, removal of those items typically will not cause the same level of anxiety and distress that is experienced by individuals with hoarding disorder. The forced removal of items often reinforces the need of the individual with hoarding disorder to excessively hoard items to guard against further distress and loss. Therefore, when a housing provider takes the action of clearing the individual's home of the clutter and/or pursuing an anti-social behaviour route, these interventions will often have little sustained effect, as they are addressing the symptoms, rather than the problem itself. (NHF 2015)
- 2.7. A widely accepted definition of hoarding includes a person having difficulties with:
 1. Compulsive acquisition of objects, with marked and gross associated difficulties with discard, creating avoidance of discard behaviour.
 2. Living spaces becoming so full of objects (i.e. excessively cluttered) that the use of rooms becomes circumscribed or very restricted. For example, the person may be unable to use the bathroom, or sleep in their own bed because of the accumulation of belongings/possessions.
 3. Significant associated distress and/or functional impairment. The key thing here is it does

not have to be both. People can struggle with hoarding with extreme functional impairment, without apparent significant distress.

(Steketee et al., 2000)

- 2.8. There are typically three types of hoarding: first, inanimate objects – this is the most common and could consist of one type of object or collection of a mixture of objects such as old clothes, newspapers, food, containers or papers. Second, animal hoarding: this is often accompanied with the inability to provide minimal standards of care. The hoarder is unable to recognise that the animals are at risk because they feel they are saving them. The homes of animal hoarders are often eventually destroyed by the accumulation of animal faeces and infestation by insects. Third, a relatively new phenomenon is data hoarding. This presents itself as a need to store copies of emails, and other information in an electronic format. It could also involve the storage of data collection equipment such as computers, electronic storage devices or paper (Nottinghamshire County Council, 2015).
- 2.9. Strong attachment to items interferes with the ability to discard. People may be very attached to possessions that have personal meaning, giving them particular value. Kellett et al (2010) identified three main types of value: intrinsic value – something that is of itself valuable e.g. foreign currency; instrumental value – the value in being able to make future use of an item e.g. old clothes that could be used to repair other clothes, items that can be recycled; and sentimental value – the affect associated with possessions, e.g. old photos, diaries, or albums, as they signify or represent parts of the self, that may act as reminders of a person's life, or relationships with others (BSP, 2015).
- 2.10. Minimising or wrongly labelling hoarding can further alienate those who are in desperate situations, struggling, often in isolation, with little or no support. Recognition of the difficulties faced by people who hoard (and their friends, relatives and neighbours) might also mean that some of the issues affecting motivation to change and engagement with statutory services can be addressed. If the person with hoarding difficulties feels they are heard and respected without judgement, therapeutic efforts may pay dividends. It is essential that those working with or supporting people with hoarding difficulties can also access services, training and advice. Identifying specific issues relevant to hoarding behaviour will increase our understanding and ability to offer appropriate interventions (BPS, 2015).

Characteristics of hoarders

- 2.11. Although hoarding is commonly associated with socially isolated older people, the characteristics of hoarders vary widely. The Midlands Psychology Group (2014) draw attention to the role of social inequality whether through class, gender, ethnicity, sexuality or disability. Hoarding difficulties have been identified as more common amongst men, widows, the unemployed and those from less wealthy backgrounds (Samuels et al., 2008).

- 2.12. As well as reflecting mental health issues hoarding difficulties can impact socially on hoarders, neighbours and housing providers. Tolin et al. (2008) found that 8%-12% of people who hoard have been threatened with or experienced eviction. Losing post in the morass of objects can increase the risk of eviction, because the person may not necessarily be aware that the process has been initiated. Housing providers face the difficult task of working with people who may be unknown to mental health care services, and may receive little or no specialist psychological consultation or supervision in their work.
- 2.13. According to Grisham and Norberg (2010) clinical studies have demonstrated that hoarding often co-occurs with other psychological disorders. In a large clinical sample, almost all individuals with a hoarding diagnosis met criteria for another mental health disorder, and these individuals had significantly more co-occurring disorders than non-hoarding individuals with OCD. Hoarding difficulties are usually co-presented with a range of symptoms such as depression, anxiety, post-traumatic stress disorder, attention deficit/hyperactivity, intellectual or developmental difficulties, and autism. The two conditions in which hoarding is most likely to occur are elderly self-neglect (or 'Diogenes Syndrome') and obsessive-compulsive disorder (OCD). According to the British Psychological Society (BPS) (2015) it is important that people with hoarding difficulties get access to appropriate psychological interventions and advice that potentially can relieve distress or disability.
- 2.14. A growing body of research suggests that hoarding is associated with a lower quality of life. First, hoarding appears to occur more frequently in the unemployed and poor. Although longitudinal studies are needed to determine if hoarding is a cause or consequence of financial insecurity, a recent study indicated that hoarding may at least contribute to financial insecurity. Five percent of one sample reported they had been fired because of hoarding, and on average, employed individuals reported 7 psychiatric work impairment days per month (Grisham and Norberg, 2010).
- 2.15. Second, hoarding has been linked to poorer health status. Individuals who hoard are very likely to be overweight or obese and suffer from a severe medical condition. Third, several clinical and community studies have reported a low rate of marriage among compulsive hoarders. Those who are married or cohabitating tend to have a lower degree of hoarding severity. Fourth, hoarding is associated with high rates of family frustration. Family members who cohabit with hoarders report being embarrassed about the condition of their home, arguing about the clutter, and feeling rejection and hostility toward the hoarder (Grisham and Norberg, 2010).
- 2.16. The Liverpool Housing Trust describes hoarders as people who:
- Believe that their possessions connect them to the outside world
 - Form attachments to possessions instead of people

- Have trouble paying attention, organising and making decisions
- Are visually stimulated and believe that they can't retain information
- Believe that all they acquire has a beautiful or useful purpose

(Liverpool Housing Trust, 'Out of the Box')

2.17. They have developed a hoarding self-assessment form which enables people to determine the extent to which they have a hoarding problem (see Appendix 1). The form attempts to assess thoughts, feelings and behaviours in relation to hoarding e.g. 'Do you focus on every part of an item and find unusual detail that others may not see?', 'Do you feel distressed when you imagine discarding items that you feel might have a use?', and 'Do you have difficulty discarding possessions regardless of value?' Responses are based on a Likert scale of 0 to 10 with 0 representing 'not at all' and 10 'very much'. The form can be used to determine the extent to which respondents require help and support regarding hoarding.

Impact of hoarding

2.18. The impact of hoarding on hoarders, family and neighbours is well documented. Specific issues relating to hoarding identified by Midland Heart include: the risk of fire and death; risk of crushing; loneliness and social isolation; poor sanitation; poor nutrition; damage to property; risk to staff safety; pests and vermin; and complaints from neighbours. Animal hoarding which involves the obsessive collecting of animals, often with an inability to provide minimal standards of care, may also occur. Also, hoarding behaviour may compromise the ability of gas/electric services to be inspected or maintained leads to higher risk of faults developing, house fires starting and/or dangerous gas leaks. Liverpool Housing Trust have developed a 'Hoarding Disorder Impact Assessment' which assesses the impact of hoarding in different rooms around the home (see Appendix 2).

2.19. According to the British Psychological Society (BPS), the health needs of those with severe and complex mental health problems have long been known to be worse than in the general population. People with severe hoarding difficulties are likely to be at risk of neglecting their own physical healthcare needs and have greater difficulty accessing physical health services. Isolation increases the likelihood that the person may not be known to local GPs creating further risk that physical health is compromised. People with hoarding difficulties have been shown to be nearly three times more likely to be overweight or obese, and significantly more likely to report a wide range of chronic and severe medical problems (Tolin et al., 2008), with the most common conditions including diabetes, seizures, head injury, sleep apnoea, and cardiovascular, arthritic, haematological and lung conditions (Ayers et al., 2014).

2.20. Büscher et al (2014) undertook a rigorous review of literature on compulsive hoarding which looked at the impact of hoarding on the mental, physical and social well-being of family members. Three main

themes deriving from the review included 'withdrawal', 'isolation' and 'sanctuary'. Withdrawal refers to the retreat of the family of the hoarder from the outside world. One husband described 'keeping the world out' (Wilbram et al. 2008). The research cites Tolin et al. (2008) who reported a high incidence of social withdrawal in children of hoarders, especially those aged between 11 and 20 years because of embarrassment about the condition of the home. Importantly, there is a significant correlation between living in a hoarded house and not wanting people to visit.

- 2.21. 'Shattered families' refers to the impact hoarding has on family dynamics. Conflict was expressed through arguments about clutter, failing to discard items, and compulsive acquiring. One source of difficulty is the issue of control. This was found to be experienced by family members when they tried to take charge of the hoarding situation by implementing strategies to reduce the amount of clutter in the house. There can also be a loss of relationships and social life for the family members of hoarders. Rallying around describes various responses that family members make to hoarding behaviour. The persistence of family members acting as 'key carers' (Wilbram et al. 2008) and in seeking help (Tolin et al. 2008, 2010) indicated that family members maintained hope that things would get better.

Legal Framework

- 2.22. In instances of deliberate hoarding or when the client is unwilling to accept help, the situation may necessitate the use of legislation to minimise the associated risks. Many different pieces of legislation can be used to resolve cases of domestic hoarding depending on the nature and severity of the case. However, the case studies discussed in Chapter 5 below suggest that enforcement action can lead to client disengagement with agencies. Also, as Brown and Pain (2014) suggest, removing clutter is only addressing the symptom of hoarding, not the problem, and forced clean-ups can worsen symptoms and lead to recidivism. Nonetheless, it is important to consider the legal framework regarding hoarding².

The Mental Capacity Act (MCA) 2005

- 2.23. The Mental Capacity Act (MCA) 2005 provides a statutory framework for people who lack the capacity to make decisions by themselves. The Act has five statutory principles and these are legal requirements of the Act:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision.

² The following draws largely on guidance on hoarding published by Kirklees Council (April 2016)

4. An act done, or decision made, under this act for, or on behalf of, a person who lacks capacity must be done, or made in his or her best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

- 2.24. When a person's hoarding behaviour poses a serious risk to their health and safety, professional intervention will be required. With the exception of statutory requirements, the intervention or action proposed must be with the individual's consent. Article 8 of the European Convention on Human Rights (the right to respect for private and family life) – is engaged. Interference with a person's life must be lawful, necessary and pursue a legitimate aim. In extreme cases, taking statutory principle 3 (above) into account, the very nature of the environment may lead the professional to question whether the customer has capacity to consent to the proposed action or intervention and trigger a capacity assessment. All interventions must be undertaken in accordance with the 5 statutory principles and using the 'two stage' test of capacity (see MCA Code 4.11 – 4.25).
- 2.25. The MCA Code of Practice states that one of the reasons why people may question a person's capacity to make a specific decision is that "the person's behaviour or circumstances cause doubt as to whether they have capacity to make a decision" (MCA Code of Practice, 4.35). Extreme hoarding behaviour may therefore in the specific circumstances of the case, prompt an assessment of capacity. (Kirklees guidance pp. 7-8)

Safeguarding Children

- 2.26. Safeguarding Children refers to protecting children from maltreatment, preventing the impairment of their health or development and ensuring that they are growing up in circumstances consistent with the provision of safe and effective care. Growing up in a hoarding property can put a child at risk by affecting their development and, in some cases, leading to the neglect of a child, which is a safeguarding issue. The needs of the child at risk must come first and any actions we take must reflect this. Where children live in the property, a Safeguarding Children alert should always be raised.

Safeguarding Adults

- 2.27. Safeguarding Adults means protecting an adult's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent, and stop, both the risks and experience of abuse or neglect, while at the same time making sure that the adult's wellbeing is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action. This must recognise that adults sometimes have complex interpersonal relationships and may be ambivalent, unclear or unrealistic about their personal circumstances.

The Care Act 2014

2.28. The Care Act, 2014 builds on recent reviews and reforms, replacing numerous previous laws to provide a coherent approach to adult social care in England. Local authorities (and their partners in health, housing, welfare and employment services) must now take steps to prevent, reduce or delay the need for care and support for all local people. The Care Act introduced three new indicators of abuse and neglect to Adult Safeguarding. The most relevant to this framework is self-neglect. The guidance states; this covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding. In practise, this means that when an adult at risk has care and support needs because of a physical or mental impairment or illness, their case may require a safeguarding enquiry.

Environmental Health Powers

2.29. Environmental Health has certain powers which can be used in hoarding cases, some are mentioned below. There is also a link to the Chartered Institute of Environmental Health which notes the growing list of statutory powers available to address hoarding. With the use of case studies and surveys this institute reviews the incidence and diversity of cases coming to the attention of environmental health authorities with the aim of identifying better ways to resolve issues. The main environmental health legislation that can be used in relation to hoarding cases include:

- Public Health Act 1936 Section 79: Power to require removal of noxious matter by occupier of premises
- Public Health Act 1936 Section 83: Cleansing of filthy or verminous premises
- Public Health Act 1936 Section 84: Cleansing or destruction of filthy or verminous articles
- Prevention of Damage by Pests Act 1949 Section 4: Power of LA to require action to prevent or treat Rats and Mice
- Prevention of Damage by Pests Act 1949 Section 80: Dealing with Statutory Nuisances (SNs)
- Town and Country Planning Act 1990 Section 215: Power to require proper maintenance of land

Good practice

2.30. As well as considering the definition, characteristics, impact and cost of compulsive hoarding, it is important to consider good practice. The below discusses good practice on hoarding derived from a range of sources. One key finding is that the most effective responses to hoarding are likely to be multi-agency in character. Relevant services could include mental health, housing, adult social care, community safety, environmental health, and animal welfare services. Referrals can come from a range of sources including from the person themselves, neighbours, family or friends, and professionals. Evidence from Midlands Heart suggests that the most successful interventions are based on partnership working, serious case reviews, raised awareness, and the training and support of

staff. Whilst some of the good practice discussion below is drawn from international cases, most derive from UK 'Core Cities'³.

South Australia

- 2.31. In 2007, a South Australian specific protocol was developed to manage cases of compulsive hoarding (Merkel 2007). The protocol identified the potential roles and responsibilities that several agencies might play in the management of compulsive hoarding. It acknowledged that many agencies find it difficult to achieve successful outcomes. A referral and management pathway was also developed to provide further guidance to relevant agencies. The Catholic Community Services in Sydney, with funding assistance from the New South Wales State Government, have established a single referral point through the use of a 'Squalor Hotline', which both the community and agencies are encouraged to use. Upon receipt of a referral, staff assess the property and initiate a multidisciplinary response. This usually involves case specific meetings and the development of specific action plans.

Canada

- 2.32. The Seniors Association of Greater Edmonton (SAGE), Canada looked at community approaches to hoarding. Research undertaken by SAGE (2013) suggested that older adults with hoarding behaviour are often at a high risk of being homeless. The research examined the value of a collaborative community-based approach to hoarding and found that individuals remaining in their homes are safer, and communities benefit from collaborative sharing of expertise and maximising of resources.
- 2.33. The research found that working together collectively, in a multi-disciplinary fashion, provides both the opportunity for developing an approach that respects the individual living with hoarding behaviour and provides support to ensure successful intervention. Addressing hoarding through an integrated approach across the lifespan reduces the burden on the health care system by avoiding the need for acute care or transitional care beds (SAGE, 2013: 4).
- 2.34. Further, it showed that providing in-home practical and emotional supports to address hoarding before it reaches a point of crisis enabled the individual to live more safely and more independently in their own homes for longer. It improved the capacity for Home Care staff to bring services to the home of a person who lives with extreme clutter, in a manner that provides a safer work environment. It reduces the individual's risk of injury due to extreme clutter because they have engaged in a harm reduction action plan. It also reduces the risk to self from poor sanitation and infestation of harmful pests because clients will engage in steps to eliminate such dangers. (SAGE, 2013: 6). Key findings from the SAGE research were that:

³ Birmingham, Bristol, Leeds, Liverpool, Manchester, Newcastle, Nottingham and Sheffield

1. Education and training is needed for first responders, landlords and others involved in different levels of service provision.
2. Therapeutic supports are necessary to identify and sustain behavioural change.
3. Financial help for some clients is crucial for taking the first step in an action plan, to prevent eviction and/or to stay housed in a safe and functional manner.
4. Multi-disciplinary teams are essential to this work.
5. Temporary housing would be an asset to individuals whose action plans makes it unsafe for them to live in their homes for a period of time. This could be due to a number of things: blocked exits due to excessive accumulation of belongings, a large number of animals and/or an unsanitary home environment.
6. There is a need to develop interagency protocols and common tools.

(SAGE, 2013: 16).

Birmingham

- 2.35. The West Midlands OCD, BDD & Hoarding Support Group was formed in 1998, following the Annual Obsessive Action Conference in London. The group holds monthly group meetings which include open discussions between hoarders, friends and carers, with occasional input from professionals who have studied causes and treatments of OCD. The Group's committee work hard to formulate an interesting and informative programme of meetings and social activities. They engage a selection of visiting speakers who will cover a whole range of topics which in the past have proven beneficial to hoarders and carers alike. The group has network links with the charity organisations such as OCD-Action, OCD-UK and No Panic. They have built up a small reference library of books, tapes and conference papers to loan members. The West Midlands Fire Service, Birmingham City Council Environmental Health Section, and Birmingham Clinical Commissioning Groups have all been active in providing support to hoarders, helping coordinate agency responses, and awareness raising.
- 2.36. Birmingham is also home to *Clouds End CIC*, an organisation which provides support to hoarders and relevant agencies. According to *Clouds End CIC*, the organisation works with people in their homes with a gentle, non-judgmental approach. The client is always in control and the plan developed will always be determined by the needs and abilities of the client themselves. This way a successful outcome is achievable and the possibility of future sustainability is stronger. Their aim is to gain trust with clients to help them develop the skills and confidence needed to regain control over the possessions that have overwhelmed them. They work with support workers or carers that may be involved with the individual's progression. The organisation offers a range of services including one-to-one support to hoarders, working with social landlords to support hoarders or develop support programmes, undertaking project work with groups, and offering online hoarding awareness courses.

Bristol

- 2.37. *WE Care & Repair* is the Home Improvement Agency for the West of England. They are a not-for-profit

organisation with charitable status whose guiding purpose is to enable older and disabled people to continue living independently. The *Silverlinks* peer support volunteer programme at *WE Care & Repair* have implemented an initiative to train a small group of staff and specially recruited volunteers (aged over 50) to work with clients who hoard and help them address hoarding behaviour in a sustainable way. They help older people with hoarding issues to:

- have essential house repairs
- have adaptations to their house due to disability.
- move to a more suitable home.
- have more peace of mind from the distress caused by hoarding.
- make their own home safer and healthier and more pleasant to live in.

2.38. All volunteers:

- Receive specialist training about hoarding.
- Receive training in a variety of other relevant topics offered throughout the year.
- Receive ongoing supervision and support.
- Work alongside *WE Care & Repair* caseworkers, technical officers and handypersons as well as other relevant organisations.
- Attend regular volunteers' meetings

Kirklees Council

2.39. Kirklees Council has implemented guidance on implementing a multi-agency framework to deal with hoarding within the borough. An initial assessment is undertaken by Adult Social Care although it is recognised that not all individuals that hoard will have care and support needs. As such, an assessment may result in a more appropriate pathway being followed to support the adult, instead of the safeguarding process. Kirklees has set up a hoarding panel to manage all hoarding cases, which meets every 6-8 weeks. This panel consists of all relevant partners and is chaired by the West Yorkshire Fire and Rescue Service.

2.40. The multi-agency hoarding framework is closely linked with the Multi Agency Protocol for Managing Self Neglect. The Hoarding Panel establishes if a case being considered involves wider issues of an adult at risk of self-neglect and establishes if a referral needs to be made to the local authority under the self-neglect protocol. If that is the case, it may be that arrangements under that protocol supersedes the need for the Hoarding Panel to manage that particular case.

2.41. The multi-agency framework guidance uses the Clutter Image Rating (CIR) (Nottingham County Council) tool to determine whether intervention is required. They also provide examples of questions agencies may wish to ask to determine whether they are concerned about someone's safety in their

home, or where they suspect a risk of self-neglect and/or hoarding:

- How do you get in and out of your property?
- Do you feel safe living here?
- Have you ever had an accident, slipped, tripped up or fallen? How did it happen?
- How do you move safely around your home? (Where floor is uneven or covered or there are exposed wires, damp, rot or other hazards)
- Has a fire ever started by accident? Is the property at risk from fire?
- Is there hot water, lighting and heating in the property? Do these services work properly?
- Do you have any problems keeping your home warm?
- When did you last go out in the garden? Do you feel safe to go outside?
- Are you able to use the bathroom and toilet ok? Have a wash, bath, shower etc.?
- Where do you sleep?
- Are there any obvious major repairs that need carrying out at the property?
- Are you happy for us to share your information with other professionals who may be able to help you?

(Kirklees Council, 2015).

2.42. However, Kirklees suggest that as most clients with a hoarding problem will be embarrassed about their surroundings it is important to ascertain information whilst being as sensitive as possible.

Liverpool Housing Trust (LHT)

2.43. LHT have developed a model called 'Outside The Box' which links practical support and therapeutic intervention together – providing long-term solutions to the challenges posed by hoarding disorder. It is based on the principle that people can be helped to deconstruct their patterns of negative thoughts and actions in order to find new options and new ways of thinking. The model was influenced by discussions with Liverpool's 'Improving Access to Psychological Therapies' (IAPT) service⁴ (*Talk Liverpool*) which found that hoarding clients struggled to maintain their motivation in between therapy sessions, as they had nobody to act as 'co-therapist'. As such, LHT's Specialist Support Workers act as a 'bridge' between hoarding clients and therapists. An advantage of this approach is that clients do not regard the support workers in the same way of traditional housing management staff who may have been involved in sanctions against the tenant.

2.44. The 'Outside the Box' programme was developed in partnership with mental health experts 'Talk Liverpool' who work with tenants suffering from a hoarding disorder. Clients attend group therapy

⁴ The Improving Access to Psychological Therapies (IAPT) programme supports the frontline NHS in implementing National Institute for Health and Clinical Excellence (NICE) guidelines for people suffering from depression and anxiety disorders. It was designed to provide faster access for people with depression and anxiety disorders like OCD to talking therapies such as Cognitive Behavioural Therapy (CBT).

sessions with other hoarders to help them understand and overcome hoarding habits by changing feelings towards possessions. LHT sometimes hire contractors to work with clients to help them clear hoarded rooms.

- 2.45. LHT have also developed a hoarding toolkit. The Toolkit separates the property into 4 general areas (kitchen, bathroom, bedrooms and living) to break the hoard down into smaller, more manageable and less intimidating areas. The LHT 'Outside The Box' toolkit splits the process of managing a hoard within each room into 3 stages:

1. Boxed in: This is generally the point in time when the hoard is causing distress to the tenant and having a significant impact on their health and wellbeing and they have lost the ability to utilise their property and the rooms within it for their intended purpose. In liaison with Liverpool John Moores University they have developed a Hoarding Disorder Self-Assessment tool to find out how much the person's thoughts, feelings and behaviours are impacted by their possessions and how much insight they have into their Hoarding. This includes a 'Room Rating Scale' and 'Feelings Tower' which helps LHT to measure people's feelings, pace work correctly and minimise trauma. They also undertake a 'Hoarding Disorder Impact Assessment' and work with the Fire and Rescue Service to identify the risks.

2. Sorting: The 'Sorting' stage is about working with the tenant to work through their hoard and decide how to best manage it. It begins with identifying a starting point. To enable this a photograph is taken of the room/area. An Acetate sheet is then placed over the photograph to split the room into 4 areas. The tenant will then decide which section of the room they wish to start with. At this stage of the process LHT begin working with MerseyCare/Talk Liverpool to start the process of CBT Therapy.

3. Boxed off: This represents the completion of sorting the hoard for a particular room/area. 'Boxed Off' attempts to embed the learning of the process and to provide the support requirement to enable long term management of the Hoarding Disorder. During the 'Boxed Off' stage the tenant is encouraged to complete the Room Rating again to show the progression they have made, and to firmly establish their belief that change is possible for them. The Feeling Tower is also revisited to discuss the range of feelings they have had during the LHT Outside The Box process. The 'Boxed Off Pledge' – is a final action plan to manage their possession and acquiring for the long term – it is a person centred relapse prevention plan (see Appendix 7).

London Borough of Hammersmith and Fulham (LBHF)

- 2.46. LBHF made the decision that the Adult Community Social Work Team (ACSW) would be the lead agency working with people who hoard within the borough. This approach was adopted in 2010 after it

was identified that key social work skills can be effective when working with people who hoard. This experience has so far indicated that an innovative social work perspective can achieve greater results than a typical care management approach in this area.

2.47. All cases of hoarding are referred to ACSW, with the exception of cases that are already allocated to social workers in the Learning Disability and Mental Health teams. The London Fire Brigade, housing associations, the London Ambulance Service, the LBHF housing department, general practitioners and community nurses amongst other agencies are encouraged to refer any cases of hoarding that they encounter to ACSW. People who are referred to ACSW do not necessarily have to have adult social care needs, as is typical practice with safeguarding and care management referrals. Agencies are asked to provide as much information about the hoarding as they are able to, for instance:

1. Basic data-set regarding the client, name, address, date of birth, etc.
2. What is being hoarded
3. Risk identified to the service user and/or others
4. Agencies involved
5. Referrer's current level of engagement with client and
6. Details of any health, mental health or mental capacity issues.

2.48. The extent of hoarding in the client's home is then assessed using the Clutter Index Scale (International OCD Foundation 2013) on a scale of 1-9. Homes identified as being at clutter scale level 4, 5 or 6 require a joint visit from social work services and either the London Fire Brigade and/or environmental health and/or a housing officer depending on the circumstances. The visiting officers will be jointly responsible for assessing the risk and completing the hoarding assessment form.

2.49. A referral to the Increasing Access to Psychological Therapies (IAPT) service (*Talk Liverpool*) may be considered if the service user is not already known to mental health services. A case conference may be called by the social worker with all agencies involved to develop a multi-agency action plan which is owned and acted on by all involved. Where possible the service user must be involved in the case conference. Consideration should be given to the risks to the service user and others, especially if the individual is living in a multi-occupancy property.

2.50. If a home is identified at level 7, 8 or 9, then an urgent multi-agency case conference is called with the purpose of developing an action plan. Immediate serious consideration is given to risks, especially of fire. The social worker works with the service user to identify ways of minimising risk. If the service user is not engaging, the case is discussed with relevant agencies involved to identify action needed.

2.51. However, the guidance recognises that there is no quick and easy solution in working with cases of severe hoarding, and that a case of hoarding will usually require long-term support that is dependent

on a strong relationship. Therefore, they are allocated to one specific social worker to start an appropriate intervention.

2.52. Also, LBHF have also established a local hoarding panel attended by the London Fire Brigade, learning disability team, housing, public health, *Mind*, Community Mental Health Team and IAPT (*Talk Liverpool*) where discussion of local cases and agreed approach takes place (Brown and Pain, 2014).

London Hoarding Task Force

2.53. The idea of hoarding task forces originates in the USA, where task forces have been established in more than 85 communities. The Pan-London Hoarding Task Force was convened by Peabody Housing Trust and meets approximately every 2 months. Attendees come from housing providers, the London Fire Brigade, and independent experts. The objectives of this group are to:

- Establish uniform local authority protocols for managing cases of hoarding
- Establish a database of people who hoard, in order to capture numbers and costs incurred
- Review case studies and update on changes to legislation or sector practices
- Provide clarity about the expectations and legal powers of statutory organisations; Share information
- Provide support information advice and training for staff involved with hoarding
- Include other experts as and when necessary.

(NHF, 2015).

Newcastle First Contact

2.54. First Contact Newcastle Referral Scheme is managed by the Quality of Life Partnership. It is a multi-organisational scheme that offers free information, support and advice to older people in Newcastle to help them stay safe, healthy and independent. Clients can be referred in by one of the 13 participating organisations involved in the scheme or self-refer either online, or by post or fax. Older hoarders receive help and support from a range of organisations. This includes the Tyne and Wear Fire and Rescue Service can offer free fire safety advice, fit smoke alarms for free and help people to plan their emergency escape route in case of a fire. Newcastle City Council's 'Envirocall' arrange a separate rubbish collection if the client requires removing large items or amounts of material. Clients can contact the Council's Public Health and Environmental Protection regarding hoarding issues on the client's or a neighbour's home. This may be because the client has concerns about poor living conditions such as a large amount of clutter in or around their home, pests, noise nuisance, unsafe electrics or fire risks.

Nottinghamshire County Council

2.55. Nottinghamshire County Council has developed a framework for collaborative multi-agency working within Nottingham City and Nottinghamshire using a 'person centred solution' based model. The

protocol offers clear guidance to staff working with people who hoard. It was developed in partnership with Nottinghamshire Fire and Rescue Service, Ashfield District Council's Environmental Health Team and the Nottinghamshire Hoarding Steering Group.

2.56. The Nottinghamshire County Council guidance (2015) suggests that not all individuals that hoard will receive support from statutory services such as Mental Health teams. As such, they suggest that any professional working with individuals who may have, or appear to have, a hoarding condition should ensure they complete a 'Practitioners Assessment' form (see Appendix 1) and use a clutter image rating tool kit (Nottingham County Council) (see Appendix 2) to decide what steps to take. Evidence of animal hoarding at any level should be reported to the RSPCA as well as other relevant agencies. (Nottinghamshire County Council, 2015: 13)

2.57. The Nottinghamshire County Council (2015) guidance also suggests that a blend of out-patient and home visits should be considered. Out-patient appointments may be necessary to complete clinical assessments (without the distraction or uncomfortableness of the home environment), and domiciliary visits are vital to assess the level at which the rooms in the home function. Practitioners may consider undertaking interviews with hoarders as part of an initial assessment and to determine motivation for change. Questions could include:

1. What do you see as the problem, if there is a problem at all?
2. What is causing you distress at the moment?
3. What are your priorities for change?
4. Is your living environment, your home, causing you distress or are you happy with it?
5. Have people said to you that your living environment needs to change?
6. If your living environment changed, how would this affect you?
7. If your living environment were different, what could you then do?
8. If your living environment were different, what could you no longer do?
9. Do you consider your living environment to be how you would want it to be?
10. Do you think that you have a problem with any or all of the following:
 - i. Buying things that you do not need?
 - ii. Organising the things that you have?
 - iii. Keeping your things clean?
 - iv. Getting rid of things?
11. Do you consider that you just need more storage?
12. Do you consider that throwing things away is wasteful?
13. Do you think that throwing things away would be harmful to the environment?
14. Do you keep things because they might come in useful one day?

(Nottinghamshire County Council, 2015: 13)

2.58. In 2015 the National Housing Federation (NHF) published a report on key considerations regarding hoarding and good practice. The report drew on learning from a series of regional events organised by the National Housing Federation and *Sitra*⁵ in February and March 2015. The principal aim of the events was to raise awareness of the complex issues surrounding hoarding disorder, to share learning and highlight innovative practice, and to identify future housing workforce training and development needs. The following describes examples of good practice published in the report.

Orbit Care and Repair

2.59. Orbit Care and Repair run the 'Orbit Independent Living Compulsive Hoarding Project' in conjunction with Coventry University. Orbit 'Care and Repair' work with people with hoarding tendencies from an occupational therapy perspective. This enables them to conduct individual assessments and create tailor-made interventions to tackle barriers which prevent clients from achieving what they want to in life. This approach recognises that each client is unique and requires support that is tailored to meet their very specific needs. At times this support may include a form of cognitive behavioural therapy, at others it may involve a case worker providing hands-on home support (NHF, 2015).

Therapeutic interventions

2.60. There is a wide range of therapeutic interventions that can be used to support people experiencing hoarding difficulties. In most larger cities such as Birmingham, Leeds, Manchester, Liverpool and Newcastle hoarding support groups have been established run by either volunteers or professionals. In the London Borough of Hammersmith and Fulham, mental health charity *Mind* runs a monthly hoarding support group where members can meet and share their own experiences. The support group also has guest speakers who run question and answer sessions. Social workers can refer service users to this group, and the group facilitators can provide feedback to social workers. This group has become so successful that a second group has now been set up due to the first group running over capacity (Brown and Pain, 2014). There is a wide range of therapeutic interventions available to severe hoarders.

Cognitive behaviour therapy

2.61. One of the therapies most commonly used by practitioners supporting hoarders is cognitive behaviour therapy (CBT). CBT is a talking therapy that can help people manage problems by changing the way they think and behave. During CBT, individuals gradually learn to discard unnecessary possessions with less distress, diminishing their exaggerated perceived need or desire to save for these possessions. They also learn to improve skills such as organisation, decision-making, and relaxation (UK Hoarding, 2016)

⁵ Sitra is a membership organisation providing leadership, influencing policy through expertise, promoting best practice and providing consultancy, training, information and advice.

- 2.62. Regular sessions of CBT over a long period of time are usually necessary and will almost always need to include some home-based sessions, working directly on the clutter. This requires motivation, commitment and patience, as it can take many months to achieve the treatment goal. The goal is to improve the person's decision-making and organisational skills, help them overcome urges to save, and ultimately clear the clutter, room by room (NHS, 2016).
- 2.63. The therapist will not throw anything away, but will help guide and encourage the person to do so. The therapist can also help the person develop decision-making strategies, while identifying and challenging underlying beliefs that contribute to the hoarding problem. The person gradually becomes better at throwing things away, learning that nothing terrible happens when they do so, and becomes better at organising items they insist on keeping. At the end of treatment, the person may not have cleared all their clutter, but they will have gained a better understanding of their problem. They will have a plan to help them continue to build on their successes and avoid slipping back into their old ways (NHS, 2016).
- 2.64. One specific strategy relating to hoarding is a process by which the person simply talks about the object, rather than engaging in 'restructuring thoughts'. Therapy may include identifying values, imaginal work, practising key skills such as sorting and decision-making, thought-listing and habituation exercises. Therapy may also include the strengthening of problem-solving skills, reducing acquisition, and exposure tasks. According to the British Psychological Society (BPS), it is important that clinical psychologists avoid persuasion, as this can lead to further strengthening of beliefs that disposal is unnecessary.

Group work

- 2.65. Increasingly, groups are being set up around the country to work specifically with people who have hoarding difficulties. According to Frost, Skeketee, and Kamala (2003) group work offers a number of advantages in the treatment of hoarding. Groups help reduce participants' isolation and offer an opportunity for them to become more comfortable around other people. It also has immediate benefits in reducing the sense of isolation and shame associated with hoarding (BPS, 2014).

Therapy groups

- 2.66. Gilliam et al. (2011) describe delivering CBT in weekly 90-minute sessions over 20 weeks. The groups had 4 to 12 people attending. However, there were significant concerns about engagement, with a third of people dropping out. They suggest this may have been associated with a high expectation that clients complete homework tasks (BPS, 2014).

Individual At-Home Treatment Sessions

- 2.67. Frost, Skeketee, and Kamala (2003) describe individual at-home sessions which initially focused on

developing an organizational scheme for how to store saved items and on identifying which areas or types of saved items should be addressed first. The excavation session format involved structured decision making regarding possessions. All decisions were made by the client while the therapist assistant merely asked questions to facilitate.

Family therapy

- 2.68. Family therapy acknowledges that all family members are affected by hoarding. Family members are educated about hoarding to have compassion and recognise it as a mental health issue. Addressing support and validation concerning the anger and hurt that many family members feel is another important step. The therapist needs to make sure the family understands that without their support and help, the hoarder is unlikely to get better, only progressively worse. Anecdotal reports from practitioners suggest that family therapy can be very successful when addressing hoarding behaviour although no published research currently exists on the outcomes of family therapy for hoarding (Van Pelt, 2011).

Self-help groups

- 2.69. A growing number of self-help groups have been established around the country. One of the first to be set up was in Surrey, co-facilitated by workers in the local mental health NHS trust, a local mental health charity and a carer (Holmes et al., 2014). The group runs monthly, is well attended and regularly includes psycho-education, personal testimonies and setting of personal goals. Other groups are now running as far and wide in the UK as Edinburgh, Plymouth and London. A more structured approach to self-help groups called the *Buried in Treasures Workshop* has been developed in America, with resources and a book to guide facilitators. The structured workshops run for 13 weeks. They are facilitated by non-professionals and held in non-mental health settings. The dropout rate has been reported to be 10% for these groups which, given the engagement difficulties for this population, is very encouraging and early indications are that this approach is as effective as CBT-based groups (BPS, 2014). The Compulsive Hoarding website lists a number of online self-help support groups, blogs and websites⁶.

Motivational Interviewing

- 2.70. Motivational interviewing is a method for enhancing intrinsic motivation to change. It can guide intervention carried out by non-therapists by providing suggestions about how to communicate in a non-confrontational, respectful, yet formal manner; and how to lower rather than raise resistance to change. This requires an empathic attitude which requires the interviewer to place themselves 'in the shoes' of the hoarder and the use of encouraging language which reduces defensiveness and increases motivation. The emphasis is on highlighting strengths and accomplishments; focusing intervention on safety rather than discarding; treating individuals with respect; treating each situation

⁶ Compulsive Hoarding, 'support for compulsive hoarders' located at <http://www.compulsive-hoarding.org/Support.html>

and each person individually; allowing individuals to make their own decisions; allowing individuals do things for themselves, only providing motivation guidance (Sorrentino, no date).

Summary

- 2.71. To summarise, it is estimated that between 2% and 5% of the population hoard equating to at least 1.2 million households across the UK and 22,000 people in Birmingham. Since 2013 hoarding has been recognised as a distinct mental health difficulty on its own rather than solely an aspect of obsessional compulsive difficulties or as a 'lifestyle choice'. However, hoarding may be perceived as much a social as mental health issue and most people experiencing hoarding difficulties are never diagnosed by health professionals. As such, it is important not to perceive it solely as a mental health issue.
- 2.72. Although hoarding is commonly associated with socially isolated older people, the characteristics of hoarders vary widely. Hoarding difficulties are usually co-presented with a range of symptoms such as depression, anxiety, post-traumatic stress disorder, attention deficit/hyperactivity, intellectual or developmental difficulties, and autism. The impact of hoarding on hoarders, family and neighbours is well documented. Specific issues relating to hoarding include: the risk of fire and death, risk of crushing, loneliness and social isolation, poor sanitation, poor nutrition, damage to property, risk to staff safety, pests and vermin, and complaints from neighbours. Hoarding also impacts mentally and emotionally on family members and friends. As well as the psychological, health, social and environmental impact that compulsive hoarding may have on hoarders, family and neighbours, there are also financial costs. Estimates suggest that dealing with hoarding cases costs housing providers between £35,000 and £45,000 per case.
- 2.73. Agencies have recourse to a wide range of legislation which can be used to resolve cases of domestic hoarding depending on the nature and severity of the case. This includes legislation relating to adult and child protection legislation, although the most extensive range of legislation relates to environmental health powers. It is particularly important that agencies intervene in hoarding cases when the safety of adults or children is undermined. However, it is important to recognise that enforcement action can lead to client disengagement with agencies, and that removing clutter is only addressing the symptom of hoarding, not the problem.
- 2.74. There is extensive good practice regarding dealing with hoarding. One key finding is that the most effective responses to hoarding are likely to be multi-agency in character. Relevant services could include mental health, housing, adult social care, community safety, environmental health, and animal welfare services. Similarly, agencies may want to consider community-based, multi-disciplinary approaches which both offers an approach that respects the individual living with hoarding behaviour and provides support to ensure successful intervention. Evidence from Midlands Heart suggests that the most successful interventions are based on partnership working, serious case reviews, raised awareness, and the training and support of staff.

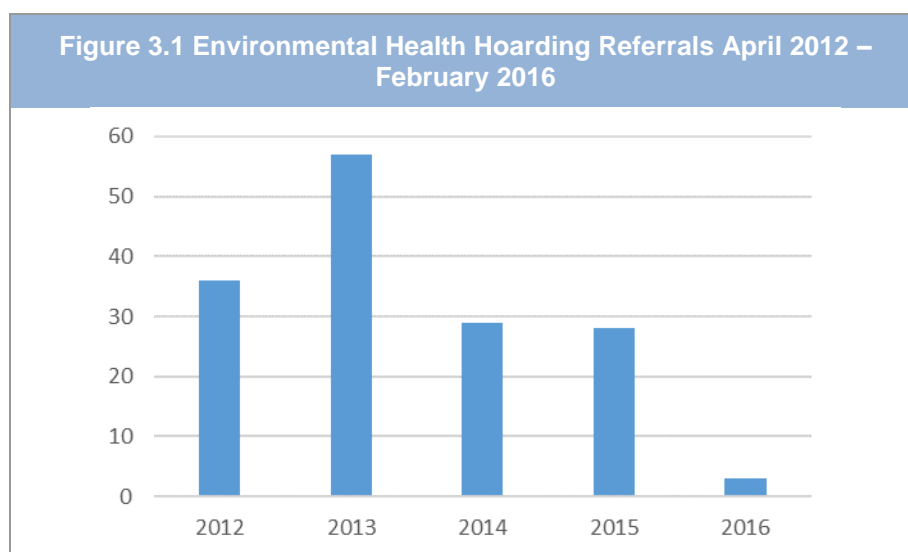
- 2.75. Some organisations such as Nottingham County Council and Liverpool Housing Trust have developed hoarding assessment forms and clutter image rating toolkits. Practitioners may also consider undertaking interviews with hoarders as part of an initial assessment and to determine motivation for change. Finally, the National Housing Federation (NHF) (2015) published guidance on hoarding which considers good practice. Examples included the Orbit 'Care and Repair' which works with people with hoarding tendencies from an occupational therapy perspective; the Pan-London Hoarding Task Force which is attended by over 20 different organisations from across London and meets around every 2 months; the Liverpool Housing Trust (LHT) 'Outside The Box' model which links practical support and therapeutic intervention together; and the London Borough of Hammersmith and Fulham which identified key social work skills as being most effective when working with people who hoard.
- 2.76. There is a wide range of therapeutic interventions that can be used to support people experiencing hoarding difficulties. In most larger cities such as Birmingham, Leeds, Manchester, Liverpool and Newcastle hoarding support groups have been established run by either volunteers or professionals. One of the therapies most commonly used by practitioners supporting hoarders is cognitive behaviour therapy (CBT). CBT is a talking therapy that can help people manage problems by changing the way they think and behave. During CBT, individuals gradually learn to discard unnecessary possessions with less distress, diminishing their exaggerated perceived need or desire to save for these possessions. They also learn to improve skills such as organisation, decision-making, and relaxation. Other therapeutic responses include group work, therapy groups, at-home sessions, family therapy, self-help groups, and motivational interviewing.

3. Analysis of secondary data

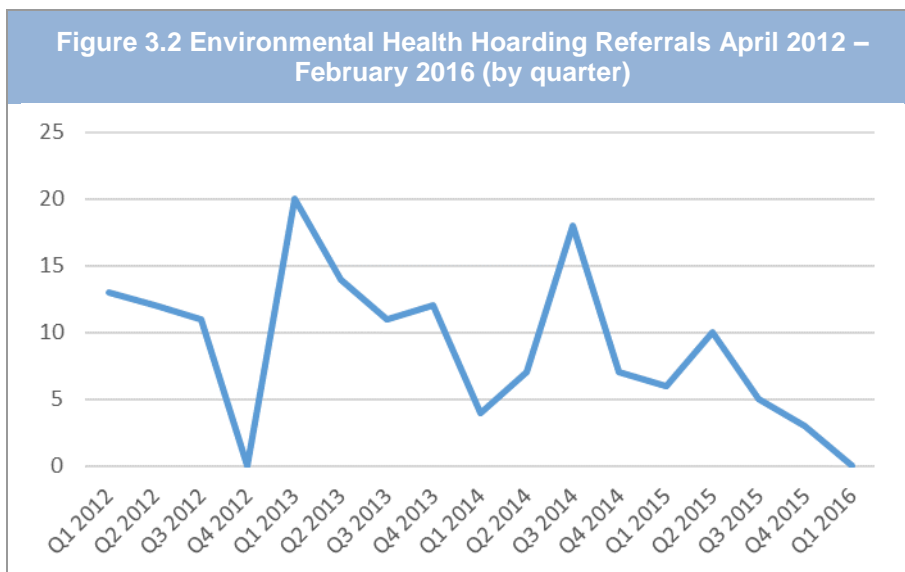
3.1. Agencies such as the Birmingham City Council Environmental Health Section and the West Midlands Fire Service (WMFS) collect extensive data on hoarding cases. As such, the following chapter analyses secondary data regarding hoarding cases on a wide range of issues such as the number of cases, referring agency, time spent by agencies supporting hoarders, and key issues. Please note that the analysis only includes cases which have been referred to agencies – there is no analysis of cases which may occur but have not been recorded.

Environmental Health data

3.2. Between April 2012 and February 2016 Birmingham City Council's Environmental Health Department recorded a total of 153 hoarding cases including 36 cases in 2012, 57 in 2013, 29 in 2014, 28 in 2015, and 3 in the first two months of 2016 equating to an average of 38 cases per year (Figure 3.1). As Figure 3.2 shows, there is no pattern in the number of cases per quarter although there has been a marked decrease in the number of cases recorded since the second quarter (July to September) 2015.

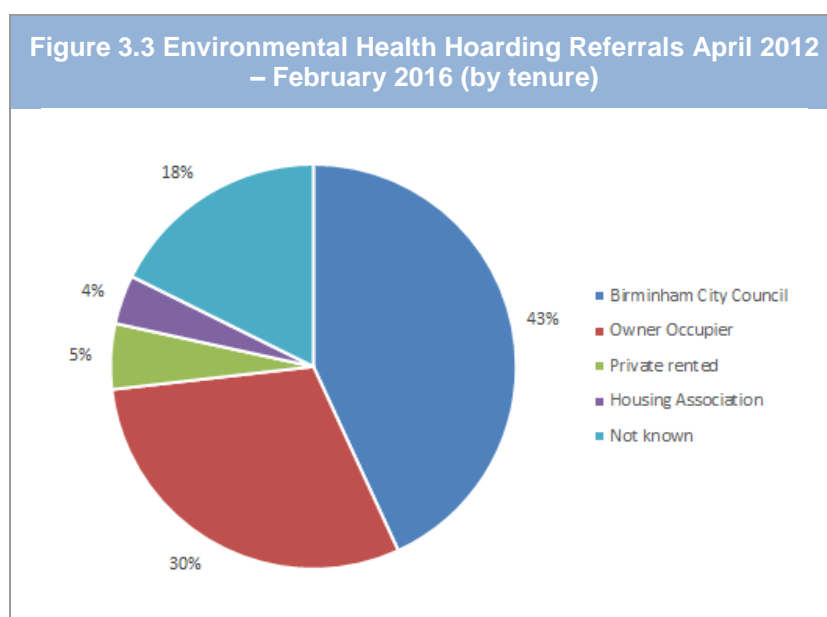


Source: Birmingham Environmental Health 2016



Source: Birmingham Environmental Health 2016

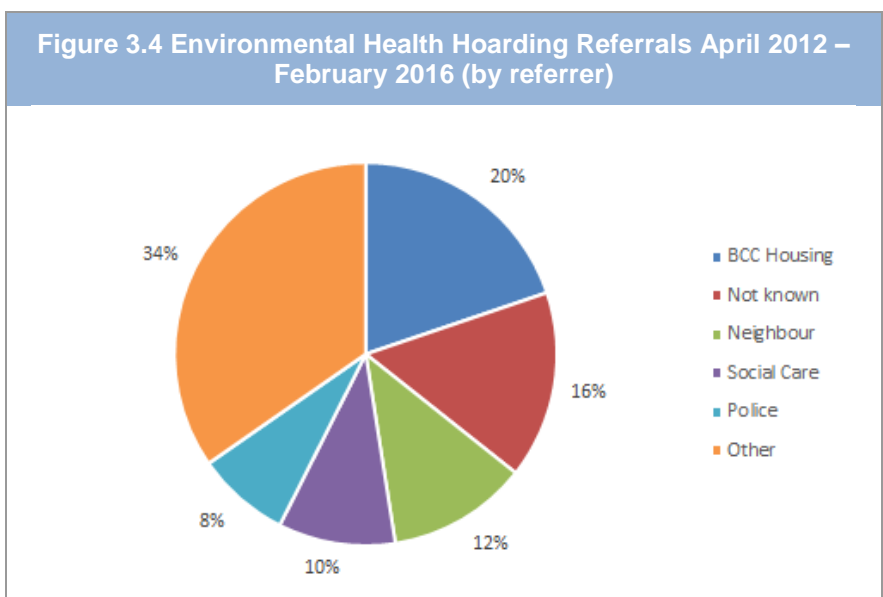
3.3. Figure 3.3 shows that over two fifths (43%) of hoarding cases referred to the council’s Environment Heath Section reside in council housing, with almost a third (30%) residing in owner occupied housing. Smaller proportions of hoarding cases resided in the private rented housing (5%) or housing association properties (4%). In around a fifth of cases (18%) the tenure of the hoarded property was not known. Given that only 15% of properties in Birmingham are owned by the local authority⁷, it is likely that the relatively large proportion of hoarding cases residing in this tenure reflects the ability of neighbours to contact the council Housing Department regarding hoarding, or local authority housing officers’ awareness of hoarding cases.



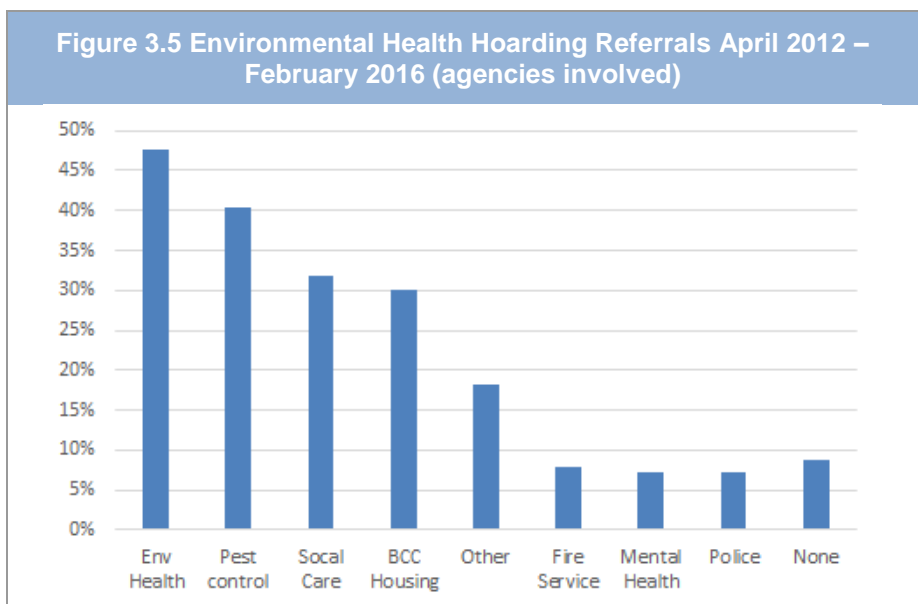
Source: Birmingham Environmental Health 2016

⁷ ONS 2011, Table KS402EW – Tenure, April 2016

3.4. In total, 25 different agencies referred hoarding cases to the Environmental Health Section (Figure 3.4). A fifth (20%) of hoarding cases were made by Birmingham City Council Housing Department, with smaller proportions deriving from a neighbour (12%), social care (10%), or the police (8%). However, over a third of cases (34%) were referred by other agencies or people including utility providers, general practitioners, letting agents, and hospitals. In some cases (16%), the referrer was not known. As Figure 3.5 shows, a wide range of agencies are involved in providing help and support to people facing hoarding difficulties. The Environmental Health Section were involved in almost half (48%) of all cases, and Pest Control in two fifths (40%). Both Social Care (32%) and the Housing Department (30%) were involved in almost a third of cases.

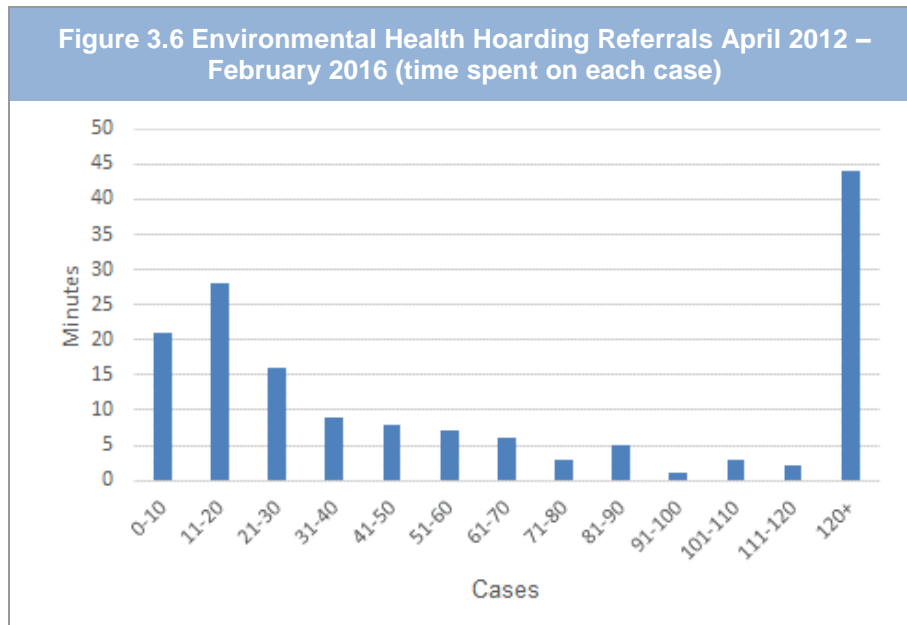


Source: Birmingham Environmental Health 2016



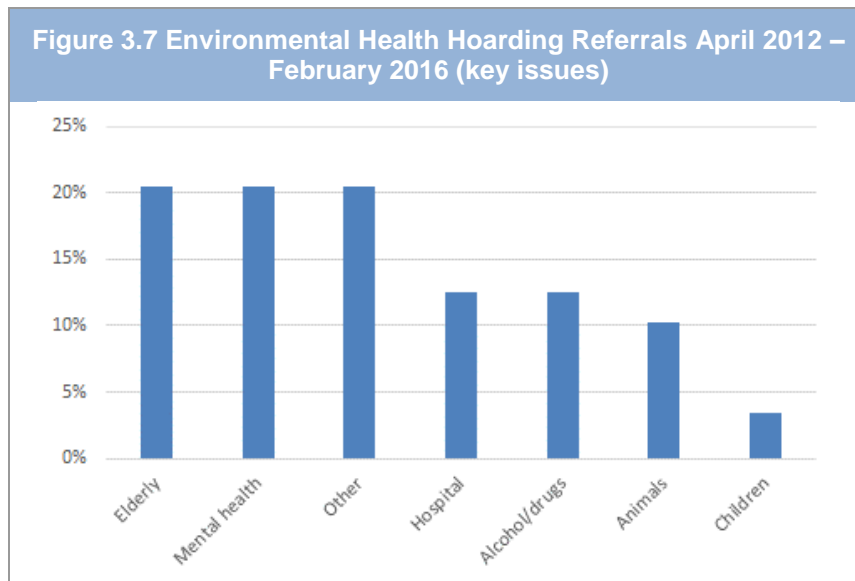
Source: Birmingham Environmental Health 2016

3.5. The Environment Health Section records the amount of time officers spend in responding to each hoarding case. As can be seen in Figure 3.6 below, a large proportion of cases take less than 2 hours to resolve. The average amount of time spent on each hoarding case is around two hours although there were 44 cases which required more than 2 hours of intervention (the largest amount of time spent on a single case was 37 hours) (Figure 3.6).



Source: Birmingham Environmental Health 2016

3.6. The Environmental Health Section recorded key factors in 88 hoarding cases. Whilst a wide range of factors were recorded, these have been summarised into 7 key factors. Importantly, Figure 3.7 shows that a fifth (20%) of hoarding cases involved either older people or people with mental health issues (some cases involved older people with mental health conditions such as dementia). Around an eighth (13%) of hoarding cases involved someone who had been hospitalised, or had drugs or alcohol misuse issues. A smaller proportion of hoarding cases involved safeguarding issues regarding animals (10%) or children (3%) A fifth (20%) of hoarding cases involved other factors.



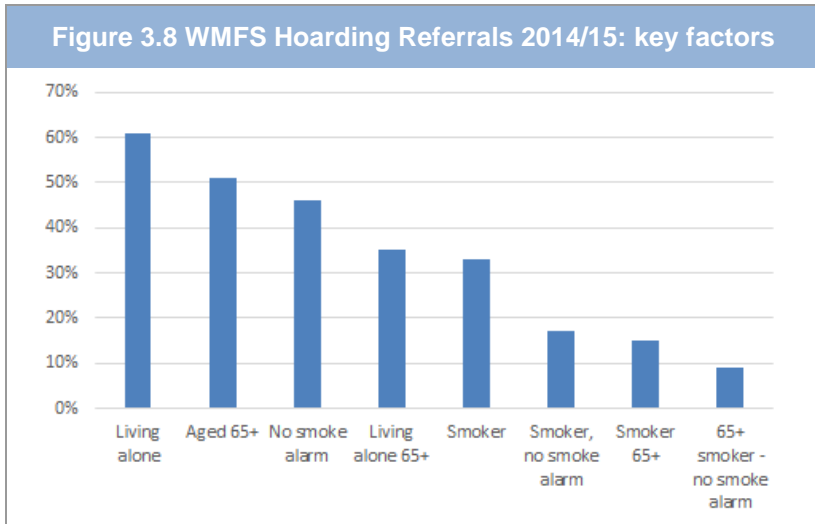
Source: Birmingham Environmental Health 2016

West Midlands Fire Service data

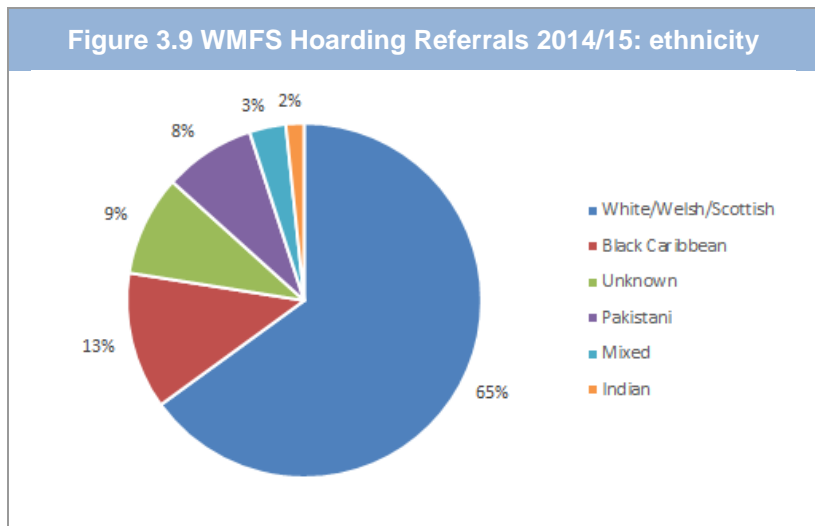
- 3.7. The West Midlands Fire Service (WMFS) collects data on severe hoarding cases. During 2014/15 WMFS recorded 120 cases of severe hoarding requiring intervention. As Figure 3.8 indicates, key factors recorded by the WMFS regarding hoarding include living alone (60%) and being aged 65 years or over (51%). Over a third (35%) of severe hoarders recorded by the WMFS were both living alone and aged over 65. Severe hoarders regarded by WMFS to be most at risk were older smokers living alone without smoke alarms. In relation to ethnicity, Figure 3.9 shows that almost two thirds (65%) of recorded severe hoarding cases were White British, Welsh or Scottish. There were fewer severe hoarding cases of Black Caribbean origin (13%), Pakistani (8%) origin, mixed (3%), or Indian (2%). Generally, compared to Birmingham's 2011 ethnic profile⁸, White British hoarders are slightly over-represented, and Pakistani hoarders slightly under-represented.
- 3.8. The WMFS also record the location of severe hoarding cases. Figure 3.10 shows that over half (55%) of severe hoarding cases throughout Birmingham South occurred in the areas of Haymills (21%), Sheldon (21%), and Kingsnorton (13%). Similarly, Figure 3.11 shows that over half (58%) of severe hoarding cases throughout Birmingham North occurred in the areas of Ladywood (21%), Ward End (21%), and Perry Barr (17%). These tend to be areas of Birmingham with higher than average levels of social and economic deprivation⁹.

⁸ ONS 2011, Table KS210EW – Ethnic Group, April 2016

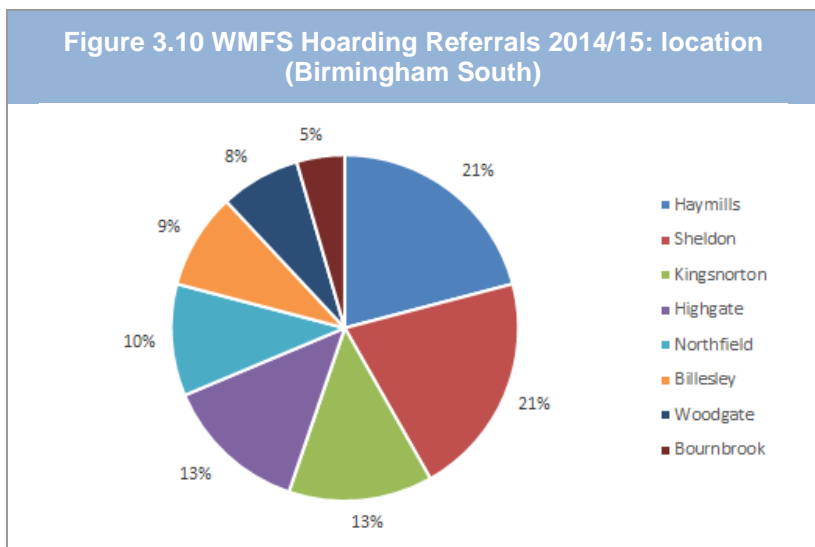
⁹ Birmingham Health and Wellbeing Board ward profiles located at: <http://hwb.birmingham.gov.uk/joint-strategic-needs-assessment/birmingham-ward-profiles/>



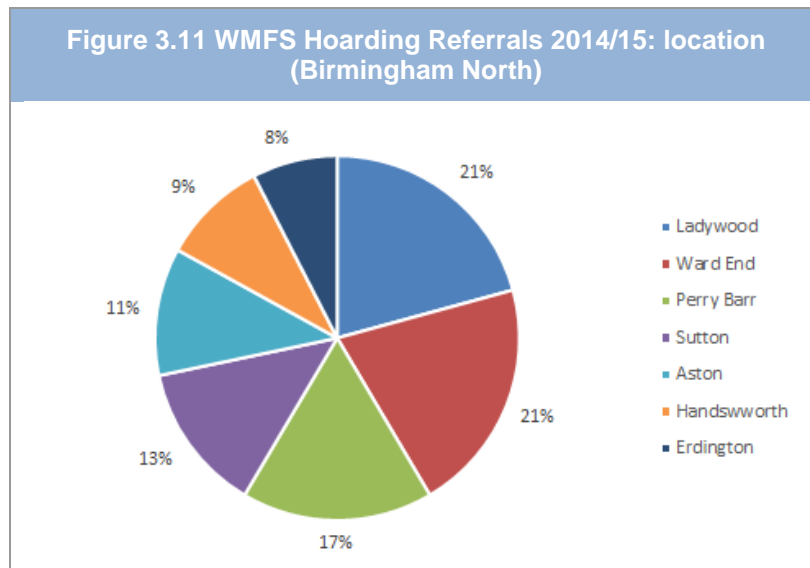
Source: WMFS 2016



Source: WMFS 2016



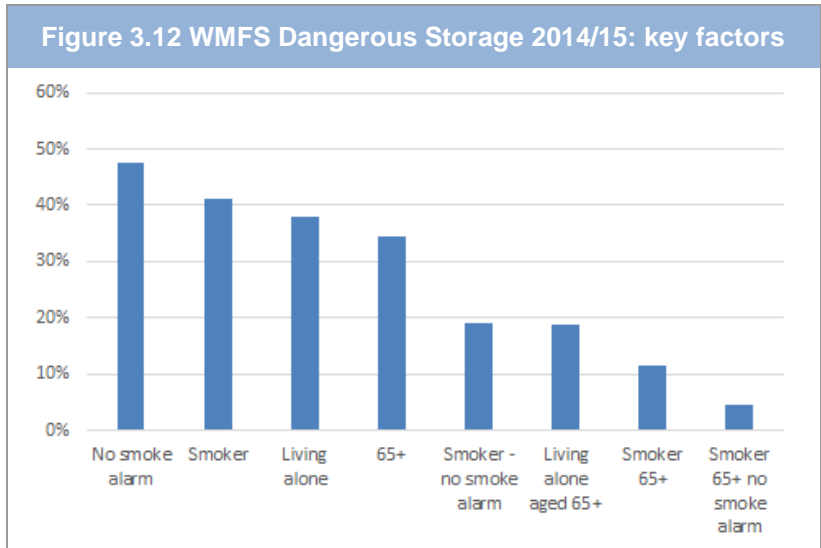
Source: WMFS 2016



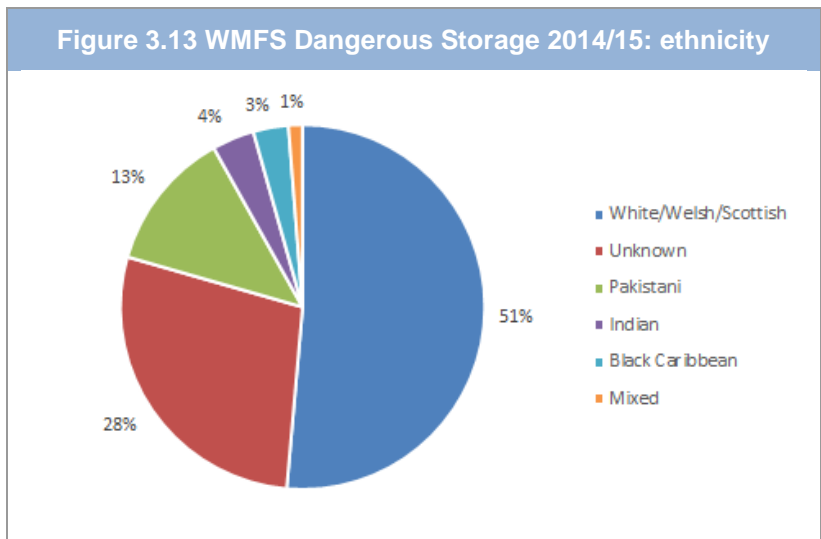
Source: WMFS 2016

- 3.9. The West Midlands Fire Service (WMFS) also collects data on cases where excessive or dangerous storage is affecting safety or is a fire risk. During 2014/15 WMFS recorded 321 cases of dangerous storage requiring intervention. As Figure 3.12 indicates, key factors recorded by the WMFS regarding dangerous storage included no smoke alarm (48%), being a smoker (41%), living alone (38%), and being aged 65 years or over (35%). Nearly a fifth (19%) of dangerous storage cases were people both aged over 65 years and living alone.
- 3.10. In relation to ethnicity, Figure 3.13 shows that over half (51%) of recorded dangerous storage cases were White British, Welsh or Scottish. There were fewer severe hoarding cases of Pakistani (12%) origin, Indian (4%) origin, Black Caribbean (3%) origin, or mixed (1%) origin. Generally, compared to Birmingham's 2011 ethnic profile¹⁰, White British dangerous storage cases are slightly under-represented, and Black Caribbean dangerous storage cases slightly over-represented.
- 3.11. The WMFS also record the location of dangerous storage cases. Figure 3.14 shows that over four fifths (81%) of dangerous storage cases throughout Birmingham South occurred in the areas of Haymills (30%), Billesley (13%), Sheldon (13%), and Highgate (13%). Similarly, Figure 3.15 shows that over four fifths (82%) of dangerous storage cases throughout Birmingham North occurred in the areas of Ladywood (30%), Handsworth (22%), Aston (17%), and Ward End (12%).

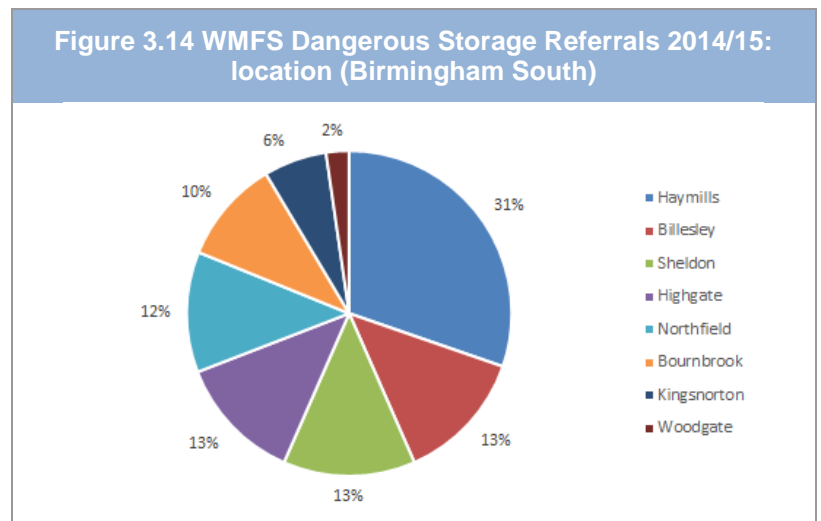
¹⁰ ONS 2011, Table KS210EW – Ethnic Group, April 2016



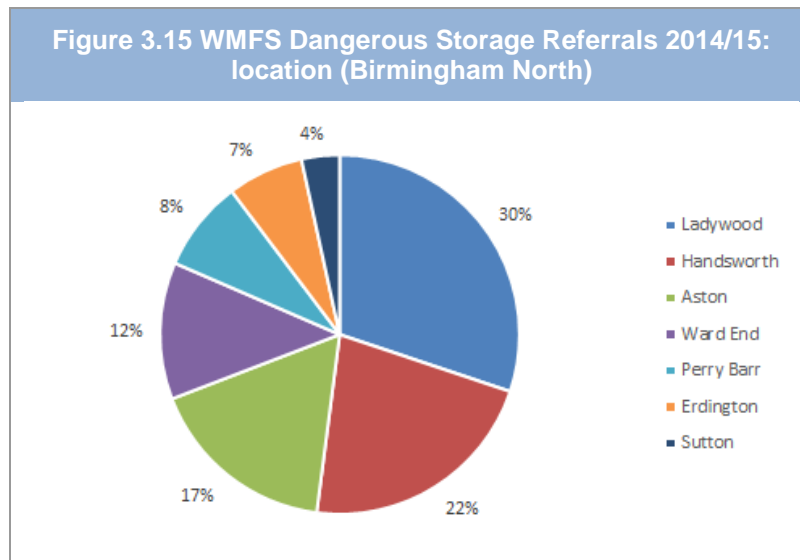
Source: WMFS 2016



Source: WMFS 2016



Source: WMFS 2016



Source: WMFS 2016

Financial costs

3.12. As well as the psychological, health, social and environmental impact that compulsive hoarding may have on hoarders, family and neighbours, there are also financial impacts. If people are living with a huge amount of possessions, they may not be able to access their financial paperwork. They may not be working, but also may not be claiming benefits to which they are entitled. This increases the risk of them living in poverty and becoming more marginalised from society. Maintaining attendance at work appears to be more challenging for people with hoarding difficulties than for those with other mental health problems. Tolin et al's research (2008) suggested that people who hoard had an average of seven work-impairment days a month. This places them at high risk of losing jobs and increasing financial difficulties and isolation. In addition, losing a job may have significant impact on sense of identity. The costs incurred by outside agencies attempting to help or resolve the problem can quickly escalate.

3.13. Mental health services may pay to have homes cleared, but may find the person becomes highly distressed at the manner in which the clearing was done and is unable to maintain change. The BPS (2015) estimate that environmental health departments are typically managing about four cases of hoarding per year¹¹. Of these, between one and two has no mental health services involvement (Holroyd and Price, 2009). Environmental health officers are often left trying to negotiate clearance, then using legal means to permit forced clearance. All of this entails significant cost, and while environmental health services may attempt to recoup their costs, this is often not possible and may require further lengthy legal work and additional expense. (BPS, 2015).

3.14. According to Catalyst Housing Association, the average cost of managing a hoarding case from start to

¹¹ This is much lower compared with estimates discussed above or comments made by hoarding survey respondents.

finish is calculated to be around £45,000. This is higher than the Liverpool Housing Trust (LHT) figure which estimates that the cost incurred by a housing association during the lifetime of a tenancy of a hoarder to be over £35,000. The Liverpool Housing Trust (LHT) figure includes but is not limited to:

- Missed Gas Appointments (£1,500)
- Disruption to planned replacement programmes (£4,000)
- Potential costs due to eviction & court action (£6,500)
- Clearance Costs (£3,500)
- Repairs required to the property after the clearance (£6,500)
- Long Voids (£1,800)
- Relet Costs (£800)
- Staff Time (£10,000)

3.15. The average 38 cases per annum supported by the Birmingham Environmental Health Section combined with the 120 severe hoarding cases supported by the West Midlands Fire Services (WMFS) during 2014/15 equates to potential costs of between £5.53m and £7.11m. This suggests that early intervention may not only lead to improved outcomes for hoarders, but may be more cost-effective in the longer-term.

Social Return on Investment

3.16. According to the Social Return on Investment Network (2012), actions and activities create and destroy value. Although the value created goes beyond what can be captured in financial terms, this is, for the most part, the only type of value that is measured and accounted for. As a result, things that can be bought and sold take on a greater significance and many important things get left out. Decisions made like this may not be as good as they could be as they are based on incomplete information about full impacts.

3.17. Social Return On Investment (SROI) was developed from social accounting and cost-benefit analysis. SROI measures change in ways that are relevant to the people or organisations that experience or contribute to it. It tells the story of how change is being created by measuring social, environmental and economic outcomes and uses monetary values to represent them. This enables a ratio of benefits to costs to be calculated. For example, a ratio of 3:1 indicates that an investment of £1 delivers £3 of social value.

3.18. SROI is about value, rather than money. Money is simply a common unit and as such is a useful and widely accepted way of conveying value. There are two types of SROI:

- Evaluative, which is conducted retrospectively and based on actual outcomes that have already taken place.
- Forecast, which predicts how much social value will be created if the activities meet their intended outcomes.

3.19. Forecast SROIs are especially useful in the planning stages of an activity. They can help show how investment can maximise impact and are also useful for identifying what should be measured once the project is up and running. In relation to hoarding this means comparing the benefits/costs of implementing the policy to support hoarders compared with the benefits/costs of not implementing it. However, it is important to note that there are some factors which makes determining the cost-effectiveness of supporting hoarders difficult:

- Different clients may require different types and levels of support
- Not all cases will incur the same the same costs e.g. eviction and court action
- The SROI is based on costs for one year (some clients may require longer support)
- The costs do not consider the need for repeat clearances

Cost	No.	Cost per unit	Total
Initial contact	2 hours	£64	£128
Risk assessment	1	£500	£500
Case assessment	6	£64	£385
Clearance	1	£3,500	£3,500
Repairs	1	£6,500	£6,500
Therapeutic support	10 x 1 hour	£120	£1,200
Ongoing contact	1 hour per month	£64	£770
Net cost per case			£12,983
Cases 2015/15			158
Total costs			£2,051,346
Financial gains			
<i>Cost avoided per case range</i>		<i>£35,000</i>	<i>£45,000</i>
Environmental health cases 2014/15	38	£1,330,000	£1,710,000
West Midlands Fire Service cases 2015/15	120	£4,200,00	£5,400,00
Total financial gains		£5,530,000	£7,100,000
Difference between costs and gains		£3,478,564	£5,058,654
Savings per case		£22,017	£32,017
Gains to cost ratio		2.7:1	3.5:1

3.20. As can be seen from the above, supporting hoarding cases would cost approximately £12,983 per

case. However, this compares with costs of between £35,000 and £45,000 if hoarders are not supported. Supporting hoarders saves between £22,000 and £32,000 per case. This equates to a cost/benefit ratio of between 2.7:1 and 3.5:1 i.e. every £1 invested in supporting hoarders leads to financial gains of between £2.70 and £3.50.

Cost-benefit analysis of charging for services

3.21. As well as considering the social return on investment value of implementing hoarding support services, it is necessary to consider cost-benefit analysis of charging for services and considering when this might be appropriate. Agencies such as Environmental Health and the West Midlands Fire Service have a statutory duty to respond to instances of hoarding which present risk to the household or neighbours. As noted above, according to the Liverpool Housing Trust, on average clearing hoarded homes costs around £3,500 per case. However, given that the actual costs of clearing homes varies widely (and there is no specific data available regarding the cost of clearing hoarded homes in Birmingham), it is not possible to accurately determine a cost/benefit analysis for charging. However, it is possible to determine the advantages and disadvantages of raising charges:

Advantages

- Charging will enable agencies to recoup the costs of clearing and repairing hoarded properties
- The possibility of incurring costs may discourage some hoarders

Disadvantages

- Hoarding is due to a range of complex factors – clearing the property is only part of the solution
- Charging may not act as a disincentive i.e. they may continue to repeat hoard
- The cost of clearing and repairing hoarded properties may vary widely, so it is difficult to determine a standard charge
- Most hoarders are unable to meet the substantial costs involved in clearing hoarded properties
- Incurring costs may alienate the hoarder from agencies meaning that they are less likely to seek support

3.22. Given the above, it is evident that the disadvantages of raising charges outweigh the advantages. Generally, it is recommended that hoarders are not charged for services related to clearing and repairing hoarded properties. It is recognised that there may be circumstances where agencies may clear hoarded properties more than once leading to high costs. However, it is recommended that occupants of hoarded properties be charged only after alternative options have failed and after careful consideration of the impact of costs on the hoarder.

Summary

- 3.23. To summarise, between April 2012 and February 2016 Birmingham City Council's Environmental Health Department recorded a total of 153 hoarding cases. Also, in 2014/15 the West Midlands Fire Service (WMFS) recorded 120 cases of severe hoarding and 321 cases of dangerous storage. Analysis of secondary data regarding these cases displays clear characteristics. In relation to tenure, a relatively large proportion of hoarding cases reside in the social rented sector. However, it is possible that this is due to social housing tenants or housing officers being more likely to report hoarding cases. Supporting this assumption, whilst a wide range of organisations referred hoarding cases to the Environmental Health Section, a fifth derived from the Birmingham City Council Housing Department. It is perhaps unsurprising, given its complexity, that a large number of agencies are involved in supporting hoarding cases. Whilst most hoarding cases usually involve around 2 hours support, a large proportion of cases required much more extensive support.
- 3.24. Analysis of data from both Environmental Health and WMFS suggest that there are a range of health and social factors which contribute to hoarding. However, the three which are most clearly evident are the age of the hoarder, whether living alone or with family, and whether the hoarder had mental health needs. It is apparent that many of the hoarding and dangerous storage cases involve older, single people living alone. Some hoarding cases involved older people who had been hospitalised due to mental health issues such as dementia. Other issues such as drug or alcohol misuse impact on the likelihood of hoarding. Ethnic identity appears to not substantially on the likelihood of hoarding. However, there is a geographic dimension to the data with hoarding more likely to occur in deprived areas of Birmingham.
- 3.25. As well as the psychological, health, social and environmental impact that compulsive hoarding may have on hoarders, family and neighbours, there are also financial impacts. Estimates of responding to hoarding range from between £35,000 to £45,000 per hoarding case. The average 38 cases per annum supported by the Birmingham Environmental Health Section combined with the 120 severe hoarding cases supported by the West Midlands Fire Services (WMFS) during 2014/15 equates to potential costs of between £5.53m and £7.11m. However, a Social Return on Investment (SROI) analysis suggests that implementing a hoarding support scheme would lead to financial gains of between £2.70 and £3.50 for every £1 invested. Whilst it is not possible to undertake a similar analysis regarding charging for services in relation to hoarding, it is apparent that the disadvantages of charging outweigh the advantages. As such, it is recommended that generally, hoarders are only charged after alternative options have failed and after careful consideration of the impact of costs on the hoarder.

4. Survey with service providers

Introduction

4.1. As part of the research an online survey was devised to determine the extent of hoarding in Birmingham, its impact on hoarders, families and neighbours, the effectiveness of multi-agency approaches to hoarding, and examples of good practice. Specific issues included:

- The extent of hoarding within Birmingham
- Key characteristics of people experiencing difficulties with hoarding
- Symptoms or issues of people experiencing hoarding difficulties
- Main risks to safety caused by hoarding
- The impact of hoarding difficulties on hoarders, family and neighbours
- The criteria for determining when organisations should provide support to people experiencing hoarding difficulties
- Training and support
- Resources required to provide support to people experiencing hoarding difficulties
- Multi-agency approaches to dealing with hoarding
- Information-sharing processes
- Awareness raising
- Best practice

4.2. The questionnaire included only open-ended questions. Respondents were contacted by email requesting that they complete the survey. The survey was completed by 46 service providers from a range of organisations including local government organisations, adult and social care organisations, health and mental health organisations, housing organisations, older people organisations, and the West Midlands Fire Service. Also, a semi-structured interview was undertaken with a representative of from *Clouds CIC*, an organisation which supports people experiencing hoarding issues.

Survey Results

4.3. Respondents were asked about the extent of hoarding within Birmingham. As discussed in Chapter 2, it is estimated that between 2%-5% of the population or at least 16,500 people in Birmingham experience hoarding difficulties. However, estimates from survey respondents vary widely and suggest that the number of hoarders referred to agencies in Birmingham is much smaller compared with estimates. As Table 4.1 shows, over four fifths (82%) of respondent organisations support 10 or fewer respondents per annum. A small number of respondents stated that their organisation supports a relatively high number of people with hoarding difficulties including 3 respondents (2 from the same organisation) whose organisation supports more than 50 hoarding clients per annum. The two

organisations cited as receiving the largest number of hoarding referrals per annum were the West Midlands Fire Service (WMFS), and the Birmingham City Council Environmental Health Section. A respondent from WMFS stated that they deal with as many as 25 cases of hoarding per week with 150 cases of extreme hoarding reported in 2014/15. Birmingham City Council's Environmental Health Department received 655 complaints about 'filthy and verminous' properties over the last 5 years. However, it should be noted that these figures are likely to underestimate the extent of hoarding within Birmingham as they only include those cases referred to agencies. Respondents also stated that the severity of referred hoarding cases varied ranging from clients with low level hoarding issues to those in need of urgent support.

	No	%
0-1	8	17%
2-3	15	33%
3-4	1	2%
5-10	14	30%
11-15	1	2%
16-20	2	4%
21-30	1	2%
31-40	0	0%
41-50	1	2%
50+	3	7%
Total	46	100%

Source: *Hoarding stakeholder survey 2016*

- 4.4. Respondents were asked about the main characteristics of hoarders. There was no general agreement regarding the usual characteristics. According to one respondent "hoarding appears to be a way of life for all types of people including the young, old, women and men". However, the main characteristics cited by respondents included gender, age, social class, and people with mental health issues. There were differences amongst respondents regarding the usual gender of hoarders. Whilst some respondents stated that they see a mix of male and female hoarders, some stated that hoarders tend to be older males. In contrast, 3 respondents stated that hoarders tend to be females aged 30 years or older with mental health issues or a learning disability.
- 4.5. Whilst some respondents stated that age is not a determining factor (one respondent stated they see hoarders aged between 18-70+ years, whilst another had come across a 'horrendous' case of a woman aged in her 20s), other respondents stated that hoarders were more likely to be older people. According to one respondent, the hoarders they see are usually aged over 50, live alone, and have an underlying mental health or substance misuse issue. Another stated it would appear that those with hoarding tendencies appear to be older than average and more socially isolated. It was suggested by one respondent that hoarders tend to be aged over 50 years, live alone, and have experienced a traumatic experience. 'Memory age' was also cited as a factor which could determine hoarding.

- 4.6. Although 'social class' was less likely to be cited as a factor determining hoarding a few respondents stated it is important. For example, one respondent stated that within the area they work hoarders tend to be from a lower social class, whilst another stated that all three hoarding cases they had seen were unemployed. According to one respondent hoarders are generally single and have either never worked or only worked for a short time. Finally, it was stated by one respondent that hoarders often reside in social housing and receive welfare support, whilst another stated some of the worst cases of hoarding occurred in inner-city high-rise tower blocks.
- 4.7. The most common factor cited by survey respondents as determining hoarding was mental health issues. Generally, it was recognised that most hoarders suffer from mental health issues or learning difficulties. The mental health issues cited by respondents varied although the most common were bipolar disorder, depression, and anxiety. Some hoarders also display substance misuse issues. Also, it was suggested that traumatic life events such as redundancy, divorce and bereavement could influence a person's propensity to hoard. Such circumstances often led to social isolation and lack of support for mental health issues. One respondent suggested that adverse life events in childhood could later influence the likelihood of hoarding in adulthood.
- 4.8. Respondents were asked to describe the symptoms or issues of people experiencing hoarding issues. As above, respondents were most likely to cite mental health issues as common symptoms including depression and anxiety. However, respondents also cited social isolation and self-neglect as key issues. Many hoarders display one or more mental health issues and/or learning difficulties. Such issues frequently led to self-neglect and increasing social isolation. Residing in a cluttered environment increased the person's inability to function on a daily basis and frequently led to hoarders feeling desperate.
- 4.9. Some hoarders had recently experienced a traumatic experience such as bereavement. This meant that they formed an emotional attachment to objects so were less willing to discard them. In the case of self-neglect, anecdotal evidence suggests that previous bereavement and loneliness may trigger and intensify hoarding behaviour. Self-neglect was another symptom cited by respondents with some hoarders displaying poor personal hygiene. Anxiety was another common symptom cited either due to the poor environmental conditions caused by hoarding, or due a sense of loss associated with letting go of objects. Some hoarders have substance misuse issues limiting daily functions.
- 4.10. Respondents described the social isolation associated with hoarding. Hoarders are frequently socially isolated and have few close family or friends to turn to for support. Some were described as 'living a life of solitude' or 'keeping themselves to themselves'. Respondents stated that Hoarders often feel that their situation has become 'too bad' for anyone to help and lack motivation for change. Social isolation means that hoarders are frequently reluctant to seek help and support from relevant agencies.

Also, social isolation leads to low self-esteem and lack of confidence. Another reason for not seeking support is that hoarders may feel embarrassed about their situation. This means that relevant agencies may need to be proactive in forming a supportive relationship with hoarders and encouraging them to socialise and seek support and practical help. However, the most important factor cited by respondents is hoarders acknowledging that they have a problem with which they require help and support.

- 4.11. Respondents described the main risks to safety caused by hoarding. Many risks were identified although the main ones included: a general risk to health and safety due to unstable collections of objects and the risk of falls; serious risk of fire caused by collections of objects such as papers and other flammable objects; some floors or piles may be unstable due to the weight of hoarded objects; hoarded objects prevent gas safety or other types of safety checks being undertaken; the storage of objects in bathrooms or bedrooms may limit personal hygiene or sleep; and infestation of insects and vermin. The faeces associated with insects and vermin could lead to contamination of worktop surfaces and hygiene issues regarding the preparation of food.
- 4.12. Fire was the risk, especially in high-rise buildings, most commonly cited by respondents. Hoarding of objects meant that in the event of fire escape routes were likely to be obstructed. Risk of fire also places neighbouring properties at risk. People residing in properties with hoarding are more likely to suffer falls. A combination of the above factors means that hoarders are more likely to experience ill-health. Unsanitary conditions mean that hoarders are more likely to suffer respiratory and other types of diseases exacerbated by damp, cold conditions. Hoarding may also impact on existing health conditions such as malnutrition and hypothermia. The social isolation of hoarders also means that health conditions are less likely to be diagnosed.
- 4.13. The impact of hoarding on hoarders, family and neighbours was well documented by survey respondents. The impact of hoarding can be severe leading to mental and physical health issues, impacting on quality of life, and affecting family relationships and neighbours. In some instances, it can lead to relationship breakdown. Hoarders may experience insomnia, exhaustion and anxiety. According to respondents hoarding means that family and friends may be reluctant to visit leading to a deterioration of relationships. This increases social isolation and further increases the likelihood of mental health issues such as depression and anxiety.
- 4.14. For hoarders with children there may be safeguarding issues. Hoarding can also severely impact on neighbours in terms of fears about general health and safety, risk of fire, or insect and vermin infestation. Emotional responses from neighbours may manifest themselves in a myriad of ways including compassion, anger or disgust. The pressure from family and friends or neighbours to resolve the hoarding issue can lead to hostility. However, the social isolation and stigma associated with

hoarding means that issues with neighbours are likely to remain unresolved. As such, neighbours may resort to formal means of complaining about hoarders leading to sanctions from relevant agencies. In extreme cases, hoarders may be threatened with eviction.

- 4.15. Respondents were asked if the criteria for determining when organisations should provide support to people experiencing hoarding difficulties are clear. As Table 4.2 shows, over half (59%) of respondents felt that criteria are not clear. A few respondents stated that they cite legislation e.g. Sections 83 and 84 of the Public Health Act 1936 (referring to filthy or verminous premises or articles) when responding to hoarding properties. However, it was acknowledged that not all hoarding properties are filthy or verminous premises. One respondent stated that they refer to the 2014 Care Act in relation to hoarding issues. This can enable the appointment of an advocate when there is hoarding and the person does not appear able to set their own care needs. This can apply even if the person has capacity though they would need to consent to the appointment. Hoarding in private or social rented properties may breach conditions of tenancy which may trigger intervention by housing management. Some respondents refer cases to the Community Mental Health Team for psychiatric assessment.

Table 4.2 Clear criteria?		
	No	%
Yes	4	9%
No	27	59%
Partly	10	22%
Unsure	5	11%
Total	46	100%

Source: RRR Consultancy stakeholder survey 2016

- 4.16. As stated above, a majority of respondents stated that there are no clear criteria for determining when organisations should provide support to people experiencing hoarding difficulties. Some hoarders may be receiving support from Community Mental Health Teams but choose not to disclose their hoarding issue. It may only be e.g. when hoarders receive a home visit from floating support workers that the issue becomes visible. Similarly, it was suggested that hoarders are sometimes secretive and unwilling to discuss the problem meaning it is difficult for agencies to know when to intervene. There is a lack of clear guidance and pathways regarding how agencies should respond to hoarding cases.
- 4.17. Importantly, it was suggested by a number of respondents that there needs to be a more 'joined-up' approach between agencies such as housing teams and mental health units. The West Midland Fire Service (WMFS) stated that they attempt to bring different agencies together using local links and contacts although there are no criteria for determining when to discuss hoarding cases. Some agencies apply internal procedures e.g. they may discuss possible responses to hoarding cases with managers and senior staff. According to one respondent referrals to external agencies regarding hoarding cases can take months. However, unless there are serious underlying mental health issues

most hoarding cases do not reach the threshold criteria for adult social care requirements. Nonetheless, it is instances where there is a clear duty of care to adults or children that elicit the swiftest and most effective response.

4.18. According to one respondent, even where there is legislative guidance e.g. Public Health Act 1936 clearing a property may only constitute a ‘quick fix’ which does not address underlying causes of the problem or offer long-term solutions. Decisions as to which agency or internal department is responsible for dealing with a hoarding case may be hampered by financial costs. Some respondents made reference to existing resources. For example, Lewisham LBC and Nottingham County Council have developed hoarding pathway guidance whilst a number of agencies have developed visual clutter rating toolkits to help determine when organisations should be involved.

4.19. A majority (57%) of respondents stated that they had not received sufficient training and support to help people with hoarding difficulties (Table 4.3). Courses attended by respondents included those arranged by the Birmingham Care Development Agency (BCDA) which were positively perceived by respondents. A number of charities had offered training on hoarding and related issues. Some respondents stated that they had received training regarding hoarding but that refresher courses would be useful. One respondent had attended a summit on hoarding but stated that like many other respondents had undertaken their own research on hoarding online. Practitioners tended to learn about hoarding ‘on the job’ and by liaising with colleagues from different organisations. According to one respondent training about hoarding is ‘low on the agenda’. Finally, respondents stated that even if they had previously received training, more would be useful as hoarding cases are usually complex and can take months or even years to address.

Table 4.3 Sufficient training?		
	No	%
Yes	8	17%
No	26	57%
Partly	12	26%
Total	46	100%

Source: RRR Consultancy stakeholder survey 2016

4.20. Respondents were asked if their organisation has sufficient resources required to support people experiencing hoarding difficulties. Respondents stated that most agencies have limited resources to support hoarders and some lack specialist staff. Most respondents stated that their organisation does not have sufficient resources. According to one respondent: “in my experience the resources are not available and there is no statutory guidance for people experiencing this issue” This impacts on support for hoarders in various ways. For example, some respondents stated that they are not always able to undertake home visits to hoarders. It was suggested that once a hoarder is identified they need

constant support and consistency: “this is a long process and we have to temper the action we take against the mental stability and cooperation of the hoarder”. According to one respondent they “do the best they can” given limited resources. For some respondents there is a sense of frustration at being unable to secure the services of external organisations. It would be useful if guidance was available indicating which organisations offer specialist support. However, sometimes all that is required is providing moral support and ‘hand holding’ to hoarders. A useful resource is the hoarder’s family who can offer emotional help and support. Finally, one respondent stated that they are becoming “inundated” with cases in relation to hoarding as service providers are beginning to realise they can help. However, this role is in addition to their usual duties.

- 4.21. As discussed in the literature review above, good practice suggests that multi-agency approaches to hoarding are essential. Respondents cited an extensive range of agencies who may be involved in supporting hoarders including: housing providers, landlords, environmental health services, pest control services, community mental health teams, adult social care/services, substance misuse services, fire services, older people services, general practitioners, local health centres, occupational therapists, BME groups, utility companies, voluntary organisations, animal welfare organisations, bereavement counselors, and professional de-clutterers. The key organisations identified by respondents included local authority housing and environmental health departments, social services, mental health teams and the Fire Service with Birmingham City Council regarded as playing a key role in coordinating support service. However, it was acknowledged that different hoarding cases will require different combinations of support as the nature of organisational responses is dependent on the risk assessment associated with each individual case.
- 4.22. According to respondents a multi-agency approach to hoarding is “absolutely essential”, “critical for successful outcomes and sustainability”, and “is the only way”. One reason is because hoarding encompasses many different health and social care factors and people will need different approaches depending on what is affecting them. Also, it was recommended that different agencies have different roles to play in supporting hoarders and can utilise different specialisms and organisational strength. Whilst a coordinated response may involve mental health workers, environmental health workers, and housing workers it was suggested that voluntary organisations may also be able to play a role in relation to community engagement. However, according to one respondent coordinated, multi-agency responses to hoarding are sometimes restricted by a lack of data-sharing protocols.
- 4.23. In relation to multi-agency working respondents were asked if organisations successfully work together in responding to issues around hoarding or if there a need for better integration and collaboration. It was noted that environmental health, housing providers, and the fire services work well together. For some respondents different organisations work well together leading to successful outcomes regarding hoarding cases. Also, successful outcomes are unlikely to be achieved unless relevant agencies

communicate and cooperate. However, it was suggested that it can be more difficult to involve mental health teams or social workers in hoarding cases unless the individual is willing to engage even when they are unable to make rational decisions. Nonetheless, it was suggested that ad hoc teams can be successfully formed in relation to specific hoarding cases. That hoarding cases may involve safeguarding issues can encourage agencies to better cooperate.

- 4.24. For most respondents there is a need for better integration and cooperation between different agencies. Throughout Birmingham, agency awareness of hoarding appears to be increasing although there remain gaps in knowledge and awareness, particularly in relation to health, and there is a lack of a strategic cooperation. Similarly, it was suggested that there is a need for better integration and collaboration along with cultural changes in decision-making processes. One issue is that different organisations may have differing perspectives on hoarding cases e.g. housing providers may be seeking eviction whilst mental health teams are seeking to provide individual support.
- 4.25. Organisations may be eager to help hoarding cases but without cooperation outcomes may be limited. For example, the Fire Service is willing to supporting hoarding cases but is only able to make progress with the cooperation of other agencies such as mental health teams. For one respondent, it is assumed that Adult Social Care will take the lead on hoarding although social workers do not always have relevant training. One reason for a lack of cooperation is due to limited funding to support hoarding cases. Also there is a need for organisations to better understand one another's roles in relation to hoarding. Finally, it was suggested once again data protection issues can limit successful inter-agency cooperation in relation to hoarding.
- 4.26. One key issue already mentioned by a number of respondents relates to poor information-sharing processes between organisations. One respondent described the process as sometimes akin to "trying to get blood out a stone". One reason is that it is not always easy to define data-sharing protocols between organisations so they can be difficult to implement. For some respondents, information-sharing is necessary but should be on a 'need to know' basis only. This is particularly important if the hoarder has built up a good relationship with a case worker and sharing information about the individual could erode trust. Also, the reclusive characteristic of some hoarders means that it is important for the personal details of individuals to be protected. One respondent stated that due to data protection issues it can be particularly difficult to obtain information from the NHS or Social Work Department.
- 4.27. However, it was acknowledged that whilst data protection is important information-sharing is important especially if there are safe-guarding issues relating to adults or children. According to one respondent is the responsibility for agencies to ensure that information is shared between agencies to ensure

successful outcomes to hoarding cases. For other respondents it would be advantageous for a multi-disciplinary hoarding service which would share information about specific cases to be established. This would involve protocols about the type and extent of information to be shared between agencies. At the moment more informal information-sharing takes place whereby professionals supporting hoarding cases communicate. Two successful hoarding liaison schemes in Berkshire were cited as examples of good practice where data sharing between agencies was initially an issue but had been resolved.

- 4.28. In relation to best practice respondents cited a range of general examples including: adopting a multi-agency approach; building trust between clients and agencies; ensuring that there is consistency of service and staff when supporting hoarders; helping to clear and clean hoarders' rooms; with the consent from the hoarder involving family and friends in providing support; encouraging hoarders to seek counselling and other types of therapeutic support; and being patient as it takes time to change hoarders' habits. More specific examples included the use of visual image scales such as those produced by Nottingham County Council and Lewisham LBC (see Chapter 2) to help determine the severity of hoarding cases. Another specific example of good practice included HOMES (Health, Obstacles, Mental Health, Endangerment, Structure). HOMES is a multi-disciplinary hoarding risk assessment tool which provides a structural measure through which the level of risk in a hoarded environment can be conceptualized¹².
- 4.29. Some respondents suggested the use of (Vulnerable Adult Risk Management) (VARM) principles. The VARM process is designed to be used for those vulnerable adults who do not fall within existing processes. Each agency appoints a 'champion' or lead to take part in the process: to meet, discuss, identify, and document risk for high-risk cases, and to formulate an action plan. While the process covers all types of harm, it has been used in cases of hoarding. Clouds End CIC was cited by one respondent which as an organisation that runs a support group specifically for hoarders in Solihull. It was suggested that the Court of Protection can offer some help in terms assessing a person's ability to conduct a tenancy etc. However, it was stated that this is extremely costly and unfortunately landlords will often have to take breach of tenure issues instead. Also, it was suggested that as hoarders are often reluctant to receive visitors at home, Birmingham Mental Health Team workers often see them at a GP surgery. They then liaise with the Community Mental Health Team (CMHT) to arrange help and support.
- 4.30. Finally, respondents were asked about how to raise awareness regarding help and support with hoarding in Birmingham. Respondents suggested a range of strategies including:

¹² See http://vet.tufts.edu/wp-content/uploads/HOMES_SCALE.pdf and Appendix 3

- Better information sharing between agencies
- More group working between agencies
- A media campaign to increase public awareness about the issue
- Production of short films about hoarding
- Posters in public places about hoarding
- The use of social media to increase awareness of hoarding
- More information about how to find help and support
- More awareness raising events
- Leaflets being sent to all households about the dangers of hoarding
- Notices in GP surgeries about how to find help
- More debate and discussions in the public sector about hoarding
- More training for staff
- Hoarding toolkits for frontline staff
- More research on the issue of hoarding

Summary

- 4.31. It is apparent from the survey responses discussed above, that whilst hoarding is problematic, it is difficult to determine its extent throughout Birmingham. Whilst most respondent agencies see only a few people displaying hoarding difficulties each year, at least two agencies (West Midlands Fire Service and Environmental Health, Birmingham City Council) see more than 50 cases each year. Also, it is apparent that there are no clear characteristics which could describe hoarders – they are equally likely to be young or old, male or female. However, there was agreement amongst respondents that hoarders tend to display complex issues, and that these may manifest themselves in terms of social, health or mental health issues. Such issues frequently led to self-neglect and increasing social isolation. Some hoarders had recently experienced a traumatic experience such as bereavement meaning that they formed an emotional attachment to objects so were less willing to discard them. Respondents described the social isolation associated with hoarding. Hoarders are frequently socially isolated and have few close family or friends to turn to for support.
- 4.32. Respondents stated a wide range of risks associated with hoarding although the main one cited was risk of fire. Hoarding of objects meant that in the event of fire escape routes were likely to be obstructed. Risk of fire also places neighbouring properties at risk. Risk of fire also places neighbouring properties at risk. The impact of hoarding can be severe leading to mental and physical health issues, impacting on quality of life, and affecting family relationships and neighbours. In some instances, it can lead to relationship breakdown. For hoarders with children there may be safeguarding issues. Hoarding can also severely impact on neighbours in terms of fears about general health and safety, risk of fire, or insect and vermin infestation.

- 4.33. Generally, respondents stated criteria for determining when organisations should provide support to people experiencing hoarding difficulties are not clear. This means it can be difficult for agencies to determine when they need to provide help and support to hoarders. Decisions as to which agency or internal department is responsible for dealing with a hoarding case may be hampered by financial costs. Most agencies have limited resources to support hoarders and some lack specialist staff. For some respondents there was a sense of frustration at being unable to secure the services of external organisations. Also, most respondents stated that they had not received sufficient training and support to help people with hoarding difficulties.
- 4.34. Importantly, it was suggested that there needs to be a more 'joined-up' and ongoing approach to hoarding and a need for better integration and cooperation. It was clear from respondents that a multi-agency approach to support hoarders is essential. This is because hoarding encompasses many different health and social care factors and people will need different approaches depending on what is affecting them. Whilst a coordinated response may involve e.g. mental health workers, environmental health workers, and housing workers, voluntary organisations may also play a role in relation to community engagement. However, it was acknowledged it can be difficult to involve mental health teams or social workers in hoarding cases unless the individual is willing to engage even when they are unable to make rational decisions. Generally, it was suggested by respondents that information-sharing processes between organisations are not always successful. It was acknowledged that whilst data protection is important information-sharing is important especially if there are safe-guarding issues relating to adults or children.
- 4.35. It is apparent from respondents that there is a wide range of best practice examples that agencies can draw on. These included generic changes such as adopting a multi-agency approach; building trust between clients and agencies. More specific suggestions included the use of visual image scales, adopting risk assessment tools such as HOMES (Health, Obstacles, Mental Health, Endangerment, Structure), and adopting Vulnerable Adult Risk Management (VARM) principles. Also, it clear from respondents that there is a need to improve agency and public awareness of hoarding and the type of help and support available. This could take the form of public awareness campaigns which uses a wide range of traditional and social media.

5. Case Studies

Introduction

- 5.1. There are a number of complex and inter-related factors which may determine why people face hoarding issues e.g. economic issues, housing issues, health issues, mental health issues, bereavement, or financial issues. There is no single 'trigger' which leads to hoarding i.e. a number of individual, interpersonal and structural factors all play a role. Also, these issues and problems may require a multi-agency response.
- 5.2. As such, the case study 'journey' method was adopted as a means of determining peoples' experiences of hoarding. The journey approach seeks to uncover the ways in which individual situations and actions link with wider processes. This involved comprehensively and chronologically charting each person's situation, any significant events and experiences in their lives, their engagement with services (and the outcome of this interaction).
- 5.3. In total, 10 case studies undertaken as part of the research including three which were provided by the West Midlands Fire Service (WMFS). The case studies were chosen to reflect the range of factors which lead to hoarding and provide insight into life journeys. They further help understand the links between hoarding and a range of issues. Please note that names have been changed to ensure the anonymity of the cases.

Case 1

- 5.4. Edna is a 75-year-old female with various medical conditions including epilepsy, hyperthyroidism, arthritis, and incontinence. She is also a heavy smoker. Her mobility is limited and reducing. She has had two mental health admissions – one in the 1960s, followed by another in the 1980s. She was allocated her current flat after one of these admissions. The earliest reference to Edna on the Fire Service database was dated July 2002. Edna was referred to the Fire Service by the local Adults of Working Age Service. The 2002 Fire Service record described Edna as having 'longstanding mental health problems'.
- 5.5. Edna received injections for her mental health issues every three weeks at an outpatient facility. Her health needs were reviewed every 6 months, although she occasionally missed health review appointments. A review of clinical letters showed that her mental health condition was generally good. However, during some mental health reviews she described having auditory hallucinations.
- 5.6. In December 2009 Edna was visited at home by a nurse because she failed to attend an appointment to receive her injection. Edna's treatment by injection was discontinued and replaced by oral medication. The nurse noted that Edna's sitting room, kitchen, toilet and bathroom were cluttered.

This increased risk within Edna's home including a risk of fire. Edna was not willing to consider moving house. She had financial problems and was at risk of her power supply being terminated. Her next of kin was assisting with a clear up of the property.

- 5.7. Due to mobility issues, in 2010 Edna's clinical appointments were replaced with home visits. Health visitors noted the extent of hoarding. In November 2010 Edna's case was transferred to the Birmingham Mental Health Service for Older People. Edna was visited by a psychiatrist, a community psychiatric nurse, and a community support worker. In November 2011 she was admitted to hospital after having had a seizure while shopping. She was assessed by the Psychiatric Liaison Service and her mental health was assessed as stable.
- 5.8. In 2012 Edna was referred to Birmingham City Council's Housing Services because of vermin. A joint visit by the Pest Control Service and Fire Service was carried out. Edna agreed she would take appropriate steps to eradicate vermin whilst she occupied the property to avoid compulsory decluttering. In August 2013 professional meetings were introduced following an incident when a tea towel caught fire. The meetings included the Community Mental Health team, Housing Services, Vulnerable Person's Fire Officer, Social Care and next of kin. Edna declined to attend the meetings although her next of kin passed on information and decisions. The meetings took place around every two months.
- 5.9. As a result of these meetings:
- It was acknowledged that Edna finds it difficult to negotiate with people.
 - She was assessed by a psychiatrist as having capacity to make decisions about her home and her living arrangements.
 - The CMHT carried out a joint visit with the Housing Officer.
 - The Housing Officer arranged regular visits from a Community Support Officer to remove any hoarded items that Edna had sorted.
 - The Neighbourhood Police Station was informed of Edna's vulnerability.
 - The Community Support Worker visited Edna on a regular basis.
 - Edna had financial problems but was committed to servicing debts.
 - Free fire safety checks were offered to all neighbouring properties and a smoke alarm and fire retardant bed linen were provided to Edna.
 - The Community Support Worker and Vulnerable Person's Fire Officer worked jointly to clear 30 bags of hoarded material in Edna's living room.
- 5.10. Edna was admitted to hospital admission after experiencing an epileptic fit while shopping. Edna appeared to enjoy her stay on the hospital ward. As such, it was suggested that Edna attend an Enhanced Assessment Unit so that her needs could be assessed by social workers over a longer

period. However, Edna refused the admission. Eventually, a deep-clean was undertaken at Edna's home. On return, she was provided with package of care to help her deal with hoarding. Edna's apartment remained relatively clean and uncluttered for some time. However, the care package was discontinued after Edna received a bill for the care and cleaning. Her home environment began to quickly deteriorate.

5.11. Subsequently, the Housing Department began the legal process of terminating Edna's tenancy (although she remains in the property). She was referred to Birmingham Adult Social Care who allocated a social work student to help her with decluttering and cleaning. However, the home environment remained cluttered and Edna was reluctant to discuss alternative housing options. Edna's mental health issues continued and she was diagnosed first as suffering from bipolar disorder and then organic hallucinosis. Edna was visited by a social worker and fire officer in February 2016. Edna's home remains cluttered and a fire risk. The photos below show the extent of hoarding before and after Edna's home was decluttered.

Pre Clear by Fire Service and Support Worker



Post Environmental Clean Clear by Fire Service and Support Worker



6 Weeks post clear



Case 2

- 5.12. Pat is a 50-year-old female smoker living alone. Whilst family live nearby, her relationship with them is difficult as there is history of physical and mental abuse from family members and her ex-husband. She has a child that was taken into in full-time foster care 4 years ago, and will soon be placed in permanent care. Pat has fortnightly phone calls with her daughter. Whilst Pat's daughter has a social worker, Pat has no social support.
- 5.13. Pat has no washing or cooking facilities at home and has to rely on her mother for a weekly hot meal and bath. Pat's case study notes describe as an 'extreme hoarder'. Her first floor maisonette is full of belongings she bought for her daughter. Entrance to the maisonette is made difficult by the number of objects cluttering the hallway from floor to ceiling. Pat has a dog who resides in the hallway. There are large amounts of rubbish and papers amongst the belongings. Pat keeps a television permanently on to deter burglars. The hoarding extends to the landing. Pat also has a 2m by 2m shed in the communal garden which is full of her daughter's belongings. She has begun hoarding in a neighbour's flat occupied by someone with mental health issues. Pat has placed hoarded items in one of her neighbour's bedroom and sleeps on the neighbour's sofa.
- 5.14. Pat received counselling regarding her mental health issues but stopped as she felt she was not making progress and lacked support. She made some attempt to clear her property in the hope that her daughter would be returned to her care. However, she stopped decluttering once she realised it was unlikely that she would be given custody of her daughter. The Housing Department and West Midlands Fire Service (WMFS) attempted to declutter the hallway but progress was slow as Pat became agitated and upset. Pat explained that having the items around her made her feel safe, but that she understood the need to declutter. She understood the dangers that hoarding presented and is a risk to both herself and neighbours. As such, she signed an agreement with the Fire Service and

Housing Department to enable them to help her declutter. Unfortunately, Pat stopped communicating with Fire Service and Housing Department and the hoarding has spread to communal areas.

Case 3

- 5.15. Bet is a 45-year-old female residing in a ground floor maisonette. The West Midlands Fire Service (WMFS) were asked to service a smoke alarm. On entering the property, they realised that Bet is 'severe hoarder'. When the fire crew arrived it took them 20 minutes to access the smoke alarm. The clutter by the door was covered in cat excrement. On leaving the property, the Fire Service had to decontaminate equipment. All rooms are cluttered. Bet has mobility issues and uses a walking stick. Her access is limited to the hallway. She has no space to cook, wash or rest.
- 5.16. Bet was being supported by Social Services but this ceased in November 2015 when she was assessed as having full mental capacity. The Housing Department may refer her to Social Services should the need arise. Bet finds it difficult to engage with people. She has been supported by two different social workers over the last three years. She was motivated to clear the property herself and wanted to work with *Clouds End CIC*. She made some limited attempt to clear the property. She disposed of around two bags of rubbish every fortnight.
- 5.17. Neighbours reported that Bet had been sleeping in her car, although she refuted this claim and said she spends most nights at her daughter's. However, it was apparent that Bet was sleeping and cooking in her car using candles to keep warm. A local councillor asked relevant agencies what could be done about Bet's case. The Fire Service tried to contact her on several occasions but was unable to as she moves around. During the last visit the Fire Service could only just open the front door to assess the case. Bet was referred to the Adult Safeguarding Team. The RSPCA contacted Bet about her cats and they were assessed as being in good health. However, neighbours noted that the cats are no longer in the property and are being fed outside. The Fire Service last attempted to contact Bet in March 2016 to help her clear the hoarding but she could not be contacted. Due to the risk hoarding poses to herself and neighbours, the Housing Department are considering housing Bet elsewhere.

Case 4

- 5.18. Jack is a 77-year-old male who lives alone in a privately owned property. He has been divorced twice and has three sons and several grandchildren from his first marriage, and 2 sons from his second. He has no contact with his sons from his first marriage, although has limited contact with sons from his second marriage who are studying away at university. Jack is a retired professional who used to run his own business. He had to retire when he started to experience a range of symptoms including dementia, diabetes and epilepsy. Eventually, his business failed and his wife divorced him. Jack has been living alone since the divorce and is struggling to cope.
- 5.19. His tendency to hoard before the divorce has since become more acute. Jack hoards items relating to

his previous occupation such as professional magazines. Many of the magazines remain unopened. Some rooms in the house are inaccessible due to the large number of items. He keeps a grand piano in a small kitchen as well as a bird cage. He used to keep a bird but was unable to keep it for health reasons. He keeps a cat which defecates throughout the house because it is unable to access the overgrown garden. Jack struggles to maintain his health. Although diabetic he regularly eats and drinks sugary food. The nurse could not enter the property due to the level of hoarding so referred him to social services.

- 5.20. Jack struggles to dispose of items he believes have some use. Hoarding impacts on his health e.g. the kitchen is inaccessible and he is unable to cook. He eats snacks throughout the day and eats out for breakfast and dinner. He tries to be compliant when asked to declutter his property. He cleared sufficient space to enable the district nurse to care for him. The social worker and other agencies helped him clear the house and undertake repairs to floors and ceilings. However, he is unable to maintain the decluttering process. His social worker cleared over 6 bags of items but once the social worker left the property he put them back. Within a few weeks the house returned to its cluttered condition.
- 5.21. Jack's social worker helped him with a range of issues including financial problems and issues with utility companies. The social worker helped Jack set up direct debits, set up a budget plan, and negotiated the writing off of a tax bill. Jack's doctor also helped with some of these issues. Jack is not currently being supported by a social worker but is likely to be referred again soon.

Case 5

- 5.22. Sally is a 55-year-old female who is in a relationship with no children. She is currently keeping control of her tendency to hoard but is concerned it could return. She believes that hoarding tendencies could be inherited or a consequence of social conditioning as other members of her family display hoarding traits. However, she identifies her hoarding as a response to stressful situations and events e.g. relationship breakdown, bereavement, long-term illness, occupational stress, and caring commitments.
- 5.23. Sally is reluctant to dispose of objects she no longer needs. The hoarding becomes more prominent during periods of stress. Whilst in a relationship her partner would encourage her to declutter. However, the hoarding impacted on the relationship. After the relationship breakdown Sally's hoarding worsened. She would buy unnecessary objects even if she already owned them. Friends and family began to help with the hoarding and she received counselling for her emotional problems. She is in a new relationship and keeping her hoarding tendencies under control.

Case 6

- 5.24. Stan is a 74-year-old male living alone in high-rise flat. The accommodation is warden-run supported housing. He is very isolated and has little social contact with neighbours or family and finds it difficult to engage with people. Although he has a dishevelled appearance he is in good health and has not seen his GP in over two years. Social services are concerned about his mental health issues although they have been unable to undertake an assessment. However, he is considered to be in need of safeguarding. Stan is articulate and a retired bookstore owner. His small flat contains over 4,000 books and a range of items such as shopping trolleys, boxes, bike frames etc. Every day he returns home with more items. Due to hoarding both Stan's kitchen and bathroom are inaccessible. He eats out and washes in the public toilets in the local park and carries a toothbrush with him. There is space leading to a chair and limited access to the bedroom. During the last two years neighbours began to complain about smells emanating from the flat.
- 5.25. Stan was referred to Social Services after the Fire Services attempted to undertake a smoke alarm check. The extent of hoarding meant that they were unable to access the property. After a number of attempts, they managed to install a smoke alarm. However, Stan believes that as he does not use electricity or a microwave a fire is unlikely. The Housing Department and Social Services have undertaken a joint review although as they believe he has mental capacity they are unable to force changes. They are considering evicting Stan and re-housing him in more suitable accommodation. A key-safe scheme access was agreed which enabled Environmental Health Section to carry out an assessment of the flat. They estimate it will cost around £4,000 to declutter Stan's flat. Since August 2015, Stan has been receiving support from a social worker. The social worker contacted a hoarding expert to help support Stan. Also, a number of charities have approached him offering help and support. However, his reluctance to engage with people means that his hoarding problem persists.

Case 7

- 5.26. John is a 51-year-old male living on own in a rented flat. He has never married and has no children. He has friends but finds it difficult to maintain relationships when suffering depression. The depression began when John was made redundant four years ago. At the same time, he suffered a relationship breakdown and bereavement. His whole life suddenly changed when he lost his job, home and relationship. John had always enjoyed fixing and restoring objects as a hobby but did not begin to hoard until he became redundant. Once he lost his job acquiring items to fix and restore became obsessive. Being occupied helped John deal the substantial changes to his life. His plan was to fix and sell items that other people might regard as rubbish such as electrical items, bikes, clothes and bags. However, he was not always able to sell the items and they began to accumulate throughout his property.
- 5.27. John regarded hoarding as an 'anchor' or 'security blanket' and a means of coping with problems. He stated that his fear of loss made him reluctant to emotionally detach from objects. He denied that he

had a problem with hoarding until around two years ago when was referred by the Fire Service to agencies for help and support. The Housing Department visited in order undertake repairs but were prevented by the hoarding. As such, they initially wanted him to completely declutter the property. He had heard of tenants who were forced to allow access to clearance companies who remove all hoarded items. John stated that he was not emotionally prepared for a sudden decluttering and that agencies should adopt a more sympathetic approach. He regards acknowledging and talking about hoarding as part of the solution. He has partially decluttered his property and feels that he is keeping on top of his hoarding at the moment, but aware that if triggered, without support it could all come back and become out of control again.

Case 8

- 5.28. Barb is an older female aged around 80 who has lived on her own for almost three years. She had a very successful career and appears confident and in control of her life. She is well organised and is perceived as a strong character by most people. She works as a volunteer at the local hospice and is very busy supporting local people and charities.
- 5.29. However, she experienced a number of difficult events and situations throughout life. Her parents separated when she was a child which she perceives as 'leaving a scar'. She had a very good relationship with her father but had to live with her mother. Staying with family at Christmas but receiving no presents meant that even as an adult Christmas was always a difficult time for her. Barb and her sister became estranged and she had not seen her for 35 years when she died in December 2015. The death of her sister led to a number of emotional issues resurfacing. Both sisters displayed hoarding tendencies. Barb struggled with the death of her mother 40 years ago and hoarded many of the items she left behind. The same occurred when her husband died three years ago. Hoarding is a means of coping with loss. She has had a range of health problems including ovarian and bladder cancer in 2008. She looked after her husband until he died three years ago.
- 5.30. Barb's home is clean but full of hoarded items. She admits she buys unnecessary items and is unable to refuse a bargain even if she does not need the item. She boxes up the items and stores as much as she can although they frequently overflow. She does not like to dispose of acquisitions or for items to be moved by another person. Barb's husband used to help keep the hoarding under control especially when it worsened during stressful periods such as times of loss. She had a cleaner who would help declutter her property. Since the cleaner left due to other commitments Barb has found it difficult to control her hoarding. When her husband died her daughter helped her declutter some items. She tried counselling but found talking about difficult issues upsetting. Since her sister died Barb her hoarding has increased. She needs help and support from the 'right person' – someone she can trust who likes cats and chatting.

Case 9

- 5.31. Victor is an 87-year-old academic living alone in his own home. He suffers from severe health issues and is developing mental health problems. He never married and has no children. Over the last few years he has become increasingly isolated from family and friends. He was close to a brother and sister but they moved to Scotland some years ago. He has some contact with a long-standing friend who is also in her mid-80s. However, she stopped visiting him around three years ago because of the cluttered house. She wrote him last year saying she would not continue the friendship unless he sought help with his hoarding and health problems. Victor visited his friend on a couple of occasions but not for some time.
- 5.32. From the front Victor's terraced home looks to be in good condition. The rear of the house is accessed through a shared alleyway. The rear garden is very overgrown and there is only a narrow path to the rear entrance which lacks a back door. The extent of hoarding from floor to ceiling means that it is difficult to access most rooms. The house is very cold with no running water or electricity. Neighbours began to complain about smells, rats and the extent of hoarding. Victor walked the streets all day and night and he was hardly ever at home making it difficult to agencies to engage with him. Sifa Fireside and similar agencies provided Victor with food and clothing. He has a range of problems including Chronic obstructive pulmonary disease (COPD) and ulcerated legs. His friend used to dress his legs until it became too much for her and advised that he seek proper health care.
- 5.33. Victor was admitted to A&E after collapsing in the street. His poor health condition meant that hospital staff first believed him to be homeless. During his stay in the hospital Victor was referred to Social Services. Through their shared data system, they found that a social worker was already attempting to engage and support him. Victor's friend had told the social worker that he had been hoarding for some time but that it had worsened over latter years. His physical and mental health had deteriorated over some years. After being assessed, the hospital social workers decided that Victor would be best supported in a care home. As no family was able to act on his behalf, the Council sold Victor's home and the proceeds used to pay for his care.

Case 10

- 5.34. Jack is a 70-year-old man living on own. He has been assessed as suffering from mental health issues including Obsessive Compulsive Disorder and is currently being assessed for dementia. His only family is a nephew who supports him as much as possible. Jack has a limited income but constantly buys items from charity shops. He finds it difficult to dispose of items and hoarded items fill his property from floor to ceiling. There are few narrow 'walkways' through hoarded items which enable limited access to some rooms. He mainly sleeps in a chair because the bedroom is full of items. Jack displays a fear of letting go of objects. He believes that this fear is associated with loneliness and a need to avoid loss. His hoarding increased as his mental health deteriorated. In response to hoarding and financial issues

Jack was referred to Social Services by a Community Psychiatric Nurse in December 2015. He is also being supported by his nephew. The Council are helping him move to a more affordable supported housing scheme.

Summary

5.35. The cases discussed above highlight the extent to which hoarding impacts on people, neighbours and agencies. It is apparent that although some cases share similar characteristics such as being elderly and alone, they are complex and involve a range of different social, health factors. In many of the cases hoarding appears to be in response to life changing events such as relationship breakdown, bereavement or redundancy. In some instances, hoarding has led to life-changing events such as a child being placed in foster care. It is apparent that it negatively impacts on relations with family, friends and neighbours. Mental health issues such as depression or anxiety also predominate irrespective of whether in response to events or some other underlying cause. In the case of bereavement people may place a strong emotional attachment to the deceased belongings. These are frequently combined with other types of health issues such as diabetes or epilepsy. Most people discussed above find it difficult to engage with both family and friends and agencies. This makes providing appropriate help and support both more urgent and difficult. Finally, it is apparent that the most successful outcomes to interventions involve a multi-agency response.

6. Conclusions and recommendations

- 6.1. It is apparent from the research findings that hoarding remains a significant issue both nationally and locally. It is estimated that between 2% and 5% of the population hoard equating to at least 1.2 million households across the UK and 22,000 people in Birmingham. The data analysed in Chapter 3 represents a total of around 600 hoarding and dangerous storage cases over a 12-month period. This means that most hoarding cases remain 'hidden'. Surveys of agencies suggest that it is difficult to determine the extent of hoarding throughout Birmingham. Whilst most respondent agencies saw only a few people displaying hoarding difficulties each year, at least two agencies (West Midlands Fire Service and Environmental Health, Birmingham City Council) see more than 50 cases each year.
- 6.2. The literature, data and case studies discussed as part of this research suggest that hoarding is a complex and multifarious issue. Hoarding difficulties are usually co-presented with a range of symptoms such as depression, anxiety, post-traumatic stress disorder, attention deficit/hyperactivity, intellectual or developmental difficulties, and autism. In many of the cases hoarding appears to be in response to life changing events such as relationship breakdown, bereavement or redundancy. As well as the psychological, health, social and environmental impact that compulsive hoarding may have on hoarders, family and neighbours, there are also financial costs. Estimates suggest that dealing with hoarding cases costs housing providers between £35,000 and £45,000 per case. This equates to potential costs of between £5.53m and £7.11m per annum in Birmingham. Given the extent of such costs, social return on investment analysis indicates that every £1 invested in a supporting hoarders scheme would lead to financial gains of between £2.70 and £3.50.
- 6.3. Whilst the literature suggests that the characteristics of hoarders vary widely the analysis of secondary data and case studies indicate common factors. A relatively large proportion of Birmingham hoarding cases reside in the social rented sector. However, it is possible that this is due to social housing tenants or housing officers being more likely to report hoarding cases. Although evidence suggests that a range of health and social factors contribute to hoarding the three most evident were the age of the hoarder, whether living alone or with family, and whether the hoarder had mental health needs. Some hoarding cases involved older people who had been hospitalised due to mental health issues such as dementia. It is possible that hoarding cases involving older people is due to them being more likely assessed as displaying safeguarding issues. Again, the case studies showed that mental health issues such as depression or anxiety as key factors whether in response to specific events or some other underlying cause. In the case of bereavement people may place a strong emotional attachment to the deceased belongings. Other issues such as drug or alcohol misuse impact on the likelihood of hoarding. There is also a geographic dimension with hoarding more likely to occur in deprived areas of Birmingham. However, it is important to recognise that there is no 'typical hoarder' and that public awareness campaigns should be aimed at all members of local communities.

6.4. It is evident from survey responses that criteria for determining when organisations should provide support to people experiencing hoarding difficulties are not clear. This means it can be difficult for agencies to determine when they need to provide help and support to hoarders. Importantly, it was suggested that there needs to be a more 'joined-up' and ongoing approach to hoarding and a need for better integration and cooperation. It was clear from respondents that a multi-agency approach to support hoarders is essential. Generally, it was suggested by respondents that information-sharing processes between organisations are not always successful. It was acknowledged that whilst data protection is important information-sharing is important especially if there are safe-guarding issues relating to adults or children.

6.5. Both the literature review and survey responses indicate a wide range of best practice examples that agencies can draw on. These included generic changes such as adopting a multi-agency approach; building trust between clients and agencies. More specific suggestions included the use of visual image scales and adopting risk assessment tools. Also, it clear from respondents that there is a need to improve agency and public awareness of hoarding and the type of help and support available. This could take the form of public awareness campaigns which uses a wide range of traditional and social media.

6.6. Specific recommendations deriving from the evidence include:

- To adopt the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) (2013) definition of hoarding as: "a pattern of behaviour that is characterized by the excessive acquisition of and inability or unwillingness to discard large quantities of objects that cover the living areas of the home and cause significant distress or impairment". However, hoarding may be perceived as much a social as mental health issue and most people experiencing hoarding difficulties are never diagnosed by health professionals. As such, whilst the DSM-5 definition of useful, it is important not to perceive hoarding solely as a mental health issue.
- To consider implementing a hoarding support programme which would include:
 - Initial contact
 - Risk assessment
 - Case assessment
 - Clearance and repairs (using public, private or voluntary agencies)
 - Therapeutic support (using public, private or voluntary agencies)
 - Ongoing contact (minimum 12-month period for severe cases)
- The likely costs of such a programme are outlined by the Social Return on Investment Analysis (SROI) undertaken in Chapter 3. The SROI shows that that implementing a hoarding support scheme would lead to financial gains of between £2.70 and £3.50 for every £1

invested.

- Adopt a multi-agency approach to hoarding cases to ensure a collaborative approach between relevant agencies and organisations. This would include establishing a Birmingham-wide Hoarding Forum consisting of key agencies drawn from the statutory, voluntary and private sectors. Similar to the London Borough of Hammersmith and Fulham model (LBHF), it is recommended that Birmingham City Council Adult Social Care Services Section is the lead organisation. This is because, as the LBHF model suggests, social workers are best placed to understand the complex needs of hoarders. However, it is important that any decisions made regarding hoarding cases are based on a multi-agency approach. This would also involve the establishment of a multi-agency conference team which meets to discuss hoarding cases on a monthly basis.
- Improve information sharing between agencies regarding hoarding including the implementation of information-sharing protocols to facilitate the swift sharing of information. This would include agreeing data collecting protocols on hoarding to ensure consistency of data collection across agencies i.e. agree the type of information to be collected.
- Agencies should be proactive rather than reactive in response to hoarding cases i.e. offer early intervention where possible. This would include:
 - Adopting the Liverpool Housing Trust 'Self-Assessment' form (in liaison with increasing public awareness of the issue) (see Appendix 1)
 - Adopting the Liverpool Housing Trust 'Hoarding Disorder Impact Assessment form' (see Appendix 2)
 - Adopting the Nottinghamshire County Council 'Hoarding Assessment Referral' form (see Appendix 3)
 - Using the 'Clutter Image Rating' scale (see Appendix 4) (Nottingham County Council) to determine agency responses. Specific actions would include:
 - Levels 4, 5 or 6 require a joint visit from social work services and either the Fire Brigade and/or environmental health and/or a housing officer depending on the circumstances.
 - If a home is identified at level 7, 8 or 9, then an urgent multi-agency case conference is called with the purpose of developing an action plan. Immediate serious consideration is given to risks, especially of fire.
 - To implement monthly follow-up visits for a minimum 12-month period for hoarders identified at levels 7,8 or 9. This will help to determine the extent to which agency interventions are succeeding and to minimize the likelihood of repeat hoarding. Although this will

incur additional costs, the SROI discussed in Chapter 3 indicates that this is a worthwhile investment.

- Adopting the Liverpool Housing Trust 'My Acquiring Rules' form (see Appendix 5)
- Adopting the Liverpool Housing Trust 'My Boxed Off Pledge' form (see Appendix 7)
-
- Implement an awareness raising campaign using traditional and social media. This could include awareness raising events, stalls in public places, leaflets and posters in public places, newspaper articles, and the design of a dedicated website and/or Facebook page. The aims of the awareness raising campaign are to improve public awareness of the issue and sources of (self)-help and support. This would include encouraging hoarders, family, friends and neighbours to seek advice and support from relevant agencies.
- Implement training across agencies to ensure that both front-line staff and managers know best how to deal with hoarding cases. This could be led by public agencies such as the West Midlands Fire Service (WMFS) (who already undertake extensive training and awareness raising regarding hoarding), or private and voluntary agencies such as *Clouds CIC* (who already undertake training with social landlords, a hoarding training awareness workshop, and offer an online hoarding awareness course). Topics could include:
 - Identifying hoarding
 - The causes of hoarding
 - Types of hoarding
 - Assessing hoarding (including the use of assessment forms and visual aids)
 - Techniques for supporting hoarders
 - The type of support services available locally
 - Multi-agency responses to hoarding
 - Reducing repeat incidents
- The essential components of the above could be made available to relevant agencies and organisations in written form.
- To consider adopting community approaches to hoarding. Similar to the Canadian model discussed in Chapter 2, this would involve encouraging local communities to help identify hoarding cases. This then leads to a collaborative approach whereby community members, with the guidance of professionals, help support hoarders e.g. helping to clear properties. Members would help determine which hoarded articles could be recycled and which should

be discarded. Involving hoarders in community activities may help reduce feelings of social isolation and increase the likelihood of engagement with agencies.

- To adopt a sympathetic approach to hoarders and awareness of the emotional difficulties involved in decluttering. All of the agency workers involved in this research agents displayed a sympathetic approach to hoarders. However, some case-study participants stated that they had experienced unsympathetic agents who displayed a “how can you live like this” attitude. It is likely that this attitude stems from a lack of awareness regarding the causes of hoarding and can be resolved by improved awareness raising and training.
- Ensure that help and support to people experiencing hoarding issues is ongoing e.g. to maintain support once a property has been decluttered. As suggested above, the SROI discussed in Chapter 3 suggests that ongoing support is an important component ensuring successful resolution of hoarding cases. It is recommended that in relation to severe hoarding cases (i.e. those determined as levels 7-9 on the clutter image rating scale) follow-up home visits take place on a monthly basis for a 12-month period. Less severe cases (4-6 on the clutter image rating scale) could be undertaken less frequently. This will help reduce client feelings of isolation and minimise the likelihood of repeat cases.
- As discussed on Chapter 3, it is evident that the disadvantages of raising charges against hoarders outweigh advantages. Generally, it is recommended that hoarders are not charged for services related to clearing and repairing hoarded properties. It is recognised that there may be circumstances where agencies may clear hoarded properties more than once leading to high costs. However, it is recommended that occupants of hoarded properties be charged only after alternative options have failed and after careful consideration of the impact of costs on the hoarder.
- For legal action against hoarders to be considered only as a last resort. Some case study participants had experienced both enforcement action and support (sometimes from the same organisations). Enforcement action led to hoarders experiencing stress, loss of control and less willingness to engage with agencies. Also, enforcement action sometimes resulted in an increased likelihood of hoarding.

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Appendix 1: Liverpool Housing Trust Hoarding Self-Assessment Form

Complete this form at the start and end of your work with Outside The Box

THOUGHTS	NOT AT ALL ←————→ VERY MUCH
Do you focus on every part of an item and find unusual detail that others may not see?	0 1 2 3 4 5 6 7 8 9 10
Do you generate lots of ideas when thinking about the use of items?	0 1 2 3 4 5 6 7 8 9 10
Do you focus on the non-essential detail of items?	0 1 2 3 4 5 6 7 8 9 10
FEELINGS	NOT AT ALL ←————→ VERY MUCH
Do you feel distressed when you imagine discarding items that you feel might have a use?	0 1 2 3 4 5 6 7 8 9 10
Do you often desire an item even if you do not have sufficient space to accommodate the item?	0 1 2 3 4 5 6 7 8 9 10
Do you often feel a need to save items because they might be of use?	0 1 2 3 4 5 6 7 8 9 10
BEHAVIOURS	NOT AT ALL ←————→ VERY MUCH
Do you have difficulty discarding possessions regardless of value?	0 1 2 3 4 5 6 7 8 9 10
Do you have difficulty organising all your possessions?	0 1 2 3 4 5 6 7 8 9 10
Do you rely on visual cues to remember things?	0 1 2 3 4 5 6 7 8 9 10
Do you often have problems deciding what to do with an item?	0 1 2 3 4 5 6 7 8 9 10

Source: Liverpool Housing Trust 'Outside The Box'

Appendix 2: Liverpool Housing Trust Hoarding Disorder Impact Assessment Form

Name	
Address	
Referrer Name	
Agency/Contact	
Date of Assessment	
Please include any other relevant information	

Kitchen

Unable to prepare food	<input type="checkbox"/>	Unable to use oven/fridge	<input type="checkbox"/>	Unable to use sink	<input type="checkbox"/>
Presence of spoiled food	<input type="checkbox"/>	Presence of insects/pests	<input type="checkbox"/>	Bibs/rubbish overflow	<input type="checkbox"/>
Presence of mold	<input type="checkbox"/>	Presence of dampness	<input type="checkbox"/>	Unable to move safely	<input type="checkbox"/>
Unstable piles of items	<input type="checkbox"/>	Exits blocks/unusable	<input type="checkbox"/>		

Bathroom

Unable to use bath	<input type="checkbox"/>	Unable to use toilet	<input type="checkbox"/>	Unable to use sink	<input type="checkbox"/>
Presence of spoiled food	<input type="checkbox"/>	Presence of insects/pests	<input type="checkbox"/>	Bibs/rubbish overflow	<input type="checkbox"/>
Presence of mold	<input type="checkbox"/>	Presence of dampness	<input type="checkbox"/>	Unable to move safely	<input type="checkbox"/>
Unstable piles of items	<input type="checkbox"/>	Exits blocks/unusable	<input type="checkbox"/>		

Bedrooms

Unable to use bed	<input type="checkbox"/>	Presence of spoiled food	<input type="checkbox"/>	Presence of mold	<input type="checkbox"/>
Unstable piles of items	<input type="checkbox"/>	Presence of insects/pests	<input type="checkbox"/>	Bibs/rubbish overflow	<input type="checkbox"/>
Presence of dampness	<input type="checkbox"/>	Unable to move safely	<input type="checkbox"/>	Exits blocks/unusable	<input type="checkbox"/>

Source: Liverpool Housing Trust 'Outside The Box'

Appendix 3: Nottinghamshire County Council Hoarding Assessment Referral Form

MULTI AGENCY HOARDING ASSESSMENT REFERRAL FORM			
Referral Date		Referral Time	
Referrer: Agency: Contact address Email/telephone		Primary Agencies Referred to	For example. Police, Fire, ADC (Private Sector enforcement team), Mental Health team, Adult Social Care, District Nurse
Occupants Name		Occupants Address, telephone	
Age		Male/Female	
Ethnic Origin (please highlight or insert tick ✓)	White British Irish Turkish/Turkish Cypriot Gypsy/Traveller Other Chinese or other ethnic group Chinese Vietnamese	Mixed White and Black Caribbean White and Black African White and Asian Other Black or Black British Caribbean African	Asian or Asian British Indian Pakistani Bangladeshi Tamil No information Other

Please note all agencies you are aware of involved with this case at present	
Circumstances leading to hoarding alert	

Property information (excluding full address)			
Area			
Property type			
Tenure Council/Private/ Rented			
Disability or vulnerability None <input type="checkbox"/>	Mobility Wheelchair user Stick user short distance <input type="checkbox"/>	Impairment Hearing/Sight/Other <input type="checkbox"/>	Mental Health Dementia Limited Capacity/Any other diagnosis <input type="checkbox"/>
Any dependent children in the property			
Other supporting circumstances	<p>E.g. Are items limiting the free movement and/or entrance/exit to the property?</p> <p>Are items stacked in such a way that they are a risk to the occupier and visitors/emergency services?</p> <p>Is the occupier living in one room?</p> <p>Have there been complaints from Neighbours?</p>		
Notes:			

Clutter Rating

Please tick one of the Red, Amber or Green boxes to indicate the current level of risk.

Low Risk	<p>All Doors, Stairways and windows accessible</p> <p>No evidence of pests</p> <p>Clutter obstructs SOME functions of key living area – Looks untidy</p> <p>Safe Maintained sanitation conditions</p>
Medium Risk	<p>Blocking of Doors, some windows, possibly major exit</p> <p>Light infestation of pests (e.g. bed bugs, lice, fleas, rats)</p> <p>Clutter obstructing functions of key living space, stairs, entrances, hallways etc.</p> <p>Evidence of non-maintained sanitation conditions (e.g. food preparation surfaces heavily soiled, lots of dirty dishes, obvious odours which irritate etc.)</p> <p>Evidence of burns to the carpet , clothing etc.</p>
High Risk	<p>Whole rooms accessible, exits blocked, windows not able to be opened</p> <p>Utilities cut off (e.g. no heating, gas capped)</p> <p>Heavy infestation of pests (rats seen, heard, reported by neighbours, cockroaches fleas etc.)</p> <p>Key living spaces not available for use, person living in one room</p> <p>Evidence of urine/excrement in room, rotting food, very insanitary conditions</p> <p>Evidence of previous fire or burns in the carpet, clothing etc.</p>

Appendix 4: Nottinghamshire County Council Clutter Image Rating

Clutter Image Rating (CIR) – BEDROOM

Please select the CIR which closely relates to the amount of clutter



1

2

3



4

5

6



7

8

9

Clutter Image Rating (CIR) – LOUNGE

Please select the CIR which closely relates to the amount of clutter



1



2



3



4



5



6



7



8



9

Clutter Image Rating (CIR) – KITCHEN

Please select the CIR which closely relates to the amount of clutter



1

2

3



4

5

6



7

8

9

Appendix 5: Nottinghamshire County Council Hoarding Actions

Level One Actions

<p>Level 1 Clutter image rating 1 - 3</p>	<p>Household environment is considered standard. No specialised assistance is needed. If the resident would like some assistance with general housework or feels they are declining towards a higher clutter scale, appropriate referrals can be made subject to age and circumstances.</p>
<p>1. Property structure, services & garden area</p>	<ul style="list-style-type: none"> • All entrances and exits, stairways, roof space and windows accessible. • Smoke alarms fitted and functional or referrals made to Nottinghamshire Fire and Rescue Service to visit and install if criteria met. • All services functional and maintained in good working order. • Garden is accessible, tidy and maintained
<p>2. Household Functions</p>	<ul style="list-style-type: none"> • No excessive clutter, all rooms can be safely used for their intended purpose. • All rooms are rated 0-3 on the Clutter Rating Scale. • No additional unused household appliances appear in unusual locations around the property. • Property is maintained within terms of any lease or tenancy agreements where appropriate. • Property is not at risk of action by Environmental Health.
<p>3. Health and Safety</p>	<ul style="list-style-type: none"> • Property is clean with no odours, (pet or other). • No rotting food. • No concerning use of candles. • No concern over flies. • Residents managing personal care. • No writing on the walls. • Quantities of medication are within appropriate limits, in date and stored appropriately.
<p>4. Safeguard of Children & Family members</p>	<ul style="list-style-type: none"> • No concerns for household members.
<p>5. Animals and Pests</p>	<ul style="list-style-type: none"> • Any pets at the property are well cared for. • No pests or infestations at the property.

6. Personal Protective Equipment (PPE)

- | |
|--|
| <ul style="list-style-type: none">• No PPE required.• No visit in pairs required. |
|--|

Level One: Multi-Agency Actions

Level 1	Actions
Referring Agency	<ul style="list-style-type: none"> • Discuss concerns with the Individual. • Raise a request to Nottinghamshire Fire and Rescue Service for a Home Safety Check and to provide fire safety advice. • Refer to Social Care for a care and support assessment. • Refer to GP if appropriate.
Environmental Health	<ul style="list-style-type: none"> • No action.
Social Landlords	<ul style="list-style-type: none"> • Provide details on debt advice if appropriate to circumstances. • Refer to GP if appropriate. • Refer to Social Care for a care and support assessment if appropriate. • Provide details of support streams open to the resident via charities and self-help groups. • Ensure residents are maintaining all tenancy conditions. • Refer for tenancy support if appropriate. • Ensure that all utilities are maintained and serviceable.
Practitioners	<ul style="list-style-type: none"> • Complete Hoarding Assessment form. • Make appropriate referrals for support to other agencies. • Refer to social landlord if the client is their tenant or leaseholder.
Emergency Services	<ul style="list-style-type: none"> • Nottinghamshire Fire and Rescue Service- Carry out a Home Safety Check if it fulfils Service criteria and share with statutory agencies. • Nottinghamshire Police and East Midlands Ambulance Service- Ensure information is shared with statutory agencies & feedback is provided to referring agency on completion of home visits.
Animal Welfare	<ul style="list-style-type: none"> • No action unless advice requested.
Safeguarding of Adults and Children	<ul style="list-style-type: none"> • Properties with adults presenting care and support needs should be referred to the appropriate Social Care referral point.

Level Two Actions

Level 2 Clutter Image Rating 4 – 6	Household environment requires professional assistance to resolve the clutter and the maintenance issues in the property.
1. Property structure, services & garden area	<ul style="list-style-type: none"> • Only major exit is blocked. • Concern that services are not well maintained. • Smoke alarms are not installed or not functioning. • Garden is not accessible due to clutter, or is not maintained • Evidence of indoor items stored outside. • Evidence of light structural damage including damp. • Interior doors missing or blocked open.
2. Household Functions	<ul style="list-style-type: none"> • Clutter is causing congestion in the living spaces and is impacting on the use of the rooms for their intended purpose. • Clutter is causing congestion between the rooms and entrances. • Room(s) score between 4-5 on the clutter scale. • Inconsistent levels of housekeeping throughout the property. • Some household appliances are not functioning properly and there may be additional units in unusual places. • Property is not maintained within terms of lease or tenancy agreement where applicable. • Evidence of outdoor items being stored inside.
3. Health and Safety	<ul style="list-style-type: none"> • Kitchen and bathroom are difficult to utilise and access. • Offensive odour in the property. • Resident is not maintaining safe cooking environment. • Some concern with the quantity of medication, or its storage or expiry dates. • Has good fire safety awareness with little or no risk of ignition. • Resident trying to manage personal care but struggling. • No risk to the structure of the property.
4.Safeguard of Children & Family members	<ul style="list-style-type: none"> • Hoarding on clutter scale 4 -7. Consider a Safeguarding Assessment. • Properties with adults presenting care and support needs should be referred to the appropriate Social Care referral point. • Please note all additional concerns for householders.
6. Personal Protective Equipment (PPE)	<ul style="list-style-type: none"> • Latex Gloves, boots or needle stick safe shoes, face mask, hand sanitizer, insect repellent. • Is PPE required?

Level Two: Multi-Agency Actions

Level 2	Actions In addition to actions listed below these cases need to be monitored regularly in the future due to RISK OF ESCALATION or REOCURRENCE
Referring Agency	<ul style="list-style-type: none"> • Refer to landlord if resident is a tenant. • Refer to Environmental Health if resident is a freeholder. • Raise a request to the Fire and Rescue Service to provide a home Safety Check with a consideration for monitored smoke alarms/ assistive technology. • Provide details of garden services. • Refer to Social Care for a care and support assessment. • Referral to GP. • Referral to debt advice if appropriate. • Refer to animal welfare if there are animals at the property. • Ensure information sharing with all necessary statutory agencies.
Environmental Health	<ul style="list-style-type: none"> • Carry out an inspection of the property utilising the referral form. • At the time of inspection, Environmental Health Officer decides on appropriate course of action. • Consider serving notices under Environmental Protection Act 1990, Prevention of Damage by Pests Act 1949 or Housing Act 2004. • Consider Works in Default if notices not complied by occupier.
Social Landlord	<ul style="list-style-type: none"> • Visit resident to inspect the property & assess support needs. • Refer internally to assist in the restoration of services to the property where appropriate. • Ensure residents are maintaining all tenancy conditions. • Enforce tenancy conditions relating to residents' responsibilities. • Ensure information sharing with all necessary statutory agencies.
Practitioners	<ul style="list-style-type: none"> • Carry out an assessment of the property utilising the referral form. • Ensure information sharing with all agencies involved to ensure a collaborative approach and a sustainable resolution.
Emergency Services	<ul style="list-style-type: none"> • Nottinghamshire Fire and Rescue Service Carry out a Home Safety Check, share risk information with Statutory agencies and consider assistive technology. • Nottinghamshire Police and East Midlands Ambulance Service Ensure information is shared with statutory agencies & feedback is provided to referring agency on completion of home visits via the referral form.

Animal Welfare	<ul style="list-style-type: none">• Visit property to undertake a wellbeing check on animals at the property.• Educate client regarding animal welfare if appropriate.• Provide advice / assistance with re-homing animals.
Safeguarding Adults and Children	<ul style="list-style-type: none">• Properties with adults presenting care and support needs should be referred to the appropriate Social Care referral point.

Level Three Actions

<p>Level 3 Clutter image rating 7 - 9</p>	<p>Household environment will require intervention with a collaborative multi-agency approach with the involvement from a wide range of professionals. This level of hoarding constitutes a Safeguarding alert due to the significant risk to health of the householders, surrounding properties and residents. Residents are often unaware of the implication of their hoarding actions and oblivious to the risk it poses.</p>
<p>1. Property structure, services & garden area</p>	<ul style="list-style-type: none"> • Limited access to the property due to extreme clutter. • Extreme clutter may be seen at windows. • Extreme clutter may be seen outside the property. • Garden not accessible and extensively overgrown. • Services not connected or not functioning properly. • Smoke alarms not fitted or not functioning. • Property lacks ventilation due to clutter • Evidence of structural damage or outstanding repairs including damp. • Interior doors missing or blocked open. • Evidence of indoor items stored outside.
<p>2. Household Functions</p>	<ul style="list-style-type: none"> • Clutter is obstructing the living spaces and is preventing the use of the rooms for their intended purpose. • Room(s) scores 7 - 9 on the clutter image scale. Rooms are not used for intended purposes or very limited. • Beds inaccessible or unusable due to clutter or infestation. • Entrances, hallways and stairs blocked or difficult to pass. • Toilets, sinks not functioning or not in use. • Resident at risk due to living environment. • Household appliances are not functioning or inaccessible. • Resident has no safe cooking environment. • Resident is using candles. • Evidence of outdoor clutter being stored indoors. • No evidence of housekeeping being undertaken. • Broken household items not discarded e.g. broken glass or plates. • Property is not maintained within terms of lease or tenancy agreement where applicable. • Property is at risk of notice being served by Environmental Health.

<p>3. Health and Safety</p>	<ul style="list-style-type: none"> • Human urine and excrement may be present. • Excessive odour in the property may also be evident from the outside. • Rotting food may be present. • Evidence may be seen of unclean, unused and or buried plates & dishes. • Broken household items not discarded e.g. broken glass or plates. • Inappropriate quantities or storage of medication. • Pungent odour can be smelt inside the property and possibly from outside. • Concern with the integrity of the electrics. • Inappropriate use of electrical extension cords or evidence of unqualified work to the electrics. • Concern for declining mental health.
<p>4. Safeguard of Children & Family members</p>	<ul style="list-style-type: none"> • Properties with adults presenting care and support needs should be referred to the appropriate Social Care referral point. • Please note all additional concerns for householders.
<p>5. Animals and Pests</p>	<ul style="list-style-type: none"> • Animals at the property at risk due the level of clutter in the property. • Resident may not able to control the animals at the property. • Animals' living area is not maintained and smells. • Animals appear to be under nourished or over fed. • Hoarding of animals at the property. • Heavy insect infestation (bed bugs, lice, fleas, cockroaches, ants, silverfish, etc.). • Visible rodent infestation.
<p>6. Personal Protective Equipment (PPE)</p>	<ul style="list-style-type: none"> • Latex Gloves, boots or needle stick safe shoes, face mask, hand sanitizer, insect repellent. • Visit in pairs required.

Level Three: Multi-Agency Actions

Actions	Level 3
Referring Agency	<ul style="list-style-type: none"> • Raise Safeguarding Alert within 24 hours if there are care and support needs. • If the individual does not meet the Safeguarding thresholds for a referral, consider contacting Social Care regarding possible care and support needs assessment. • Raise a request to Nottinghamshire Fire and Rescue Service within 24 hours to provide a Home Safety Check. • Refer to Environmental Health via the referral form.
Environmental Health	<ul style="list-style-type: none"> • Carry out an inspection. • At time of inspection, EHO decides on appropriate course of action. • Consider serving notices under Environmental Protection Act 1990, Prevention of Damage by Pests Act 1949 or Housing Act 2004.
Landlord	<ul style="list-style-type: none"> • Visit resident to inspect the property & assess support needs. • Attend multi agency hoarding meeting or VPP/PPP. • Enforce tenancy conditions relating to residents responsibilities.
Practitioners	<ul style="list-style-type: none"> • Refer to “Hoarding Guidance Questions for practitioners”. • Complete Practitioners Assessment Tool. • Ensure information sharing with all agencies involved to ensure a collaborative approach and a sustainable resolution.
	<ul style="list-style-type: none"> • Nottinghamshire Fire and Rescue Service- Carry out a Home Safety Check, share risk information with Statutory agencies and consider assistive technology. • Nottinghamshire Police and East Midlands Ambulance Service- Ensure information is shared with statutory agencies & feedback is provided to referring agency on completion of home visits via the referral form. • Attend hoarding multi agency meetings/VPP/PPP on request. • Ensure information sharing with all agencies involved to ensure a collaborative approach and a sustainable resolution. • Provide feedback to referring agency on completion of home
Animal Welfare	<ul style="list-style-type: none"> • Visit property to undertake a wellbeing check on animals at the property. • Remove animals to a safe environment. • Educate client regarding animal welfare if appropriate. • Take legal action for animal cruelty if appropriate. • Provide advice / assistance with re-homing animals.

Appendix 6: Liverpool Housing Trust (LHT) 'My Acquiring Rules' form

If you're having difficulties not acquiring items that you see, it can be helpful to ask yourself some questions to slowdown your thoughts to enable you to make a balanced decision.

Ask yourselves the questions below and then tick the ones you think will work best for you. Once you have done this you can create your own Acquiring Rules.


➤ How many do I already have of this item and is that enough?		➤ Do I have enough time to use this item?	
➤ Do I have a specific plan to use this item within a timeframe?		➤ Does this fit in with my own values and goals?	
➤ Do I have an immediate use for this?		➤ Does this just seem important because I'm looking at right now?	
➤ Is it of good quality/accurate or reliable?		➤ Do I really need it?	
➤ If I don't get this now could I get it in the future if I really need it?		➤ Do I have enough space for this?	
➤ Will not having this help me overcome my clutter problem?		➤ Can I get by without it?	
➤ Do I want it taking up space in my home?		➤ What are the advantages and disadvantages of getting this?	
➤ Would I die without this item?		➤ Would my safety be jeopardised without it?	
➤ Do I really need this item or would it just be convenient to have?		➤ Do I already own something similar?	
➤ Am I only thinking about getting this because I feel bad right now?		➤ In a week will I regret not getting this item?	
➤ Do I have a specific place to put this item?		➤ Is it good quality?	
➤ If it needs fixing do I have time to fix it?		➤ Is this a want or need?	

Source: Liverpool Housing Trust 'Outside The Box'


Appendix 7: Liverpool Housing Trust (LHT) 'My Boxed Off Pledge' form

MY BOXED OFF PLEDGE


MY BOXED OFF PLEDGES ARE:

- To reduce the amount of items I acquire
- To keep my home clean and tidy 

I WILL DO THIS BY:

- Use my Acquiring Rules when required
- Keeping to my Housekeeping Plan 

WHAT I'VE LEARNED:

- ✓ I am able to live my life without all the possessions that I had
- ✓ I feel better when my home has less clutter in it
- ✓ My Acquiring Rules works well for me 

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