

Experiences of the People of North East Essex in Relation to Dermatology Services

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Sara Poole
Information & Guidance Team
For Suffolk & Northeast Essex Integrated Care System
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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. We also provide an information service to help people access, understand, and navigate the health and social care system. 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 health and social care services and choice in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthened as a voice of the public with a role in ensuring lived experience was heard at the highest level.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are meeting 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 complex experiences such as the one's shared in this report.

1.2 Background

Healthwatch Essex were approached by Suffolk & north east Essex to undertake a series of projects focussing on the lived experiences of people in the area in relation to their health, care and wellbeing.

1.3 Acknowledgements

Healthwatch Essex would like to thank all the members of the public and professionals who took part in this project through the survey and interviews. Our thanks are also made to those individuals who took the time to meet with us and share their personal, heartfelt and emotive stories.

1.4 Terminology

BCC-Basal-cell Carcinoma

PCC-Primary Care Centre

Hidradenitis Suppurative- a painful, long-term skin condition that causes abscesses and scarring on the skin.

Granuloma Annulare- a rash that often looks like a ring of small pink, purple or skin-coloured bumps.

1.5 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 projects time frame. 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

The aim of this project is to gather people's experiences of using the dermatology service in north Essex. Current waiting times for a first appointment with the dermatology department is 47 weeks at Colchester hospital and 16 weeks at Ipswich hospital-[Estimated outpatient wait times - East Suffolk & North Essex NHS Foundation Trust \(esneft.nhs.uk\)](https://www.esneft.nhs.uk)

‘Skin conditions are the most common reason for patients to present in primary care. Around one in four patients visit their GP with skin problems each year. Many skin conditions are long term, with significant morbidity and requiring high levels of self-care. Skin cancer incidence and dermatology referrals are rising with high demands on secondary care services and increasingly long delays for dermatology specialist review.’

The Royal College of General Practitioners (RCGP)

2.1 Engagement methods

Survey

A survey was created and distributed via our network of stakeholders and partners, as well as on our social media platforms and a dedicated page on our own website.

Interviews

In order to gain a more in-depth understanding of GP services we conducted one-to-one interviews with participants.

Case Studies

To further understand the experience of GP services we gathered details of lived experiences from members of the public.

3.0 Key Findings and Recommendations

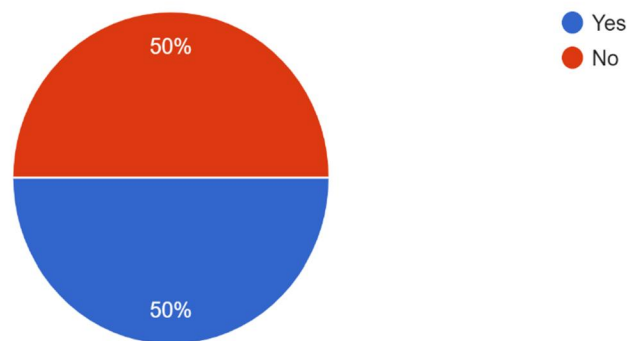
3.1 The Survey

In order to better understand people's experiences of accessing/using the dermatology service in northeast Essex, we circulated a survey which garnered the following data.

Of the 20 people who responded to the survey, 50% were waiting for an appointment and 50% were not.

1. Are you currently waiting for a dermatology appointment?

20 responses



We then asked how long they had been waiting for an appointment. The following responses were garnered.

'About five months at present. I have been trying for years. I was referred some years ago, only to be informed later that the dermatology department had imploded and didn't exist at that time.'

'Six months for a second appointment.'

'Nine months.'

'14 weeks for a follow up appointment.'

'10 months-this is my third time through the system.'

'Since early 2020.'

'A year.'

'Four months.'

'The referral is going through now.'

'Five months.'

We then asked for respondents to tell us about their experience whilst waiting for their appointment; has their condition got worse? Is it effecting their emotional/mental health? Have they looked into alternative therapies/private healthcare? etc. Much of the feedback stated that their condition had become worse and in many cases was started to affect their confidence and mental health.

‘I paid for a private consultation, the result of which kick-started the process I am currently in.’

‘My condition has stayed the same - I went back to my old medication because without anything it deteriorates quickly.’

‘My condition worsened, I got creams from the GP and used YouTube advice and support groups. I was offered December 2022 for a morning appointment out of my local area and at a time and day I could not make, as I am a carer with one only respite afternoon.’

‘I have changed my diet which has helped.’

‘My condition has worsened and is becoming more visible, which has affected my confidence around others. Alternative therapies are ineffective. I cannot afford private health care.’

‘I am completing this survey on behalf of my mother. She was told in August 2019 that she has Basal Cell Carcinoma on her shoulder. She was given chemo cream and told she may need radiotherapy. We then found out that she couldn't have radiotherapy as she had had two high dose cycles during her breast cancer treatment in 1996. We were left while they decided what to do next. Moving forward to March 2020 and COVID. We did not hear another thing. The GP has admitted that we have been lost in the system due to COVID. Still waiting..... despite chasing’

‘I am on the cancer pathway but waiting times are longer than stated, there is little discussion or advice, and after a biopsy there was no face to face follow up - I was told I will receive a letter. It's remote and heartless.’

‘It's worse. I am now looking for private care as I can no longer wait.’

‘My condition has got worse, affecting my mental health and confidence.’

‘My condition has got worse and spread on my body.’

‘I was told there was over a year's wait for something which was affecting my mental health, stopping me from leaving my home and socialising.’

‘It was a very quick referral from my GP and within two weeks, I had an appointment to get the mole removed.’

‘I was offered surgery in 2020 for a tag, given a short notice date which coincided with a pre-booked holiday in the far east. Then when I re-applied, I was refused.’

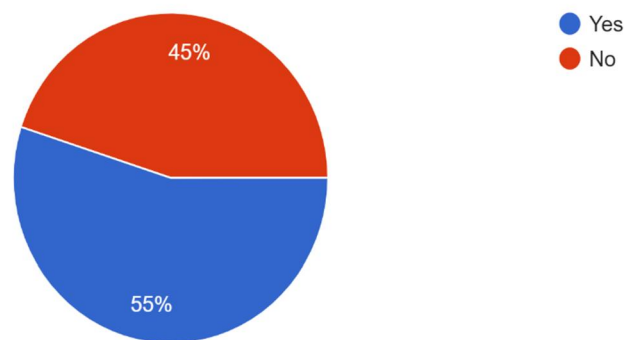
‘My condition continues with no sign of stopping.’

‘I have looked into a private appointment.’

In Question 4 we asked if they had attended an appointment during/since the Covid pandemic and for them to tell us about that experience. 55% of the respondent's had attended an appointment during/since the Covid pandemic.

4. Have you attended a dermatology appointment during/since the Covid-19 pandemic?

20 responses



Comments received were as follows:

‘Face to face appointment, I was referred back into the system and was told that I needed to see the specialist again in a month’s time. My GP received a letter in November that stated I had just been seen by the specialist. I saw them in July.....’

‘I had a BCC removed from my back at the beginning of Covid and another two removed last December.’

‘The appointment was face to face and I was not impressed with consultant.’

‘My appointment was via telephone, with preceding photographs. A prescription was made but did not clear the condition. I was re-referred to a very long wait.’

‘My condition was seen in 2020, wasn’t followed up, and left unresolved. Late in 2022 I had to ask my G.P for a cancer pathway referral.’

‘I had a face-to-face appointment and am waiting for a follow up. The doctor wasn’t able to provide medication for the condition due to me taking other medications and wasn’t sure how one could affect the other.’

‘I have been told a number of my moles/ growths are cosmetic and will not be dealt with by the NHS even though they cause me a great deal of issues.’

‘I attended an appointment today after waiting for 10 months. I was not seen by the consultant named in my letter but another doctor. She did not seem very confident and when she did a skin scrape, she had to be reminded by the nurse to wear gloves and to label the bottle for the specimen. She told me it will be a month or two for the results and then I may need a biopsy. No medication was offered to me in the meantime.’

‘I eventually travelled to Ipswich as Colchester could not give me a time scale and my mental health was so poor it begun effecting my work. Ipswich offered me a cancellation.’

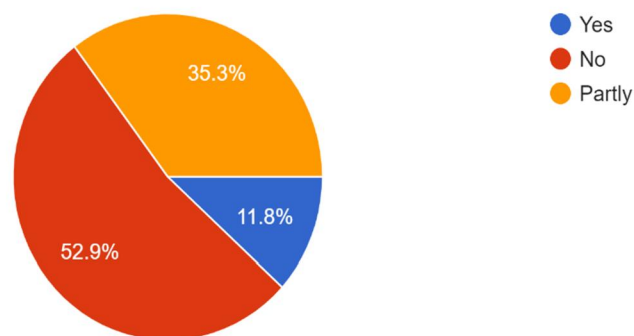
‘I submitted photos then had a face-to-face appointment with the GP, then the dermatology nurse. Removal is planned for this Thursday at the PCC.’

‘My appointment was face to face. I took photos of my skin condition, but the dermatologist didn’t look at them. She decided that what I had were bites. I felt totally not listened to and felt insulted. My skin condition continues still and can be very unpleasant.’

We then moved on to explore how satisfied were respondents with their appointment, the referral process and the care provided. Over 50% of the respondents were not happy with their dermatology experience. They then explained why below:

6. Were you satisfied with your appointment, including the referral process and care provided?

17 responses



Comments received were as follows:

‘I have been trying for years with no success. At least I am getting somewhere now, in my mid-60s.’

‘She- (the doctor) said that I would need a monthly blood test and that she would then see me every month. Why say that if you have no intention of carrying it through?’

‘Staff at dermatology very good, there was no waiting around for the appointment nor when I went in to have BCCs removed.’

‘The appointment offered was a time, day and location I could not attend as a carer with one respite afternoon and nothing local or afternoons appointments available for foreseeable future.’

‘I had no confidence in her (the consultant)’

‘I have had one telephone appointment, and one prescription, in close to two years, while my condition steadily worsens. This is not effective healthcare.’

‘I have been ignored, left to fester, and can’t trust the NHS.’

‘We still have not been seen’.

‘The doctor should be aware of medication conflicts.’

‘My son is still waiting to be seen.’

‘GPs are not well trained for this kind of problem, every time you go, they always say its eczema and don't look properly into it.’

‘I was told that my issues are cosmetic. I have large growths of my head which itch and bleed but was told the NHS won't remove them.’

‘It was good to finally have the appointment but frustrating that I still have to wait for so long for test results and then a treatment plan.’

‘There are excessive wait times, with no clear idea of how long it would be meaning that I travelled out of area.’

‘It was very quick and effective from start to finish.’

‘I was totally misdiagnosed.’

‘No, I am happy with the service care I have received. ‘

‘The lady who I spoke to was exceptionally unhelpful and almost rude, lacking personal skills.’

‘I think they are the worst department I have had dealings with at Colchester Hospital.’

‘It's an absolutely shocking service. The cancer has spread across her shoulder more now. The GP is trying to treat her but there is no response from Dermatology. ‘

The final questions in the survey asked for demographic information regarding the respondents:

Of the 20 respondents:

6 were aged 65-74

3 were aged 55-64

2 were aged 35-44

1 were aged 75+

5 were aged 45-54

3 were aged 25-34

Overwhelmingly, responses were from females; 15 identified as female and five as male.

19 respondents stated that their gender was not different to the sex they were assigned at birth. One respondent stated their sex was different.

15 people stated their ethnic background was White: British/English/Northern Irish/Scottish/Welsh, two were White: any other white background, one was Asian/Asian British; any other Asian/Asian British background and one person preferred not to say.

8 respondents stated that they were not carers or considered themselves to have a disability or a long-term condition.

9 considered that they did have a long-term condition.

1 considered they had a disability.

3 considered they were a carer.

The first half of the respondent's postcode were:

6-C07

6-C05

4-C015

3-C013

Case Studies:

Several people wanted to give us further feedback regarding their experience:

Bob

‘Although I appreciate that on the scale of things my condition is not life threatening etc I suspect there is no understanding of the daily misery it can cause.’

Sue

‘My health issue is one that I wouldn’t wish on my worst enemy. I find myself struggling with stopping myself get depressed when it flares up. I’m generally a very easy-going person. I wish they wouldn’t mess us around.’

Anne

‘I was referred to dermatology as I was diagnosed with Granuloma Annulare, and our skin specialist at Colchester was retiring so I then got junior skin specialists and locums to look at my condition and was told to put steroids on my legs which made the condition worse! After that I cancelled an appointment but have been left with disfigured lower legs and never wear skirts or short dresses for that reason. I was going to go to my GP and get some skin grafts done or at least they should put the damage right but was discharged and told the only way to get anywhere as there was no skin specialist for some time in Colchester was to go private which I could not afford.’

Doug

‘The service is largely inaccessible. The long waiting times render the service largely ineffective. A prescription may last several weeks, but there won’t be another prescription for months.’

Sarah

‘You are always made to feel you are not important.’

Margreat

‘I feel hopeless to be honest. The wait is long, and the confidence is low. With everything else that’s happening in the UK now, it is just depressing.’

Phil

‘You are just not listened to. I am still suffering with the problem, but I can’t be bothered to start all over again.’

Gemma

'I wish I had been told of the long wait time by the GP as I would have considered other options sooner.'

Yumi

'I am diagnosed with Hidradenitis Suppurative.

I'm currently with Winstree medical practice and I haven't been able to get an appointment to get further help with this condition.

I'm awfully confused and just want to see someone about my condition as I think it's getting worse and with my expired implant that I called last August to have removed, still in my arm, I think it's causing hormone imbalance.'

Babs

'I was referred to Colchester Dermatology in March 2022. After treatment, I was given a blue card and was told that I could use this card, without having to go through my GP, within three months. In April/May a pimple appeared on my right-hand index finger but when I rang dermatology, I was told that I could not have an appointment until September. In the meantime, I could not see a GP and kept getting antibiotics from nurses/the Urgent Treatment Centre/and a doctor. from 111 on 5th June, who told my own surgery that I must be referred to dermatology. I was put on the two-week pathway on 7th June 2022, and I sent a photo of the lesion on my finger on 8th June 2022. Colchester sent me to Ipswich Hospital Dermatology, on 13th June and I had a biopsy on the 24th of June and as a result of this I was referred to Broomfield Plastics on 3rd August. By this time my finger needed dressing regularly at Ambrose Avenue Surgery, I was on strong painkillers and was caring for my disabled husband. I had my lesion excised on 26th August at Broomfield Hospital and it included plastic surgery. I had several follow-up appointments at Broomfield for dressings and hand therapy started in November and is still ongoing.

I do not have full use or flexibility now of my finger. No-one should EVER have to go through what I have had to endure over the last nine or ten months with my finger. I had a suspicious spot on my face last November, saw my GP, and was fast tracked to Colchester and had a consultation and it was excised in January. I understand that there is a national shortage of Dermatologists, but this really isn't acceptable.'

Interviews

Derek*

'I am 82 years old and in 2019 I saw my GP as I had a growth on my forehead which kept bleeding due to it catching on my hat. The GP referred me to dermatology and the

consultant said they would remove it. I had an appointment sent through but unfortunately it clashed with a trip that had already been booked overseas to visit family, so I was unable to attend. I decided to restart the process when I returned from my trip, but Covid hit, and I had to wait. When I was referred the second time, I was seen at Ipswich hospital and was told that it was cosmetic so it would not be removed under the NHS. I had no choice but to pay for the procedure privately at a cost of around £400. I am frustrated that the clinical decision changed over the course of the pandemic which led me to having to pay for private treatment.'

Mia*

'I noticed that a mole on my arm had changed shape and was getting bigger. I sent photos to my GP; they saw me straight away and I was referred to dermatology. I had an appointment within a week with a nurse and then the mole removed a week later. This was sent off for tests and was found to be pre-cancerous. Luckily, I was having regular blood tests for another medical condition at the time, so I knew that there was nothing serious happening. I also had a follow up appointment which included an all over body check and nothing else was found. The whole process was quick and easy, letters and appointments arrived swiftly. I have had some ongoing health issues recently and I have to say that this process was the least stressful and the best communication out of all the health departments I have to deal with.'

Jacob*

'I have spent nearly ten years going to see my GP about my skin issue, I was prescribed various creams which did nothing to help and even when I told a GP that nothing was helping, he still gave me more of the same cream and told me it was probably a fungal infection. I had been given fungal creams before and they didn't help. Some of the steroid creams I was given did make a difference but also thinned my skin, so I was told not to use them long term. I was finally referred to dermatology and saw a consultant who was great, very helpful and listened to me. He prescribed me cream which really helped and my condition almost disappeared. But when I ran out of the cream and tried to get more but the GP couldn't find out on my records what it was that I had been given so couldn't prescribe me more. I didn't have any follow-up with the dermatologist either, so I ended back at square one.

I then had another dermatology referral, but this time was a send photo's/a phone call due to the Covid pandemic. The consultant was difficult to understand over the phone. I also felt that she couldn't really understand/diagnose my condition without seeing it in person, but she prescribed me two creams and said to go back if they didn't help. They didn't help and I didn't have any contact information to go back to her with an update and neither was I contacted for any sort follow up.

March 2022 and my third referral to dermatology was made, I was finally given an appointment on 25th of January 2023. During this time my condition has spread from my

groin area to my armpits, neck, chest and shins. It is very red and sore and looks horrible. This does have an impact on my mental health, it can't not with the amount of time that I have spent trying to get it diagnosed and to be given an effective treatment plan. I saw the consultant who decided to carry out a skin scrape, but she had to be reminded by the nurse to wear gloves and to label the specimen bottle. This did not inspire confidence. She told me that the results would take 'a month or two' to come through and that she would also refer me for an urgent biopsy.

The date for the 'urgent' biopsy took two months to come through, I had this procedure on the 24th of March. I asked about the skin scrape results as I had not heard anything, and the doctor told me that they were not on my file. Two months since the skin scrape was done and still not results. I understand that I must now wait four weeks for the results of the biopsy. I have no idea if I will then be given another appointment with a dermatologist to discuss the results and to have a treatment plan or not. I have a sinking feeling that my battle is not finished and that I will have to chase for results and more appointments. I understand that the NHS is under pressure, but this is not effective healthcare.'

4.0 Conclusion

The general feeling from respondents was very negative regarding this area of the NHS. The long waiting times for appointments and lack of communication/information regarding this has resulted in distrust, a lack of confidence in the system and frustration.

'I feel hopeless to be honest. The wait is long, and the confidence is low.'

Lack of follow ups and monitoring of skin conditions has led to people having to go back through the referral process numerous times, seeking private treatment or trying to cope with the situation on their own. This is not an effective use of resources and causes more distress for the patient. It costs the system more with patients having to return to their GP and going through the referral process again.

The mental health was another aspect that respondents talked about. The affect that the waiting times had on their mental health is a concern. The feeling that they are not listened to or the impact that their condition has on their lives is not taken seriously. This could lead to other NHS services having to be accessed so these patients can have suitable support.

'Although I appreciate that on the scale of things my condition is not life threatening etc I suspect here is no understanding of the daily misery it can cause.'

There is a lack of understanding as to which conditions are covered by the NHS and which are not and how that remit seemed to change over the course of the pandemic. Clearer information needs to be given to patients, so they can make an informed choice regarding further treatment options.

Recommendations:

- Spreading the waiting list over Ipswich and Colchester hospitals-only 16 weeks wait at Ipswich and 47 for Colchester. Why aren't Colchester patients being offered earlier appointments when possible? Is this a possibility? Multi-disciplinary teams who can investigate long term/on-going cases that are not responding to treatment?
- Better communication-clearer with treatment plans/general communication. Keeping patients informed regarding their time on the waiting list and making sure that they know they have not been forgotten. To receive a text message the day before an appointment that that has taken ten months to be booked, asking to let the department know if it is no longer needed and that being the only contact since the referral was made is not acceptable and doesn't make patients feel very cared for. Improve communication regarding treatment plans and test results. Confidence in the service is very low and improved communication would help towards gaining some of that confidence back.
- Listening to patients-mental health and how their condition affects them. Keeping in touch while they are waiting for their appointment. Monitoring their mental health and offering supported when needed.

- Identifying carers and attempting to cater for their needs regarding appointment times and venues. Flexibility within that system where possible and understanding that patients with caring responsibilities need to have time to plan.
- GP's attitude and support. Possible extra training for GP's so that patients who present with recurring skin issues are given extra support and further investigations. Understanding the impact that a long-term skin condition can have on a patient's daily life and mental health.