



The health and wellbeing effects of living with mould in North East Essex

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healthwatch
Essex

The health and wellbeing effects of living with mould in North East Essex



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1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience.

One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing, understanding, and navigating health and social care services and their choices in relation to aspects of those services.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are encountering daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share difficult experiences such as the one's shared in this report.

1.2 Topic Background

It is widely accepted that living in a property with mould can have a negative impact on health, but stories abound regarding property owners doing little to help and many potentially underestimating the severe repercussions that it can lead to.

'Give it a lick of paint, wipe it off, open your windows, turn your heating on', etc., are all responses you will see in the body of the report, but these are symptomatic of the lack of understanding and in many cases will not solve the root cause. They also show no realisation that if not treated properly it will have long term, potentially serious health effects.

With the high profile, tragic death of a baby boy in housing association accommodation in Rochdale (caused directly from exposure to mould), we have no excuse to continue underestimating the devastating effects, and we must not ignore the widespread problem.

The issues cross Healthcare, Social Care and Housing and must be tackled in a cohesive and coordinated way.

1.3 Acknowledgements

Healthwatch Essex would like to thank the hundreds of people who engaged with us, participated in this project, and completed the survey.

Our thanks are also made to those individuals who took the time to speak with us and share their personal stories.

We would also like to thank our many partners, contacts, and networks who worked with us to share the project and survey throughout all of North East Essex and help generate such a strong level of interest and feedback.

1.4 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement period. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

As we enter the new era of Integrated Care, it's important to assess how well we can now respond to the problems and issues that the population faces.

This report provides a starting block, a point of reference to show the gap between the size of the problem and the response being given until now. How the recommendations are responded to and built upon can become a perfect case study of just how integrated the SNEE ICS area can be, and how effectively it can work with housing and social care.

In order to move forward, we need to assess the current situation. This report is made up entirely of people's lived experience. It asks people what has happened, how have they been responded to, what has been done, how they've been helped. The responses are honest and genuine.

The impact of having to live in damp, mouldy housing can be devastating. Coming home every day from school, or the shops, or work, to be faced with mould and damp that it seems will never go away is going to have a huge toll, physically and mentally.

Waking up every day to mould in the corner of your ceiling, or around your window or bed, despite constantly cleaning it and painting over it will be emotionally draining for almost anyone.

Breathing damp air with potentially harmful spores, constantly and daily will inevitably put a strain on the respiratory system.

And the thought of looking after a new baby in that environment, keeping them warm and dry, and away from infection, is incomprehensible.

By acting together sooner, we can help those with preventable health conditions.

From this report, we aim to provide key learnings and recommendations in order to help develop policies and processes that are specific, measurable and achievable.

2.1 Engagement methods

Participants were contacted through the Healthwatch Essex website, through local North East Essex based Facebook groups, the Healthwatch Essex newsletters, our own Facebook page, Instagram account and Tik-Tok. Word of mouth also played an important role along with promotion of the project via our extensive networks.

Our partners, other organisations and working groups in North East Essex, together with our volunteers and many individuals inside and outside of the NHS and ECC helped and supported our efforts to engage with and reach as many people throughout the area as possible.

They were engaged with in two ways:



Survey

A survey was created to gain perspective and insight from residents who have had experience of living with mould.



Interviews

Individual interviews were conducted to collect personal stories from members of the public. Interviews took place by telephone during February and March 2023 and all participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.

2.2 The Survey

The survey consisted of 11 core questions, mixing multiple choice questions and 'free text' information boxes enabling the participants to expand on their answers. There were an additional three demographic questions.

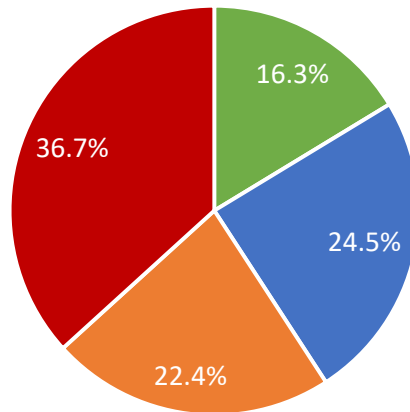
It was devised to encompass:

- Property ownership
- Reporting
- Response
- Effects on health
- How things could be improved or built upon

The survey was primarily in an online format but was also available to be printed off and filled out manually as required. The Information and Guidance Team at Healthwatch Essex were also available if the survey needed to be completed in any other format, such as over the telephone. The questions, and responses received, were as follows:

An important consideration was to assess and record the length of time people have had to live with a mould problem, and this was the basis of our first question.

How long has your property been affected by mould

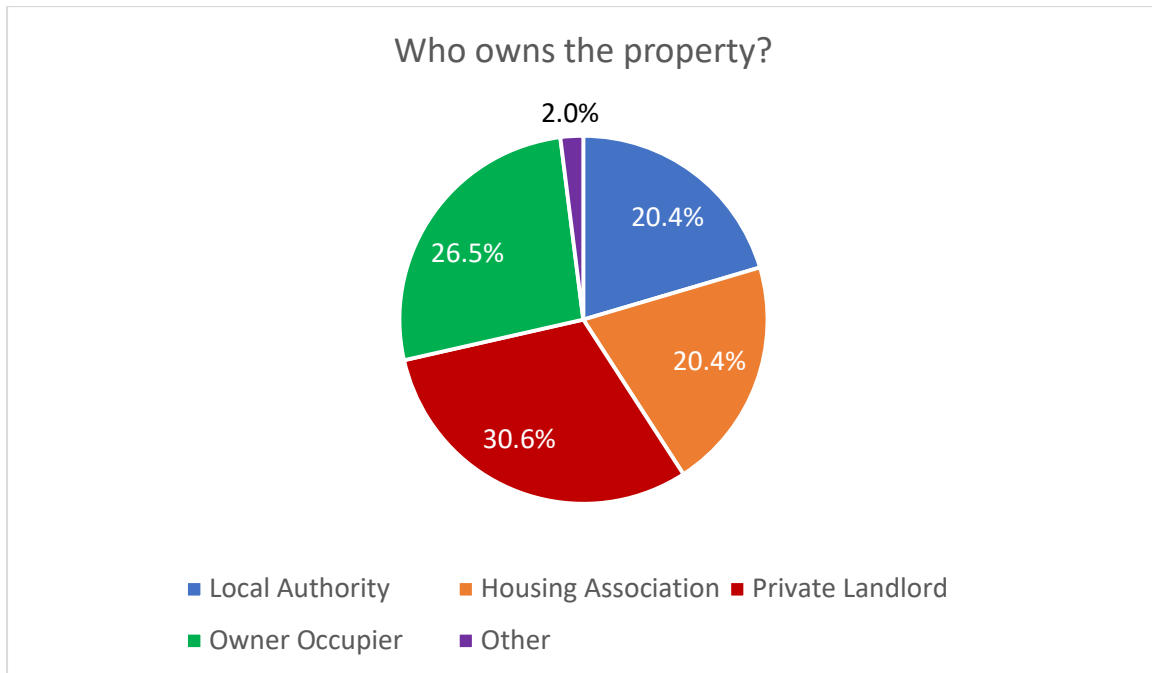


■ Less than 1 year ■ 1-2 years ■ 2-5 years ■ More than 5 years

There is clearly a significant issue here, with very nearly 60% of respondents being affected with mould for two or more years, and the majority of those, over five years. This clearly needs addressing as the long-term implications could be severe and the health of individuals at real risk.

We are all aware of the proverb that a stitch in time saves nine, but it also saves money. Early intervention has to be prioritised; not just to clean and paint, but spending more money and time and resources to ensure the root cause is identified and dealt with.

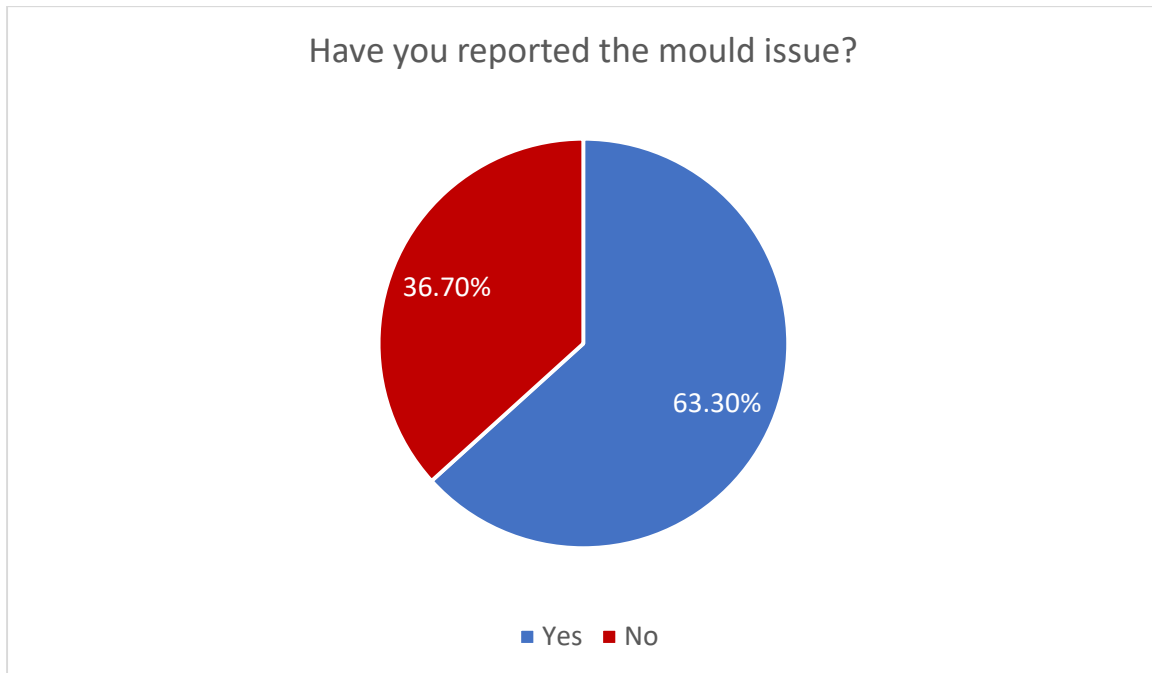
A longer-term strategy, combined with effective and comprehensive intervention will save money, help people stay well, and potentially save lives. It must be remembered that the property owner has ultimate responsibility for this, and in our next question, we explored this.



The responses show a reasonably even split, including owner occupiers. It's clear that any policy and strategy decisions made, should be done so with these figures in mind - the problem is across the board and each 'sector' should have a nuanced approach.

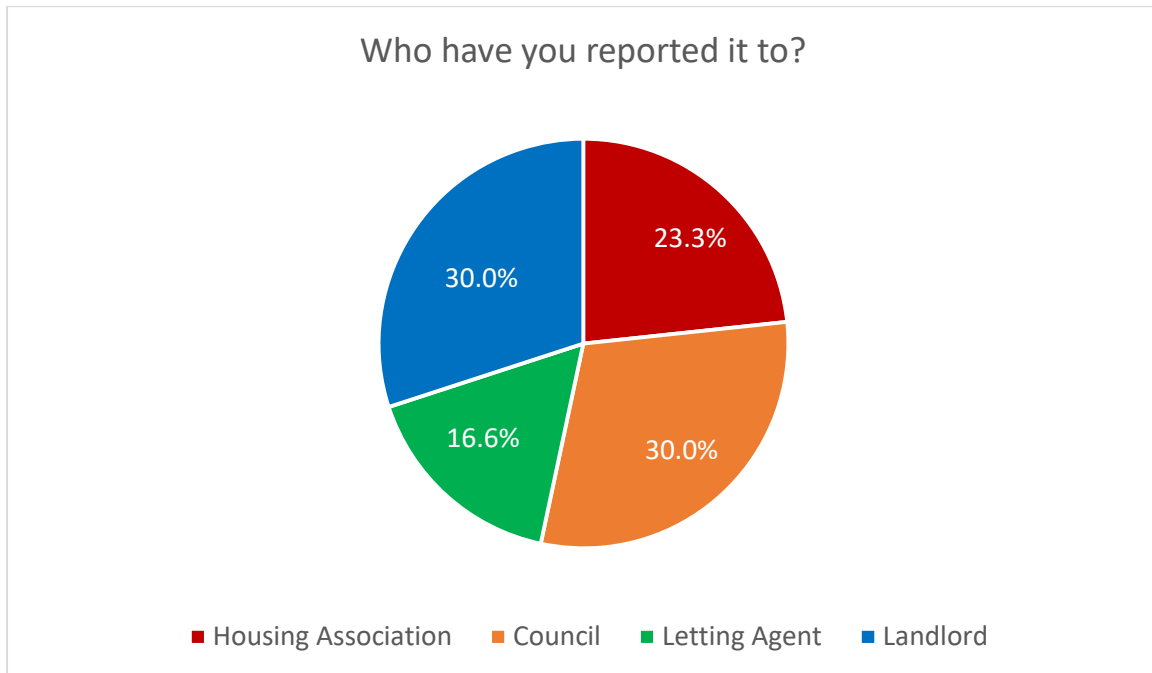
It also highlights an educational need for owner occupiers to be aware of how to effectively intervene (although there isn't a breakdown within this data set regarding those in new-builds and within a 10-year NHBC Buildmark).

If problems are going to be assessed and resolved, reporting is vital and should be done in a timely and comprehensive manner. In our next question, we asked if the mould issue had actually been reported to the relevant party.



There could be an assumption that many of those who have not reported it are owner occupiers (as they accounted for 26.5% of all respondents), but it remains vital that education and awareness ensures the highest rates of reporting as possible, regardless of ownership.

Residents must have confidence that it will not cause them problems if they report, and confidence that the reporting will be acted upon rather than ignored. We followed this up by asking who the mould issue had been reported to.



It's important that residents are aware of how to report, who to report to, where to get advice, and how to complain if no action is taken or the solutions don't work. The pathway should be clearly set out and readily available, to avoid confusion which will create a barrier to reporting.

How a report is responded to, of course, can have a significant effect. Recipients of reports must respond with appropriate gravity and empathy.

We asked participants what responses they had received when reporting mould issues and garnered the following responses.

'We will come and paint it with mould paint.'

'They have not tried to help in any way.'

'I have received no response.'

'I was just told to open the window occasionally.'

'I was told to improve ventilation in the property, but even with the windows open all summer the mould got worse.'

'Use bleach to remove it, heat the room and buy yourself a Unibond dehumidifier.'

'They said they would put in an extractor fan, but they haven't.'

'Wipe it with vinegar.'

'They told me how to clean and keep the windows open.'

'You must be drying your clothes in the house too much,'

'It's been ignored time after time.'

'We were originally told that it's our fault caused by condensation.'

'They were unhelpful.'

'Open the window and keep wiping it away with mould removal products.'

'I was told there was a nine month wait for them to assess it.'

'After continuous complaints they are finally coming out in February to remove the mould.'

'They said they will send someone round.'

'Clean down with bleach and ventilate.'

'They delayed then just came one or two times but didn't fix the mould problem.'

'To wipe it down and repaint'.

'I've had them out three times before, and they wasn't helpful at all. Today they decided that they are finally going to replaster and render the wall after reporting it to the MP who got in contact with them.'

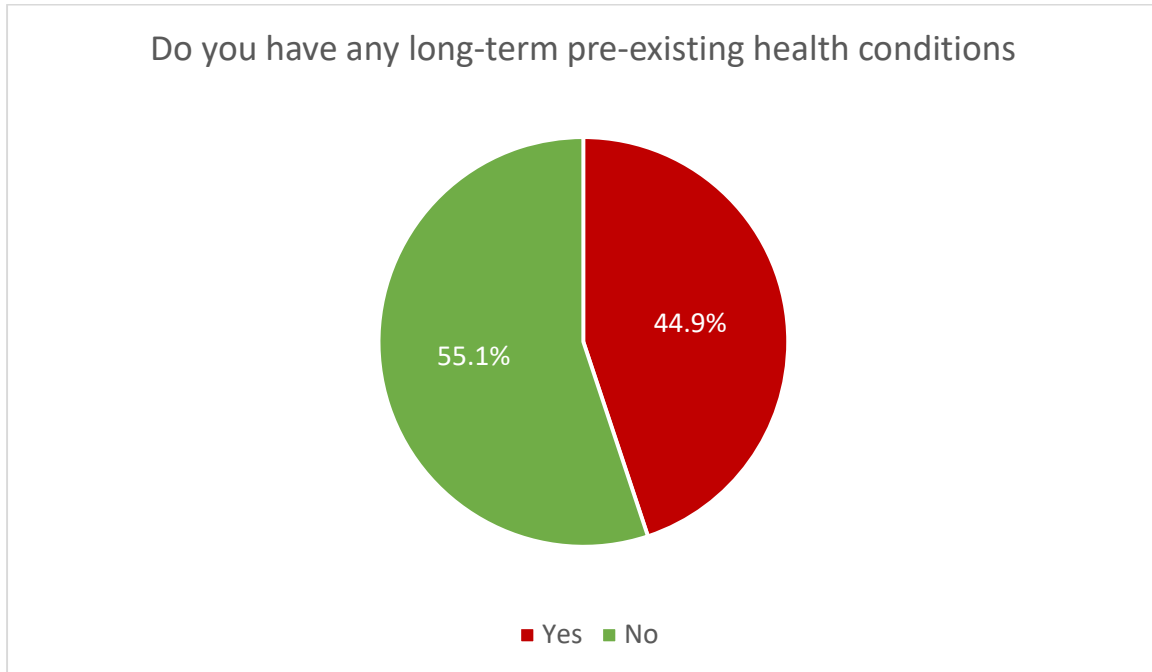
'That they've told the landlord and are 'waiting to hear'.'

'They did eventually come out, but then there was more mould.'

'They put a useless extractor fan which is ineffective in the kitchen.'

'Nothing has been done.'

Respondents were then asked to share information about their health.



Below is a representative sample of the conditions that were mentioned:

Asthma

Anxiety

Depression

Allergies

Eczema

Rheumatoid Arthritis

Long covid

Breathing difficulties

Mental health

Premature baby

Heart failure

Factor V Leiden

Prostate cancer

Sickle cell

Arthritis

Diabetes

Cardiology issues

Brain Injury

Loss of mobility

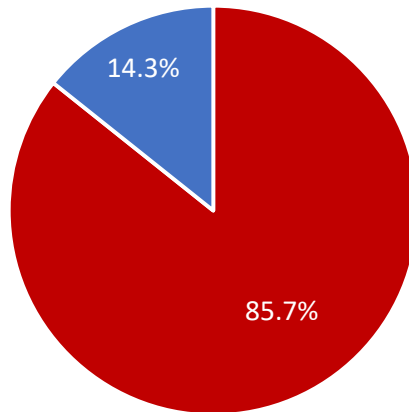
Heart condition

No sense of smell or taste

Please note that Asthma was mentioned **multiple** times.

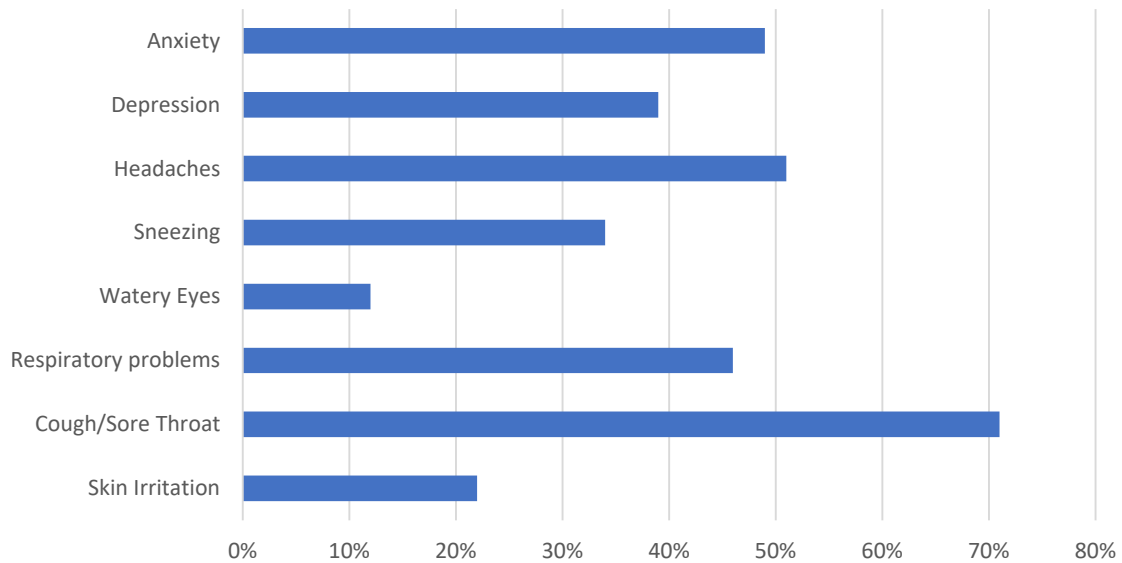
We also looked at some specific mental and physical wellbeing issues in our questioning.

Has the mould affected your health and wellbeing?



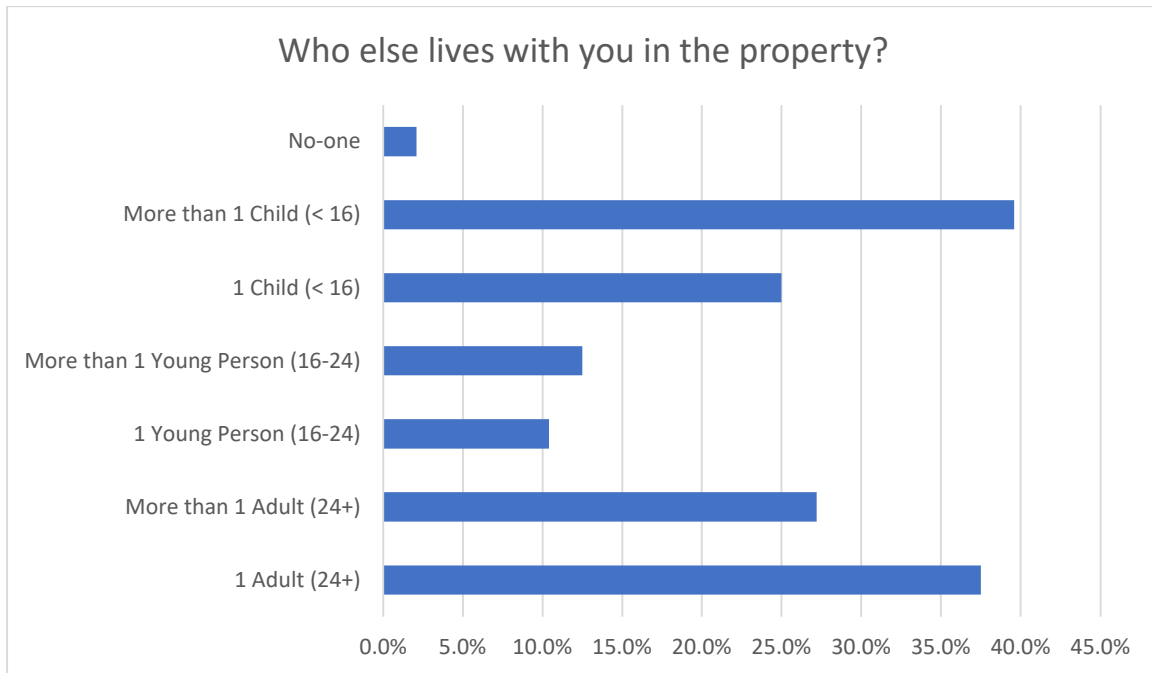
■ Yes ■ No

Health and wellbeing (tick all that apply)



Attention must be drawn to the high incidents of anxiety and depression, as well as the serious physical conditions such as headaches, coughs and sore throats and respiratory problems.

We then gathered information on the numbers of people directly affected.



97.9% of people who responded live with others, and 64.6% have children under 16 resident in the home. It's hugely important to remember that the numbers of people affected is a high multiple of the number of households overall.

Participants also shared with us what they feel needs to be done about the issue of mould. They are the ones having to live with this every day - they must be listened to. Their thoughts and feelings must not be dismissed.

We asked what the greatest help to them would be in addressing the mould issue, and a sample of the responses are listed below.

'Being moved.'

'A powered air vent.'

'Our landlord taking a look at the loft as the insulation is barely there and there is nothing between the roof tiles and loft space. Heating costs an average of £10 a day and is only on for two hours maximum.'

'My youngest child (3 years old) has had a constant cough for more than four months. She now uses an inhaler.'

'Decent insulation. The rooms where the mould is growing are freezing.'

'Getting ventilation and replacing the rotten walls.'

'I would like the areas of mould treated and repainted and windows and doors replaced as mould grows really quickly in these areas.'

'That they listen to you instead of you being blamed for it or fobbed off with a silly response.'

'A clear answer to how to eradicate it (not the random ones you find online).'

'Replaster the wall which they have agreed to do finally.'

'Fixing blown windows.'

'Not having to spend money and energy cleaning it over repeatedly.'

'Knowing it is cleared up for good, and any recurrences will be treated immediately.'

'I have old single glazed windows with metal frames.'

'Double glazed windows would help.'

'Being able to afford to put the heating on.'

'Getting it sorted.'

'Someone to look at the issue and tell me how to treat the problem and what is causing it.'

'I don't know who to ask.'

'Advice on the best way to reduce mould.'

'Our mould appears to be caused by central heating and the lack of air circulation. We are currently able to keep on top of it by cleaning with black mould remover and opening windows etc.'

'Getting the cause of the mould sorted out.'

'An efficient extractor fan as the kitchen is so small, walls are not properly insulated, windows (over 45 years old and breaking down) run with condensation and, if we boil a pan (lid on) it steams up the whole bungalow, with water running down the inside walls which means we have to wash the walls down daily or mould will come back, being disabled this is a hard task. These bungalows are owned by

Tendring District Council and meant to be suitable for elderly and disabled. The mould can be so bad we have to decorate every 6 months.'

'Colchester Borough Homes actually sorting the mould when it was reported.'

'To find the cause of the mould issue and try to fix it.'

'Knowing who to call to fix it.'

'Repointing of external walls, window replacements, structural inspection, insulation.'

'It being looked at properly and dealt with correctly.'

'Just help to control it.'

'To get rid of it permanently.'

'Greater awareness in both the public and GPs. I think many of the long-term health conditions of our population could well have a route in mould sensitivity. I don't feel as though I would be taken seriously by my GP because I don't have respiratory symptoms. My nervous system on the other hand has very much suffered.'

'Scare the crap out of agencies/landlords to make them TAKE IT SERIOUSLY.'

'Better insulation and heating.'

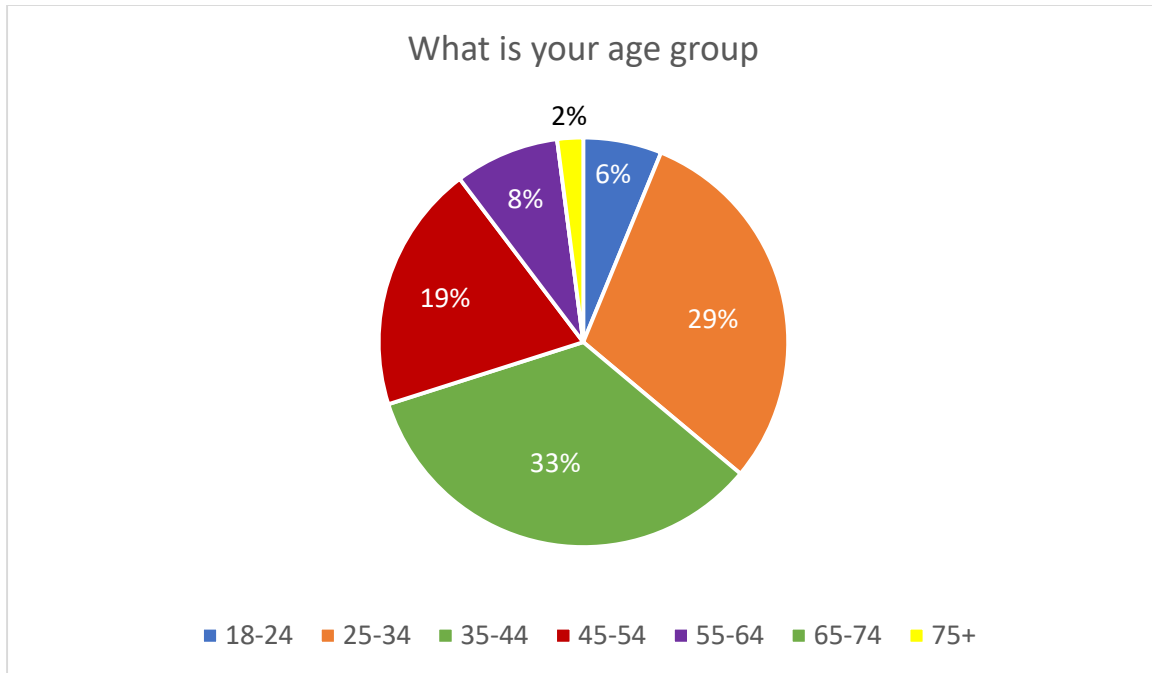
'Affordable dehumidifiers.'

'Having the mould removed but having the ventilation system working in the flat, we have no extractor fans, the system is broken and although mould has been getting removed by myself it keeps coming back because the root of the problem is ventilation.'

Some of these solutions raised are incredibly simple and just common sense, but people are still struggling to get action. There are also many, many references to not getting to the root cause of the mould problem.

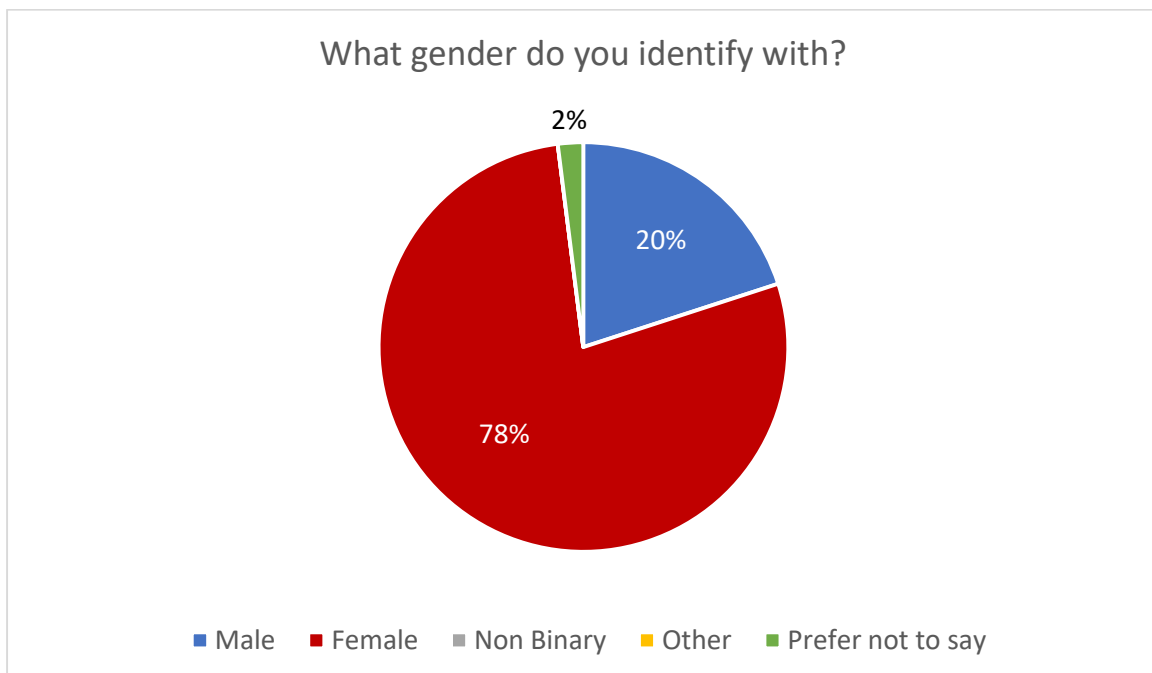
We also explored participant demographics in our engagement.

We firstly asked about participant age.



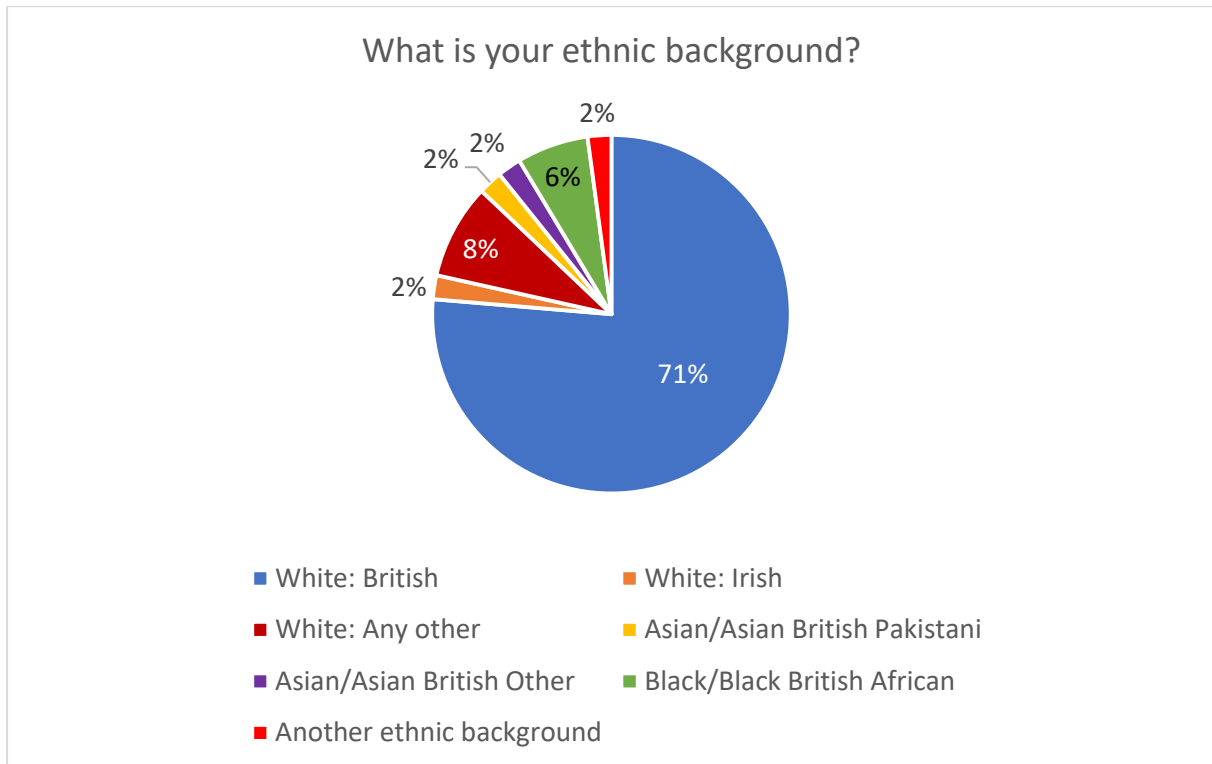
Response levels were very high from those aged 25-44, accounting for 62% of all responses. 29% were from the age 25-34 demographic.

We then asked about gender identity.



Our survey respondents were predominantly women, with a 78% response from this cohort.

Ethnicity was our next question.



It's important to note that 12% of the respondents are non-white. This is a higher figure than in other consultations which the Healthwatch Essex IAG team have carried out over the last 12 months and more so, implies that the problem is disproportionately affecting people from ethnic minorities.

2.3 Interviews

Many people offered to talk to us directly and tell us about their stories in depth. We would like to thank everyone who took the time to talk to us and share their experiences, helping us to produce this report. From those that we have spoken to, we would like to highlight 3 case studies reflecting the lived experience of people in North East Essex.

Case Study 1

Keira* moved into her new home with her family in 2019. It was her first home with a mortgage and an exciting but stressful time. Keira had been on low dose anti-depressants since the birth of her son but considered herself to be in good overall health.

After moving in, Keira's health started deteriorating mentally and physically. She had no idea why, but put it down to the stresses and anxiety of moving, having a new mortgage, being the main breadwinner, etc.

She took great care of her diet as she felt it could be a trigger to her ill health and she had symptoms similar to that of Chronic Fatigue. She reduced her sugar intake and started cutting out gluten and other unhealthy foods. The Paleo Ketogenic diet was recommended to her, and she started following that, and after some time she also came off her anti-depressants. She found her energy levels boosted, but having to cut out so many foods didn't feel right.

She still did not feel well in herself but put it down to stress and anxiety. Then later, Keira started to have problems sleeping, and being awake for two to three hours became a nightly occurrence. She was reluctant to see her GP as she was certain she would be diagnosed with depression and put back on medication.

Instead, she saw a Nutritional Therapist who was also qualified in functional medicine. A urine test showed very high levels of toxicity in her body, which was a red flag for her. She made some further adjustments to her diet which did lead to some improvement.

However, it wasn't until she went to stay with a friend for a week, that she realised something else was going on. After just a few days, she felt remarkably better.

"I thought - 'I wish I'd brought my trainers because I could actually go for a jog!'"
Unfortunately, as soon as she got home, the stomach aches and cramps returned, as did her cough, and her energy levels dropped back down.

Keira then got an appointment with a Functional Registered Practitioner who asked if she had any mould in the house. She knew there were some small pockets around but decided to have a close inspection.

It was then that she found huge areas of mould halfway up the walls behind the wardrobes in the bedroom and some other large areas behind the kitchen cupboards. Finally, everything started to fit into place. The root cause of the problems she's encountered since she first moved into her property had been found and something could be done about it.

Keira feels very lucky to have been able to afford a private Functional Practitioner and thinks she might have had to wait many years to find what was going on without them.

Short term, the walls can be kept clean with mould cleaner, anti-fungal spray, ventilation, etc. For the longer term, a specialist firm is doing the necessary remedial work to ensure the problem does not return.

Case Study 2

Shaima* lives with her husband and two teenage sons in a property owned by a housing association.

It has had mould since shortly after they first moved in five years ago. Shaima is certain that the mould pre-existed their move and says it was obviously patched up when the previous tenant left.

When she first contacted them about the problem, they were dismissive but said someone would get back to her. When she didn't hear anything for weeks, she called them again and was told they were very busy, but someone would be in touch.

When somebody did contact her, she was given basic advice on how to clean the mould and ventilate it - advice that she found demeaning and again dismissive. No-one came to see the problem; they just wanted to minimise it and pretend it wasn't happening.

“How can anyone tell us what to do when they haven't got a clue how bad the problem is, or what's causing it?”

Cleaning the mould off the walls is a constant job and ventilating it through the winter means you need the heating on all the time, which they can't afford to do. She worries all the time and feels frustrated that the housing association don't care.

Shaima's younger son has asthma which has worsened since they moved in. Both of her children have had chesty coughs through the winter that they have been unable to shift, and they have both been given antibiotics which have worked for a while, but the coughs and wheezing have come back. Their GP is nice, and they have always done a regular asthma review, but they've never asked her about their home, or if they have any mould.

Shaima herself is on anti-depressants but doesn't want to be. She is very worried about the future and anxious about her son's longer-term health but doesn't think she's depressed. However, she feels she should follow the advice of her GP.

Her husband has poor health and long-term mobility issues and now spends more time at home. She is increasingly worried that his health will deteriorate if the mould isn't fully sorted out. He's had worsening respiratory problems but nothing specific has yet been diagnosed.

The housing association finally had someone come out last year. They did a good job scraping, treating and repainting and she felt great about it. However, it only lasted a few months, and they haven't come back, so she's again having to clean all the time.

If a maintenance person can just come out to them three or four times a year, Shaima would be happy. With the work they do, combined with her cleaning she thinks the family's health would be okay. Without it, they are all under incredible strain and worry, while their health declines.

Case Study 3

Mo* lives in a local authority property with her husband. They are both “getting on a bit now” and have various age-related conditions, including respiratory problems. Her husband Aaron* is diagnosed with COPD.

They've had mould for years, but it used not to bother her as she cleaned it regularly and it all seemed fine. But over time the mould got worse, and it needed more and more cleaning and that was getting difficult for her.

She reported it and thought they would come and sort it all out and everything would be fine, but this hasn't been the case.

Mo says, “They've been completely useless” and it became “a never-ending battle to get them to listen and do anything.” Over time, the mould has got worse and although she's always told that the work will be done, she has waited for over a year now. She feels depressed about it every day. If she's not cleaning it, she's thinking about it. She tries not to, but she can't just ignore what she can see all the time.

Mo is always worried that the mould is affecting her husband. Between them they have GP and hospital appointments quite often, and the doctors are always cross to hear they have damp and mould to deal with.

It makes her feel “absolutely miserable”. All she can do is try to keep on top of it, but she can't make it go away. Since first reporting it, she has been feeling abandoned and like no-one cares.

The good news is that they have finally been told that someone is coming out in the next few weeks. She is hopeful that they will do a proper job, not just paint over it or something like that. It will be a huge weight off her mind to get it dealt with, but her dealings with them over the last year or more leaves her thinking they will give it a quick paint job and disappear as that's what they've seemed to do with neighbours.

**names have been changed to protect participant anonymity.*

3.0 Key Findings and Recommendations

Key Findings

Property ownership, socio-economic groups and ethnicity.

- All sectors and all groups are affected by mould and damp living conditions.
- This is not just a problem with 'rogue landlords' or dilapidated Local Authority housing stock, it is a problem across all housing sectors. Many owner occupiers with mortgages are badly effected (26.5% of respondents are owner occupiers).
- Significantly, there is also a significantly high number of responses from ethnic minorities in this survey and report (compared to other reports delivered by Healthwatch Essex IAG Team).

Timescales

- 59% of our respondents have been living with a mould problem for more than two years and the majority of those over five years.
- The length of time taken to respond to complaints is too long.
- The time taken to act on the problems and carry out correct and comprehensive remedial work is clearly below what should rightly be expected.

Response

- Complainants and reports are often met with a dismissive response and are sometimes completely ignored.
- Residents are given little or no information about what will be done or what they can expect.
- The information given on how to manage and deal with the problem isn't consistent and is often not correct.

Works quality

- Short term, quick fix sticking plaster response is the norm.
- Residents' health conditions not factored in, including babies and the vulnerable.
- Residents expected to self-manage.

Recommendations:

Response to reporting

- Training on the seriousness of mould problems for those taking initial calls and answering emails is essential. They must at all times be empathetic, and validating of the residents worries.
- Consistent advice should be given on what residents can do to help themselves - through a printed guide or webpage or emailable PDF.
- Information on residents age and health should be confirmed and logged and factored into any decision-making process.
- Clear and honest communication on what will happen next. If there is a backlog of six months, then tell the resident. Don't fob them off or lie to them. Be honest and manage their expectations.
- Include guidance on health-related issues and the need to consult a GP.

Information on how to report problems

- Promotional campaigns should be further developed and improved to highlight the importance of reporting - alongside confirmation that residents

will be listened to. This should include the potentially serious health implications of living with mould.

- Clear and specific email addresses and phone numbers should always be provided.
- Websites need to be assessed by members of the public, not by those that wrote and built them - too many seem obvious and clear to those inside organisations, but just lead residents and the public down rabbit holes.
- Community groups need to be involved, including foreign language information and an understating across the board that minority ethnic groups are disproportionately impacted.

Inspection and programme of works

- All organisations, including letting agents, management companies and authorities should have a clear and robust inspection regime that has mould and damp as a priority reporting issue.
- SLA's should be put in place with minimum standards on initial specialist assessment and works timelines dependant on the severity of the problem.

Help for owner occupiers

- What to look for when finding a specialist damp and mould company, including links to relevant UK and US Standards (The USA is very advanced in this area due to the humidity of the air in so many places, and the prevalence of air conditioning units).

4.0 Conclusion

This report is titled ‘The health and wellbeing effects of living with mould in North East Essex’, but the key findings and recommend focus almost entirely on the response to reports, and the management of the removal of the mould. That’s because it’s here that the problems occur and here that the solutions lie.

The spores emitted by mould cause wide ranging health problems, especially for the young, the old, and those with asthma and allergies. However, it’s not just about respiratory issues and allergic reactions - the problems go much wider, including into the mental health arena.

45% of the people we engaged with have long term, pre-existing health conditions, and 86% have had their health and wellbeing affected by living with mould, including anxiety (49%) and depression (39%), alongside other mental issues, and physical problems such as respiratory problems, coughs and headaches.

The topic is a perfect triangulation point between Healthcare, Social Care, and Housing.

- Can we get GPs to ask the right questions about a patient’s housing when presented with a worsening asthma case, or cases of anxiety and depression?
- Can they effectively refer into social care and housing teams?
- Can Social Care teams identify the need to assess specific mould related housing conditions and healthcare requirements of vulnerable people who present to them?
- Can housing bodies ensure that every member of their various teams, at every level, has a full understanding of the implications of having to live with mould?

Across the board, GP’s, charities, social care workers, carers and other bodies should be encouraged to voice their concerns by contacting housing owners and providers in support of those they are caring for and dealing with.

It is hugely important that the serious health implications of living with mould and damp are recognised throughout the population, alongside a realisation that the repercussions of not effectively dealing with the problem can have the most devastating consequences.

5.0 Terminology and Acronyms

ECC - Essex County Council

SNEE ICS - Suffolk & North East Essex Integrated Care System

GP - General Practice or General Practitioner

SLA - Service Level Agreement

Owner Occupier - A person living in a home they own themselves (often through a mortgage).

NHBC Buildmark - A common 10-year insurance scheme covering problems, faults and repair issues with buildings bought new from a builder or developer.

IAG Team - Healthwatch Essex's Information & Guidance Team.

COPD - Chronic obstructive pulmonary disease.

Factor V Leiden - a mutation of one of the clotting factors in the blood.