

# Islington Hoarding Protocol

*Supporting individuals with hoarding disorder or who display hoarding related behaviours*



**JOINT WORKING PROTOCOL**

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# 1 Summary

- 1.1 Hoarding disorder is the acquisition of, and inability to discard, items even though they appear (to others) to have no value. 2-5% of the population are thought to be either suffering from hoarding disorder or manifest hoarding behaviours.
- 1.2 Hoarding disorder has been a recognised mental disorder in its own right since May 2013 in the USA and recognition is anticipated in the UK in 2017.
- 1.3 The most commonly hoarded items are old clothes, magazines, CDs/video tapes, letters, pens, old notes, bills, newspapers, receipts, cardboard boxes, pins, clothing rags, old medication, bodily products (hair, nails, faeces etc), used nappies, rotten food, animals (dead and alive), wool or fabric.
- 1.4 There is no one cause for hoarding, but research suggests that it is thought that its origins can begin in childhood but tend to most severely interfere with the individual's life in their mid-30s and then worsen as they get older.
- 1.5 Refusal by hoarders to engage with professionals or other intervention poses a challenge to progress.
- 1.6 Severe cases usually require the involvement of several agencies (including the fire service, mental health services, adult social care, housing providers and environmental health services).
- 1.7 The Protocol establishes the Islington Hoarding Panel as a multi-agency forum for professionals and agencies dealing with hoarding cases within the borough to discuss and jointly find ways to resolve difficult cases.
- 1.8 The Panel will normally only accept cases where the hoarding is severe and an agency has reached an impasse in its efforts to resolve the situation with the individual involved.
- 1.9 The protocol recommends the use of a clutter image rating scale and a hoarding assessment tool to provide an initial assessment of a hoarding issue.
- 1.10 A referral to the London Fire Brigade is essential in severe cases or where there are flammable, hazardous, electrical or other unusual risk items.
- 1.11 The protocol gives information on how three key assessments (mental health assessment, mental capacity assessment and needs assessment) can be considered for the individual concerned.
- 1.12 The protocol outlines options available under the law including the Mental Capacity Act 2005, the Mental Health Act 1983, the Environmental Protection Act 1996, the Court of Protection and Inherent Jurisdiction.

## 2 Contacts

### Help with hoarding for yourself or someone else

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#### Islington Council's Access and Advice Service



020 7527 2299  
Minicom: 020 7527 6475



[access.service@islington.gov.uk](mailto:access.service@islington.gov.uk)



222 Upper Street, London, N1 1XR

Islington wants to support and advise anyone who is concerned or just wants some advice about hoarding. You can contact us even if:

- You just want to speak with somebody about yourself or someone you may be worried about, or
- You want to speak with someone about hoarding or
- You want some help or support with your behaviour which appears hoarding-related, or

The Access and Advice Team will put you in touch with somebody who will listen and assist you.

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### For organisations and agencies wishing to make a referral to the Islington Hoarding Panel

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[helpwithhoarding@islington.gov.uk](mailto:helpwithhoarding@islington.gov.uk)

It is essential that you read section 9 below for guidance before making a referral to the Hoarding Panel.

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### 3 Acknowledgements

Thanks and appreciation to the following who participated in discussions and / or contributed to this protocol:

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## 4 Introduction

- 4.1 2-5% of the population are thought to be either suffering from hoarding disorder or manifest hoarding behaviours. Dealing with them effectively and providing appropriate care and support to this significant section of the population by addressing the cause rather than the effects of hoarding, will have wide ranging effects for sufferers and professionals alike. Hoarding disorder has begun to be recognised as a mental disorder in its own right meaning that the potential options available for treatment have been significantly extended.
- 4.2 Avenues to the Court of Protection have been opened up as hoarding disorder may now be considered an impairment in or disturbance of the functioning of the mind or brain for the purpose of the Mental Capacity Act 2005, as amended. So too can it be a condition for which the Mental Health Act 1983 may apply (as amended) as it also fits the definition of “mental disorder” within this Act.
- 4.3 Housing providers often face the problem of dealing with hoarding in isolation. Other agencies such as the fire brigade and environmental health can become involved but a lack of coordination between the different organisations can mean that actions are much less effective than they could be. Housing providers do not need to deal with this issue in isolation, core services like adult social care, mental health and health services should be involved, particularly as hoarding is a safeguarding matter.
- 4.4 Quite often, the potential sufferer themselves will not self-refer; most referrals have been noted to come from concerned families, neighbours, housing services or associations, fire services and/or the police.

## 5 Purpose and Scope of the Protocol

- 5.1 This protocol is for all professionals and agencies working within the borough of Islington including those in the health, mental health, housing, social care, fire, police and environmental health services. It is intended to assist them to plan, coordinate, assess, diagnose and treat adults who display symptoms of hoarding disorder or hoarding-related behaviours.
- 5.2 Together with its partners, Islington Council has commissioned a strategy to place hoarding high on its Health and Well-Being Agenda and Joint Strategic Needs Assessment. There is a commitment to enable practitioners across the board to adopt a multi-agency approach to hoarding so that cases can progress towards an effective outcome.
- 5.3 This Protocol is not intended to be considered or act as a replacement for any of the statutory procedures relating to the functions of the Safeguarding Adults Board where a safeguarding alert is triggered in accordance with Sections 42 to 47 and Section 68 of the Care Act 2014 and Chapter 14 of the Care and Support Statutory Guidance. It is also not intended to displace any duties or responsibilities towards children who may be found in or potentially suffering from or involved with hoarding disorder or the effects of hoarding-related behaviours which may be more appropriately progressed under the Children Act 1989 and other relevant legislation.
- 5.4 The Hoarding Panel is intended to act under the auspices of the Islington Safeguarding Adults Partnership Board, as a multi-agency forum within which hoarding cases or issues may be progressed.

## 6 Aims of the protocol

### 6.1 This protocol aims to:

- a. Fulfil the local authority's collective responsibility towards all adults in the community who may or do suffer from this condition or display hoarding behaviours;
- b. Generate awareness of how to respond to hoarding;
- c. Support individuals and their advocates
- d. Provide a support network for agencies dealing with hoarding cases and enable sharing of best practice;
- e. Provide guidance on how to deal with hoarding and those who may display hoarding-related behaviours;
- f. Demonstrate and implement appropriate compliance with the statutory duties of cooperation and integration regarding adults who may have needs for care and support outlined within the Care Act 2014;
- g. Provide working tools for assessment, information gathering and processes relating to dealing with hoarding disorder;
- h. Clear a pathway to a more effective and appropriate treatment and/or care and support plan for sufferers;
- i. Improve the effectiveness of integrated working between those involved to the benefit of the individual concerned, other residents and the different services involved;
- j. Avoid 'satellites' of information held by separate services and agencies.



## 7 Core Values

7.1 Islington's core values to support, work with, assess and treat people who display hoarding related behaviours and/or who have hoarding disorder are:

<b>NON-JUDGMENTAL</b>	<ul style="list-style-type: none"><li>• No judgments are made about anyone who may display hoarding related behaviours / have hoarding disorder</li></ul>
<b>HERE TO SUPPORT YOU</b>	<ul style="list-style-type: none"><li>• We focus on support and not stigma</li></ul>
<b>UNDERSTANDING AND WELCOMING</b>	<ul style="list-style-type: none"><li>• There is no shame in asking for advice or support. If you do have a collection of items which you want support to manage, we would not just immediately take it away</li></ul>
<b>INDEPENDENCE</b>	<ul style="list-style-type: none"><li>• We would support the individual to live their life as independently and safely as possible</li></ul>
<b>SAFEGUARDING</b>	<ul style="list-style-type: none"><li>• Safeguarding and protecting adults who may be vulnerable or require support is our duty and priority</li></ul>
<b>YOU AT THE CENTRE</b>	<ul style="list-style-type: none"><li>• The individual and/or their advocate remain at the centre of support planning and assessment</li></ul>
<b>WORKING EFFECTIVELY WITH YOU</b>	<ul style="list-style-type: none"><li>• The individual should be supported by professionals who are trained on hoarding related behaviours so they are best able to work with individuals</li></ul>

## 8 What Is Hoarding Disorder?

- 8.1 Hoarding disorder is defined as the acquisition of, and inability to discard, items even though they appear (to others) to have no value.
- 8.2 It is more than mere collectionism which is considered a widespread and benign activity.
- 8.3 Hoarding disorder has been a recognised mental disorder in its own right since May 2013 when it was included in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The DSM-5 defines "mental disorder" as:

*"A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behaviour (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above."*

- 8.4 However DSM-5 is not universally recognised. In Britain the International Classification of Diseases (ICD-10) is the accepted classification but it does not yet contain a definition of hoarding disorder in its own right. It is expected that hoarding disorder will be included in ICD-11 which is due to be published in 2017.
- 8.5 This does not mean that practitioners cannot rely on DSM-5 or indeed use existing ICD-10 classifications and codes in the interim. During this gap before ICD-11 will be issued, persons who display hoarding related behaviours and/or hoarding disorder will continue to exist and/or present. Practitioners have options under current alternative sources in the UK to deal with this if they chose not to recognise or follow the DSM-5 – this is because many of the DSM-5 diagnostic criteria for hoarding disorder are actually recognised or have their equivalents in ICD-10. Practitioners must read Appendix A of this protocol where the status and relationship between DSM-5 and ICD-10 equivalents is explained, allowing an interim solution if practitioners want to await ICD-11 rather than rely on the current DSM-5.

### Case study

AB is a 64 year old Islington resident. Her landlord received complaints from neighbours about the smell coming from her property. The landlord tried to contact her but after several failed attempts they served a notice on her to vacate the property.

The landlord also made a referral to the SHP floating support service in the hope that they could give support to her to address the hoarding and any other difficulties she might have.

SHP arranged a multi-agency meeting with mental health services, social services and the landlord to discuss the best way forward to support AB. They agreed that, with AB's consent, they would make a referral for her to move to sheltered accommodation.

AB was assessed and accepted to move into Sheltered Accommodation. The support helped AB to look at her belongings and start the process of removing unnecessary items from her property while she prepares for the move.

As a result of the multi-agency approach AB avoided becoming homeless and the condition of her property and the impact this was having on her neighbours were resolved.

## DSM-5 Definition and Diagnostic Criteria

- 8.6 The diagnostic criteria set down in the DSM-5 are a useful starting point for assessing hoarding disorder. The diagnostic criteria<sup>1</sup> can be summarised as:
- a. A persistent difficulty discarding or parting with personal possessions, regardless of their actual value.
  - b. The difficulty is due to a **perceived need to save the items** and **distress associated with discarding them**.
  - c. The symptoms result in the **accumulation** of large numbers of possessions that congest and **clutter active living areas** and substantially compromise their **intended use**. If all living areas are uncluttered it is only because of the intervention of third parties (eg family members, cleaners, authorities).
  - d. The symptoms cause **clinically significant distress or impairment** in social, occupational or other important areas of functioning (including maintaining a safe environment for self and others).
  - e. The hoarding symptoms are **not due to another medical condition**. (Eg brain injury, cerebrovascular disease, Prader-Willi Syndrome).

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<sup>1</sup> Professor David Mataix-Cols, Lecture on Hoarding January 2013

- f. The hoarding is **not better accounted for by the symptoms of another DSM-5 disorder** (eg hoarding due to OCD, decreased energy in Major Depressive Disorder, delusions in Schizophrenia or another Psychotic Disorder, Cognitive deficits in Dementia, restricted interests in Autism Spectrum Disorder).
- 8.7 Hoarding disorder is not the same as Diogenes syndrome which is a behavioural disorder of the elderly, features of which include extreme self-neglect, domestic squalor, and tendency to hoard excessively (sylllogomania). This is associated with self-imposed isolation, refusal of help, and a marked indifference or lack of awareness. Diogenes syndrome has been referred to as senile breakdown, social breakdown, senile squalor syndrome, and messy house syndrome.
- 8.8 Hoarding disorder has made its way out of the shadow of its former umbrella “Obsessive Compulsive Disorder” (“OCD”) category because research found that those who suffered from hoarding disorder or displayed hoarding behaviours did not respond to OCD treatments. By comparison, OCD is an anxiety disorder characterised by intrusive thoughts that produce uneasiness, apprehension, fear, worry. The repetitive behaviours employed are aimed at reducing the anxiety or by a combination of such obsessions and compulsions.
- 8.9 This means the difference between OCD and hoarding disorder may be described as follows:
- OCD:** There is an anxiety – the act (usually a repetitive action) is done – the effect is to reduce the anxiety. The emphasis is on **reduction** of a feeling.
- Hoarding Disorder:** There is a value placed on an item/items – the act (usually accumulation/acquisitional) is done – the effect is that the items become indiscardable. The emphasis is on **increasing** accumulation or items.

## Causes and Symptoms

- 8.10 In many cases, the symptoms will be quite obvious, in terms of clutter, excessive items in the property or even spilling onto gardens or public areas, non-engagement, referrals from other agencies, for example environmental health, fire services and/or local authority housing management or housing associations.
- 8.11 The most commonly hoarded items are old clothes, magazines, CDs/video tapes, letters, pens, old notes, bills, newspapers, receipts, cardboard boxes, pins, clothing rags, old medication, bodily products (hair, nails, faeces etc), used nappies, rotten food, animals (dead and alive), wool or fabric, but there are a host of other items. Reasons given for hoarding demonstrate a perceived need or intrinsic value attributed by the hoarder (eg “I may need it someday”), to emotional value (“I feel safe around my possessions”), to identification with those possessions (“I feel the object is part of me.”)

- 8.12 There is no one cause for hoarding, but research suggests that it is thought that its origins can begin in childhood but tend to most severely interfere with the individual's life in their mid-30s and then worsen as they get older. Hoarders may harbour distorted beliefs in the importance of their possessions or their responsibilities towards them, with excessive emotional attachment. They may also demonstrate or suffer from information processing deficits such as indecisiveness, perfectionism, procrastination and/or disorganisation.
- 8.13 Sufferers may be unable to cope with distress and thereby avoid it by accumulating clutter and end up disabled because of it.
- 8.14 It is not uncommon for there to have been a **triggering traumatic** event in the hoarder's life after which point they started hoarding, such as bereavement, a loss or some personal trauma experienced.
- 8.15 Refusal by hoarders to engage with professionals or other intervention poses a challenge to progress. Good professional practice would explore all remaining avenues for the individual to engage. This is because being met with a "shut door" is in the nature of the disorder or hoarding behaviour. It is worth remembering that non-engagement is not exclusive to those suffering from hoarding disorder. It should be treated within the same practical, professional and legal framework as someone who suffers from any other condition or disorder (for example, Alzheimer's disease, schizophrenia etc).
- 8.16 **Blitz Cleans:** one of the most popular responses to hoarding is to perform a "blitz clean" – the clearing out all or most of the offending items. Blitz cleans often feature repeatedly in the individual's case notes or history. Whilst there may sometimes be a need for a blitz clean to deal with environmental health or fire safety concerns it more often only serves the person or agency that is concerned or complaining about the hoarding rather than offering a long-term solution for the hoarding sufferer. Blitz cleans are likely to significantly distress the hoarder and is a costly action to take. It does not address the cause of the hoarding behaviour and may exacerbate their symptoms. Without a longer-term solution such as hoarding specific CBT and/or other professional intervention the individual could well resume their hoarding activities.

## Not Just a Clinical Issue

- 8.17 People who display hoarding behaviours or who suffer from hoarding disorder are not just the responsibility or concern of the clinical profession.
- 8.18 **Housing Providers:** Very often the clinician will be at the end of the list of professionals who have become aware of someone exhibiting hoarding behaviour. Housing providers (including the local authority and housing associations) are often the first to receive complaints or concerns and will often face a clash of responsibilities between their tenants and seeking to ensure that a potentially vulnerable adult receives appropriate care and support.
- 8.19 Without appropriate intervention and support by relevant agencies housing providers' only other option will be to initiate proceedings in the county court for possession of the property, an access injunction or other action to assert

their rights as landlords under housing or antisocial behaviour legislation. This could see an individual involved in legal proceedings when it may not be the most effective route for their personal progression through their manifesting condition.

- 8.20 **Mental Health Services:** those who display hoarding behaviours or who suffer from hoarding disorder are more likely to be dealt with by Mental Health Services if hoarding disorder is a recognised mental illness. This service will often be the key liaison and conduit between the social services and clinicians involved with the individual concerned. It is essential for mental health professionals to be properly equipped and trained to identify, assess and plan treatment for those displaying hoarding behaviours and/or those who do suffer from hoarding disorder.

## Basic Treatment Options

- 8.21 These include motivational interviewing, intense cognitive behavioural therapy and skills training and other cognitive restructuring techniques.
- 8.22 London Borough of Islington is working with its partners in the CCGs, NHS and Health related sectors to work towards offering a treatment scheme within the borough of Islington accessible to all.

## 9 The Islington Hoarding Panel

- 9.1 This Protocol establishes the Islington Hoarding Panel as a forum for professionals and agencies dealing with hoarding cases within the borough to discuss and jointly find ways to resolve those cases.
- 9.2 The Panel's role is to:
- a. review the circumstances of cases and the actions taken so far
  - b. challenge and advise on the options available
  - c. help the relevant organisations to coordinate and complete their actions
  - d. remove barriers to cooperation
  - e. signpost to agencies or organisations that could contribute
- 9.3 The Panel is available to all organisations and agencies within Islington that are signatories to this protocol. Individuals wanting advice or assistance with hoarding issues should contact the council's Access and Advice Service.
- 9.4 The Panel will normally only accept cases for discussion in the following circumstances:
- a. Where the hoarding is graded at 5 or above on the hoarding clutter image rating scale (**Appendix A**) and:
  - b. The presenting organisation has attempted to follow the guidance in this protocol (see section 10) but has been unable to resolve the situation, or
  - c. The presenting organisation has been unable to gain the cooperation of other organisations to take action, or
  - d. The presenting organisation has good reason to believe that there is severe hoarding (5 or greater on the hoarding clutter scale) but has been unable to gain access to the property or engage with the person involved despite persistent attempts and needs the assistance of other agencies.
- 9.5 The Panel may recommend a course of action to progress a particular case or problem. It has no decision-making powers to direct organisations or Council departments to take or desist from a course action, but it acts as this protocol's mechanism to manage and progress hoarding cases and maintain good practice standards. Organisations who wish to depart from recommendations of the Panel should be able to provide written reasons to the Panel and for their own records.
- 9.6 The Panel has no financial budget and is not able to provide or direct resources either from within the Council or from other organisations.
- 9.7 The Panel members are named representatives from the Council and other organisations. The following services will normally be represented at all Panel meetings:

- Adult Social Care\*
- Mental Health Service\*
- The landlord service
- London Fire Brigade
- A service user

\* *These services must be present at all Panel meetings at least by telephone.*

9.8 The following services are expected to attend when requested by the Panel coordinator:

- Children's Services<sup>2</sup>
- Environmental Health
- Floating support service
- Metropolitan police
- Health services
- RSPCA (where animals are, may be or have been involved)
- Any other relevant or involved service, individual or organisation

9.9 The Council's adult social care service will coordinate Panel meetings including:

- receiving requests for cases to be considered
- deciding which cases are considered (with feedback to the requesting organisation)
- requesting attendance from relevant organisations
- requesting information for the Panel from organisations
- arranging meetings of the Panel
- keep a note of proceedings of the Panel

9.10 The Panel will nominate a case lead for each case it considers. The case lead will normally be the representative of the organisation that requested the Panel hearing unless it is more effective or appropriate to nominate another agreed case lead.

9.11 The case lead will take responsibility for putting the recommendations of the Panel into effect and ensuring the cooperation of the other services. The case lead may refer the case back to the Panel for further discussion if the circumstances of the case have substantially changed, an impasse has been reached or they have been unable to secure the cooperation of other services.

9.12 The Panel will meet every six weeks or less often depending on its case load or any intervening urgent matters requiring an earlier meeting.

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<sup>2</sup> where the potential hoarding involves and/or poses a risk to a child or where a parallel referral to Children's Services has been made



## Referrals to the Hoarding Panel

- 9.13 Organisations should email requests for a hearing by the Hoarding Panel to [helpwithhoarding@islington.gov.uk](mailto:helpwithhoarding@islington.gov.uk).

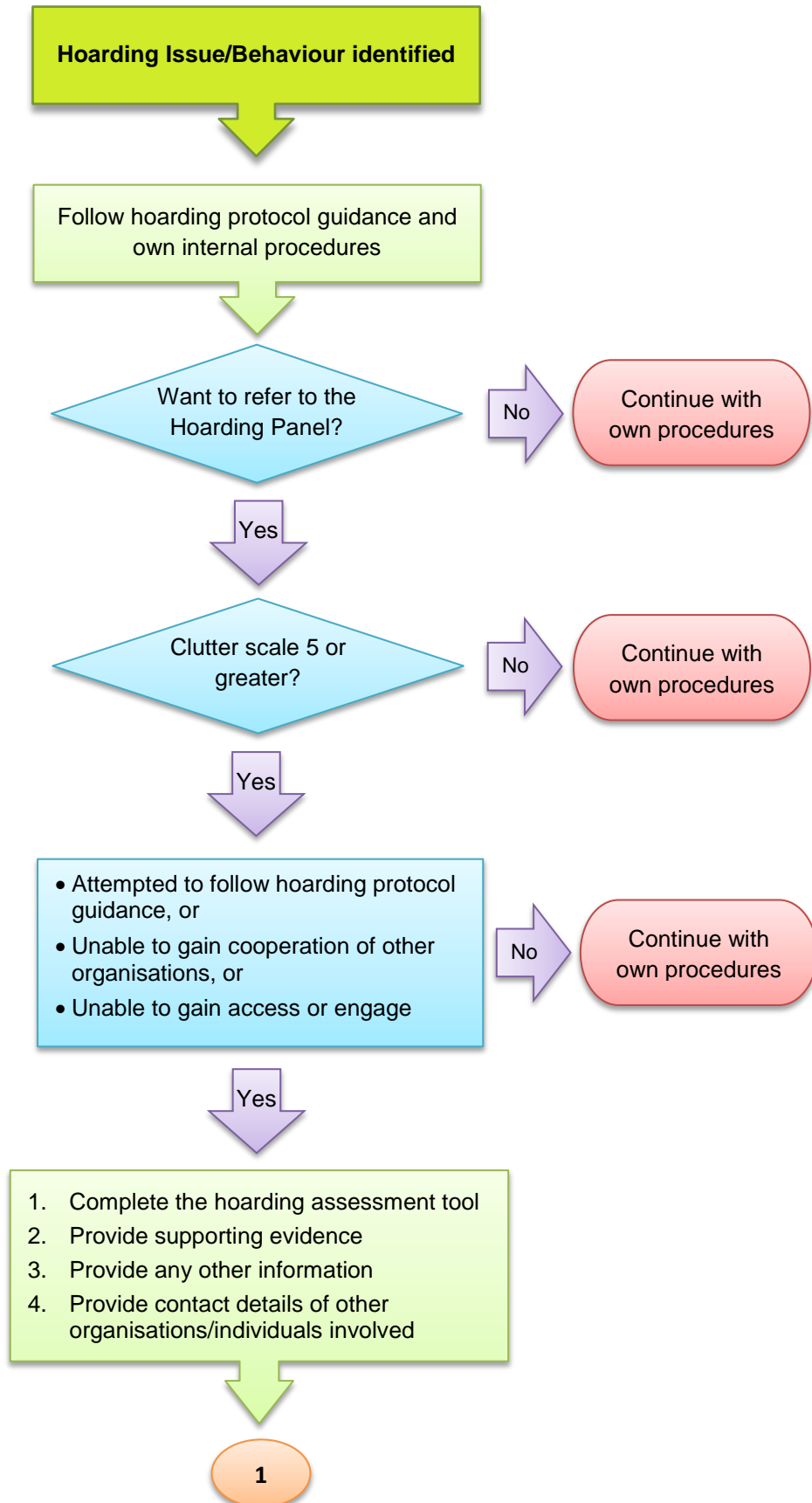
Requests must be accompanied by:

- a completed Clutter Image Rating Scale (see Appendix A);
- a completed hoarding assessment tool (see Appendix B);
- Photographs of the property/clutter where available;
- evidence supporting one or more of the criteria b), c) and d) in 9.4 above. In the case of 9.4 b), evidence should include referral to London Fire Brigade, consideration of vulnerability, contacts with next of kin, involvement of other support services, safeguarding, tenancy conditions enforcement, antisocial behaviour enforcement, clearing and cleaning work undertaken;
- any other relevant information held by the organisation;
- contact details for all other organisations and individuals who are or have been involved in the case.

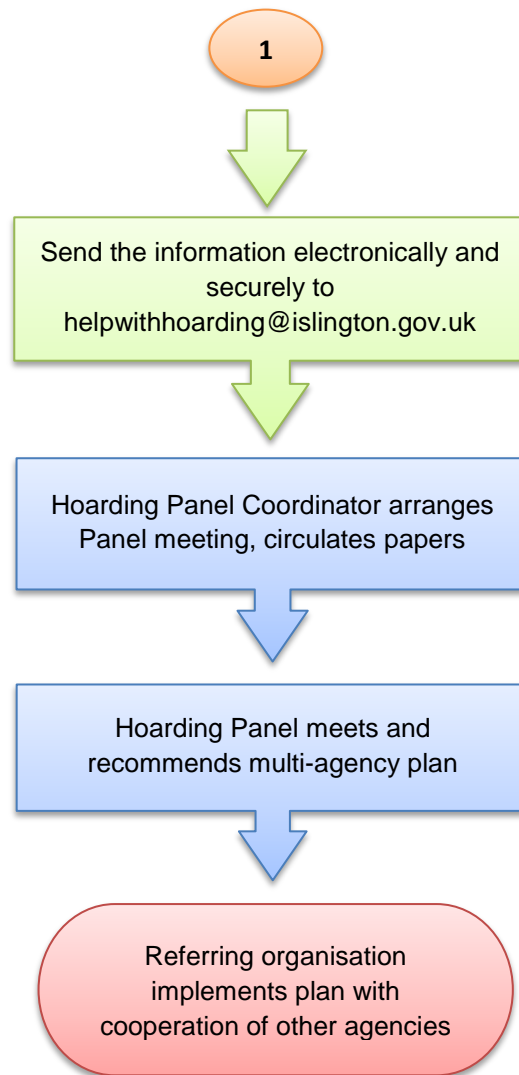
All information must be sent electronically and securely in accordance with this Protocol's information sharing agreement (Appendix A).

- 9.14 Reference to the Hoarding Panel does not mean that immediate procedures to minimise risks to individuals are delayed – referrals to the London Fire Brigade must be made in cases where hoarding is rated at 5 or above on the Clutter Rating Image Scale (Appendix A) or where it is under 5 but there are flammable, hazardous, electrical or other unusual risk items.
- 9.15 Where you are concerned about the potential safety of or risk posed by hoarding related behaviours to a child, you must make a parallel referral to Children's Social Services in case child protection measures need to be implemented. You should notify Children's Services whether or not you have also made a parallel referral to the Hoarding Panel. You should also notify the Hoarding Panel if you have made a referral to Children's Services as it may well be that the Panel will want a representative from Children's Services to attend any relevant meeting.

## Hoarding Panel referrals



## Islington Hoarding Protocol



## 10 Guidelines for handling hoarding cases

- 10.1 Firstly establish whether the person does appear to be displaying hoarding related behaviours or suffering from hoarding disorder and that they are not just exercising their right to collect items or express different lifestyles and habits. Some things to look for:
- Are rooms in their property (bathroom, toilet, bedroom, kitchen) not used or unusable for the purposes to which they have been designed, because of an excess of clutter?
  - Can appliances and furniture (cooker, fridge, settee, chairs etc) be used?
  - Are they unable to freely open their front or back door?
  - Are all plug sockets and pipes hidden from view or trapped in by possessions?
  - Are rooms packed with items to such an extent that it could pose a fire, health or safety hazard?
  - Is their mobility around the property or otherwise limited by the amount of items?
  - Do the items pose any environmental or other health and safety related obstacle/issue?
- 10.2 Assess the level of the hoarding by using the CIRS (clutter image rating scale) for each room. See Appendix A.
- 10.3 Then complete the hoarding assessment tool. See Appendix B.
- 10.4 Bear in mind that there is a very low legal threshold requiring when a local authority has a duty to conduct a Needs Assessment where it appears that they may have needs for care and support. The duty is more likely to be triggered in such circumstances and social services would need to be notified so they can commence a Needs Assessment under the Care Act 2014.

### Referral to London Fire Brigade

- 10.5 Make a referral to LFB for an urgent home fire safety visit to be carried out. The report that they produce will determine whether there are any immediate dangers relating to the hoarding that may need to be addressed.
- 10.6 Referral to the London Fire Brigade must be made immediately in cases where hoarding is rated at 5 or above on the Clutter Rating Image Scale (Appendix A) or where it is less than 5 but there are flammable, hazardous, electrical or other unusual risk items.

### **Case study**

Peggy is 79 and has lived in London since the late 1960s. Degree educated, she became street homeless and also lived in hostels before being housed by Islington Council. Peggy kept to herself, rarely interacting with anyone in the community, until a local outreach team began calling on her in 2012.

Peggy has hoarding tendencies. Her flat was filthy and crammed to head-height with old newspapers and magazines, which were rotting with mould, as well as with items she had found in the street and at car-boot sales. As well as this being a fire hazard (Peggy is a heavy smoker) the mould quickly spread, destroying clothes, furniture, personal items and food (her fridge was also broken).

One day, a large stack of newspapers collapsed on top of Peggy. It took a whole morning for her support worker and a volunteer to clear just the living room; and the exercise had to be repeated a few months later.

Peggy needed a great deal of help. Her flat had roof leaks and though only one tap worked with a small trickle of cold water she hadn't asked for repairs. She wasn't registered with a doctor and hadn't seen a GP in 40 years. Personal hygiene and mobility were poor and she was found to be suffering from diabetes. Through a consistent dialogue with her support worker about her hoarding Peggy was able to improve her perspective about caring for her home and keeping it clean and clear of debris.

Eventually she was found more suitable accommodation and moved with the help of volunteers in 2014. It has taken two years of intensive support but now she is happy in her new home, she has medical care and she is managing to keep her hoarding tendencies under control.

## **Resident is vulnerable**

- 10.7 Take advice from Social Services or other agencies as appropriate. In cases where the tenant is elderly or vulnerable in some way, Social Services or some other agency needs to be involved in trying to remedy the initial problem and, if possible, prevent its reoccurrence.
- 10.8 Particular note needs to be made if there are or appear to be children involved in the property, with the hoarding related behaviours and where the potential hoarding poses or may pose a risk to a child – in such cases, immediately refer to Children's Social Care or the Emergency Duty Team. It is more likely that any protection or assistance provided or considered for the child will be performed under the Children Act 1989 and relevant Child Protection Measures / Guidance.

## Support agencies

- 10.9 See support agencies at section 14 for additional help and support that may be available.

## Contact Next of kin

- 10.10 In some cases members of the resident's family or friends may also be able to provide help or support – often family members or concerned third parties will approach services for assistance to work with an individual. Be mindful of the need for obtaining the individual's consent where appropriate.

## Information gathering

- 10.11 At the beginning of the process, gather as much information as possible. Remember confidentiality when speaking to neighbours/friends/family. Staff should not disclose any unnecessary information or information about the lifestyle of the hoarder.

## Safeguarding considerations

- 10.12 If children reside in the affected household, Children's Service must be contacted for advice as above.
- 10.13 Where there is a concern that the individual or another adult within the household is either vulnerable, rendered vulnerable or affected to the extent there is cause to suspect they experience or risk abuse or neglect, the Adult Safeguarding procedures need to be followed and you should contact Adult Social Care Services immediately notifying them of a potential adult safeguarding matter.

## Tenancy conditions enforcement

- 10.14 Consider whether the problem can be resolved purely by taking steps to ensure that the resident complies with their conditions of tenancy or lease or whether the resident needs some assistance to try to deal with the hoarding behaviours in issue (for example because they are elderly or appear to be vulnerable).
- 10.15 It may be possible to obtain an injunction to remedy and prevent further incidents of hoarding but in the most extreme cases, where all other ways of resolving the problem have failed it may be necessary to commence possession proceedings.

- 10.16 Possession proceedings are unlikely to be helpful where a person does display hoarding related behaviours because:
- there are likely to be mental capacity issues which may impact their ability to understand or participate in proceedings, or
  - the individual may be breaching their tenancy because of a potential mental illness rather than for cooperation reasons.
- 10.17 The result would be counter-productive as it may lead to just “moving the problem around” as opposed to resolving the issue. Relying on strict contractual or tenancy rights should only be considered once this protocol has been exhausted and there are no capacity issues relating to the individual.

### **Antisocial behaviour enforcement**

- 10.18 It is possible, if complaints have been received from neighbouring properties that the hoarding-related behaviours could be classed as antisocial behaviour, in which case proceedings can be brought against an individual in this manner. A thorough assessment as to whether the individual manifesting the hoarding-related behaviour is vulnerable should be made before any action is considered. Persons demonstrating hoarder-related behaviours or who suffer from hoarding disorder are likely to consider that their behaviour is not problematic or irrational, so it may be counter-productive to argue the case with them on the basis of what is normal, rational or acceptable. However, it may be possible to lead the person to understand that their hoarding is having a detrimental effect on others.

### **Arranging for the removal of hoarded material**

- 10.19 This section needs to be read in conjunction with paragraph 8.16 (Blitz Cleans) above. In cases where the resident is not vulnerable and the only reason for mass accumulation of items is because the resident concerned has not made proper arrangements to dispose of large amounts of material or an accumulation of bulky items, you should aim to come to an agreement with the resident concerned to dispose of the items and prevent a repeat of the activity.
- 10.20 Consider staggered time frames for clearance; i.e. over a period of 6 or 12 months, agreeing a small area to be cleared each month and re-visiting to ensure compliance.
- 10.21 In all cases you should carry out a health and safety risk assessment of the property and consider employing specialist contractors where appropriate.

## Cleaning the property

- 10.22 This section is also to be read in conjunction with paragraph 8.16 (Blitz Cleans) above. It may be appropriate for a 'special cleanse' of the property to be arranged. Again, consider a staggered cleanse if possible.
- 10.23 A "one-off" cleanse or the removal of a couple of bulky items will not offer a solution to the potential or actual hoarding problem, either because of the nature of the hoarding related behaviours, the need for a more general clean-up of the property or the continued vulnerability of the resident concerned. In these cases it will be necessary to seek assistance from other sources. This may be a formal request for Social Services or using Environmental Services or a referral to the Hoarding Panel.

## Pest Control Services

- 10.24 You may encounter situations where, in addition to the hoarding, there are infestation problems such as cockroaches, ants, bed bugs, beetles, mice or wasps. The council's pest control service provides a chargeable service to council tenants and offers advice to other Islington residents. However in hoarding cases, to ensure that infestations are dealt with promptly and that preventative action is taken immediately to prevent further infestation, the charge to individual tenants may be waived.
- 10.25 Where the individual dwelling infestation is of fleas, this problem is deemed to be the responsibility of the tenant or leaseholder. If the council's pest control service undertakes the works the normal practice would be to recover the cost direct from the occupier. However, the service can use its discretion about whether to recharge the resident concerned in cases of hardship or vulnerability. It may also be advisable to carry out treatment to prevent other people from being infested.
- 10.26 The council's pest control services may be contacted at:
- Public Protection Division, Islington Council, 222 Upper Street,  
London N1 1XR  
Tel: 020 7527 3190 Fax: 020 7527 3210  
Email: pest.control@islington.gov.uk

## Referring to the Hoarding Panel

- 10.27 In cases where the hoarding is severe (5 or above on the clutter scale, see Appendix A), the individual will not come to an agreement to deal with the hoarding and all reasonable measures have failed then consider a referral to the Hoarding Panel. Remember to show evidence that you have complied with each section of this best practice guideline where appropriate before referring to the Hoarding panel.



10.28 The hoarding panel will agree a strategy to try to address the hoarding problem and to give advice to the referrer to reduce the reoccurrence of the problem. This may involve Social Services putting in place a care package which could involve regular practical help in the home which, apart from providing practical assistance to the resident concerned, could also help to ensure that hoarding does not reoccur.

## 11 Needs, mental health and mental capacity assessment

- 11.1 The term “hoarding assessment” can comprise many types of assessments or assessment tools. It does not presume the person being assessed either has hoarding disorder or that they display hoarding related behaviours. For the purpose of this protocol a “hoarding assessment” may be an umbrella term which will in practice comprise:



- 11.2 Each of the three assessments works with a particular aspect of the individual, without which the picture is likely to be incomplete and potentially prevent an opportunity to provide support, advice, treatment or care. There are also legal obligations to provide advice and information and to contribute to preventing and/or delaying needs for care and support arising, which may be compromised without the above complete approach when assessing someone who may display hoarding related behaviours. See **Appendix A** for more information and for practitioner-based guidance.
- 11.3 The hoarding assessment tools at Appendix A and Appendix B do not replace the need to conduct the above trio of assessments – this is because the tools are hoarding-specific and the three assessments above are not. The tools are aimed at assisting a wider assessment of needs / mental health and are not statutory, whereas the needs, mental health and mental capacity assessments are statutory.

## 12 Options under the law



- 12.1 There are a number of different options open to the Panel to consider, each governed by different types of laws. For example there are possibilities to serve the best interests of the individual under the Mental Capacity Act 2005, the Mental Health Act 1983 or The Environmental Protection Act 1996 to name a few. The Panel or the Case Lead can always take legal advice before making this decision if they want to.
- 12.2 Once the decision is made and it is discussed with the individual if it can be, and/or their advocate if the individual has one, then the regular procedures which usually attach to that option will apply. These will include
- The Court of Protection where mental capacity is an issue;
  - Inherent Jurisdiction where a person may have capacity but are influenced by someone else to the extent that they do not have the freedom to make their own decisions.
  - Options under the Mental Health Act 1983 including orders for assessment, treatment and hospitalisation;
  - Environmental health law.
- 12.3 See Appendix A for further information and further practitioner-based guidance.

## 13 Care and clinical treatment

- 13.1 Care and clinical treatment includes motivational interviewing, intense cognitive behavioural therapy and skills training and other cognitive restructuring techniques.
- 13.2 Islington Council is working with its partners in the CCGs, NHS and Health related sectors to work towards offering a treatment scheme within the borough of Islington accessible to all.

### Safeguarding

- 13.3 The law about safeguarding vulnerable adults has now been given a statutory footing by the Care Act 2014, which now requires local authorities to establish a Safeguarding Adults Board (“SAB”) to protect adults in their areas where they have reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there):
  - a. Has needs for care and support (whether or not the authority is meeting those needs);
  - b. Is experiencing, or is at risk of, abuse or neglect, and
  - c. As a result of those needs is unable to protect him/herself against the abuse or neglect or the risk of it.
- 13.4 Local authorities have a duty to make or cause to be made whatever enquiries they think necessary to enable the local authority to decide whether any action should be taken in the adult’s case, and if so by whom. Greater detail about these procedures and requirements can be found in Chapter 14 of the *Care and Support Statutory Guidance* which replaced the “No Secrets” Guidance on Adult Safeguarding on 01 April 2015.
- 13.5 The SAB also has a statutory duty to conduct a Safeguarding Adults Review (“SAR”) where:
  - a. There is reasonable concern about how the SAB, its members or other members with relevant functions worked together to safeguarding the adult; AND
  - b. Condition 1 or 2 is met:
    - Condition 1:** The adult has died, and the SAB knows or suspects the death arose from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died);
    - Condition 2:** The adult is still alive, and the SAB knows or suspects that the adult has experienced serious abuse or neglect.
- 13.6 This protocol and the Hoarding Panel are not intended to replace the functions of the SAB or Safeguarding duties in general. Islington’s safeguarding

processes are paramount to the Panel. This protocol is not an alternative to proceeding with any necessary or appropriate safeguarding processes or duties outlined in the Care Act 2014 and the *Care and Support Statutory Guidance*. This protocol is intended to facilitate and enable more effective cooperation between relevant agencies at the initial stages of identifying, assessing, planning for, supporting and treating those who display hoarding related behaviours and/or are diagnosed with hoarding disorder.

- 13.7 The current definition of “abuse and neglect” in Chapter 14 of the *Care and Support Statutory Guidance* includes self-neglect. This category specifically refers to examples of self-neglect as including “behaviour such as hoarding.” A person or professional may raise a safeguarding referral at any time. Where no such referral has been made, the Panel may and should make a safeguarding referral on such cases where it has been decided that a safeguarding enquiry needs to be made or continue. The Panel should assist and cooperate with safeguarding processes.
- 13.8 Similarly, the duties for a SAB intervention or SAR arise when either the adult has died or not died but experienced serious abuse or neglect as defined by the Care Act 2014 and the Chapter 14 *Care and Support Statutory Guidance*. Where these circumstances do not apply, this Protocol remains operative and its emergency procedures may be invoked if necessary, save where there is knowledge or suspicion of abuse or neglect.
- 13.9 The functions of the Panel are subservient to the SAB but can of course assist and inform it as an important information gathering and issue-specific sub-committee where a SAR and/or SAB intervention may be triggered.

## Clinical Treatment Options

- 13.10 There is no known cure for hoarding disorder presently. The focus is therefore more on managing the symptoms through appropriate and hoarding-specific therapies.
- 13.11 Hoarding disorder can be diagnosed as a stand-alone condition (i.e. it is the primary condition from which the individual suffers), or it can manifest as a symptom of another primary and/or underlying condition (for example dementia, schizophrenia, Prader-Willi Syndrome, OCD.. etc).
- 13.12 Treatment for sufferers of hoarding disorder or those displaying hoarding behaviours should be hoarding specific, though there may be occasions where if hoarding is diagnosed or manifest but is a symptom of a different primary condition, then it is likely that effective treatment of the primary condition may well impact the hoarding symptoms. For example:
- a) Person A suffers from schizophrenia. This manifests in symptoms of paranoia and hoarding. The essential root cause of the hoarding in this case is the schizophrenia; therefore effective treatment of the schizophrenia is likely to reduce the paranoia and hoarding symptoms. This correlates with one of the elements of the DSM-5 diagnostic criteria for diagnosis of hoarding disorder, namely that there should be no better explanation for the hoarding.

13.13 When hoarding disorder is diagnosed as a stand-alone condition, it should receive a hoarding-specific treatment plan.

13.14 New psychological treatments for hoarding include:

- a. Motivational Interviewing
- b. Skills training (organising, decision-making, problem solving)
- c. Exposure to sorting, discarding and not acquiring
- d. Cognitive restructure
- e. Hoarding-specific CBT for long-term benefit
- f. Intensive – 25 sessions, skilled therapists, home visits

## 14 Useful Contacts

### 14.1 Services in Islington

#### **Links for Living**

<http://linksforliving.islington.gov.uk/kb5/islington/asch/home.page>

A comprehensive and up-to-date directory of organisations working in Islington. Links for Living signposts to organisations providing information and advice on health and wellbeing, support and care needs.

#### **Adult social care**

[www.islington.gov.uk/services/social-care-health/Pages/default.aspx](http://www.islington.gov.uk/services/social-care-health/Pages/default.aspx)

Information and advice about Islington adult social care services

#### **Adult mental health**

[www.candi.nhs.uk/our-services](http://www.candi.nhs.uk/our-services)

Information on mental health services

#### **Islington's family directory:**

[directory.islington.gov.uk/kb5/islington/directory/family.page](http://directory.islington.gov.uk/kb5/islington/directory/family.page)

Information for parents and carers, children and young people and the practitioners working with them.

#### **Every Voice**

[www.everyvoice.org.uk](http://www.everyvoice.org.uk)

Championing the voices of BME people and organisations

#### **Islington Refugee Forum**

[www.islingtonrefugeeforum.org](http://www.islingtonrefugeeforum.org)

#### **Islington Faith Forum**

[www.islingtonfaithsforum.org.uk](http://www.islingtonfaithsforum.org.uk)

### 14.2 General information and advice about hoarding

#### **Information and advice about hoarding**

[www.helpforhoarders.co.uk](http://www.helpforhoarders.co.uk)

[www.hoardinguk.org](http://www.hoardinguk.org)

[www.compulsive-hoarding.org](http://www.compulsive-hoarding.org)

#### **NHS information and advice on treatment**

[www.nhs.uk/Conditions/hoarding/Pages/introduction.aspx](http://www.nhs.uk/Conditions/hoarding/Pages/introduction.aspx)

**South London and Maudsley (SLAM) Centre for Anxiety Disorders and Trauma**

<http://www.national.slam.nhs.uk/services/adult-services/cadat/>

**National Institute for Clinical Excellence**

<http://www.nice.org.uk/guidance/cg31>

**Royal College of Psychiatrists**

[www.rcpsych.ac.uk/healthadvice/problemsdisorders/hoarding.aspx](http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/hoarding.aspx)

**Professional practice note of the Chartered Institute of Environmental Health**

[www.cieh.org/uploadedfiles/core/policy/publications\\_and\\_information\\_service/s/policy\\_publications/publications/hoarding\\_ppn\\_may09.pdf](http://www.cieh.org/uploadedfiles/core/policy/publications_and_information_service/s/policy_publications/publications/hoarding_ppn_may09.pdf)

**American Psychiatric Association**

[www.psychiatry.org/hoarding-disorder](http://www.psychiatry.org/hoarding-disorder)

**International OCD Foundation Hoarding Center**

<http://hoarding.iocdf.org/>



## 15 Glossary

<b>Diogenes Syndrome</b>	This is a behavioural disorder of the elderly featuring extreme self-neglect, domestic squalor, and a tendency to hoard excessively (sylllogomania). This is associated with self-imposed isolation, refusal of help, and a marked indifference or lack of awareness. It can also be known as senile breakdown, social breakdown, senile squalor syndrome and messy house syndrome.
<b>Hoarder</b>	A word that describes somebody who suffers from hoarding disorder
<b>Hoarding Assessment</b>	The combination of a Needs Assessment, Mental Capacity Assessment and a Mental Health Assessment
<b>Hoarding Assessment Tool</b>	Those documents in Appendices A and B
<b>Hoarding Behaviours</b>	These are persons who are not yet or not diagnosed with Hoarding Disorder, but who display a range of characteristics, symptoms and/or behaviours associated with hoarding disorder or, or who appears to hoard items.
<b>Hoarding Disorder</b>	The acquisition of, and inability to discard, items even though they appear (to others) to have no value
<b>Mandatory Representatives</b>	Those service representatives who must form part of the Panel enquiring into a referral
<b>Obsessive Compulsive Disorder</b>	An anxiety disorder characterised by intrusive thoughts that produce uneasiness, apprehension, fear, worry – by repetitive behaviours aimed at reducing the anxiety or by a combination of such obsessions and compulsions.
<b>Preferred Representatives</b>	Those service representatives who may form part of the Panel enquiring into a referral

## 16 Acronyms

APA	American Psychiatrists Association
CIRS	Clutter Image Rating Scale
COP	Court of Protection
DSM-5 or DSM-V	Diagnostic and Statistical Manual of Mental Disorders
HD	Hoarding Disorder
HIPAA	Health Insurance Portability and Accountability Act
HRS	Hoarding Rating Scale
ICD	International Classification of Diseases
MCA	Mental Capacity Act 2005
MHA	Mental Health Act 1983
OCD	Obsessive Compulsive Disorder
SAB	Safeguarding Adults Board (statutory body established under the Care Act 2014)
SIR	Structure Inventory (Revised)
WHO	World Health Organisation

# Appendix A. Clutter Image Rating Scale

## Clutter Image Rating Scale – Kitchen



1



2



3



4



5



6



7



8



9

### Clutter Image Rating Scale - Bedroom



1



2



3



4



5



6



7



8



9

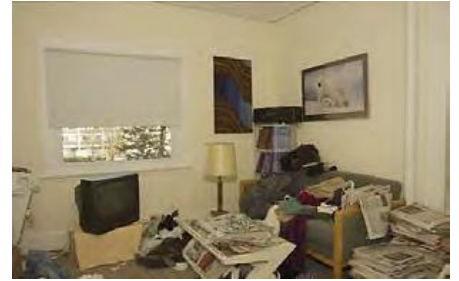
### Clutter Image Rating Scale – Living Room



1



2



3



4



5



6



7



8



9

Source: Frost RO, Steketee G 2006a, *Compulsive Hoarding and Acquiring: Therapist Guide*. New York. Oxford University Press. The Clutter Image Rating (CIR) Tool, p. 188. Used with permission of Oxford University Press, USA.

## **Appendix B. Hoarding Assessment Tool**

Islington Hoarding Assessment Tool	
Date of assessment	
Assessed by	Organisation and department

Client	
Name	Age
Consent Obtained <input type="checkbox"/> Not Obtained <input type="checkbox"/>	Reason if consent is not obtained
Address	Telephone
Other residents	

Property details	
Occupation status Owner <input type="checkbox"/> Tenant <input type="checkbox"/>	Landlord organisation
Landlord contact name	Landlord contact details
Flat <input type="checkbox"/> Maisonette <input type="checkbox"/> House <input type="checkbox"/> Sheltered accommodation <input type="checkbox"/> Other:	
On what floor is the front door?	On what floor is the bathroom?
On what floor is the toilet?	How many steps to the front door?
How many steps in the property?	How many rooms (excluding kitchen and bathroom)?

<b>Islington Hoarding Assessment Tool</b>		
<b>Hoarding</b>		
Brief description of the problem		
What is the client's attitude to the hoarding?		
Will she / he allow access?		
<b>Clutter index rating scale (1 to 9)</b>		
Kitchen	Living Room	Bathroom
Bedroom 1	Bedroom 2	Bedroom 3
Other rooms		

<b>Fixtures and appliances</b>							
<i>Please indicate whether the following are in working order.</i>							
	Yes	No	Unknown		Yes	No	Unknown
Stove/Oven				Fridge/Freezer			
Kitchen sink				Bathroom sink			
Washer/Dryer				Toilet			
Electricity				Water heater			
Boiler/Heating				Shower/Tub			



<b>Islington Hoarding Assessment Tool</b>				
<b>Living conditions</b>				
	None	Some	Severe	Comments
Structural damage to house				
Rotten food in house				
Insect or rodent infestation in house				
Large number of animals in house				
Animal waste in house				
Clutter outside of the house				
Cleanliness of the house				
Other (e.g. human faeces)				

<b>Safety</b>				
	Not at all	Some	Very much	Description
Does any part of the house pose a fire hazard? (e.g. unsafe electrical cords, flammable object next to heat sources like boiler, radiator, stove)				
How difficult would it be for emergency personnel to move equipment through the home?				
Are the exits from the home blocked?				
Are any of the stairwells unsafe?				
Is there a danger of falling due to the clutter?				

<b>Islington Hoarding Assessment Tool</b>					
<b>Daily living</b>					
<i>Please indicate the extent to which clutter interferes with the ability of the client to do each of the following activities</i>					
	N/A	Can do	Can do with difficulty	Unable to do	Comments
Prepare food (cut up food, cook it)					
Use refrigerator					
Use stove					
Use kitchen sink					
Eat at table					
Move around inside the house					
Exit home quickly					
Use toilet (getting to the toilet)					
Use bath/shower					
Use bathroom sink					
Answer door quickly					
Sit in your sofas and chairs					
Sleep in your bed					
Clean the house					
Do laundry					
Find important things (e.g. bills)					
Care for animals					

<b>Islington Hoarding Assessment Tool</b>	
<b>Preliminary client assessment</b>	
Mental health issues	
Dementia	
Mental capacity	
Frail /elderly	
Disability	
Other factors	
Family and other social support	
Financial situation, ability/willingness to pay for services	

<b>Hoarding interview</b>			
1. Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?			
Not at all	Mildly	Moderately	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. To what extent do you have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?			
No difficulty	Mil	Moderate	Extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford?			
No problem	Mild problem	Moderate problem	Severe problem
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Islington Hoarding Assessment Tool</b>			
4. To what extent do you experience distress because of clutter, difficulty discarding or problems with buying or acquiring things?			
No distress	Mild distress	Moderate distress	Severe distress
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. To what extent does the clutter, problems discarding, or problems with buying or acquiring things impair or interfere with your life (daily routine, job/school, social activities, family activities, financial difficulties)?			
Not at all	Mildly	Moderately	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Initial hoarding severity rating</b>			
None	Mild	Moderate	Severe
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Other agencies to be involved</b>
<b>Conclusions / recommendations</b>

## Appendix C. Needs, Mental Health and Mental Capacity Assessment

### 1 Needs Assessment

- 1.1 Where it appears to a local authority that an adult may have need for care and support, the law says that a local authority has a duty to assess whether that adult has needs for care and support and if so what those needs are. This type of assessment is focused on assessing what the person's needs for care and support in general may be, rather than seeking to establish whether they have hoarding disorder.
- 1.2 A needs assessment must be conducted under the Care Act 2014, the relevant Care and Support Regulations and the Care and Support Statutory Guidance. You must also follow this legislation's requirements in terms of involving independent advocates where appropriate and also assess any carers and/or young carers who may be involved with the individual concerned. A needs assessment may also be conducted in combination with a Mental Health Assessment where it is appropriate and possible to do so in accordance with Part 1 of the Care Act 2014 and the Care and Support Statutory Guidance.
- 1.3 The Care Act 2014 also requires that where it appears to a local authority that an individual may have substantial difficulty in understanding, retaining, weighing/using or communication information **relating to their involvement with the assessment process**, an independent advocate must be appointed unless there is an appropriate alternative person available to facilitate and support the individual's involvement in the assessment process (and they are not paid to provide care/treatment or do so as voluntary work).
- 1.4 Where hoarding is suspected, the needs assessment should aim to gather the following information:
  - Photographs of the collected items and rooms
  - A rating against the Clutter Image Rating Scale (see Appendix A)
  - Records held by any relevant agency or professional service
  - Reports made by neighbours, family members and/or other third parties
  - Police reports / interventions
  - RSPCA reports / interventions
  - Fire services reports / interventions
  - Past assessments conducted by social services, mental health and/or any clinicians

- Additional assessments needed, for example by environmental health or the fire brigade
- Case notes from other services such as housing, tenancy management, council services and external agencies.

## 2 Mental Health Assessment

- 2.1 What the Needs Assessment and Mental Capacity Assessments cannot do is clinically diagnose hoarding disorder or any other clinical condition, even though they often assist in building a detailed picture of what a person's needs and/or symptoms may be. A mental health assessment completes the trilogy of assessments recommended as comprising a "hoarding assessment" and will often be the gateway to a treatment and/or therapeutic pathway for the individual, if they need it.
- 2.2 Mental Health Assessments need to be compliant with the Mental Health Act 1983 (as amended) and the Mental Health Act Code of Practice (the latest version of this Code was published in April 2015). Hoarding Disorder is ultimately a recognised mental disorder and will require assessment by the relevant Mental Health Team for final diagnosis and can take place either with the Needs Assessment or separately. The Social Services assessments will be invaluable to gathering evidence and information which will then serve to assist the Mental Health Assessment. If a mental health assessment is not possible to complete or there is the possibility of delay, reasons must be provided as to why and this must be considered by the Panel.
- 2.3 While these assessments will comprise the assessment process to be undertaken when dealing with anyone referred for or discovered to be displaying hoarding related behaviours, the approach to the individual concerned should be pitched from the point of view of the component part assessments. This is likely to encourage better engagement from the individual concerned and be less potentially stigmatising for the service user. The assessment process procedure outlined below will be commissioned and timetabled by the Hoarding Information Panel's Case Lead.

## 3 Mental Capacity Assessment

- 3.1 Being able to make decisions about one's life is central to personal autonomy. If someone is displaying hoarding related behaviours and it is affecting them or someone else or there are concerns about how best to support the individual, the person's ability to make decisions related to those concerns and/or any items accumulated needs to be documented and assessed even though there is a legal presumption that everyone has capacity unless assessed otherwise. Your mental capacity assessment must be compliant with the Mental Capacity

Act 2005 (as amended) and the Mental Capacity Act 2005 Code of Practice (Chapters 2, 3 and 4). The decision to be assessed will usually be:

**“Does the person lack capacity to make decisions about cleaning / organising their property / accommodation?”**

- 3.2 Although it may appear circular to assess such capacity where there may be no formal diagnosis of hoarding disorder which may serve as the prerequisite impairment of or disturbance in the functioning of the mind or brain, you are likely to already have sufficient evidence of hoarding related behaviours which you should reference in your assessment.
- 3.3 You should consider whether an IMCA needs to be involved and whether or not there are other decisions which require the individual's capacity to also be assessed.

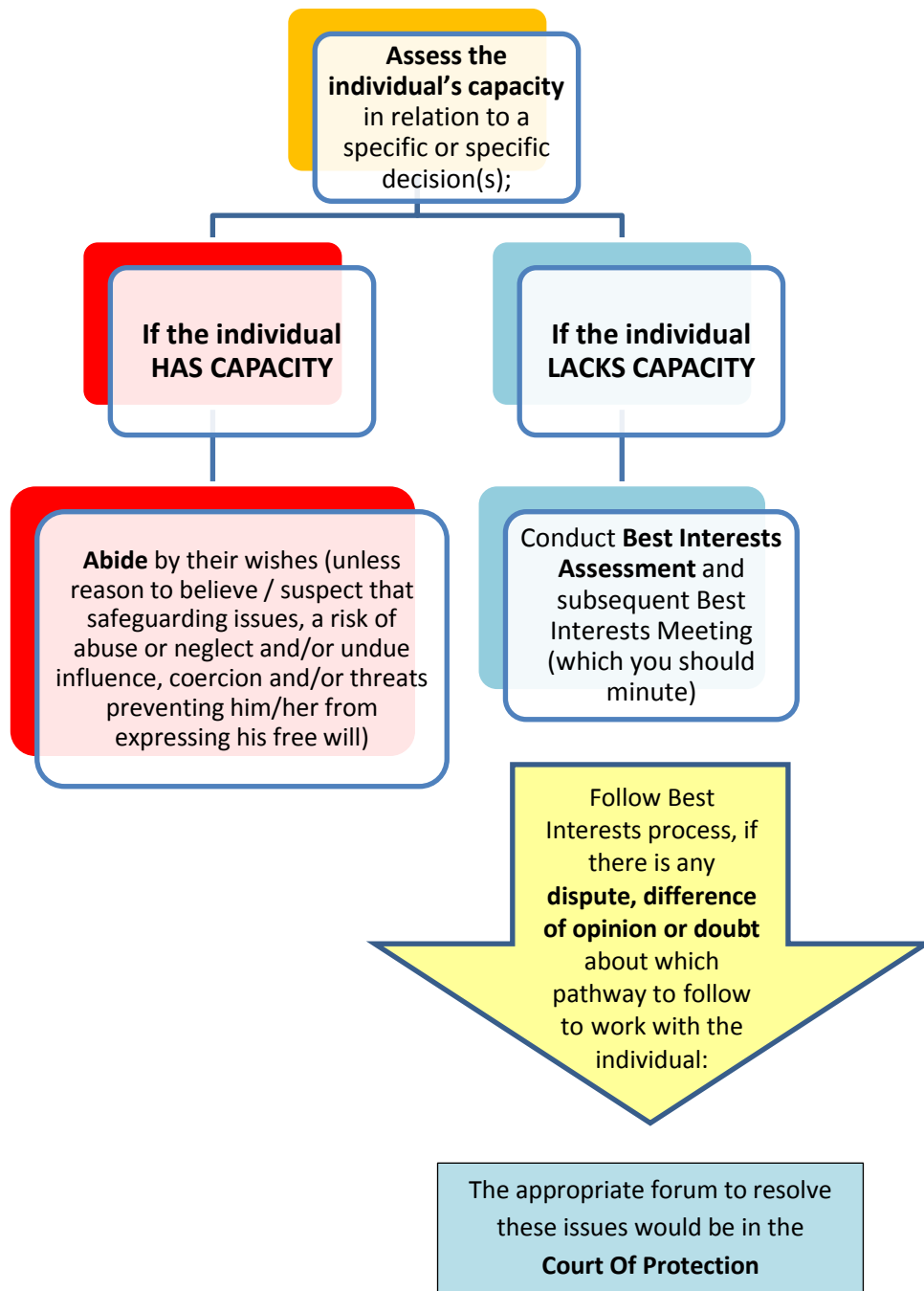
## Appendix D. Options under the law

### 1 The Court of Protection

- 1.1 The Court of Protection is a superior court created by the Mental Capacity Act 2005 to hear and make decisions about persons who lack mental capacity to make a specific decision. The law's starting point is that everybody is presumed to have mental capacity unless a properly conducted mental capacity assessment concludes otherwise. A person is allowed to make unwise decisions – an unwise decision does not mean the person lacks capacity. The legal procedure and expectations of what a mental capacity assessment should contain are set out in Sections 2 and 3 of the Mental Capacity Act 2005 and Chapters 2, 3 and 4 of the Mental Capacity Act 2005 Code of Practice (“the Code”).
- 1.2 The reason the Court of Protection is a potential option when dealing with persons who either have been diagnosed with hoarding disorder or persons who display hoarding related behaviours, is because Sections 2 of the Mental Capacity Act 2005 defines persons who lacks capacity as someone who
- “if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or disturbance in the functioning of, the mind or brain.”*
- 1.3 Hoarding Disorder is a clinically recognised mental disorder / illness to which this Act can apply. As capacity is decision, time and place specific, assessments on the particular decision at the material time must be conducted, so that the Court has the most recent evidence of capacity. Even if you are not advancing to Court, you should always work from as current a capacity assessment as possible. Older assessments on other decisions will not be considered as assisting establishing capacity in relation to the particular decision in question now.



1.4 The general sequence of events when dealing with assessing capacity is:



1.5 To lodge an application at the **Court of Protection** you as the practitioner will need to complete the following forms:

- a. **Form COP3** Assessment of Capacity (to which you can append any/all evidence of capacity gathered to date on the decision in question).

You can find this form at the following link:

<http://hmctsformfinder.justice.gov.uk/courtfinder/forms/cop003-eng.pdf>

- b. **Form COP24** Witness Statement (to which you can append any relevant evidence to support the application)

You can find this form at the following link:

<http://hmctsformfinder.justice.gov.uk/courtfinder/forms/cop024-eng.pdf>

Your legal representative will most likely advise and assist you to complete the other essential forms involved in making an application to the Court of Protection (for example the COP1 “Application Form” and the COP2 “Permission Form”), unless you are completing those yourself.

- 1.6 If you have to attend Court and/or there is a hearing, the Court of Protection can only decide between the range of potential options for the individual who lacks capacity which are put before it and will not introduce new options to the process. This is why your Best Interests Assessment should present as wide a range of options ranging from the least restrictive to the most even. You should include potential options even if some may appear obvious and/or not to be pursued – everything must be considered and weighed up in the “balance sheet” exercise.
- 1.7 The Court will then make a decision and may make directions, depending on what the Court is being asked to consider and grant. You should take legal advice when considering the Court of Protection as an option so your application can have the best chance of being put forward clearly and with advice.
- 1.8 Very often in hoarding cases, the specific decision to be made will be:
  - a. “Does P lack capacity to make decisions in relation to cleaning / tidying their accommodation?” or
  - b. “Does P lack capacity to make decisions about their care and welfare?”This is not an exhaustive list, however if you want to approach the Court of Protection because you think someone cannot make a decision because they display hoarding related behaviours and/or are diagnosed with hoarding disorder, then capacity to make the first decision in “a” above will often be the primary decision needing to be assessed.
- 1.9 Usually at the beginning of your capacity assessment there will be a space or opportunity for you to describe the impairment of or disturbance in the functioning of the mind or brain relating to the individual. According to the legislation and guidance, if there is no impairment/disturbance in the functioning of the mind or brain, then there are no grounds to assess whether capacity is lacking under the Mental Capacity Act 2005.
- 1.10 Though there may be no official diagnosis made of hoarding disorder or a hoarding related condition, you should still be able to complete your capacity assessment. In a similar way to someone who has not yet been diagnosed with

dementia or Alzheimer's disease, for example, yet displays those symptoms, your assessment should outline all the known symptoms displayed by the individual, notwithstanding their degree of insight. Some individuals displaying hoarding related behaviours engage articulately or have clear insight, yet demonstrate inability to part with items and/or display distress at the thought or prospect of doing so (when taken with all the other relevant diagnostic criteria).

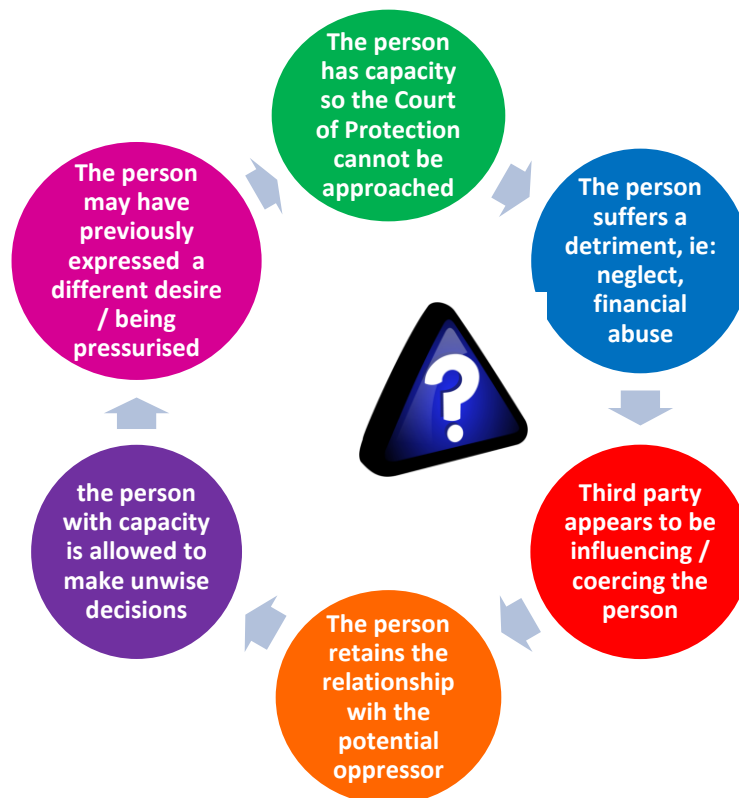
- 1.11 Where you consider that someone may display hoarding related behaviours or may need support with organising their possessions/accommodation, it would be helpful to bear in mind the diagnostic criteria for hoarding disorder when assessing that individual's capacity.
- 1.12 Mental capacity assessments which do not comply with Chapters 2, 3 and 4 of the Mental Capacity Act 2005 Code of Practice will not be able to be relied upon as lawful evidence of capacity. Without a proper capacity assessment, the Court of Protection has no power to hear the matter.
- 1.13 If it is not possible to either completely assess, assess in time or otherwise establish that an individual lacks capacity to make a specific decision or decisions, but the professionals feels there is sufficient evidence supporting that the individual may or does lack capacity, then an application for interim orders or directions under Section 48 of the Mental Capacity Act 2005 may be made to the Court of Protection. Such application can be made where the professionals feel that:
  - a. there is reason to believe that an individual lacks capacity in relation to a matter; and
  - b. the matter is one to which the Court's powers under the Mental Capacity Act 2005 extends and
  - c. the professionals consider it is in the individual's best interests to make the order sought, or give directions, without delay.

## **2 The Inherent Jurisdiction**

- 2.1 Where a person is unable to make a decision because of an impairment or disturbance of the functioning of the mind or brain, they are said to lack capacity for the purposes of Section 2 of the Mental Capacity Act 2005 and are afforded access to the Court of Protection. Where a person has no such impairment but has capacity to make a relevant decision, they may exercise their personal autonomy to make their own decisions and take appropriate action against anyone doing them harm.
- 2.2 However a person may have capacity to make a decision yet their will may be overborne by another resulting in that capacity being curtailed, restricting their personal autonomy to make their own decision of their own free will without deference to considering the influence of that other person, or being coerced.

- 2.3 The law does not suggest that because someone has capacity to make a decision, they should not have the same access to protection and redress as those who lack capacity. While the Court of Protection may not be approached because the person has capacity, there is the option of approaching the High Court under its “inherent jurisdiction” to prevent a disparity of protection to adults rendered vulnerable for reasons other than a disturbance or impairment in the functioning of the mind or brain.
- 2.4 The “inherent jurisdiction” means a power of the Court, usually the High Court, to hear any matter that comes before it unless a statute or other instrument comes along and removes that power or gives it to another court or tribunal. For example, before the Mental Capacity Act 2005 (“the Act”) came into force, the High Court used to hear and intervene in matters concerning persons who lacked capacity. The Act came along and created the Court of Protection, and redirected such matters away from the High Court towards the Court of Protection.
- 2.5 There is a legal presumption that everyone has capacity unless assessed otherwise. Where a person lacks capacity, decisions may be made on their behalf if it is in their best interests. Persons who lack capacity have a mechanism of protection in the form of access to the Court of Protection where there may be a dispute about where their best interests may lie.
- 2.6 Persons who have capacity and who may be (or are being) subject to undue influence, coercion or are being overborne in expressing decisions which do not originate from their own free will, yet who take no action to protect themselves, may be protected by an application to the High Court under its “inherent jurisdiction” to hear such cases. The Court of Protection cannot deal with such cases.

2.7 Often, practitioners find themselves in a legal conundrum because:



2.8 If you cannot approach the Court of Protection to hear such a case, you could go to the High Court under the inherent jurisdiction to seek to protect an individual from such situations on the basis that their free will to make a decision is being unduly influenced, coerced and/or impeded by the actions of a third party, rendering them “incapacitated” from making that decision.

2.9 In such cases, the High Court’s inherent jurisdiction “bridges the gap” between the protection the Court of Protection affords those vulnerable adults who lack capacity because of a disturbance / impairment of the functioning of the mind/brain, and those vulnerable adults whose free will is impeded from being exercised by reason of undue influence, coercion, violence or threats but are not eligible to approach the Court of Protection for a remedy to have their best interests served.

2.10 The current main case on inherent jurisdiction is *DL v A Local Authority and Others* [2012] EWCA Civ 253. This case clarified that the inherent jurisdiction survived the passing of the Mental Capacity Act 2005 and its Code of Practice enough to provide protection for an elderly couple said to “lack capacity” as a result of undue influence and duress brought to bear upon them by their son, DL. Lord Justice MacFarlane held that:

*“...the inherent jurisdiction is no longer correctly to be understood as confined to cases where a vulnerable adult is disabled by mental*

*incapacity from making his own decision about the matter in hand and cases where an adult, although not mentally incapacitated, is unable to communicate his decision. The jurisdiction, in my judgment, extends to a wider class of vulnerable adults..... The jurisdiction...is in part aimed at enhancing or liberating the autonomy of a vulnerable adult whose autonomy has been compromised by a reason other than mental incapacity because they are...:*

- a. Under constraint<sup>3</sup>; or*
- b. Subject to coercion or undue influence<sup>4</sup>; or*
- c. For some other reason deprived of the capacity to make the relevant decision or disabled from making a free choice, or incapacitated or disabled from giving or expressing a real and genuine consent.”*

2.11 The Courts have recognised that the strength of the will of the person and their relationship with the persuader, are crucial – paragraph 20 of DL states that

*“where the influence is that of a ... close and dominating relative... the influence may be... subtle, insidious, pervasive and powerful. In such cases.. very little pressure may suffice to bring about the desired result.”*

2.12 There may be cases where such a dominating relative exists yet the value of that relationship to the individual acts as a nexus for the influence and persuasion to occur. However in considering whether or not to intervene in the decisions of a person who has capacity (which arguably infringes their Article 8 ECHR rights), the Courts must conduct the correct balancing exercise so as to be sure that:

*“Any interference with the right to respect for an individual’s private or family life is justified to protect his health and or to protect his right to enjoy his Article 8 rights as he may choose without the undue influence (or other adverse intervention) of a third party.”*

2.13 From this it is clearer why the concept of “undue influence” has so deep-seated a root with much wider legal resonance when it comes to the inherent jurisdiction matters. Where a local authority seeks to protect and not infringe a person’s rights, there may be more scope to suggest that arguably no balancing exercise arises.

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<sup>3</sup> Para 22 of the judgment, quoting para 78(i) – constraint is said to mean “confined, **controlled**...”

<sup>4</sup> Para 22 of the judgment, quoting para 78(ii) – coercion/undue influence is said to mean “...where a vulnerable adult’s capacity or will to decide has been sapped and overborne by improper influence of another.. where the influence is that of a ... close and dominating relative... the influence may be... subtle, insidious, pervasive and powerful. In such cases.. very little pressure may suffice to bring about the desired result.”

2.14 If after careful consideration of the evidence and advice obtained you are proceeding to the High Court under the inherent jurisdiction, the procedure is very much like the Court of Protection:

## Claim Form

- There will be a claim form to complete which your Legal Team should complete upon instructions
- You should include a **Draft Order** so the Court is clear what directions and/or outcomes you want from this process

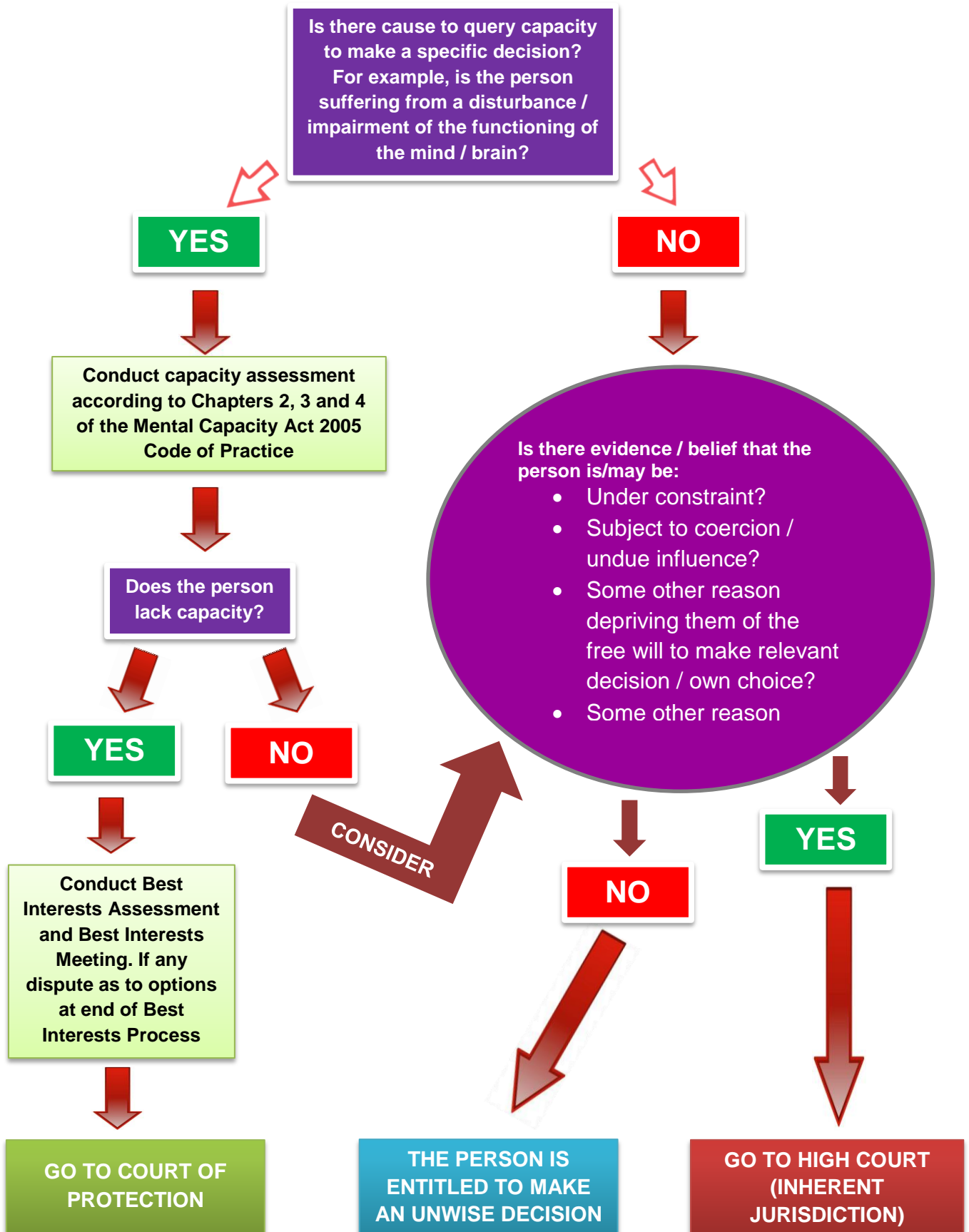
## Witness Statements

- You should complete a witness statement and include other evidence / exhibits - your Legal Team can advise on what is required

## Court Decision

- The Court may want to list a hearing but it does not always mean that you will be asked to speak in Court
- The Court may make further directions so that it can make a final decision later (for example it may want further reports / evidence etc..)

2.15 The following may assist in deciding where to go for which type of vulnerable adult:





### **3 Mental Health Act 1983 Options**

- 3.1 Section 1(2) of the Mental Health Act 1983 defines “mental disorder” as “any disorder or disability of the mind.” Hoarding disorder is captured by this definition.
- 3.2 Where the Mental Health Act 1983 applies, so will its options, such as the options for assessment, treatment and hospitalisation under Sections 2 or 3 of the Mental Health Act 1983. Pursuing these avenues with someone who displays hoarding related behaviours and/or who is diagnosed with hoarding disorder, should be no different to when working with any other person who may have “any disorder or disability of the mind.” What will need to be particular to the person displaying hoarding related behaviours will be the options for assessment and treatment.
- 3.3 You will need to consider the diagnostic criteria when assessing someone who may display hoarding related behaviours. This is the clinical definition and starting point from which all clinical and/or mental health assessments are recommended to commence.
- 3.4 In terms of treatment, while it appears there is no cure as yet developed for hoarding disorder itself, containment and management of the disorder and/or its symptoms appears to be the most positive outcome of treatments available. Such treatments or methods of support include intensive Cognitive Behavioural Therapy, Motivational Interviewing, Skills Training and other Cognitive Restructuring Techniques.

### **4 Environmental Health Law Orders / Notices**

- 4.1 People who display hoarding related behaviours or need support with this aspect of their lives, or who have been diagnosed with hoarding disorder, may sometimes be the subject of proceedings brought under either Housing or Environmental Legislation – they may need support and you will need to consider whether or not they have capacity to litigate.
- 4.2 Hoarding disorder itself is a mental illness and therefore strict legal procedures or enforcement notices may not be fully either understood, comprehensible or even capable of being processed by the person, particularly if they lack capacity to make relevant decisions pertaining to their behaviours or circumstances. You should always check the individual’s ability and capacity to understand either litigation or being on the receiving end of statutory notices which agencies such as Environmental Health may be entitled to issue.

## 5 Environment Health Law

- 5.1 Residential Environmental Health Officers are given their powers by the Public Health Acts 1936 and 1961, National Assistance Act 1948, Prevention of Damage by Pests Act 1949 and the Environmental Protection Act 1990. These can be used to require the cleaning of homes and occupiers and in very rare and extreme circumstance physically removing the occupier to facilitate this.
- 5.2 The Residential Environmental Health team in Islington are usually involved in extreme cases as an option of last resort when there is a significant threat to public health e.g. smell or flies or there is a significant threat to health to the occupier e.g. a build-up of human waste or an infestation of pests.
- 5.3 The process can be traumatic for the occupiers and should only be considered in exceptional circumstances when all other informal and supportive efforts have been exhausted.
- 5.4 Pest proofing, cleaning and clearing works can be legally required to be carried out. In these circumstances a legal notice requiring such works would only ever be served on an occupier whom it is felt has the sufficient mental capacity (for example the mental capacity to clean and clear the property themselves or the capacity to choose not to do so and be aware of the consequences of not complying with the notice). This includes the Environmental Health Officer carrying out the works in default. (This capacity is usually assessed through an appropriate mental health assessment)
- 5.5 Soiled material is often cleared but sterile personal belongings are not removed. Removal of any personal belongings or items of value would only ever done with the consent of either the occupier or a under strict supervision by someone for example with an adult social care property protection role.
- 5.6 The most effective, least traumatic cleaning option is often when consent and co-operation is forthcoming from the occupier.

## 6 Environmental Health Options

- 6.1 Environmental Health Officers have three legal options available them to require that certain actions are done or carried out, bearing in mind that the more extreme the option, the greater risk of trauma to the occupier:
  - a. **Works in default with consent** – Facilitating works in their home with their written consent
  - b. **Works in default without consent** – Carrying out works in occupiers home without their consent

- c. **Works in default without consent and removal of occupier** – This is only ever done in exceptionally rare and extreme circumstance and where occupier is chronically sick or disabled. This would always involve working with the occupiers GP, Community Physician and Social Worker.

## Appendix E. Alignment and Relationship between DSM-5 and ICD-10

### 1 ICD-10 Equivalents and Relationship to DSM-5

- 1.1 ICD.10 does not yet contain a definition of hoarding disorder in its own right. It is expected that hoarding disorder will be included in ICD-11 which is due to be published in 2017.
- 1.2 However, the APA's DSM-5 Development webpage describes the relationship between DSM and the WHO's ICD as follows<sup>5</sup>:

*“DSM-5 and the ICD should be thought of as companion publications. DSM-5 contains the most up-to-date criteria for diagnosing mental disorders, along with extensive descriptive text, providing a common language for clinicians to communicate about their patients. The ICD contains the code numbers used in DSM-5 and all of medicine, needed for insurance reimbursement and for monitoring of morbidity and mortality statistics by national and international health agencies. The APA works closely with staff from the WHO, CMS, and CDC-NCHS to ensure that the two systems are maximally compatible.”*

- 1.3 The DSM's document entitled *Understanding ICD-10-CM and DSM-5: A Quick Guide for Psychiatrists and Other Mental Health Clinicians*<sup>6</sup> explanation was provided about the compatibility of these two references, for example:
  - a. In October 2014 the US health care system changed its diagnostic codes from ICD-9-CM to ICD-10-CM. Everyone is now using these ICD-9-CM codes and mental health practitioners know these codes from using the DSM-IV-TR (they are also included in the DSM-5).
  - b. DSM-5 contains all of the information needed to assign HIPAA-compliant, valid ICD-10-CM codes to the psychiatric diagnoses that you make for patients.
  - c. The ICD-10-CM codes are alpha-numeric. In DSM-5, they can be found in parentheses within the diagnostic criteria box for each disorder.
  - d. For quick reference, ICD-10-CM codes can also be found in the “DSM-5 Classification” in the front of the manual, and as alphabetical and numerical listings in the appendices.

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<sup>5</sup> <http://www.dsm5.org/about/Pages/faq.aspx#10>

<sup>6</sup> <http://www.dsm5.org/Documents/Understanding%20ICD%2002-21-14%20FINAL.pdf>

## Appendix F. Information Sharing Protocol

### Information Sharing Protocol Islington Hoarding Panel



# ISLINGTON

#### 1 Purpose

- 1.1 This Information Sharing Agreement (ISA) defines the arrangements for processing data between partner organisations of the Islington Hoarding Panel.
- 1.2 This ISA sits underneath Islington Council's overarching information sharing Protocol (ISP)

#### 2 Parties to the agreement

- 2.1 Originating Organisation  
Islington Council (Housing and Adult Social Services)  
7 Newington Barrow Way  
London  
N7 7EP
- 2.2 This ISA applies to all organisations that are involved in or communicate with the Islington Hoarding Panel (IHP) at any time.

#### 3 Why is the information being shared?

- 3.1 Appropriate information sharing among partner organisations of the Islington Hoarding Panel is essential to safeguard and promote the wellbeing of adults at risk in Islington and in particular those believed to be hoarders and/or suffering from hoarding disorder.
- 3.2 In line with the Care and Support Statutory Guidance sharing of information is key to providing an effective response where there are emerging safeguarding concerns.
- 3.3 IHP partners recognise that the initial legal responsibility for personal information resides with the organisation that first created or received it – in this

case being the participating Data Controllers. But if personal information is shared, the responsibility extends to the recipient in the receiving organisation, regardless of how transitory that storage of the personal information might be by the receiving organisation.

3.4 It is the expectation that staff and volunteers in IHP partner organisations will share information to:

- safeguard adults at risk of harm
- Decide if there is sufficient reason not to seek consent, and seek any that is considered necessary; and
- If consent is refused or no response is received, decide whether disclosure should be made in the absence of consent
- enable all IHP partners to work together effectively in line with relevant legislation, including The Data Protection Act 1998, The Children Act 1989 and 2004, Human Rights Act 1998 the Care Act 2014 and the Mental Capacity Act 2005

## 4 Roles and Responsibilities

4.1 The agencies signing this agreement accept that the procedures laid down in this document provide a secure framework for the sharing of information between their agencies in a manner compliant with their statutory and professional responsibilities.

4.2 As such they undertake to:

- Implement and adhere to the procedures and structures set out in this agreement.
- Ensure that where these procedures are complied with, then no restriction will be placed on the sharing of information other than those specified within this agreement.
- Engage in a review of this agreement with partners annually, or as agreed.

## 5 What information is being shared

5.1 Personal data including demographic details, identifiers such as NHS number, address, photograph, CCTV image together with personal records, health and social care plans, safeguarding concerns and other information held by partner agencies relating to possible concerns about safeguarding and/or hoarding by or affecting a person at risk.

5.2 Information held by partner agencies which may be of assistance to a safeguarding enquiry, a safeguarding adults review or a Domestic Homicide Review

- 5.3 Sensitive and/or personal information and data for the purposes of analysing trends in safeguarding. These may include but not be limited to:
- Information relating to training, learning and development of staff in safeguarding adults, mental capacity act, deprivations of liberty safeguards
  - Information relating to partner organisations' Disclosure and Barring Service checks and implementation of Islington Safer Recruitment Guidance
  - Information required to complete the Islington Safeguarding Adults Return to Department of Health
- 5.4 Information to enable audit, quality assurance and self-assurance of safeguarding practice, policies, procedures and arrangements of IHP and/or individual partner agencies
- 5.5 Generally there is no restriction on sharing depersonalised information. However, partner organisations accept that a duty of confidence, contractual or other legal restriction may apply in certain circumstances to sharing some depersonalised information. Partner organisations must take great care when depersonalising information to ensure that an individual's identity cannot be revealed.

## **6 Legal justification for sharing**

- 6.1 The Islington Hoarding Panel operates under the umbrella of the Islington Safeguarding Adults Board. Section 45 of the Care Act 2014 places a duty on partner organisations and others to comply with a request from the Safeguarding Adults Board to supply information to it or to some other person specified in the request if the request is made for the purpose of enabling the Safeguarding Adults Board to exercise its functions and provided other specified conditions are met.

## **7 Has consent been gained?**

- 7.1 The starting point in relation to sharing personal and/or confidential information is that practitioners will be open and honest with families and individuals about why, what, how and with whom information will or could be shared.
- 7.2 In line with the Caldicott Review 2013 and the Care and Support Statutory Guidance, informed consent should be obtained from the relevant individuals, but, if this is not possible and other adults are at risk of abuse or neglect, it may be necessary to override the requirement.
- 7.3 Where an individual lacks capacity, staff are expected to make a judgement about whether sharing the information is in their best interests or in the public

interest. When considering whether disclosure is in the public interest, for example to prevent or assist in detecting a crime, the rights and interests of the individual must be taken into account. A fair balance between the public interest and the rights of the individual must be ensured.

- 7.4 All IHP partner organisations must confirm that they have in place a policy that addresses consent requirements and that is monitored, and supports compliance with the Data Protection Act 1998 and the Care Act 2014.
- 7.5 The reasons for breaching client confidentiality must be fully recorded and clearly reference the evidence and information on which the decision is based.

## **8 How will the data be shared?**

- 8.1 Wherever possible, physical data transfer will be avoided. It is preferable to 'share' data through enabling authorised others to view and update data within partner organisations' record management systems.
- 8.2 Where data is 'sent' electronically, this will be done through secure email systems, encrypted data and/or password protected documents.
- 8.3 Due care will be taken in sharing paper records and the requesting and disclosing professionals will ensure that any personal or sensitive information is transferred in a secure manner.

## **9 How will the data be stored?**

- 9.1 Sensitive data will be securely stored by the respective IHP partner organisations.
- 9.2 Personal data will be securely stored by the respective IHP partner organisations, and wherever possible, using access controlled case management systems to restrict the viewing of and access to an individual's records.

## **10 Security & Risk Management**

- 10.1 All staff must use their organisations approved secure email system when emailing sensitive information. Where Health Professionals are unable to comply with their organisation's policies regarding the safe and secure transfer of data they must ensure that a risk assessment is undertaken by their Information Security/Governance department at the earliest opportunity.
- 10.2 Each organisation must ensure that mechanisms are in place to address the issues of physical security, security awareness and training, security



management, systems development, role based security/practitioner access levels, receiving and transfer of data and system specific security policies.

- 10.3 Any concerns or complaints received relating to the processing of personal data will be dealt with promptly and in accordance with the internal complaints procedures of that partner organisation and, where appropriate, may be raised with other partner organisation's responsible manager.

## **11 Breach and Escalation Rules**

- 11.1 Any breaches will be recorded as prescribed under Islington's Security Incident Policy. Each organisation signed up to this agreement needs to notify the partner organisations should any breaches occur.

## **12 Who will handle the handle the information?**

- 12.1 Professionals in IHP partner organisations and Islington Council may handle the information on a strictly need-to-know basis for the purposes set out in this agreement. Professionals must be able to justify fully the reasons for their obtaining any particular detail about an individual or any sensitive information about a partner organisation or the work of the IHP.
- 12.2 Each organisation must ensure that relevant staff have the necessary level of security clearance.
- 12.3 Each organisation must ensure that all relevant staff receive training, advice and ongoing support in order to be made aware, and understand the implications, of this ISA and any associated documentation.

## **13 How long will the information be kept?**

- 13.1 Each IHP partner organisation is expected to have a Records Management policy with detailed guidance on retention periods for the full range of health and social care records as well as business and corporate records that is in line with the NHS and Social Care Code of Practice and medico-legal requirements.

## **14 How will the information be destroyed?**

- 14.1 Once the information has been flagged for review when the retention period ends, the relevant Manager in the relevant IHP partner organisation will approve the deletion of the record. The IHP partner organisation will then arrange for the case record or sensitive data and all associated files to be

permanently deleted or destroyed with a complete description added to the record destruction log of when the data was deleted or destroyed.

## 15 Related procedures/policies

15.1 This information sharing agreement sits alongside the information sharing agreement of the Islington Safeguarding Adults Board and other inter-agency information sharing agreements in operation. It is designed to enhance existing arrangements rather than replace them.

15.2 These policies apply to all ISAB members and ISAB partner organisations, Islington council staff, partner organisations, contractual third parties and agents who use Islington Council facilities and equipment, or have access to, or custody of, customer information or Islington Council information.

- Islington Code of Conduct for Employees
- Islington ICT Security Policy Framework
- Islington ICT User Management Policy
- Islington ICT Security Incident Policy
- Islington Third Party Access Policy
- ICT email Policy
- ICT Physical Security of Information Policy
- ICT Information Risk Policy
- Data Transport Policy

15.3 The above policies can be viewed by clicking on the following link: [Islington ICT Policies](#)

15.4 IHP partner organisations are expected to have equivalent or comparable information policies in place.

## 16 Governance, Approval and Review

16.1 By participating in the Islington Hoarding Panel you are deemed to have agreed to be bound by the terms of this information sharing agreement.