

BMJ Open

'This isn't what mine looked like': a qualitative study of symptom appraisal and help seeking in people recently diagnosed with melanoma

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-005566
Article Type:	Research
Date Submitted by the Author:	26-Apr-2014
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Primary Subject Heading:	Oncology
Secondary Subject Heading:	Dermatology, Diagnostics, General practice / Family practice, Qualitative research
Keywords:	Dermatological tumours < DERMATOLOGY, PRIMARY CARE, QUALITATIVE RESEARCH

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9 **'This isn't what mine looked like': a qualitative study of symptom**
10 **appraisal and help seeking in people recently diagnosed with**
11 **melanoma**
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ABSTRACT**Objective**

To explore symptom appraisal and help-seeking decisions among patients recently diagnosed with melanomas, and to compare experiences of people with 'thinner' (<1mm) and 'thicker' (>2mm) melanomas, as thickness at diagnosis is an important prognostic feature.

Design

Qualitative interview study.

Participants

Adult patients within ten weeks of melanoma diagnosis.

Setting

Two UK dermatology clinics: Cambridge and Edinburgh.

Results

63 patients were interviewed (29-93 years, 31 women, 30 thicker melanomas (superficial spreading 10, nodular 10, others 10). All described their skin changes using rich lay vocabulary. Many included unassuming features such as 'just a little spot' as well as common features of changes in size, colour and shape. There appeared to be subtly different patterns of symptoms: descriptions of vertical growth, bleeding, oozing and itch were features of thicker melanomas irrespective of pathological type.

Appraisal was influenced by explanations such as normal life changes, prior beliefs, and whether skin changes matched known melanoma descriptions. Most decisions to seek help were triggered by common factors such as advice from family and friends; family experiences of melanoma or media coverage also prompted people with thinner melanomas. Eleven patients reported previous reassurance about their skin changes by a HCP, with little guidance on monitoring change or when it would be appropriate to re-consult.

Conclusions

Patients diagnosed with both thinner and thicker melanomas often did not recognise or interpret their skin changes as warning signs or prompts to seek timely medical attention. The findings provide guidance for melanoma awareness campaigns on more appropriate images, helpful descriptive language, and the need to stress the often apparently innocuous nature of potentially serious skin changes. The importance of appropriate advice, monitoring and safety-netting procedures by HCPs for people presenting with skin changes is also highlighted.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This study is the first exploration of symptom appraisal and help-seeking among people diagnosed with ‘thinner’ melanomas (T1, very good prognosis, 5 year disease-free prospects 95%), compared with those with ‘thicker’ melanomas (T3 and T4, less good prognosis, 5 year disease-free prospects <45%).
- The study did not identify clear discriminating features in the diagnostic pathway, or features of thinner versus thicker melanomas.
- The findings highlight a mismatch between the information people need when assessing their skin changes and the information and images currently available, thus providing opportunities to incorporate more appropriate descriptive language, images and information into targeted community awareness campaigns as well as by the NHS and charities via their websites and promotional materials.
- A small but important minority of participants did not have their developing melanomas recognised during their first primary care consultation, and were not provided with enough information about on-going assessment of further skin changes or when to return to their clinician. These ‘safety-netting’ opportunities could be improved by more systematic approaches by HCPs.
- Using semi-structured interviews close to diagnosis allowed in-depth exploration of the participants’ experiences and views, but the accounts are necessarily retrospective and subject to recall and framing bias.

INTRODUCTION

Diagnosing melanoma earlier is high on the UK health policy agenda. Since its announcement in the 2007 Cancer Reform Strategy, the National Awareness and Early Diagnosis Initiative (NAEDI) has supported activities to promote the earlier diagnosis of cancer [1], and aims to 'save an additional 5,000 lives every year by 2014/15 and to narrow the inequalities gap at the same time' [2]. In December 2013 a Parliamentary Roundtable addressed 'Improving the early diagnosis of melanoma- how can we save more lives?', and a 'Be Clear on Cancer' symptom awareness campaign, led by Public Health England in partnership with NHS England and the Department of Health, starts a melanoma pilot this summer focusing on encouraging earlier detection of melanoma. Since 2011 'Be Clear on Cancer' symptom awareness campaigns have been undertaken for bowel, lung, kidney, bladder and breast cancer, and early evaluations show some promising but patchy results [3]. Melanoma is the next focus because it poses a significant yet largely avoidable public health threat; it is estimated that around 190 deaths from melanoma could be avoided each year if survival rates in England matched the best in Europe [4].

Worldwide melanoma incidence rates are increasing faster than any other solid tumour. In the UK the incidence has quadrupled since the 1970s [5]; similar incidence rises have been reported across Europe [6 7], the USA [8] and Australia [9]. In the UK there were more than 2,209 deaths and 12,800 new cases diagnosed in 2011, with a disproportionately high rate among people aged less than fifty years [10]. There is considerable UK regional variation in overall five year relative survival rates, with Scotland having the highest average rate of 89%, while Wales has the significantly lower rate of 74% [4]. The most important prognostic factor is the tumour thickness at diagnosis according to the Breslow scale (T classification) [11]. Patients with a primary melanoma ≤ 1 mm at diagnosis (T1) currently have 5 year disease-free prospects of over 95%, while for tumours ≥ 4 mm at diagnosis but with no detectable evidence of metastatic spread (T3, T4) this falls to $<45\%$ [10]. Tumour thickness is also associated with rapid growth which occurs more frequently in elderly men [12].

Timely diagnosis can be influenced by the diagnostic skills of GPs. A recent analysis of the Cancer Patient Experiences Survey 2009 and the 2010 RCGP cancer audit data reported that more than 90% of people diagnosed with melanoma were seen by their GPs less than three times before diagnosis, compared with 60-80% for the majority of cancer types [13]. This suggests that most melanomas are recognised by GPs and appropriately referred to specialist care in England [14].

Timely diagnosis can also be influenced by people's symptom appraisal and help-seeking behaviour. Compared with other cancers, people with melanoma have among the longest time between first noticing a symptom and presenting to their GP [15 16], suggesting that the major opportunity to diagnose melanoma earlier is prompting earlier presentation to healthcare through signs and symptom awareness campaigns [17]. This requires an understanding of how people interpret changes in their moles or new lesions. We present findings from an in-depth interview study with UK patients recently diagnosed with 'thinner'

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3 (T1) compared with 'thicker' primary melanomas (T3 and T4), which aimed to explore the
4 processes and experiences of symptom detection and help-seeking decisions leading to
5 melanoma diagnosis.
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9 10 **METHODS**

11 **Design and ethics**

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13 Semi-structured face to face in-depth interviews were conducted with adults diagnosed
14 with invasive cutaneous melanoma within the previous ten weeks. Ethics approval was
15 obtained from the Cambridgeshire 4 Research Ethics Committee (11/EE/0076).
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19 **Setting and recruitment**

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21 Potential participants were identified and recruited by the melanoma/skin cancer nurse
22 specialists via the weekly multidisciplinary team meetings of dermatologists, plastic
23 surgeons and oncologists at two regional hospitals: Cambridge University Hospitals NHS
24 Foundation Trust in the East of England, and the Edinburgh Royal Infirmary, NHS Lothian,
25 Scotland. These hospitals together serve a population of approximately 1.4 million, and the
26 MDT meetings review more than 400 new cases of invasive cutaneous melanoma each year.
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30 All adults aged 18 and over newly diagnosed with a primary invasive cutaneous melanoma
31 (staged as ≤ 1 mm (T1, 'thinner') or ≥ 2 mm (T3 and T4, 'thicker') at the two participating
32 hospitals were eligible for inclusion unless the melanoma/skin cancer nurse specialists felt
33 that they were not suitable on clinical grounds (other severe physical or mental health
34 conditions). Patients were mailed an invitation letter with a patient information sheet. As
35 T3 and T4 melanomas are diagnosed at about 25% of the rate of T1 melanomas, we
36 recruited all those with thicker melanomas who agreed to take part. At the same time we
37 purposively sampled people with T1 melanomas by age, gender, location and season to
38 ensure that we had a broad range of views and experiences, and we continued until
39 saturation of data.
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46 **Data collection**

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48 Interviews were undertaken between January 2012 and January 2013. In each area an
49 experienced researcher used a semi-structured approach, with an interview schedule
50 informed from the literature [18 19], our collective expertise from interviewing patients
51 recently diagnosed with other cancers [20], and a pilot study (n=17). The theoretical
52 approach of the Model of Pathways to Treatment [21 22] (Figure 1) was used to underpin
53 the interview schedule, exploring the processes that occurred within each time-interval and
54 focusing on: how initial symptoms were noticed; personal risk perceptions; the language
55 used to describe symptoms and changes over time; the participant's decision-making and
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3 triggers to help-seeking; and the experience of the diagnostic process of primary and
4 secondary care from the patient perspective. A calendar-landmarking technique [23] was
5 used as an adjunct to the interviews, to establish the timing and details of events which led
6 to the melanoma diagnosis, together with diaries and letters that participants referred to
7 during this process. Participants were also invited make a pencil drawing/s of their skin
8 cancer as it developed; on-going analyses are examining perceptions of lesions over time,
9 and comparing the drawings with clinical images [24]. At the end of each interview,
10 participants completed a short questionnaire to provide demographic data, and information
11 about their skin and hair colour and their skin's response to UV light using the widely
12 validated Fitzpatrick Scale [25].
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17 Interviews were undertaken as soon as possible after diagnosis, with all interviews
18 completed within 10 weeks of diagnosis, and the majority within 6 weeks. Interviews lasted
19 between 40-65 minutes and were conducted primarily in the participant's home although
20 two people chose to be interviewed in university offices. Patients were sometimes
21 accompanied by a family member, usually spouse or daughter. Audio-recordings of
22 interviews were professionally transcribed verbatim and anonymised.
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27 Analysis

28 All interview transcripts were repeatedly read and re-read by the two researchers LB
29 (nursing background) and DC (health services researcher), and the members of the 'core'
30 analysis team also read the majority of the transcripts (FW, academic GP; SS, health
31 psychologist; CC, primary care researcher). Analysis was an iterative process starting near
32 the beginning of data collection and using the 17 pilot interviews to develop our analytic
33 strategy. We used the approach of Framework analysis to create and establish meaningful
34 patterns in five phases, namely: familiarization with the data, generating initial codes,
35 inductively searching for themes among codes, index charting and mapping of data, before
36 finally defining and naming themes [26]. The coding and data management were supported
37 by NVivo software (QSR International, version 9). The Model of Pathways to Treatment
38 (Figure 1) was also used to underpin the analysis with a theoretic model for the different
39 intervals and processes that occur along the pathway to diagnosis and treatment, in order
40 to accurately assess the time intervals, their content and context. The final themes were
41 agreed through a series of meetings involving all five 'core' researchers, and a consensus
42 meeting with the wider study team.
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49 The analysis focused on the main themes within the time to presentation (TTP), defined as
50 from the first detection of skin change to the first consultation with a healthcare
51 professional [27 28]. This interval comprises the appraisal and help-seeking intervals [21],
52 and the analysis examined patient and healthcare factors as well as 'disease' factors,
53 relating to the developing melanoma. When the first consultation did not result in a
54 referral, we also included further iterative processes until the next consultation in the
55 analyses. Participants with shorter intervals tended to use diaries and have good recall of
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3 the relevant dates. People with longer intervals tended to have vaguer recollections,
4 particularly around the time they had first detected any skin change. While participants
5 were often able to discuss triggers to help-seeking, they were less able to recall the precise
6 dates of these triggers, and we therefore do not present the separate durations of the
7 appraisal and help-seeking intervals.
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10 We went on to examine our themes by comparing narratives from participants diagnosed
11 with thinner and thicker melanomas, and by the melanoma types within these groups. We
12 further validated our themes by examining the whole dataset stratified by gender, by age
13 (less than 60 vs 60 and over, and 80 and over), by educational level (no further education vs
14 further education), and by geographical location (Cambridge vs Edinburgh). Credibility was
15 increased by the two researchers together undertaking coding and producing code tables
16 throughout the analytic process, and reaching consensus from the potentially wide range of
17 interpretations across the 'core' analysis team.
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24 **RESULTS**

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26 A total of 241 adult patients were approached to take part in this study (Cambridge 114,
27 Edinburgh 127), 121 were willing to participate (50%: Cambridge 53%, Edinburgh 47%), and
28 63 were interviewed.
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33 **Patient characteristics**

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35 Table 1 shows the demographic and self-reported skin characteristics of the 63 study
36 participants, and the clinical characteristics of their melanomas, comparing participants with
37 thinner (n=33) and thicker (n=30) melanomas. The thinner melanomas were all
38 histologically reported as superficial spreading melanomas (SSM) and lentigo maligna
39 melanomas (LMM) apart from one diagnosed as part SSM and part NM ('other'). Due to our
40 sampling strategy there was a higher prevalence of nodular melanomas than in reported
41 local figures. However, only a third of the thicker melanomas were nodular melanomas
42 (NM, n=10), while a third were SSM (n=10), and the remaining third had 'other' diagnoses
43 (LMM 2, acral 1, malignant blue naevus 1, unclassified 6). Of the nine participants diagnosed
44 with melanoma on their back, seven were male, and three had thicker melanomas (NM 2,
45 SSM 1).
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50 The mean age of the whole group was 63.7 years (range 29-93 years); the mean age of
51 those with thinner melanomas was 60.5 years, and of those with thicker melanomas was
52 66.1 years. 58% of melanomas in men and 42% in women were thicker. The groups were
53 otherwise similar for socio-demographic factors: most were white British with one white
54 non-British, almost half were retired (30, 48%), and only a third had undergone higher
55 education. One quarter of the group reported a family history of melanoma, while eight
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3 participants reported previous skin cancer (melanoma 2, basal cell carcinoma (BCC) 6): we
4 were only able to verify the two melanomas with histology reports.
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8 **Duration of skin changes**

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10 Four participants (male 3, female 1) had their melanomas diagnosed opportunistically by a
11 HCP (3 GPs, 1 oncologist); all these were thinner melanomas. The time to presentation (TTP)
12 was between 1 week and 303 weeks (thinner: median TTP 21 weeks, range 1-303 weeks;
13 thicker: median TTP 19 weeks, range 1-156 weeks). Most participants who presented with
14 skin changes were referred after their first primary care consultation. The remainder were
15 referred after their second consultation (n=11); none reported more than two consultations
16 prior to referral. Comparisons between those with thinner (n=4) and thicker (n=7)
17 melanomas who were referred after a second primary care consultation are presented in
18 Table 5 and discussed later (see section on Healthcare providers and system factors).
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23 The main emerging themes within the appraisal and help-seeking intervals are discussed
24 below. Throughout this section quotations are accompanied by information about gender
25 (M, F), age, melanoma group (thinner or thicker), type of melanoma (SSM, NM, LMM,
26 other), and symptom duration as time to presentation in weeks (including first and second
27 presentations).
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32 **The appraisal interval**

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34 The 59 participants who detected their melanoma themselves described a variable and
35 complex process of appraisal and re-appraisal of their skin, against their background
36 knowledge of 'normal skin changes' and potential risk factors. We found no evidence of
37 differences between people with thinner and thicker melanomas across any of these
38 themes.
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43 **Patient factors**

44 ***Explanations for skin changes***

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46 Awareness of a skin change, either a new lesion or a change in an existing lesion, did not
47 usually cause any initial concern as it seemed so innocuous, and was often attributed to
48 normal life changes such as pregnancy or aging.
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51 *'I didn't recognise it as something that was different, because I've got quite a few moles on*
52 *my skin so therefore I thought, "Has this been here before, or am I just imagining that I*
53 *haven't seen it before?"' [F, 68, thinner, SSM, 52w]*

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55 *'Perhaps because I'd been pregnant and everything was darker anyway or you know, I didn't*
56 *take any notice.'* [F, 36, thicker, NM, 17w]
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3 Other explanations were also often made, such as an insect bite or injury when the
4 participant had been outside or in the garden.

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6 *'Since I'd been outside to a barbeque and I thought, oh well I've been bitten, it's just bitten*
7 *there on the mole.'* [F, 54, thicker, SSM, 1w]
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9 Skin changes were sometimes attributed to another skin condition (such as psoriasis) if it
10 presented in a similar way; in these cases participants' previous experiences of a benign
11 condition could influence their perception of the potential seriousness of the new skin
12 changes.
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14 15 16 17 **Prior beliefs about melanoma and its risk factors**

18 Skin changes were appraised within the context of peoples' prior beliefs about melanoma
19 and its risk factors, and their life experiences. Participants often used the terms skin cancer
20 and melanoma interchangeably, and their prior awareness of melanoma varied widely.
21 Whereas some participants noted that they had no awareness at all, others described
22 gaining some knowledge about melanoma via TV programmes, magazines, the internet, and
23 occasionally, health promotion material. A minority had heightened awareness through the
24 melanoma experience of a family member or friend, or even a celebrity. A family history of
25 melanoma or a personal previous melanoma led several people to have heightened risk
26 perception and awareness and to quickly identify skin changes as a potential melanoma; all
27 these people sought help rapidly and presented with thinner melanomas:
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32 *'I wouldn't have known what they were talking about'* [M, 62, thicker, SSM, 52w]

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34 *'...because my mum has had a melanoma ten years ago so I've always been aware to keep a*
35 *check on my moles.'* [F, 29, thinner, SSM, 3w]
36

37 Many participants showed some understanding of the risk factors associated with
38 melanoma and/or skin cancer when they discussed having lived in hot climates, or having
39 suffered from sunburn, especially as a child. However, some were quite certain that they
40 had never exposed themselves to the risk of UV damage:
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43 *'I thought I had been careful about sitting out in the sun.'* [F, 57, thicker, NM, 36w]
44

45 Prior knowledge or experience of melanoma and its risk factors did not appear to be related
46 to educational levels, nor to melanoma thickness at diagnosis.
47

48 49 50 **Do skin changes 'match' a melanoma?**

51 While some participants admitted to prior knowledge of the symptoms and signs of a
52 melanoma, such as 'jagged edges' or change in colour, only a few people had known that an
53 itchy or bleeding mole was a 'bad' sign. Only two people noticed a match between their
54 observed skin changes and their mental image of a melanoma, and this match appeared to
55 prompt appropriate help-seeking, leading to shorter times to presentation.
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3 *'I don't know when I learnt it, but it was just in my subconscious that "ooh I need to go and,*
4 *it's an itchy mole, that's not good".'* [M, 45, thicker, SSM, 4w/52w]

5 Strikingly, the majority of participants reported that their observed skin changes did not
6 match their mental image (which had arisen from the melanoma experience of a family
7 member or friend, from written and visual images, or from their knowledge of other
8 cancers, see Table 2). When the changes did not match their mental images, people
9 appeared more likely to 'normalise' their skin changes, or adopt other explanations, thus
10 delaying help-seeking and diagnosis. Thus, the appraisal interval was often prolonged when
11 there was a 'mismatch' between the mental image people had of melanoma and the way in
12 which their own skin changes developed.
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17 18 19 **Disease factors: skin changes**

20 Most participants used rich and vivid lay vocabularies to describe their skin changes, for
21 example, *'like a black fly squashed on a mirror'* [M, 48, thinner, SSM, 2w]. Table 3 shows
22 descriptions of skin changes noticed by participants, displayed according to the items of the
23 Glasgow seven-point checklist (7PCL) [29]. It also gives descriptions not commonly found on
24 checklists. For instance, many people reported surprise at the small size of their melanoma,
25 describing it as 'just a little spot'. Some also reported a 'spot on a mole', or that their skin
26 change had been 'always there' or a 'new lesion'; a few reported their lesion as 'different to
27 the others' (resonating with the Ugly Duckling sign [30]).
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32 Overall, Table 3 shows that both thinner and thicker melanomas can show any of the
33 changes described in the 7PCL. However there is a suggestion of slightly different patterns.
34 In particular, patients with thicker melanomas, both NMs and SSMs, described the so-called
35 'minor features' of bleeding, oozing and itch more often. They also described both
36 horizontal and vertical growth, again, irrespective of pathological type. Patients with
37 thinner lesions discussed changes in shape more often. We were not able to find any
38 differences in descriptions of skin changes between gender, age, educational level or
39 geographical region.
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45 46 **The help-seeking interval**

47 Reasons for waiting before seeking help included weighing up the priority of their skin
48 change against other commitments. Many participants had been encouraged by other
49 people to seek the advice of a HCP for their skin change. Emotions such as fear of a serious
50 condition, cancer or treatment, were seldom mentioned and seemed to play little part in
51 most peoples' decision-making, either to promote or delay help-seeking. More were
52 concerned about going to see their GP with only minor symptoms, and wasting the GP's
53 time.
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Patient factors

Prioritisation choices

Many participants discussed other responsibilities in their lives which felt more important than making an appointment to consult their GP about a skin change, and therefore contributed to delays in help-seeking. These competing priorities included employment, care of family members, moving house, holidays, and other health concerns.

'In the cab game you can't organise things, you can't afford to be off your work' [M, 66, thicker, other, 156w]

'The six year old has got ADHD and mild autism and he's hard work, and I suppose [you're] concentrating on him most of your life like, and don't think about yourself...' [M, 36, thicker, NM, 78w/3w]

'I'd been very busy with selling a house, buying a house, all the rest of it, and of course I've patients as well to see' [F, 72, thinner, SSM, 8w]

'I had an ulcer on my leg, and redressing that, so I think I was more taken up with that getting healed...' [F, 76, thicker, NM, 4w (Community nurse contacted GP)]

Some people mentioned repeatedly failing to make an appointment with a HCP either because of the competing responsibilities or because a skin change was 'not a priority':

'I was supposed to have phoned up, but I forgot because it was busy at work and... it just skipped my memory' [M, 59, thinner, SSM, 1w]

'I didn't class it as an emergency...I didn't think it was important enough...' [M, 64, thicker, other, 20w]

We found no differences in prioritisation choices between people with thinner and thicker melanomas.

Influence of other family members and the social network

Many participants had been encouraged by other people to seek medical help, either by an observation about the skin change itself, or an encouragement to make an appointment with their GP, see Table 4. Some participants had not been aware of their skin change until it was noticed by another person; others had known, and were also often aware that it was continuing to change, but they were ultimately encouraged to seek help by others. The other people included family members, friends, work colleagues, and people providing treatments such as beauty therapists and hairdressers. The promotion of help-seeking, whether by family members or friends, did not appear to affect time to presentation overall, but may have acted as a trigger for many people. A few people were wrongly reassured by family members or friends that their skin change was not potentially serious. This appeared to delay timely help-seeking. There was no evident difference in the influence of family members between people diagnosed with thinner or thicker melanomas.

Triggers for help-seeking

The main difference between participants with thinner and thicker melanomas was apparent with the 'triggers' that people described as they moved from the appraisal to help-seeking interval, when they realised that they 'had a reason to discuss their skin change with a HCP' - see Figure 1. While most people from both groups consulted family or their wider social network for endorsement to seek help about aspects of skin changes (changing colour, texture and size), some people with thinner melanomas also reported a heightened awareness of cancer from family experiences or the non-medical media, or noticing their skin changes as 'different to normal', while participants with thicker melanomas appeared to depend on prompts such as the more 'red flag' symptom of oozing/bleeding:

'It was a black mole and most of my moles are dark or light brown so it was a different colour' [F, 29, thinner, SSM, 3w]

'I'd seen something on that Embarrassing Bodies programme, and they did a thing about moles and what was not right and so I suppose I saw that and that sort of made me think, maybe I should go and get it looked at.' [F, 54, thicker, SSM, 1w]

'It started to bleed, that was the point at which I went to the doctor 'cos I thought it shouldn't be bleeding' [F, 64, thicker, LMM, 104w]

Healthcare providers and system factors

Issues concerning healthcare providers and the NHS were only mentioned by a minority of participants. The first and most important area of concern involved a group of participants (n=11; thinner=4 (SSM 3, LMM 1); thicker=7 (SSM 2, NM 3, acral 1, blue malignant naevus 1) who reported that they had previously shown their lesion to a HCP, and had been reassured that they did not need further treatment, see Table 5. While some just made a passing reference to their first, reassuring encounter with their GP, others gave far more detailed descriptions. A first encounter often appeared to delay a second visit to the GP by providing 'false reassurance' about the lesion. Some mentioned that they had not been given advice (oral, written or a website) on how to best monitor their lesion and what changes should alert them to returning to their GP; this could potentially result in thicker lesions at diagnosis.

'When people have told you that it's okay... I sort of took me eye off the ball really because I thought, well, they know better than I do.' [M, 75, thicker, SSM, 1w/17 w]

Some people had problems with accessing their general practice for an appointment, and, for a few busy people, this problem was exacerbated by having competing priorities.

'Trying to get an appointment with the GP here can just be horrific and because I'm out on the road.. I have to plan these things a couple of weeks ahead.' [F, 40, thinner, SSM, 3w]

A few people with thicker melanomas also mentioned a dislike of seeing doctors, either in general practices or hospitals, so this might have delayed help-seeking.

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3 *'I'm just not a hospital person or a doctor person. If I'm really ill, I ken I'll have to go, but I*
4 *have to be that way.'* [M, 52, thicker, SSM, 42w]

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6 Patients' concerns about 'wasting their GP's time' are well known, but this concern
7 appeared to be exacerbated by the small size of the skin changes, and the lack of pain or
8 other features which could signify more serious conditions. Again, this concern appeared
9 more prevalent among people with thicker than thinner melanomas.

10
11 *'My decisions on going to the GP are always influenced to some extent by a knowledge of*
12 *how busy they are and not wanting to waste their time.'* [F, 48, thicker, other, 4w/78w]

13
14 *'I think most people that I know would be afraid of the doctor saying to himself or herself,*
15 *you know, there's people just coming for nothing at all.'* [M, 93, thicker, LMM, 22w]

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18 A 56 year old woman diagnosed with a stage IIIA nodular melanoma on her lower leg
19 described her pathway over six months as follows:

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21 Appraisal (10w): *'I've always had a mole on my leg.. it was there from birth.. it never*
22 *bothered me because it was just flat and dark brown... It was possibly about six months ago I*
23 *noticed it was just a little bit raised when it had always been flat.. as if like maybe something*
24 *was stuck in there..'*

25
26 Help-seeking: *'I was due to have a smear and.. I asked the nurse to look at it.. and she said,*
27 *"Oh no, there's nothing to worry about, that's... I can tell these things," so she just sort of put*
28 *my mind at rest... I thought, "Well, she knows what she's talking about."*

29
30 Re-appraisal- 16 weeks: *'It just started obviously getting bigger and bigger. What was the*
31 *worst was every time I knocked it, it bled.. like a tick on you, because it was big and bulbous.'*

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33 Help-seeking: *'I realised it was getting bigger and my friend and I had talked about it and [I*
34 *returned to the surgery] .. it was a different nurse more senior, I have known her for years..*
35 *she sort of panicked me ..saying.. I need to get that looked at straight away.'*
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42 DISCUSSION

43 Main findings

44 This is the first study of detailed patient descriptions of their symptom experience and
45 pathways to diagnosis of thinner and thicker melanomas in the UK. Addressing the policy
46 agenda to diagnose melanoma earlier, the findings provide a number of novel insights
47 where future interventions may be targeted. The key finding is that there appear to be
48 subtly different patterns of symptoms experienced by those with thicker and thinner
49 melanomas. In particular, descriptions of vertical growth, bleeding, oozing and itch were
50 features of thicker melanomas irrespective of pathological type. Furthermore, they did not
51 appear to occur subsequent to changes in size, shape and colour, nor just be due to location
52 on the body, for example, not all thicker lesions were nodular melanomas on the backs of
53 older men. There was no clear distinction between time to presentation and melanoma
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3 thickness. It also does not appear that those with thicker melanomas have different
4 cognitive, emotional or behavioural responses to skin changes compared to those with
5 thinner melanomas, or have different pathways to or through the healthcare system. Whilst
6 help-seeking was often postponed because of other life concerns, most decisions to seek
7 help were triggered by common factors such as advice from family and friends, although
8 family experiences of melanoma or media coverage could prompt people with thinner
9 melanomas.
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13 We also found a mismatch between the textual information and published images currently
14 available, and the skin changes that were noticed. This provides opportunities to
15 incorporate more appropriate lay vocabulary and photographic images into targeted
16 community NHS and charity-run awareness campaigns such as 'Be Clear on Cancer' and
17 'Detect Cancer Early'. A small but important minority of participants did not have their
18 developing melanomas recognised during their first primary care consultation, and were not
19 provided with enough information about on-going assessment of further skin changes or
20 when to return to their clinician. These 'safety-netting' opportunities could be improved by
21 more systematic approaches by GPs.
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28 **Strengths and weaknesses**

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30 Our methodological approaches have a number of strengths. We do not know of any other
31 studies worldwide which have compared the patient experience across the appraisal and
32 help-seeking intervals between people with thinner and thicker melanomas. We recruited
33 participants systematically from dermatology clinics in two contrasting regions over 12
34 months, and interviewed all the consenting patients diagnosed with the much less common
35 melanomas $\geq 2\text{mm}$ thickness with a poorer prognosis. The thicker melanoma group included
36 equal numbers of NMs, SSMs, and other rare and unclassified types although no amelanotic
37 lesions; the diversity of types in this group suggest that the differences identified between
38 the thinner and thicker groups cannot simply be considered due to the biological differences
39 between SSMs and NMs.
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44 Furthermore, using semi-structured interviews soon after diagnosis reduced recall bias, and
45 allowed participants to speak freely about the period leading up to their diagnosis.
46 Calendar-landmarking was of value to a large minority of participants, who were able to
47 refine their recall of events and time intervals along their time to presentation [30]. Asking
48 people to draw their skin changes and developing melanomas was also of value to a number
49 of participants, allowing them to describe subtle changes in more detail, and also to
50 corroborate the accuracy of their recall of timing and events. Data saturation was reached
51 before the total sample had been interviewed, suggesting that our findings are robust and
52 representative of people diagnosed with melanoma in these regions of England and
53 Scotland. As recommended in a 2006 review of symptom interpretation as a source of delay
54 in melanoma presentation [31], we increased the rigour of our research by applying a
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3 theoretical approach (the Pathways to Treatment model, [21 22]) to frame our data
4 collection and analysis. We conducted and reported this study according to the Aarhus
5 statement guidelines on early cancer diagnosis research [27].
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8 The main weakness is that the interviews are necessarily retrospective and subject to recall
9 and framing bias. As a result, the accounts cannot be regarded as an exact description of
10 what happened. Instead, they are narratives that allowed people to describe their
11 experiences and reflect a post-hoc rationalisation of events framed by their subsequent
12 encounters with HCPs and increased knowledge since the diagnosis. Furthermore, people
13 from these two UK regions may have different beliefs and experiences of the pathway to
14 melanoma diagnosis from people in other UK regions, or from patients who did not agree to
15 take part in the study.
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20 21 **Comparison with existing literature**

22 While there is a paucity of qualitative studies undertaken with people soon after their
23 melanoma diagnosis, our findings resonate with a grounded theory study undertaken in
24 northern England, and exploring the meaning to people treated for melanoma of shorter
25 and longer time-lapses between detecting signs and receiving treatment [32], and those
26 from an interview study about factors influencing presentation in primary care, undertaken
27 with patients with suspicious pigmented lesions (only 4/40 interviewees were later
28 diagnosed with melanoma) [19]. A French questionnaire study set among 590 people with
29 melanomas also showed that relatives were involved in the detection of half of the
30 melanomas, with median delays of 4 months before the patient realized they had a
31 suspicious lesion, and further median delays of 2 months before this lesion was seen by a
32 doctor [33]. Other evidence around time to diagnosis, but not comparing thinner and
33 thicker melanomas, comes mainly from retrospective review of medical records or
34 dermatologist experience, and suggests similar times to presentation and diagnosis [34].
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43 **Implications for clinicians and policymakers**

44 Policymakers continue to face the challenge of a widespread lack of awareness of cancer
45 symptoms among the UK general population [35], and that there are significant barriers to
46 help-seeking [36]. Policy responses have included campaigns to raise symptom awareness,
47 with major investment in the new 'Be Clear on Cancer' melanoma campaign. Our findings
48 clearly demonstrate that the words and images in current use may not meet the needs of
49 the population who are likely to be assessing their skin changes at an early stage in tumour
50 development. Current images tend to represent more extreme changes which may not
51 always be present. Future melanoma awareness campaigns, as well as NHS and charity
52 websites giving information about skin checks, would be advised to provide more evidence
53 around the features of early skin changes using lay vocabulary [37], to consider their
54 selection of images of early melanomas for a better 'match' with people's observations, and
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3 to provide more evidence around prompts to encourage timely help-seeking. They should
4 also consider more targeted approaches such as focusing on: higher risk groups such as
5 older men, with tailored information, lay vocabulary and images; families and friends with
6 advice on how to check each other's skin regularly; and professional groups from the hair,
7 beauty, and exercise industries who also undertake informal skin checks.
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10 Several participants reported visiting their GP or other HCP on more than one occasion and
11 some were given false reassurance. The average GP working in the UK will only diagnose a
12 melanoma every 2-3 years but will commonly be consulted about a pigmented skin lesion,
13 often after other health issues have already been discussed in the consultation. While we
14 recognise the challenges facing GPs when differentiating potentially rare and serious
15 conditions such as melanoma from common and benign conditions, this study suggests that
16 some patients are not being provided with adequate information either about monitoring
17 their skin changes or what changes should prompt another consultation; this may lead to
18 longer time to diagnosis, and even diagnosis at a later stage with a poorer prognosis. The
19 principles of 'safety-netting' have been disseminated by the RCGP and could be applied
20 more effectively; they include recommendations for appropriate advice and written
21 information for patients about the warning symptoms, monitoring symptoms, when to
22 make a follow-up appointment, and reassurance to patients that symptoms like skin
23 changes warrant GP attention, thus 'legitimising' a follow-up visit [38].
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32 **Unanswered questions and future research**

33 While the findings of this qualitative study are of immediate importance to primary care
34 clinicians and policymakers, there are also suggestions of subtly different patterns of
35 symptoms experienced by those with thicker and thinner melanomas, irrespective of
36 pathological type. The descriptions of vertical as well as horizontal growth, and bleeding,
37 oozing or itch were particular features of thicker melanomas but not only NMs.
38 Furthermore, they did not appear to occur subsequent to changes in size, shape or colour so
39 may not necessarily be later features of melanoma. Although these symptom clusters may
40 be more related to tumour biology than differences in symptom appraisal and help-seeking,
41 these interesting differences need further exploration with bigger and more diverse
42 populations and quantitative as well as qualitative study designs.
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47 Alternative approaches to raising symptom awareness and supporting monitoring of skin
48 changes to prompt earlier help seeking may be needed. There is a growing interest in the
49 application of smartphone technology as one such approach but concerns remain around
50 their safety and utility, and is clearly an area for further research [39].
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ACKNOWLEDGEMENTS

We particularly thank all the patients who kindly gave up their time and shared their personal accounts with us. We also thank Vicky McMorrnan and Sheena Dryden, melanoma/skin cancer nurse specialists at Cambridge University Hospitals NHS Foundation Trust and the Edinburgh Royal Infirmary NHS Lothian respectively, for their enthusiastic help with recruitment. We are also grateful to our two patients who gave us insights and feedback throughout the study, to Anna Barford for her early contribution to study set-up and data collection, to James Brimicombe for advice on data management and for developing the research database, and to Mr Per Hall for his support and encouragement throughout the study and comments on the final manuscript.

Contributors

This study arose from collaboration between members of the National Cancer Research Institute (NCRI) Primary Care and Melanoma Clinical Studies Groups. FW, CC, RM, SS and DW were involved in the design of the study. JE and RM provided primary care cancer research and melanoma expertise respectively. NB and GK led recruitment at the two sites. LB and DC performed all the interviews and led the analysis, contributing to the core study team together with FW, SS and CC. FW wrote the first draft of the manuscript; all authors reviewed and edited the manuscript.

Funding

Thanks to our funding organisation the National Awareness and Early Diagnosis Initiative (NAEDI), and to their funding partners: Cancer Research UK; Department of Health, England; Economic and Social Research Council; Health and Social Care Research and Development Division; Public Health Agency, Northern Ireland, National Institute for Social Care and Health Research, Wales and the Scottish Government. All researchers were independent of the funding body and the study sponsors and funder had no role in study design; data collection, analysis and interpretation of data; in the writing of the report; or decision to submit the article for publication.

FW was supported by an NIHR Clinical Lectureship followed by a NIHR Clinician Scientist award at the time of this study. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health.

Ethics and governance approvals

The study obtained ethical approval from the Cambridgeshire 4 Research Ethics Committee (11/EE/0076). Patients gave informed written consent for participation. The study was CKCRN approved (ID number 10310), and obtained NHS governance approvals from Cambridge University Hospitals NHS Foundation Trust's Research & Development Department, and NHS Lothian (Lothian R&D Project No: 2011/R/DER/04).

Data sharing

No additional data available

Competing Interests

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) they have no support from or relationships with companies that might have an interest in the submitted work in the previous 3 years; (2) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (3) they have no non-financial interests that may be relevant to the submitted work.

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All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis

The corresponding author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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For peer review only

Table 1. Characteristics of study participants (n=63), and clinical characteristics of their melanomas, comparing thinner (n=33) and thicker (n=30) melanomas.

	Thinner melanomas ($<1\text{mm}$ Breslow thickness)	Thicker melanomas ($>2\text{mm}$ Breslow thickness)
Age at interview		
Mean age \pm s.d. (range)	60.5 \pm 14.6 (29 – 85)	66.1 \pm 15.5 (36 – 93)
Less than 60 years (n=23)	14 (61%)	9 (39%)
60 years and over (n=40)	19 (47%)	21 (53%)
Gender		
Male	14 (42%)	17 (58%)
Female	19 (58%)	13 (42%)
Education		
No further education	21 (64%)	21 (70%)
Further education	12 (36%)	9 (30%)
Fitzpatrick scale: skin colour ^a		
Type I (white skin, v fair)	7 (21%)	2 (6%)
Type II (white skin, fair)	6 (18%)	11 (37%)
Type III (creamy white, any hair)	17 (52%)	16 (53%)
Type IV (brown, Mediterranean)	3 (9%)	1 (3%)
Fitzpatrick scale: skin reaction to sun ^a		
Type I (always burns, never tans)	4 (12%)	3 (10%)
Type II (usually burns, tans with difficulty)	11 (33%)	10 (33%)
Type III (sometimes mild burn, gradually tans)	10 (30%)	11 (37%)
Type IV (rarely burns, tans easily)	6 (18%)	6 (20%)
Type V (very rarely burns, tans very easily)	2 (7%)	0
Melanoma location		
Head & neck	6 (18%)	9 (30%)
Trunk ^b	9 (27%)	4 (14%)
Upper limb	10 (30%)	7 (23%)
Lower limb	8 (24%)	10 (33%)
Melanoma type		
Superficial spreading melanoma (SSM)	25 (76%)	10 (33%)
Nodular melanoma (NM)	0	10 (33%)
Lentigo maligna melanoma (LMM)	7 (21%)	2 (7%)
Others ^c	1 (3%)	8 (27%)
Melanoma TMN stage		
Stage I ^d	33 (100%)	0
Stage II ^e	0	23 (77%)
Stage III ^f	0	7 (23%)

Stage IV	0	0
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^a Self-reported, not verified in medical records.

^b Includes melanomas on the back (thinner 6, 18%; thicker 3, 10%).

^c Thinner: mixed type (SSM & NM) x 1; Thicker: LMM 2, acral 1, malignant blue naevus 1, unclassified 6.

^d Stage IA = 27, stage IB = 6. ^e Stage IIA = 11, stage IIB = 5, Stage IIC = 7. ^f Stage IIIA = 6, stage IIIB = 1.

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Table 2. Illustrative quotations of a ‘mis-match’ between observed skin changes and ‘mental images’ of a melanoma

<p>Comparison with experience of a family member’s melanoma</p> <p>‘My mother in law had skin cancer on her back, so I expected melanoma to be much bigger: my little mole was nothing.’ [F, 53, thinner, SSM, 14w/52w]</p>
<p>Comparison with information</p> <p>‘I suppose from the descriptions that I’ve read about melanomas.. it didn’t ring any alarm bells... Okay, it has to start somewhere but, as it developed, [I expected] it would become more raised, it would be scaly and rough, it would be more inflamed-looking. But because this just remained completely flat on the skin...it didn’t meet any profile that I was expecting.’ [F, 63, thinner, LMM, 104w]</p> <p>‘It’s not like a mole, you can see a mole changing colour or shape or texture, you can read all about that, but as my wife says, nothing in the leaflets says anything about under the nail.’ [M, 60, thicker, other, 1w]</p> <p>‘..Because melanomas, he says, are black. Now, this growth on my knee, it was just like a warty growth, with a scarlet top on it, and.. there was no discolouration in it at all. ...I think that’s maybe how a lot of folk’ll not think of these things, because it doesn’t look like what you think it’s supposed to be, if you ken what I mean. It’s just like a bit of skin rising up.’ [M, 52, thicker, SSM, 42w]</p>
<p>Comparison with images</p> <p>‘I think that the way melanomas are publicised, this is what they look like, that’s really misleading ‘cos that isn’t what mine looked like until I saw it blown up on [the dermatologist]’s screen, and I thought ‘oh my God, yeah, mine does look like one of the ones on the front of the leaflet’ but... it just looks very neat, symmetrical, you know, sharp edges.’ [F, 39, thinner, other, 78w]</p> <p>‘When you go to the hospital and you see the things on the walls, and on the internet, and you see the diagrams of it, that is to me what malignant melanoma looks like. Mine didn’t look... it just didn’t come into the category of melanoma, it hadn’t [gone] funny shaped, it hadn’t been jaggy, it didn’t go dark, it didn’t get bigger...it just wasn’t what I imagined melanoma to look like. I think of [melanoma] getting bigger, crustier, bleeding ... and this was... dead flat... none of the things that were there at the back of my mind actually rang any alarm bells.’ [F, 58, thinner, SSM, 22w]</p> <p>‘It didn’t look like a melanoma. Even the booklet I’ve got given since... four or six pictures in there of actually different ones and it didn’t look like one of them. ... Even like the doctor said “I’ve noticed it on there before but I didn’t take any notice”.’ [M, 36, thicker, NM, 78w/3w]</p>
<p>Comparison with knowledge of other cancers</p> <p>‘I think if I could feel pain and know what it was, I may be more responsive to getting it treated’ [M, 74, thinner, LMM, 303w]</p>

Table 3. Descriptions of skin changes, using the Glasgow seven-point checklist (7PCL) criteria [40] and other descriptions (Dis-confirming reports in pink)

Feature - Subgroups	Way feature was described		Thinner			Thicker		
	Thinner	Thicker	SSM n=25	LMM n=7	Other n=1	NM n=10	SSM n=10	LMM/ Others n=10
1 7PCL criteria								
1.1. Changing size i Cover more skin	<i>'it had grown, it looked bigger'</i> [M,48,SSM,2w]	<i>'getting bigger, but not ultra-big, no-one noticed'</i> [M,66, other,136w]	●	●	●	●	●	●
	<i>'dark brown part was .. more raised'</i> [F,40,SSM,3w]	<i>'vertical before it curved across at the top'</i> [M,45,SSM,4w/52w], <i>'mushroomed out... bubbled up'</i> [M,78,NM,8w]	●			●	●	●
	No changing size- flat to skin		●					
1.2. Changing and/or irregular shape	<i>'it sort of made.. a pinky horseshoe'</i> [F,53,SSM,14w/52w], <i>'maple-leaf raggedy'</i> [F,63, LMM,104w]	<i>'breaking into several bits'</i> [F,48,other,4w/78w]	●	●	●		●	●
	No changing shape- smooth edge		●					
1.3. Changing and/or irregular colour	<i>'two colours, dark with a lighter section'</i> [M,37,SSM,52w], <i>'slight discolour that got darker, black like oil'</i> [M,67,SSM,208w]	<i>'red then turned black, lively-looking'</i> [M,73,other,104w], <i>'several different colours'</i> [M,82,other,3w]	●	●	●	●	●	●
	No changing colour (not always darker)		●			●	●	●
1.4. Oozing i Bleeding	<i>'a new shaving blade would nick it but didn't bleed on its own'</i> [M,74,LMM,303w]	<i>'noticed blood on the pillow'</i> [M,66,NM,78w], <i>'forever bleeding and getting a scab'</i> [M,86,SSM,52w]	●	●		●	●	●
	ii Discharge	-				●	●	●
1.5. Changing sensation i Itch	<i>'when it felt itchy and I peeled like flaked off bits of it'</i> [M,67,SSM,208w]	<i>'it was within a mole, just the smallest pimple, a red itchy spot'</i> [M,45,SSM,4w/52w]	●			●	●	●
	ii Soreness	<i>'when caught my nail on it a little bit sore'</i> [F,40,SSM,3w]	<i>'painful sort of like a wasp sting'</i> [M,60,NM,1w]	●			●	●
1.6. Inflammation i Texture change	<i>'quite bumpy'</i> [M,63,SSM,2w/104w]	<i>'bubbled up'</i> [M,78,NM,8w]	●			●	●	●
	ii Crusty, flaky	<i>'it was very dry, a bit scaly'</i> [F,37,SSM,8w]	<i>'dark leathery, I tried to keep it moisturised'</i> [F,48,other,4w/78w]	●	●		●	●

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1.7 Large size	<i>'larger than a mole, about the size of a one penny piece' [F,66,LMM,20w/78w]</i> <i>'size of a thumb nail' [F,63,LMM,104w]</i>	<i>'It was like a 2p piece' [M,82,other,3w]</i> <i>'felt this huge lump' [M,40,other,4w/68w]</i>	•	•		•	•	•
2 Other descriptions								
2.1 'Different'	<i>'look very different from all the others' [M,63,SSM,2w/104w]</i> <i>'not like the rest of my moles' [F,37,SSM,8w]</i>	<i>'quite a big mole, nothing wrong until the spot on top' [F,54,SSM,1w], 'two were different, more livelier than the other ones' [M,73,other,104w]</i>	•					•
2.2 Small size i Tiny/small mole li 'just a spot'	<i>'tiny, wee circular mole' [F,43,LMM, 22w]</i> <i>'a little black spot, just an aging spot' [F,76,LMM,16w]</i>	<i>'it was so minuscule' [M,93,LMM,22w]</i> <i>'it was nothing like a mole at all, it was just like a spot' [M,64,other,20w]</i>	•	•		•	●	•
2.3 New lesion	<i>'somebody else has noticed it so it must be a new one' [F,43,LMM,22w]</i> <i>'the mole had appeared, it was a new mole' [F,29,SSM,3w]</i>	<i>'just suddenly appeared' [F,57,NM,36w]</i> <i>'came very quick; it wasn't there and then it was there' [F,76,SSM,4w]</i>	•	•		•	•	•
2.4 'Always there'	<i>'had been there for literally years' [M,74,SSM,14w], 'a birthmark, heart shaped, an old friend' [F,39,other,78w]</i>	<i>'been there from birth' [F,56,NM,10w/16w]</i> <i>'always had that mole, it didn't bother me' [F,61,SSM,26w]</i>	•	•	•	•	•	•

Reported feature per group: • = 1-25%; ● = 25-50%; ● = 50-75%; ● = 75-100%

Table 4. Illustrative quotations of the influences of comments from extended family and friends

Noticing a skin change

'My partner's daughter says to me "Have you always had that mole on your ear?" So I thought well somebody else has noticed it so it must be a new one.' [F, 43, thinner, LMM, 22w]

'I saw my sisters at the funeral and they both mentioned it; we hadn't noticed it.' [M, 66, thicker, NM, 78w]

Acting on encouragement to seek help

'It wasn't till my daughter-in-law come over from Australia, and she said to me that she thought I ought to have it checked out because obviously in Australia they're very conscious of it all.' [F, 58, thinner, SSM, 22w]

'The girl in the beauty salon... she always asked me about this one... and then I went again and she said, "have you seen a doctor?", I said, "no, I don't because it's nothing, I feel okay", and she said, "no, please, I will make you a cup of tea, I will give you a phone number, please go this week." [F, 40, thinner, SSM, 156w]

'I was at a dinner with my daughter, and fortunately I had a low backed dress on, and one of her friends said, "I don't like the look of that mole on your back, and I suggest you have it checked out."' [F, 66, thicker, SSM, 4w]

'It dinnae change dramatically, so one day I quietly said to nurse friend, "Will you just have a look at this for me?" She just took one look and she says "You must promise me when you get home you will go and see the doctor." [F, 61, thicker, SSM, 26w]

Advice of others having little effect

'She thought it was getting darker at some stage, can't remember exactly when, but she maybe nagged me for a year or two before.' [M, 67, thinner, SSM, 208w]

'It's not as if I hadnae been told to go and see about it, because my daughter and my wife... they said, "Well you should go and see about that," but I never did, you know, until May.' [M, 64, thicker, other, 20w]

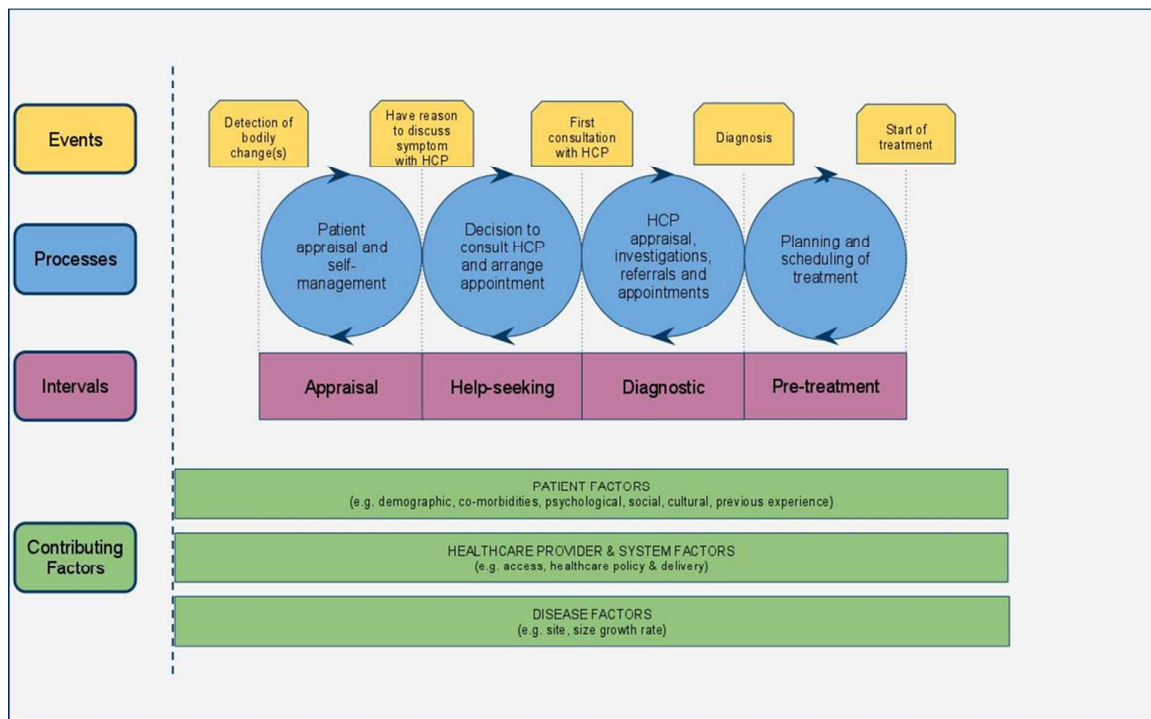
Not encouraging help seeking

'Fairly early on I discussed it with (a friend). ... But because she said, "I can't really feel it" I think I ignored it. It would have been better if she'd said to me, "I think you need to have it looked at." I think I'd have gone to the doctor then, but because she said, "No, I think it's fine" I think I left it. [F, 64, thicker, LMM, 104 w]

Table 5. Time from first detecting a skin change to first presentation, and first to second presentations to primary care, by time intervals (ordered by first TTP), gender, age, melanoma type and stage

	Time from detecting a skin change to first presentation	Time from first presentation to second presentation	Gender & age	Type & stage
Thinner melanomas				
1	2w	104w	M, 63	SSM, IA
2	4w	22w	F, 58	SSM, IA
3	14w	52w	F, 53	SSM, IA
4	20w	78w	F, 66	LMM, IA
Thicker melanomas				
5	1w	17w	M, 75	SSM, IIC
6	3w	1w	M, 73	NM, IIB
7	4w	52w	M, 45	SSM, IIA
8	4w	68w	M, 40	Other, IIIA
9	4w	78w	F, 48	Acral, IIIA
10	10w	16w	F, 56	NM, IIIA
11	78w	3w	M, 36	NM, IIA

Figure 1. Model of Pathways to Treatment (reproduced with permission from Walter et al.2012 [21])



Review only

BMJ Open

'This isn't what mine looked like': a qualitative study of symptom appraisal and help seeking in people recently diagnosed with melanoma

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-005566.R1
Article Type:	Research
Date Submitted by the Author:	18-Jun-2014
Complete List of Authors:	Walter, Fiona; University of Cambridge, Dept of Public Health and Primary Care Birt, Linda; University of Cambridge, Public Health & Primary Care Cavers, Debbie; University of Edinburgh, General Practice Scott, Suzanne; Kings College London Dental Institute, Unit of Social & Behavioural Sciences Emery, Jon; University of Melbourne, General Practice and Primary Care Academic Centre; University of Cambridge, Public Health & Primary Care Burrows, Nigel; Addenbrooke's Hospital, Kavanagh, Gina; Royal Infirmary of Edinburgh, MacKie, Rona; University of Glasgow, Weller, David; University of Edinburgh, General Practice Campbell, Christine; University of Edinburgh, Centre for Population Health Sciences
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Dermatology, Diagnostics, General practice / Family practice, Qualitative research, Oncology
Keywords:	Dermatological tumours < DERMATOLOGY, PRIMARY CARE, QUALITATIVE RESEARCH

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Manuscripts

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9 **'This isn't what mine looked like': a qualitative study of symptom**
10 **appraisal and help seeking in people recently diagnosed with**
11 **melanoma**
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ABSTRACT

Objective

To explore symptom appraisal and help-seeking decisions among patients recently diagnosed with melanomas, and to compare experiences of people with 'thinner' (<1mm) and 'thicker' (>2mm) melanomas, as thickness at diagnosis is an important prognostic feature.

Methods

In-depth interviews with patients within ten weeks of melanoma diagnosis explored the factors impacting on their pathways to diagnosis. Framework analysis, underpinned by the Model of Pathways to Treatment, was used to explore the data with particular focus on patients' beliefs and experiences, disease factors, and healthcare professional (HCP) influences.

Results

63 patients were interviewed (29-93 years, 31 women, 30 thicker melanomas). All described their skin changes using rich lay vocabulary. Many included unassuming features such as 'just a little spot' as well as common features of changes in size, colour and shape. There appeared to be subtly different patterns of symptoms: descriptions of vertical growth, bleeding, oozing and itch were features of thicker melanomas irrespective of pathological type.

Appraisal was influenced by explanations such as normal life changes, prior beliefs, and whether skin changes matched known melanoma descriptions. Most decisions to seek help were triggered by common factors such as advice from family and friends. Eleven patients reported previous reassurance about their skin changes by a HCP, with little guidance on monitoring change or when it would be appropriate to re-consult.

Conclusions

Patients diagnosed with both thinner and thicker melanomas often did not initially recognise or interpret their skin changes as warning signs or prompts to seek timely medical attention. The findings provide guidance for melanoma awareness campaigns on more appropriate images, helpful descriptive language, and the need to stress the often apparently innocuous nature of potentially serious skin changes. The importance of appropriate advice, monitoring and safety-netting procedures by HCPs for people presenting with skin changes is also highlighted.

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For peer review only

DRAFT

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This study is the first exploration of symptom appraisal and help-seeking among people diagnosed with ‘thinner’ melanomas (T1, very good prognosis, 5 year disease-free prospects 95%), compared with those with ‘thicker’ melanomas (T3 and T4, less good prognosis, 5 year disease-free prospects <55%).
- The study did not identify clear discriminating features in the diagnostic pathway, or features of thinner versus thicker melanomas.
- The findings highlight a mismatch between the information people need when assessing their skin changes and the information and images currently available, thus providing opportunities to incorporate more appropriate descriptive language, images and information into targeted community awareness campaigns as well as by the NHS and charities via their websites and promotional materials.
- A small but important minority of participants did not have their developing melanomas recognised during their first primary care consultation, and were not provided with enough information about on-going assessment of further skin changes or when to return to their clinician. These ‘safety-netting’ opportunities could be improved by more systematic approaches by HCPs.
- Using semi-structured interviews close to diagnosis allowed in-depth exploration of the participants’ experiences and views, but the accounts are necessarily retrospective and subject to recall and framing bias.

INTRODUCTION

Diagnosing melanoma earlier is high on the UK health policy agenda; it is estimated that around 190 deaths from melanoma could be avoided each year if survival rates in England matched the best in Europe [1]. Worldwide melanoma incidence rates are increasing faster than any other solid tumour. In the UK the incidence has quadrupled since the 1970s [2]; similar incidence rises have been reported across Europe [3,4], the USA [5] and Australia [6]. In the UK there were more than 2,209 deaths and 12,800 new cases diagnosed in 2011, with a disproportionately high rate among people aged less than fifty years [2]. The most important prognostic factor is the tumour thickness at diagnosis according to the Breslow scale (T classification) [7]. Patients with a primary melanoma ≤ 1 mm at diagnosis (T1) currently have 5 year disease-free prospects of over 95%, while for tumours ≥ 2 mm at diagnosis this is lower, falling to $< 55\%$ with lymph node involvement but no metastatic spread [8]. Tumour thickness is also associated with rapid growth which occurs more frequently in elderly men [9].

Timely diagnosis can be influenced by the diagnostic skills of GPs. A recent analysis of the Cancer Patient Experiences Survey 2009 and the 2010 RCGP cancer audit data reported that more than 90% of people diagnosed with melanoma were seen by their GPs less than three times before diagnosis, compared with 60-80% for the majority of cancer types [10]. This suggests that most melanomas are recognised by GPs and appropriately referred to specialist care in England.

Timely diagnosis can also be influenced by people's symptom appraisal and help-seeking behaviour. Compared with other cancers, people with melanoma have among the longest time between first noticing a symptom and presenting to their GP [11,12], suggesting that the major opportunity to diagnose melanoma earlier is prompting earlier presentation to healthcare through signs and symptom awareness campaigns [13]. This requires an understanding of how people interpret changes in their moles or new lesions. We present findings from an in-depth interview study with UK patients recently diagnosed with 'thinner' (T1) compared with 'thicker' primary melanomas (T3 and T4), which aimed to explore the processes and experiences of symptom detection and help-seeking decisions leading to melanoma diagnosis.

METHODS

Design and ethics

Semi-structured face to face in-depth interviews were conducted with adults diagnosed with invasive cutaneous melanoma within the previous ten weeks. Ethics approval was obtained from the Cambridgeshire 4 Research Ethics Committee (11/EE/0076).

Setting and recruitment

Potential participants were identified and recruited by the melanoma/skin cancer nurse specialists via the weekly multidisciplinary team meetings of dermatologists, plastic surgeons and oncologists at two regional hospitals: Cambridge University Hospitals NHS Foundation Trust in the East of England, and the Edinburgh Royal Infirmary, NHS Lothian, Scotland. These hospitals together serve a population of approximately 1.4 million, and the MDT meetings review more than 400 new cases of invasive cutaneous melanoma each year.

All adults aged 18 and over newly diagnosed with a primary invasive cutaneous melanoma (staged as $\leq 1\text{mm}$ (T1, 'thinner') or $\geq 2\text{mm}$ (T3 and T4, 'thicker') at the two participating hospitals were eligible for inclusion unless the melanoma/skin cancer nurse specialists felt that they were not suitable on clinical grounds (other severe physical or mental health conditions). Patients were mailed an invitation letter with a patient information sheet. As T3 and T4 melanomas are diagnosed at about 25% of the rate of T1 melanomas, we recruited all those with thicker melanomas who agreed to take part. At the same time we purposively sampled people with T1 melanomas by age, gender, location and season to ensure that we had a broad range of views and experiences, and we continued until saturation of data. Reasons for not selecting patients for interview included: sampling decisions (n=34), lost to follow-up (n=6), and ill-health (n=1).

Data collection

Interviews were undertaken between January 2012 and January 2013. In each area an experienced researcher used a semi-structured approach, with an interview schedule informed from the literature [14,15], our collective expertise from interviewing patients recently diagnosed with other cancers [16], and a pilot study (n=17, conducted during the early stages of the study, and including patients interviewed >10 weeks post-diagnosis (n=12), or with melanoma histology which did not fit the inclusion criteria (n=5, Breslow thickness 1-2mm or indeterminate)). The theoretical approach of the Model of Pathways to Treatment [17,18] (Figure 1) was used to underpin the interview schedule, exploring the processes that occurred within each time-interval and focusing on: how initial symptoms were noticed; personal risk perceptions; the language used to describe symptoms and changes over time; the participant's decision-making and triggers to help-seeking; and the experience of the diagnostic process of primary and secondary care from the patient perspective. A calendar-landmarking technique [19] was used as an adjunct to the interviews, to establish the timing and details of events which led to the melanoma diagnosis, together with diaries and letters that participants referred to during this process. Participants were also invited make a pencil drawing/s of their skin cancer as it developed; on-going analyses are examining perceptions of lesions over time, and comparing the drawings with clinical images [20]. At the end of each interview, participants completed a

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3 short questionnaire to provide demographic data, and information about their skin and hair
4 colour and their skin's response to UV light using the widely validated Fitzpatrick Scale [21].
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6 Interviews were undertaken as soon as possible after diagnosis, with all interviews
7 completed within 10 weeks of diagnosis, and the majority within 6 weeks. Interviews lasted
8 between 40-65 minutes and were conducted primarily in the participant's home although
9 two people chose to be interviewed in university offices. Patients were sometimes
10 accompanied by a family member, usually spouse or daughter. Audio-recordings of
11 interviews were professionally transcribed verbatim and anonymised.
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16 **Analysis**

17 All interview transcripts were repeatedly read and re-read by the two researchers LB
18 (nursing background) and DC (health services researcher), and the members of the 'core'
19 analysis team also read the majority of the transcripts (FW, academic GP; SS, health
20 psychologist; CC, primary care researcher). Analysis was an iterative process starting near
21 the beginning of data collection and using the 17 pilot interviews to develop our analytic
22 strategy. We used the approach of Framework analysis to create and establish meaningful
23 patterns in five phases, namely: familiarization with the data, generating initial codes,
24 inductively searching for themes among codes, index charting and mapping of data, before
25 finally defining and naming themes [22]. The coding and data management were supported
26 by NVivo software (QSR International, version 9). The Model of Pathways to Treatment
27 (Figure 1) was also used to underpin the analysis with a theoretic model for the different
28 intervals and processes that occur along the pathway to diagnosis and treatment, in order
29 to accurately assess the time intervals, their content and context. The final themes were
30 agreed through a series of meetings involving all five 'core' researchers, and a consensus
31 meeting with the wider study team.
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39 The analysis focused on the main themes within the time to presentation (TTP), defined as
40 from the first detection of skin change to the first consultation with a healthcare
41 professional [23, 24]. This interval comprises the appraisal and help-seeking intervals
42 [17,18], and the analysis examined patient and healthcare factors as well as 'disease'
43 factors, relating to the developing melanoma. When the first consultation did not result in a
44 referral, we also included further iterative processes until the next consultation in the
45 analyses. Participants with shorter intervals tended to use diaries and have good recall of
46 the relevant dates. People with longer intervals tended to have vaguer recollections,
47 particularly around the time they had first detected any skin change. While participants
48 were often able to discuss triggers to help-seeking, they were less able to recall the precise
49 dates of these triggers, and we therefore do not present the separate durations of the
50 appraisal and help-seeking intervals.
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3 We went on to examine our themes by comparing narratives from participants diagnosed
4 with thinner and thicker melanomas, and by the melanoma types within these groups. We
5 further validated our themes by examining the whole dataset stratified by gender, by age
6 (less than 60 vs 60 and over, and 80 and over), by educational level (no further education vs
7 further education), and by geographical location (Cambridge vs Edinburgh). Credibility was
8 increased by the two researchers together undertaking coding and producing code tables
9 throughout the analytic process, and reaching consensus from the potentially wide range of
10 interpretations across the 'core' analysis team.
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14 15 16 17 18 **RESULTS**

19 A total of 241 adult patients were approached to take part in this study (Cambridge 114,
20 Edinburgh 127), 121 were willing to participate (50%: Cambridge 53%, Edinburgh 47%), and
21 63 were interviewed.
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23

24 25 26 **Patient characteristics**

27 Table 1 shows the demographic and self-reported skin characteristics of the 63 study
28 participants, and the clinical characteristics of their melanomas, comparing participants with
29 thinner (n=33, median Breslow thickness 0.5 mm, range 0.1-0.9 mm) and thicker (n=30,
30 median Breslow thickness 3.5 mm, range 2.1-12.0 mm) melanomas. While people with
31 thinner melanomas were younger (60.5 vs 66.1 years), the groups were otherwise similar
32 for socio-demographic factors. One quarter of the group reported a family history of
33 melanoma, while eight participants reported previous skin cancer (melanoma 2, basal cell
34 carcinoma (BCC) 6): we were only able to verify the two melanomas with histology reports.
35 The thinner melanomas were all histologically reported as superficial spreading melanomas
36 (SSM) and lentigo maligna melanomas (LMM) apart from one diagnosed as part SSM and
37 part NM ('other'). Due to our sampling strategy there was a higher prevalence of nodular
38 melanomas than in reported local figures. However, only a third of the thicker melanomas
39 were nodular melanomas (NM, n=10), while a third were SSM (n=10), and the remaining
40 third had 'other' diagnoses (LMM 2, acral 1, malignant blue naevus 1, unclassified 6). Of the
41 nine participants diagnosed with melanoma on their back, seven were male, and three had
42 thicker melanomas (NM 2, SSM 1).
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50 51 52 **Duration of skin changes**

53 Four participants (male 3, female 1) had their melanomas diagnosed opportunistically by a
54 HCP (3 GPs, 1 oncologist); all these were thinner melanomas. The time to presentation (TTP)
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3 was between 1 week and 303 weeks (thinner: median TTP 21 weeks, range 1-303 weeks, 5
4 longer than 52 weeks; thicker: median TTP 19 weeks, range 1-156 weeks, 7 longer than 52
5 weeks). Most participants who presented with skin changes were referred after their first
6 primary care consultation. The remainder were referred after their second consultation
7 (n=11); none reported more than two consultations prior to referral. Comparisons between
8 those with thinner (n=4) and thicker (n=7) melanomas who were referred after a second
9 primary care consultation are presented in Table 5 and discussed later (see section on
10 Healthcare providers and system factors).
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14 The main emerging themes within the appraisal and help-seeking intervals are discussed
15 below. Throughout this section quotations are accompanied by information about gender
16 (M, F), age, melanoma group (thinner or thicker), type of melanoma (SSM, NM, LMM,
17 other), and symptom duration as time to presentation in weeks (including first and second
18 presentations).
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24 **The appraisal interval**

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26 The 59 participants who detected their melanoma themselves described a variable and
27 complex process of appraisal and re-appraisal of their skin, against their background
28 knowledge of 'normal skin changes' and potential risk factors. We found no evidence of
29 differences between people with thinner and thicker melanomas across any of these
30 themes.
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35 **Patient factors**

36 ***Explanations for skin changes***

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38 Awareness of a skin change, either a new lesion or a change in an existing lesion, did not
39 usually cause any initial concern as it seemed so innocuous, and was often attributed to
40 normal life changes such as pregnancy or aging.
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43 *'I didn't recognise it as something that was different, because I've got quite a few moles on*
44 *my skin so therefore I thought, "Has this been here before, or am I just imagining that I*
45 *haven't seen it before?"' [F, 68, thinner, SSM, 52w]*

46
47 *'Perhaps because I'd been pregnant and everything was darker anyway or you know, I didn't*
48 *take any notice.'* [F, 36, thicker, NM, 17w]

49
50 Other explanations were also often made, such as an insect bite or injury when the
51 participant had been outside or in the garden.
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53 *'Since I'd been outside to a barbeque and I thought, oh well I've been bitten, it's just bitten*
54 *there on the mole.'* [F, 54, thicker, SSM, 1w]

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3 Skin changes were sometimes attributed to another skin condition (such as psoriasis) if it
4 presented in a similar way; in these cases participants' previous experiences of a benign
5 condition could influence their perception of the potential seriousness of the new skin
6 changes.
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9 10 11 **Prior beliefs about melanoma and its risk factors**

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13 Skin changes were appraised within the context of peoples' prior beliefs about melanoma
14 and its risk factors, and their life experiences. Participants often used the terms skin cancer
15 and melanoma interchangeably, and their prior awareness of melanoma varied widely.
16 Whereas some participants noted that they had no awareness at all, others described
17 gaining some knowledge about melanoma via TV programmes, magazines, the internet, and
18 occasionally, health promotion material. A minority had heightened awareness through the
19 melanoma experience of a family member or friend, or even a celebrity. A family history of
20 melanoma or a personal previous melanoma led several people to have heightened risk
21 perception and awareness and to quickly identify skin changes as a potential melanoma; all
22 these people sought help rapidly and presented with thinner melanomas:
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27 *'I wouldn't have known what they were talking about' [M, 62, thicker, SSM, 52w]*

28
29 *'...because my mum has had a melanoma ten years ago so I've always been aware to keep a*
30 *check on my moles.'* [F, 29, thinner, SSM, 3w]

31
32 Many participants showed some understanding of the risk factors associated with
33 melanoma and/or skin cancer when they discussed having lived in hot climates, or having
34 suffered from sunburn, especially as a child. However, some were quite certain that they
35 had never exposed themselves to the risk of UV damage:
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37
38 *'I thought I had been careful about sitting out in the sun.'* [F, 57, thicker, NM, 36w]

39
40 Prior knowledge or experience of melanoma and its risk factors did not appear to be related
41 to educational levels, nor to melanoma thickness at diagnosis.
42

43 44 **Do skin changes 'match' a melanoma?**

45
46 While some participants admitted to prior knowledge of the symptoms and signs of a
47 melanoma, such as 'jagged edges' or change in colour, only a few people had known that an
48 itchy or bleeding mole was a 'bad' sign. Only two people noticed a match between their
49 observed skin changes and their mental image of a melanoma, and this match appeared to
50 prompt appropriate help-seeking, leading to shorter times to presentation.
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54 *'I don't know when I learnt it, but it was just in my subconscious that "ooh I need to go and,*
55 *it's an itchy mole, that's not good".'* [M, 45, thicker, SSM, 4w/52w]

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3 Strikingly, the majority of participants reported that their observed skin changes did not
4 match their mental image (which had arisen from the melanoma experience of a family
5 member or friend, from written and visual images, or from their knowledge of other
6 cancers, see Table 2). When the changes did not match their mental images, people
7 appeared more likely to 'normalise' their skin changes, or adopt other explanations, thus
8 delaying help-seeking and diagnosis. Thus, the appraisal interval was often prolonged when
9 there was a 'mismatch' between the mental image people had of melanoma and the way in
10 which their own skin changes developed.
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14 15 16 17 **Disease factors: skin changes**

18 Most participants used rich and vivid lay vocabularies to describe their skin changes, for
19 example, '*like a black fly squashed on a mirror*' [M, 48, thinner, SSM, 2w]. Table 3 shows
20 descriptions of skin changes noticed by participants, displayed according to the items of the
21 Glasgow seven-point checklist (7PCL) [25]. It also gives descriptions not commonly found on
22 checklists. For instance, many people reported surprise at the small size of their melanoma,
23 describing it as 'just a little spot'. Some also reported a 'spot on a mole', or that their skin
24 change had been 'always there' or a 'new lesion'; a few reported their lesion as 'different to
25 the others' (resonating with the Ugly Duckling sign [26]).
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29 Overall, Table 3 shows that both thinner and thicker melanomas can show any of the
30 changes described in the 7PCL. However there is a suggestion of slightly different patterns.
31 In particular, patients with thicker melanomas, both NMs and SSMs, described the so-called
32 'minor features' of bleeding, oozing and itch more often. They also described both
33 horizontal and vertical growth, again, irrespective of pathological type. Patients with
34 thinner lesions discussed changes in shape more often. We were not able to find any
35 differences in descriptions of skin changes between gender, age, educational level or
36 geographical region.
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43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 **The help-seeking interval**

Reasons for waiting before seeking help included weighing up the priority of their skin
change against other commitments. Many participants had been encouraged by other
people to seek the advice of a HCP for their skin change. Emotions such as fear of a serious
condition, cancer or treatment, were seldom mentioned and seemed to play little part in
most peoples' decision-making, either to promote or delay help-seeking. More were
concerned about going to see their GP with only minor symptoms, and wasting the GP's
time.
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Patient factors

Prioritisation choices

Many participants discussed other responsibilities in their lives which felt more important than making an appointment to consult their GP about a skin change, and therefore contributed to delays in help-seeking. These competing priorities included employment, care of family members, moving house, holidays, and other health concerns.

'In the cab game you can't organise things, you can't afford to be off your work' [M, 66, thicker, other, 156w]

'The six year old has got ADHD and mild autism and he's hard work, and I suppose [you're] concentrating on him most of your life like, and don't think about yourself...' [M, 36, thicker, NM, 78w/3w]

'I'd been very busy with selling a house, buying a house, all the rest of it, and of course I've patients as well to see' [F, 72, thinner, SSM, 8w]

'I had an ulcer on my leg, and redressing that, so I think I was more taken up with that getting healed...' [F, 76, thicker, NM, 4w (Community nurse contacted GP)]

Some people mentioned repeatedly failing to make an appointment with a HCP either because of the competing responsibilities or because a skin change was 'not a priority':

'I was supposed to have phoned up, but I forgot because it was busy at work and... it just skipped my memory' [M, 59, thinner, SSM, 1w]

'I didn't class it as an emergency...I didn't think it was important enough...' [M, 64, thicker, other, 20w]

We found no differences in prioritisation choices between people with thinner and thicker melanomas.

Influence of other family members and the social network

Many participants had been encouraged by other people to seek medical help, either by an observation about the skin change itself, or an encouragement to make an appointment with their GP, see Table 4. Some participants had not been aware of their skin change until it was noticed by another person; others had known, and were also often aware that it was continuing to change, but they were ultimately encouraged to seek help by others. The other people included family members, friends, work colleagues, and people providing treatments such as beauty therapists and hairdressers. The promotion of help-seeking, whether by family members or friends, did not appear to affect time to presentation overall, but may have acted as a trigger for many people. A few people were wrongly reassured by family members or friends that their skin change was not potentially serious. This appeared to delay timely help-seeking. There was no evident difference in the influence of family members between people diagnosed with thinner or thicker melanomas.

Triggers for help-seeking

The main difference between participants with thinner and thicker melanomas was apparent with the 'triggers' that people described as they moved from the appraisal to help-seeking interval, when they realised that they 'had a reason to discuss their skin change with a HCP'- see Figure 1. While most people from both groups consulted family or their wider social network for endorsement to seek help about aspects of skin changes (changing colour, texture and size), some people with thinner melanomas also reported a heightened awareness of cancer from family experiences or the non-medical media, or noticing their skin changes as 'different to normal', while participants with thicker melanomas appeared to depend on prompts such as the more 'red flag' symptom of oozing/bleeding:

'It was a black mole and most of my moles are dark or light brown so it was a different colour' [F, 29, thinner, SSM, 3w]

'I'd seen something on that Embarrassing Bodies programme, and they did a thing about moles and what was not right and so I suppose I saw that and that sort of made me think, maybe I should go and get it looked at.' [F, 54, thicker, SSM, 1w]

'It started to bleed, that was the point at which I went to the doctor 'cos I thought it shouldn't be bleeding' [F, 64, thicker, LMM, 104w]

Healthcare providers and system factors

Issues concerning healthcare providers and the NHS were only mentioned by a minority of participants. The first and most important area of concern involved a group of participants (n=11; thinner=4 (SSM 3, LMM 1); thicker=7 (SSM 2, NM 3, acral 1, blue malignant naevus 1) who reported that they had previously shown their lesion to a HCP, and had been reassured that they did not need further treatment, see Table 5. While some just made a passing reference to their first, reassuring encounter with their GP, others gave far more detailed descriptions. A first encounter often appeared to delay a second visit to the GP by providing 'false reassurance' about the lesion. Some mentioned that they had not been given advice (oral, written or a website) on how to best monitor their lesion and what changes should alert them to returning to their GP; this could potentially result in thicker lesions at diagnosis.

'When people have told you that it's okay... I sort of took me eye off the ball really because I thought, well, they know better than I do.' [M, 75, thicker, SSM, 1w/17 w]

Some people had problems with accessing their general practice for an appointment, and, for a few busy people, this problem was exacerbated by having competing priorities.

'Trying to get an appointment with the GP here can just be horrific and because I'm out on the road.. I have to plan these things a couple of weeks ahead.' [F, 40, thinner, SSM, 3w]

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3 A few people with thicker melanomas also mentioned a dislike of seeing doctors, either in
4 general practices or hospitals, so this might have delayed help-seeking.
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6 *'I'm just not a hospital person or a doctor person. If I'm really ill, I ken I'll have to go, but I*
7 *have to be that way.'* [M, 52, thicker, SSM, 42w]
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10 Patients' concerns about 'wasting their GP's time' are well known, but this concern
11 appeared to be exacerbated by the small size of the skin changes, and the lack of pain or
12 other features which could signify more serious conditions. Again, this concern appeared
13 more prevalent among people with thicker than thinner melanomas.
14

15 *'My decisions on going to the GP are always influenced to some extent by a knowledge of*
16 *how busy they are and not wanting to waste their time.'* [F, 48, thicker, other, 4w/78w]
17

18 *'I think most people that I know would be afraid of the doctor saying to himself or herself,*
19 *you know, there's people just coming for nothing at all.'* [M, 93, thicker, LMM, 22w]
20

21 A 56 year old woman diagnosed with a stage IIIA nodular melanoma on her lower leg
22 described her pathway over six months as follows:
23

24 Appraisal (10w): *'I've always had a mole on my leg.. it was there from birth.. it never*
25 *bothered me because it was just flat and dark brown... It was possibly about six months ago I*
26 *noticed it was just a little bit raised when it had always been flat.. as if like maybe something*
27 *was stuck in there..'*
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30 Help-seeking: *'I was due to have a smear and.. I asked the nurse to look at it.. and she said,*
31 *"Oh no, there's nothing to worry about, that's... I can tell these things," so she just sort of put*
32 *my mind at rest... I thought, "Well, she knows what she's talking about."*
33

34 Re-appraisal- 16 weeks: *'It just started obviously getting bigger and bigger. What was the*
35 *worst was every time I knocked it, it bled.. like a tick on you, because it was big and bulbous.'*
36

37 Help-seeking: *'I realised it was getting bigger and my friend and I had talked about it and [I*
38 *returned to the surgery] .. it was a different nurse more senior, I have known her for years..*
39 *she sort of panicked me ..saying.. I need to get that looked at straight away.'*
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46 DISCUSSION

47 Main findings

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49 This is the first study of detailed patient descriptions of their symptom experience and
50 pathways to diagnosis of thinner and thicker melanomas in the UK. Addressing the policy
51 agenda to diagnose melanoma earlier, the findings provide a number of novel insights
52 **suggesting** where future interventions may be targeted. The key finding is that there appear
53 to be subtly different patterns of symptoms experienced by those with thicker and thinner
54 melanomas. In particular, descriptions of vertical growth, bleeding, oozing and itch were
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3 features of thicker melanomas irrespective of pathological type. Furthermore, they did not
4 appear to occur subsequent to changes in size, shape and colour, nor just be due to location
5 on the body, for example, not all thicker lesions were nodular melanomas on the backs of
6 older men. There was no clear distinction between time to presentation and melanoma
7 thickness. It also does not appear that those with thicker melanomas have different
8 cognitive, emotional or behavioural responses to skin changes compared to those with
9 thinner melanomas, or have different pathways to or through the healthcare system. Whilst
10 help-seeking was often postponed because of other life concerns, most decisions to seek
11 help were triggered by common factors such as advice from family and friends.

12
13 We also found a mismatch between the textual information and published images currently
14 available, and the skin changes that were noticed by our participants. This provides
15 opportunities to incorporate more appropriate lay vocabulary and photographic images into
16 targeted community NHS and charity-run awareness campaigns such as 'Be Clear on Cancer'
17 and 'Detect Cancer Early' [27]. A small but important minority of participants did not have
18 their developing melanomas recognised during their first primary care consultation, and
19 were not provided with enough information about on-going assessment of further skin
20 changes or when to return to their clinician. These 'safety-netting' opportunities could be
21 improved by more systematic approaches by GPs.

22 23 24 25 26 27 28 29 30 31 **Strengths and weaknesses**

32 Our methodological approaches have a number of strengths. We do not know of any other
33 studies worldwide which have compared the patient experience across the appraisal and
34 help-seeking intervals between people with thinner and thicker melanomas. We recruited
35 participants systematically from dermatology clinics in two contrasting regions over 12
36 months, and interviewed all the consenting patients diagnosed with the much less common
37 melanomas $\geq 2\text{mm}$ thickness with a poorer prognosis. The thicker melanoma group included
38 equal numbers of NMs, SSMs, and other rare and unclassified types although no amelanotic
39 lesions; the diversity of types in this group suggest that the differences identified between
40 the thinner and thicker groups cannot simply be considered due to the biological differences
41 between SSMs and NMs. Furthermore, using semi-structured interviews soon after
42 diagnosis reduced recall bias, and allowed participants to speak freely about the period
43 leading up to their diagnosis.

44
45 We used novel and rigorous approaches to data collection, with the Model of Pathways to
46 Treatment to underpin the interview schedule, and four different data collection methods
47 including the use of patient drawings. Asking people to draw their skin changes and
48 developing melanomas was of value to a number of participants, allowing them to describe
49 subtle changes in more detail, and also to corroborate the accuracy of their recall of timing
50 and events. Calendar-landmarking was also of value to a large minority of participants, who

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3 were able to refine their recall of events and time intervals along their time to presentation
4 [28]. Data saturation was reached before the total sample had been interviewed, suggesting
5 that our findings are robust and representative of people diagnosed with melanoma in
6 these regions of England and Scotland. As recommended in a 2006 review of symptom
7 interpretation as a source of delay in melanoma presentation [29], we increased the rigour
8 of our research by applying a theoretical approach (the Pathways to Treatment model,
9 [17,18]) to frame our data collection and analysis. We conducted and reported this study
10 according to the Aarhus statement guidelines on early cancer diagnosis research [23].

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14 The main weakness is that the interviews are necessarily retrospective and subject to recall
15 and framing bias. As a result, the accounts cannot be regarded as an exact description of
16 what happened. Instead, they are narratives that allowed people to describe their
17 experiences and reflect a post-hoc rationalisation of events framed by their subsequent
18 encounters with HCPs and increased knowledge since the diagnosis. Although we recruited
19 all patients with thicker melanomas compared with purposive recruitment for thinner
20 melanomas we believe the groups were similar as the latter group were matched for
21 gender, age, geographic location and season. Furthermore, people from these two UK
22 regions may have different beliefs and experiences of the pathway to melanoma diagnosis
23 from people in other UK regions, and patients who did not agree to take part in the study
24 may have affected the representativeness of the sample.
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32 **Comparison with existing literature**

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34 While there is a paucity of qualitative studies undertaken with people soon after their
35 melanoma diagnosis, our findings resonate with a grounded theory study undertaken in
36 northern England that explored the meaning to people treated for melanoma of shorter and
37 longer time-lapses between detecting signs and receiving treatment [30], and those from an
38 interview study about factors influencing presentation in primary care, undertaken with
39 patients with suspicious pigmented lesions (only 4/40 interviewees were later diagnosed
40 with melanoma) [15]. A French questionnaire study set among 590 people with melanomas
41 also showed that relatives were involved in the detection of half of the melanomas, with
42 median delays of 4 months before the patient realized they had a suspicious lesion, and
43 further median delays of 2 months before this lesion was seen by a doctor [31]. Other
44 evidence around time to diagnosis, but not comparing thinner and thicker melanomas,
45 comes mainly from retrospective review of medical records or dermatologist experience,
46 and suggests similar times to presentation and diagnosis [32].
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54 **Implications for clinicians and policymakers**

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3 be more related to tumour biology than differences in symptom appraisal and help-seeking,
4 these interesting differences need further exploration with bigger and more diverse
5 populations and quantitative as well as qualitative study designs.
6
7

8 Alternative approaches to raising symptom awareness and supporting monitoring of skin
9 changes to prompt earlier help seeking may be needed. There is a growing interest in the
10 application of smartphone technology as one such approach but concerns remain around
11 their safety and utility, and is clearly an area for further research [37].
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For peer review only

ACKNOWLEDGEMENTS

We particularly thank all the patients who kindly gave up their time and shared their personal accounts with us. We also thank Vicky McMorrnan and Sheena Dryden, melanoma/skin cancer nurse specialists at Cambridge University Hospitals NHS Foundation Trust and the Edinburgh Royal Infirmary NHS Lothian respectively, for their enthusiastic help with recruitment. We are also grateful to our two patients who gave us insights and feedback throughout the study, to Anna Barford for her early contribution to study set-up and data collection, to James Brimicombe for advice on data management and for developing the research database, and to Mr Per Hall for his support and encouragement throughout the study and comments on the final manuscript.

Contributors

This study arose from collaboration between members of the National Cancer Research Institute (NCRI) Primary Care and Melanoma Clinical Studies Groups. FW, CC, RM, SS and DW were involved in the design of the study. LB and DC performed all the interviews and led the analysis, contributing to the core study team together with FW, SS and CC. FW wrote the first draft of the manuscript; all authors reviewed and edited the manuscript.

Funding

Thanks to our funding organisation the National Awareness and Early Diagnosis Initiative (NAEDI), and to their funding partners: Cancer Research UK; Department of Health, England; Economic and Social Research Council; Health and Social Care Research and Development Division; Public Health Agency, Northern Ireland, National Institute for Social Care and Health Research, Wales and the Scottish Government. All researchers were independent of the funding body and the study sponsors and funder had no role in study design; data collection, analysis and interpretation of data; in the writing of the report; or decision to submit the article for publication.

FW was supported by an NIHR Clinical Lectureship followed by a NIHR Clinician Scientist award at the time of this study. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health.

Ethics and governance approvals

The study obtained ethical approval from the Cambridgeshire 4 Research Ethics Committee (11/EE/0076). Patients gave informed written consent for participation. The study was CKCRN approved (ID number 10310), and obtained NHS governance approvals from Cambridge University Hospitals NHS Foundation Trust's Research & Development Department, and NHS Lothian (Lothian R&D Project No: 2011/R/DER/04).

Data sharing

1
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3 No additional data available
4

5 **Competing Interests**
6

7 All authors have completed the Unified Competing Interest form at
8 www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare
9 that (1) they have no support from or relationships with companies that might have an interest in
10 the submitted work in the previous 3 years; (2) their spouses, partners, or children have no financial
11 relationships that may be relevant to the submitted work; and (3) they have no non-financial
12 interests that may be relevant to the submitted work.
13
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21
22

23
24 All authors had full access to all of the data in the study and can take responsibility for the integrity
25 of the data and the accuracy of the data analysis
26
27

28
29 The corresponding author affirms that the manuscript is an honest, accurate, and transparent
30 account of the study being reported; that no important aspects of the study have been omitted; and
31 that any discrepancies from the study as planned (and, if relevant, registered) have been explained.
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Table 1. Characteristics of study participants (n=63), and clinical characteristics of their melanomas, comparing thinner (n=33) and thicker (n=30) melanomas.

	Thinner melanomas (<1 mm Breslow thickness)	Thicker melanomas (>2 mm Breslow thickness)
Age at interview		
Mean age \pm s.d. (range)	60.5 \pm 14.6 (29 – 85)	66.1 \pm 15.5 (36 – 93)
Less than 60 years (n=23)	14 (61%)	9 (39%)
60 years and over (n=40)	19 (47%)	21 (53%)
Gender		
Male	14 (42%)	17 (58%)
Female	19 (58%)	13 (42%)
Education		
No further education	21 (64%)	21 (70%)
Further education	12 (36%)	9 (30%)
Fitzpatrick scale: skin colour ^a		
Type I (white skin, v fair)	7 (21%)	2 (6%)
Type II (white skin, fair)	6 (18%)	11 (37%)
Type III (creamy white, any hair)	17 (52%)	16 (53%)
Type IV (brown, Mediterranean)	3 (9%)	1 (3%)
Fitzpatrick scale: skin reaction to sun ^a		
Type I (always burns, never tans)	4 (12%)	3 (10%)
Type II (usually burns, tans with difficulty)	11 (33%)	10 (33%)
Type III (sometimes mild burn, gradually tans)	10 (30%)	11 (37%)
Type IV (rarely burns, tans easily)	6 (18%)	6 (20%)
Type V (very rarely burns, tans very easily)	2 (7%)	0
Melanoma location		
Head & neck	6 (18%)	9 (30%)
Trunk ^b	9 (27%)	4 (14%)
Upper limb	10 (30%)	7 (23%)
Lower limb	8 (24%)	10 (33%)
Melanoma type		
Superficial spreading melanoma (SSM)	25 (76%)	10 (33%)

Nodular melanoma (NM)	0	10 (33%)
Lentigo maligna melanoma (LMM)	7 (21%)	2 (7%)
Others ^c	1 (3%)	8 (27%)
Melanoma TMN stage		
Stage I ^d	33 (100%)	0
Stage II ^e	0	23 (77%)
Stage III ^f	0	7 (23%)
Stage IV	0	0

^a Self-reported, not verified in medical records.

^b Includes melanomas on the back (thinner 6, 18%; thicker 3, 10%).

^c Thinner: mixed type (SSM & NM) x 1; Thicker: LMM 2, acral 1, malignant blue naevus 1, unclassified 6.

^d Stage IA = 27, stage IB = 6 (**T1-2a, N0, M0**).

^e Stage IIA = 11, stage IIB = 5, Stage IIC = 7 (**T2b-4b, N0, M0**).

^f Stage IIIA = 6, stage IIIB = 1 (**T1a – 4a, N1a-2c, M0**).

Table 2. Illustrative quotations of a ‘mis-match’ between observed skin changes and ‘mental images’ of a melanoma

<p>Comparison with experience of a family member’s melanoma</p> <p>‘My mother in law had skin cancer on her back, so I expected melanoma to be much bigger: my little mole was nothing.’ [F, 53, thinner, SSM, 14w/52w]</p>
<p>Comparison with information</p> <p>‘I suppose from the descriptions that I’ve read about melanomas.. it didn’t ring any alarm bells... Okay, it has to start somewhere but, as it developed, [I expected] it would become more raised, it would be scaly and rough, it would be more inflamed-looking. But because this just remained completely flat on the skin...it didn’t meet any profile that I was expecting.’ [F, 63, thinner, LMM, 104w]</p> <p>‘It’s not like a mole, you can see a mole changing colour or shape or texture, you can read all about that, but as my wife says, nothing in the leaflets says anything about under the nail.’ [M, 60, thicker, other, 1w]</p> <p>‘..Because melanomas, he says, are black. Now, this growth on my knee, it was just like a warty growth, with a scarlet top on it, and.. there was no discolouration in it at all. ...I think that’s maybe how a lot of folk’ll not think of these things, because it doesn’t look like what you think it’s supposed to be, if you ken what I mean. It’s just like a bit of skin rising up.’ [M, 52, thicker, SSM, 42w]</p>
<p>Comparison with images</p> <p>‘I think that the way melanomas are publicised, this is what they look like, that’s really misleading ‘cos that isn’t what mine looked like until I saw it blown up on [the dermatologist]’s screen, and I thought ‘oh my God, yeah, mine does look like one of the ones on the front of the leaflet’ but... it just looks very neat, symmetrical, you know, sharp edges.’ [F, 39, thinner, other, 78w]</p> <p>‘When you go to the hospital and you see the things on the walls, and on the internet, and you see the diagrams of it, that is to me what malignant melanoma looks like. Mine didn’t look... it just didn’t come into the category of melanoma, it hadn’t [gone] funny shaped, it hadn’t been jaggy, it didn’t go dark, it didn’t get bigger...it just wasn’t what I imagined melanoma to look like. I think of [melanoma] getting bigger, crustier, bleeding ... and this was... dead flat... none of the things that were there at the back of my mind actually rang any alarm bells.’ [F, 58, thinner, SSM, 22w]</p> <p>‘It didn’t look like a melanoma. Even the booklet I’ve got given since... four or six pictures in there of actually different ones and it didn’t look like one of them. ... Even like the doctor said “I’ve noticed it on there before but I didn’t take any notice”.’ [M, 36, thicker, NM, 78w/3w]</p>
<p>Comparison with knowledge of other cancers</p> <p>‘I think if I could feel pain and know what it was, I may be more responsive to getting it treated’ [M, 74, thinner, LMM, 303w]</p>

Table 3. Descriptions of skin changes, using the Glasgow seven-point checklist (7PCL) criteria [38] and other descriptions (Dis-confirming reports in pink)

Feature - Subgroups	Way feature was described		Thinner			Thicker		
	Thinner	Thicker	SSM n=25	LMM n=7	Other n=1	NM n=10	SSM n=10	LMM/ Others n=10
1 7PCL criteria								
1.1. Changing size i Cover more skin	<i>'it had grown, it looked bigger'</i> [M,48,SSM,2w]	<i>'getting bigger, but not ultra-big, no-one noticed'</i> [M,66, other,136w]	●	●	●	●	●	●
	<i>'dark brown part was .. more raised'</i> [F,40,SSM,3w]	<i>'vertical before it curved across at the top'</i> [M,45,SSM,4w/52w], <i>'mushroomed out... bubbled up'</i> [M,78,NM,8w]	●			●	●	●
	No changing size- flat to skin		●					
1.2. Changing and/or irregular shape	<i>'it sort of made.. a pinky horseshoe'</i> [F,53,SSM,14w/52w], <i>'maple-leaf raggedy'</i> [F,63, LMM,104w]	<i>'breaking into several bits'</i> [F,48,other,4w/78w]	●	●	●		●	●
	No changing shape- smooth edge		●					
1.3. Changing and/or irregular colour	<i>'two colours, dark with a lighter section'</i> [M,37,SSM,52w], <i>'slight discolour that got darker, black like oil'</i> [M,67,SSM,208w]	<i>'red then turned black, lively-looking'</i> [M,73,other,104w], <i>'several different colours'</i> [M,82,other,3w]	●	●	●	●	●	●
	No changing colour (not always darker)		●			●	●	●
1.4. Oozing i Bleeding	<i>'a new shaving blade would nick it but didn't bleed on its own'</i> [M,74,LMM,303w]	<i>'noticed blood on the pillow'</i> [M,66,NM,78w], <i>'forever bleeding and getting a scab'</i> [M,86,SSM,52w]	●	●		●	●	●
	ii Discharge	-				●	●	●
1.5. Changing sensation i Itch	<i>'when it felt itchy and I peeled like flaked off bits of it'</i> [M,67,SSM,208w]	<i>'it was within a mole, just the smallest pimple, a red itchy spot'</i> [M,45,SSM,4w/52w]	●			●	●	●
	ii Soreness	<i>'when caught my nail on it a little bit sore'</i> [F,40,SSM,3w]	<i>'painful sort of like a wasp sting'</i> [M,60,NM,1w]	●			●	●
1.6. Inflammation i Texture change	<i>'quite bumpy'</i> [M,63,SSM,2w/104w]	<i>'bubbled up'</i> [M,78,NM,8w]	●			●	●	●
	ii Crusty, flaky	<i>'it was very dry, a bit scaly'</i> [F,37,SSM,8w]	<i>'dark leathery, I tried to keep it moisturised'</i>	●	●		●	●

		[F,48,other,4w/78w]						
1.7 Large size	'larger than a mole, about the size of a one penny piece' [F,66,LMM,20w/78w] 'size of a thumb nail' [F,63,LMM,104w]	'it was like a 2p piece' [M,82,other,3w] 'felt this huge lump' [M,40,other,4w/68w]	•	•		•	•	•
2 Other descriptions								
2.1 'Different'	'look very different from all the others' [M,63,SSM,2w/104w] 'not like the rest of my moles' [F,37,SSM,8w]	'quite a big mole, nothing wrong until the spot on top' [F,54,SSM,1w], 'two were different, more livelier than the other ones' [M,73,other,104w]	•					•
2.2 Small size i Tiny/small mole li 'just a spot'	'tiny, wee circular mole' [F,43,LMM,22w] 'a little black spot, just an aging spot' [F,76,LMM,16w]	'it was so minuscule' [M,93,LMM,22w] 'it was nothing like a mole at all, it was just like a spot' [M,64,other,20w]	•	•		•	•	•
2.3 New lesion	'somebody else has noticed it so it must be a new one' [F,43,LMM,22w]'the mole had appeared, it was a new mole' [F,29,SSM,3w]	'just suddenly appeared' [F,57,NM,36w] 'came very quick; it wasn't there and then it was there' [F,76,SSM,4w]	•	•		•	•	•
2.4 'Always there'	'had been there for literally years' [M,74,SSM,14w], 'a birthmark, heart shaped, an old friend' [F,39,other,78w]	'been there from birth' [F,56,NM,10w/16w] 'always had that mole, it didn't bother me' [F,61,SSM,26w]	•	•	•	•	•	•

Reported feature per group: • = 1-25%; • = 25-50%; • = 50-75%; • = 75-100%

Table 4. Illustrative quotations of the influences of comments from extended family and friends

Noticing a skin change

'My partner's daughter says to me "Have you always had that mole on your ear?" So I thought well somebody else has noticed it so it must be a new one.' [F, 43, thinner, LMM, 22w]

'I saw my sisters at the funeral and they both mentioned it; we hadn't noticed it.' [M, 66, thicker, NM, 78w]

Acting on encouragement to seek help

'It wasn't till my daughter-in-law come over from Australia, and she said to me that she thought I ought to have it checked out because obviously in Australia they're very conscious of it all.' [F, 58, thinner, SSM, 22w]

'The girl in the beauty salon... she always asked me about this one... and then I went again and she said, "have you seen a doctor?", I said, "no, I don't because it's nothing, I feel okay", and she said, "no, please, I will make you a cup of tea, I will give you a phone number, please go this week." [F, 40, thinner, SSM, 156w]

'I was at a dinner with my daughter, and fortunately I had a low backed dress on, and one of her friends said, "I don't like the look of that mole on your back, and I suggest you have it checked out."' [F, 66, thicker, SSM, 4w]

'It dinnae change dramatically, so one day I quietly said to nurse friend, "Will you just have a look at this for me?" She just took one look and she says "You must promise me when you get home you will go and see the doctor." [F, 61, thicker, SSM, 26w]

Advice of others having little effect

'She thought it was getting darker at some stage, can't remember exactly when, but she maybe nagged me for a year or two before.' [M, 67, thinner, SSM, 208w]

'It's not as if I hadnae been told to go and see about it, because my daughter and my wife... they said, "Well you should go and see about that," but I never did, you know, until May.' [M, 64, thicker, other, 20w]

Not encouraging help seeking

'Fairly early on I discussed it with (a friend). ... But because she said, "I can't really feel it" I think I ignored it. It would have been better if she'd said to me, "I think you need to have it looked at." I think I'd have gone to the doctor then, but because she said, "No, I think it's fine" I think I left it. [F, 64, thicker, LMM, 104 w]

Table 5. Time from first detecting a skin change to first presentation, and first to second presentations to primary care, by time intervals (ordered by first TTP), gender, age, melanoma type and stage

	Time from detecting a skin change to first presentation	Time from first presentation to second presentation	Gender & age	Type & stage
Thinner melanomas				
1	2w	104w	M, 63	SSM, IA
2	4w	22w	F, 58	SSM, IA
3	14w	52w	F, 53	SSM, IA
4	20w	78w	F, 66	LMM, IA
Thicker melanomas				
5	1w	17w	M, 75	SSM, IIC
6	3w	1w	M, 73	NM, IIB
7	4w	52w	M, 45	SSM, IIA
8	4w	68w	M, 40	Other, IIIA
9	4w	78w	F, 48	Acral, IIIA
10	10w	16w	F, 56	NM, IIIA
11	78w	3w	M, 36	NM, IIA

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9 **'This isn't what mine looked like': a qualitative study of symptom**
10 **appraisal and help seeking in people recently diagnosed with**
11 **melanoma**
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ABSTRACT

Objective

To explore symptom appraisal and help-seeking decisions among patients recently diagnosed with melanomas, and to compare experiences of people with 'thinner' (<1mm) and 'thicker' (>2mm) melanomas, as thickness at diagnosis is an important prognostic feature.

Methods

In-depth interviews with patients within ten weeks of melanoma diagnosis explored the factors impacting on their pathways to diagnosis. Framework analysis, underpinned by the Model of Pathways to Treatment, was used to explore the data with particular focus on patients' beliefs and experiences, disease factors, and healthcare professional (HCP) influences.

Results

63 patients were interviewed (29-93 years, 31 women, 30 thicker melanomas). All described their skin changes using rich lay vocabulary. Many included unassuming features such as 'just a little spot' as well as common features of changes in size, colour and shape. There appeared to be subtly different patterns of symptoms: descriptions of vertical growth, bleeding, oozing and itch were features of thicker melanomas irrespective of pathological type.

Appraisal was influenced by explanations such as normal life changes, prior beliefs, and whether skin changes matched known melanoma descriptions. Most decisions to seek help were triggered by common factors such as advice from family and friends. Eleven patients reported previous reassurance about their skin changes by a HCP, with little guidance on monitoring change or when it would be appropriate to re-consult.

Conclusions

Patients diagnosed with both thinner and thicker melanomas often did not initially recognise or interpret their skin changes as warning signs or prompts to seek timely medical attention. The findings provide guidance for melanoma awareness campaigns on more appropriate images, helpful descriptive language, and the need to stress the often apparently innocuous nature of potentially serious skin changes. The importance of appropriate advice, monitoring and safety-netting procedures by HCPs for people presenting with skin changes is also highlighted.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This study is the first exploration of symptom appraisal and help-seeking among people diagnosed with 'thinner' melanomas (T1, very good prognosis, 5 year disease-free prospects 95%), compared with those with 'thicker' melanomas (T3 and T4, less good prognosis, 5 year disease-free prospects <55%).
- The study did not identify clear discriminating features in the diagnostic pathway, or features of thinner versus thicker melanomas.
- The findings highlight a mismatch between the information people need when assessing their skin changes and the information and images currently available, thus providing opportunities to incorporate more appropriate descriptive language, images and information into targeted community awareness campaigns as well as by the NHS and charities via their websites and promotional materials.
- A small but important minority of participants did not have their developing melanomas recognised during their first primary care consultation, and were not provided with enough information about on-going assessment of further skin changes or when to return to their clinician. These 'safety-netting' opportunities could be improved by more systematic approaches by HCPs.
- Using semi-structured interviews close to diagnosis allowed in-depth exploration of the participants' experiences and views, but the accounts are necessarily retrospective and subject to recall and framing bias.

INTRODUCTION

Diagnosing melanoma earlier is high on the UK health policy agenda; it is estimated that around 190 deaths from melanoma could be avoided each year if survival rates in England matched the best in Europe [1]. Worldwide melanoma incidence rates are increasing faster than any other solid tumour. In the UK the incidence has quadrupled since the 1970s [2]; similar incidence rises have been reported across Europe [3,4], the USA [5] and Australia [6]. In the UK there were more than 2,209 deaths and 12,800 new cases diagnosed in 2011, with a disproportionately high rate among people aged less than fifty years [2]. The most important prognostic factor is the tumour thickness at diagnosis according to the Breslow scale (T classification) [7]. **Patients with a primary melanoma $\leq 1\text{mm}$ at diagnosis (T1) currently have 5 year disease-free prospects of over 95%, while for tumours $\geq 2\text{mm}$ at diagnosis this is lower, falling to $<55\%$ with lymph node involvement but no metastatic spread [8].** Tumour thickness is also associated with rapid growth which occurs more frequently in elderly men [9].

Timely diagnosis can be influenced by the diagnostic skills of GPs. A recent analysis of the Cancer Patient Experiences Survey 2009 and the 2010 RCGP cancer audit data reported that more than 90% of people diagnosed with melanoma were seen by their GPs less than three times before diagnosis, compared with 60-80% for the majority of cancer types [10]. This suggests that most melanomas are recognised by GPs and appropriately referred to specialist care in England.

Timely diagnosis can also be influenced by people's symptom appraisal and help-seeking behaviour. Compared with other cancers, people with melanoma have among the longest time between first noticing a symptom and presenting to their GP [11,12], suggesting that the major opportunity to diagnose melanoma earlier is prompting earlier presentation to healthcare through signs and symptom awareness campaigns [13]. This requires an understanding of how people interpret changes in their moles or new lesions. We present findings from an in-depth interview study with UK patients recently diagnosed with 'thinner' (T1) compared with 'thicker' primary melanomas (T3 and T4), which aimed to explore the processes and experiences of symptom detection and help-seeking decisions leading to melanoma diagnosis.

METHODS

Design and ethics

Semi-structured face to face in-depth interviews were conducted with adults diagnosed with invasive cutaneous melanoma within the previous ten weeks. Ethics approval was obtained from the Cambridgeshire 4 Research Ethics Committee (11/EE/0076).

Setting and recruitment

Potential participants were identified and recruited by the melanoma/skin cancer nurse specialists via the weekly multidisciplinary team meetings of dermatologists, plastic surgeons and oncologists at two regional hospitals: Cambridge University Hospitals NHS Foundation Trust in the East of England, and the Edinburgh Royal Infirmary, NHS Lothian, Scotland. These hospitals together serve a population of approximately 1.4 million, and the MDT meetings review more than 400 new cases of invasive cutaneous melanoma each year.

All adults aged 18 and over newly diagnosed with a primary invasive cutaneous melanoma (staged as $\leq 1\text{mm}$ (T1, 'thinner') or $\geq 2\text{mm}$ (T3 and T4, 'thicker') at the two participating hospitals were eligible for inclusion unless the melanoma/skin cancer nurse specialists felt that they were not suitable on clinical grounds (other severe physical or mental health conditions). Patients were mailed an invitation letter with a patient information sheet. As T3 and T4 melanomas are diagnosed at about 25% of the rate of T1 melanomas, we recruited all those with thicker melanomas who agreed to take part. At the same time we purposively sampled people with T1 melanomas by age, gender, location and season to ensure that we had a broad range of views and experiences, and we continued until saturation of data. **Reasons for not selecting patients for interview included: sampling decisions (n=34), lost to follow-up (n=6), and ill-health (n=1).**

Data collection

Interviews were undertaken between January 2012 and January 2013. In each area an experienced researcher used a semi-structured approach, with an interview schedule informed from the literature [14,15], our collective expertise from interviewing patients recently diagnosed with other cancers [16], and a pilot study (n=17, **conducted during the early stages of the study, and including patients interviewed >10 weeks post-diagnosis (n=12), or with melanoma histology which did not fit the inclusion criteria (n=5, Breslow thickness 1-2mm or indeterminate)**). The theoretical approach of the Model of Pathways to Treatment [17,18] (Figure 1) was used to underpin the interview schedule, exploring the processes that occurred within each time-interval and focusing on: how initial symptoms were noticed; personal risk perceptions; the language used to describe symptoms and changes over time; the participant's decision-making and triggers to help-seeking; and the experience of the diagnostic process of primary and secondary care from the patient perspective. A calendar-landmarking technique [19] was used as an adjunct to the interviews, to establish the timing and details of events which led to the melanoma diagnosis, together with diaries and letters that participants referred to during this process. Participants were also invited make a pencil drawing/s of their skin cancer as it developed; on-going analyses are examining perceptions of lesions over time, and comparing the drawings with clinical images [20]. At the end of each interview, participants completed a short questionnaire to provide demographic data, and information about their skin and hair colour and their skin's response to UV light using the widely validated Fitzpatrick Scale [21].

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3 Interviews were undertaken as soon as possible after diagnosis, with all interviews
4 completed within 10 weeks of diagnosis, and the majority within 6 weeks. Interviews lasted
5 between 40-65 minutes and were conducted primarily in the participant's home although
6 two people chose to be interviewed in university offices. Patients were sometimes
7 accompanied by a family member, usually spouse or daughter. Audio-recordings of
8 interviews were professionally transcribed verbatim and anonymised.
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11 12 13 **Analysis**

14 All interview transcripts were repeatedly read and re-read by the two researchers LB
15 (nursing background) and DC (health services researcher), and the members of the 'core'
16 analysis team also read the majority of the transcripts (FW, academic GP; SS, health
17 psychologist; CC, primary care researcher). Analysis was an iterative process starting near
18 the beginning of data collection and using the 17 pilot interviews to develop our analytic
19 strategy. We used the approach of Framework analysis to create and establish meaningful
20 patterns in five phases, namely: familiarization with the data, generating initial codes,
21 inductively searching for themes among codes, index charting and mapping of data, before
22 finally defining and naming themes [22]. The coding and data management were supported
23 by NVivo software (QSR International, version 9). The Model of Pathways to Treatment
24 (Figure 1) was also used to underpin the analysis with a theoretic model for the different
25 intervals and processes that occur along the pathway to diagnosis and treatment, in order
26 to accurately assess the time intervals, their content and context. The final themes were
27 agreed through a series of meetings involving all five 'core' researchers, and a consensus
28 meeting with the wider study team.
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35 The analysis focused on the main themes within the time to presentation (TTP), defined as
36 from the first detection of skin change to the first consultation with a healthcare
37 professional [23, 24]. This interval comprises the appraisal and help-seeking intervals
38 [17,18], and the analysis examined patient and healthcare factors as well as 'disease'
39 factors, relating to the developing melanoma. When the first consultation did not result in a
40 referral, we also included further iterative processes until the next consultation in the
41 analyses. Participants with shorter intervals tended to use diaries and have good recall of
42 the relevant dates. People with longer intervals tended to have vaguer recollections,
43 particularly around the time they had first detected any skin change. While participants
44 were often able to discuss triggers to help-seeking, they were less able to recall the precise
45 dates of these triggers, and we therefore do not present the separate durations of the
46 appraisal and help-seeking intervals.
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52 We went on to examine our themes by comparing narratives from participants diagnosed
53 with thinner and thicker melanomas, and by the melanoma types within these groups. We
54 further validated our themes by examining the whole dataset stratified by gender, by age
55 (less than 60 vs 60 and over, and 80 and over), by educational level (no further education vs
56 further education), and by geographical location (Cambridge vs Edinburgh). Credibility was
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3 increased by the two researchers together undertaking coding and producing code tables
4 throughout the analytic process, and reaching consensus from the potentially wide range of
5 interpretations across the 'core' analysis team.
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10 RESULTS

11 A total of 241 adult patients were approached to take part in this study (Cambridge 114,
12 Edinburgh 127), 121 were willing to participate (50%: Cambridge 53%, Edinburgh 47%), and
13 63 were interviewed.
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17 Patient characteristics

18 Table 1 shows the demographic and self-reported skin characteristics of the 63 study
19 participants, and the clinical characteristics of their melanomas, comparing participants with
20 thinner (n=33, **median Breslow thickness 0.5 mm, range 0.1-0.9 mm**) and thicker (n=30,
21 **median Breslow thickness 3.5 mm, range 2.1-12.0 mm**) melanomas. **While people with**
22 **thinner melanomas were younger (60.5 vs 66.1 years), the groups were otherwise similar**
23 **for socio-demographic factors.** One quarter of the group reported a family history of
24 melanoma, while eight participants reported previous skin cancer (melanoma 2, basal cell
25 carcinoma (BCC) 6): we were only able to verify the two melanomas with histology reports.
26 The thinner melanomas were all histologically reported as superficial spreading melanomas
27 (SSM) and lentigo maligna melanomas (LMM) apart from one diagnosed as part SSM and
28 part NM ('other'). Due to our sampling strategy there was a higher prevalence of nodular
29 melanomas than in reported local figures. However, only a third of the thicker melanomas
30 were nodular melanomas (NM, n=10), while a third were SSM (n=10), and the remaining
31 third had 'other' diagnoses (LMM 2, acral 1, malignant blue naevus 1, unclassified 6). Of the
32 nine participants diagnosed with melanoma on their back, seven were male, and three had
33 thicker melanomas (NM 2, SSM 1).
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45 Duration of skin changes

46 Four participants (male 3, female 1) had their melanomas diagnosed opportunistically by a
47 HCP (3 GPs, 1 oncologist); all these were thinner melanomas. The time to presentation (TTP)
48 was between 1 week and 303 weeks (thinner: median TTP 21 weeks, range 1-303 weeks, **5**
49 **longer than 52 weeks**; thicker: median TTP 19 weeks, range 1-156 weeks, **7 longer than 52**
50 **weeks**). Most participants who presented with skin changes were referred after their first
51 primary care consultation. The remainder were referred after their second consultation
52 (n=11); none reported more than two consultations prior to referral. Comparisons between
53 those with thinner (n=4) and thicker (n=7) melanomas who were referred after a second
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3 primary care consultation are presented in Table 5 and discussed later (see section on
4 Healthcare providers and system factors).

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6 The main emerging themes within the appraisal and help-seeking intervals are discussed
7 below. Throughout this section quotations are accompanied by information about gender
8 (M, F), age, melanoma group (thinner or thicker), type of melanoma (SSM, NM, LMM,
9 other), and symptom duration as time to presentation in weeks (including first and second
10 presentations).

11 12 13 14 15 **The appraisal interval**

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17 The 59 participants who detected their melanoma themselves described a variable and
18 complex process of appraisal and re-appraisal of their skin, against their background
19 knowledge of 'normal skin changes' and potential risk factors. We found no evidence of
20 differences between people with thinner and thicker melanomas across any of these
21 themes.
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24 25 **Patient factors**

26 27 ***Explanations for skin changes***

28
29 Awareness of a skin change, either a new lesion or a change in an existing lesion, did not
30 usually cause any initial concern as it seemed so innocuous, and was often attributed to
31 normal life changes such as pregnancy or aging.
32
33

34
35 *'I didn't recognise it as something that was different, because I've got quite a few moles on*
36 *my skin so therefore I thought, "Has this been here before, or am I just imagining that I*
37 *haven't seen it before?"' [F, 68, thinner, SSM, 52w]*

38
39 *'Perhaps because I'd been pregnant and everything was darker anyway or you know, I didn't*
40 *take any notice.'* [F, 36, thicker, NM, 17w]

41
42 Other explanations were also often made, such as an insect bite or injury when the
43 participant had been outside or in the garden.
44

45
46 *'Since I'd been outside to a barbeque and I thought, oh well I've been bitten, it's just bitten*
47 *there on the mole.'* [F, 54, thicker, SSM, 1w]

48
49 Skin changes were sometimes attributed to another skin condition (such as psoriasis) if it
50 presented in a similar way; in these cases participants' previous experiences of a benign
51 condition could influence their perception of the potential seriousness of the new skin
52 changes.
53
54

55 56 ***Prior beliefs about melanoma and its risk factors***

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3 Skin changes were appraised within the context of peoples' prior beliefs about melanoma
4 and its risk factors, and their life experiences. Participants often used the terms skin cancer
5 and melanoma interchangeably, and their prior awareness of melanoma varied widely.
6
7 Whereas some participants noted that they had no awareness at all, others described
8 gaining some knowledge about melanoma via TV programmes, magazines, the internet, and
9 occasionally, health promotion material. A minority had heightened awareness through the
10 melanoma experience of a family member or friend, or even a celebrity. A family history of
11 melanoma or a personal previous melanoma led several people to have heightened risk
12 perception and awareness and to quickly identify skin changes as a potential melanoma; all
13 these people sought help rapidly and presented with thinner melanomas:
14
15

16
17 *'I wouldn't have known what they were talking about' [M, 62, thicker, SSM, 52w]*

18
19 *'...because my mum has had a melanoma ten years ago so I've always been aware to keep a*
20 *check on my moles.'* [F, 29, thinner, SSM, 3w]
21

22 Many participants showed some understanding of the risk factors associated with
23 melanoma and/or skin cancer when they discussed having lived in hot climates, or having
24 suffered from sunburn, especially as a child. However, some were quite certain that they
25 had never exposed themselves to the risk of UV damage:
26

27
28 *'I thought I had been careful about sitting out in the sun.'* [F, 57, thicker, NM, 36w]
29

30 Prior knowledge or experience of melanoma and its risk factors did not appear to be related
31 to educational levels, nor to melanoma thickness at diagnosis.
32

33 34 ***Do skin changes 'match' a melanoma?*** 35

36 While some participants admitted to prior knowledge of the symptoms and signs of a
37 melanoma, such as 'jagged edges' or change in colour, only a few people had known that an
38 itchy or bleeding mole was a 'bad' sign. Only two people noticed a match between their
39 observed skin changes and their mental image of a melanoma, and this match appeared to
40 prompt appropriate help-seeking, leading to shorter times to presentation.
41

42
43 *'I don't know when I learnt it, but it was just in my subconscious that "ooh I need to go and,*
44 *it's an itchy mole, that's not good".'* [M, 45, thicker, SSM, 4w/52w]
45

46 Strikingly, the majority of participants reported that their observed skin changes did not
47 match their mental image (which had arisen from the melanoma experience of a family
48 member or friend, from written and visual images, or from their knowledge of other
49 cancers, see Table 2). When the changes did not match their mental images, people
50 appeared more likely to 'normalise' their skin changes, or adopt other explanations, thus
51 delaying help-seeking and diagnosis. Thus, the appraisal interval was often prolonged when
52 there was a 'mismatch' between the mental image people had of melanoma and the way in
53 which their own skin changes developed.
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Disease factors: skin changes

Most participants used rich and vivid lay vocabularies to describe their skin changes, for example, *'like a black fly squashed on a mirror'* [M, 48, thinner, SSM, 2w]. Table 3 shows descriptions of skin changes noticed by participants, displayed according to the items of the Glasgow seven-point checklist (7PCL) [25]. It also gives descriptions not commonly found on checklists. For instance, many people reported surprise at the small size of their melanoma, describing it as 'just a little spot'. Some also reported a 'spot on a mole', or that their skin change had been 'always there' or a 'new lesion'; a few reported their lesion as 'different to the others' (resonating with the Ugly Duckling sign [26]).

Overall, Table 3 shows that both thinner and thicker melanomas can show any of the changes described in the 7PCL. However there is a suggestion of slightly different patterns. In particular, patients with thicker melanomas, both NMs and SSMs, described the so-called 'minor features' of bleeding, oozing and itch more often. They also described both horizontal and vertical growth, again, irrespective of pathological type. Patients with thinner lesions discussed changes in shape more often. We were not able to find any differences in descriptions of skin changes between gender, age, educational level or geographical region.

The help-seeking interval

Reasons for waiting before seeking help included weighing up the priority of their skin change against other commitments. Many participants had been encouraged by other people to seek the advice of a HCP for their skin change. Emotions such as fear of a serious condition, cancer or treatment, were seldom mentioned and seemed to play little part in most peoples' decision-making, either to promote or delay help-seeking. More were concerned about going to see their GP with only minor symptoms, and wasting the GP's time.

Patient factors

Prioritisation choices

Many participants discussed other responsibilities in their lives which felt more important than making an appointment to consult their GP about a skin change, and therefore contributed to delays in help-seeking. These competing priorities included employment, care of family members, moving house, holidays, and other health concerns.

'In the cab game you can't organise things, you can't afford to be off your work' [M, 66, thicker, other, 156w]

'The six year old has got ADHD and mild autism and he's hard work, and I suppose [you're] concentrating on him most of your life like, and don't think about yourself...' [M, 36, thicker, NM, 78w/3w]

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2
3 *'I'd been very busy with selling a house, buying a house, all the rest of it, and of course I've*
4 *patients as well to see' [F, 72, thinner, SSM, 8w]*

5
6 *'I had an ulcer on my leg, and redressing that, so I think I was more taken up with that*
7 *getting healed...' [F, 76, thicker, NM, 4w (Community nurse contacted GP)]*

8
9 Some people mentioned repeatedly failing to make an appointment with a HCP either
10 because of the competing responsibilities or because a skin change was 'not a priority':

11 *'I was supposed to have phoned up, but I forgot because it was busy at work and... it just*
12 *skipped my memory' [M, 59, thinner, SSM, 1w]*

13
14 *'I didn't class it as an emergency...I didn't think it was important enough...' [M, 64, thicker,*
15 *other, 20w]*

16
17
18 We found no differences in prioritisation choices between people with thinner and thicker
19 melanomas.

20 21 22 23 ***Influence of other family members and the social network***

24
25 Many participants had been encouraged by other people to seek medical help, either by an
26 observation about the skin change itself, or an encouragement to make an appointment
27 with their GP, see Table 4. Some participants had not been aware of their skin change until
28 it was noticed by another person; others had known, and were also often aware that it was
29 continuing to change, but they were ultimately encouraged to seek help by others. The
30 other people included family members, friends, work colleagues, and people providing
31 treatments such as beauty therapists and hairdressers. The promotion of help-seeking,
32 whether by family members or friends, did not appear to affect time to presentation overall,
33 but may have acted as a trigger for many people. A few people were wrongly reassured by
34 family members or friends that their skin change was not potentially serious. This appeared
35 to delay timely help-seeking. There was no evident difference in the influence of family
36 members between people diagnosed with thinner or thicker melanomas.

37 38 39 40 41 ***Triggers for help-seeking***

42
43 The main difference between participants with thinner and thicker melanomas was
44 apparent with the 'triggers' that people described as they moved from the appraisal to help-
45 seeking interval, when they realised that they 'had a reason to discuss their skin change with
46 a HCP' - see Figure 1. While most people from both groups consulted family or their wider
47 social network for endorsement to seek help about aspects of skin changes (changing
48 colour, texture and size), some people with thinner melanomas also reported a heightened
49 awareness of cancer from family experiences or the non-medical media, or noticing their
50 skin changes as 'different to normal', while participants with thicker melanomas appeared
51 to depend on prompts such as the more 'red flag' symptom of oozing/bleeding:

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54
55
56 *'It was a black mole and most of my moles are dark or light brown so it was a different*
57 *colour' [F, 29, thinner, SSM, 3w]*

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3 *'I'd seen something on that Embarrassing Bodies programme, and they did a thing about*
4 *moles and what was not right and so I suppose I saw that and that sort of made me think,*
5 *maybe I should go and get it looked at.'* [F, 54, thicker, SSM, 1w]
6

7 *'It started to bleed, that was the point at which I went to the doctor 'cos I thought it*
8 *shouldn't be bleeding'* [F, 64, thicker, LMM, 104w]
9

10 11 12 **Healthcare providers and system factors**

13
14 Issues concerning healthcare providers and the NHS were only mentioned by a minority of
15 participants. The first and most important area of concern involved a group of participants
16 (n=11; thinner=4 (SSM 3, LMM 1); thicker=7 (SSM 2, NM 3, acral 1, blue malignant naevus 1)
17 who reported that they had previously shown their lesion to a HCP, and had been reassured
18 that they did not need further treatment, see Table 5. While some just made a passing
19 reference to their first, reassuring encounter with their GP, others gave far more detailed
20 descriptions. A first encounter often appeared to delay a second visit to the GP by providing
21 'false reassurance' about the lesion. Some mentioned that they had not been given advice
22 (oral, written or a website) on how to best monitor their lesion and what changes should
23 alert them to returning to their GP; this could potentially result in thicker lesions at
24 diagnosis.
25
26
27
28

29 *'When people have told you that it's okay... I sort of took me eye off the ball really because I*
30 *thought, well, they know better than I do.'* [M, 75, thicker, SSM, 1w/17 w]
31

32 Some people had problems with accessing their general practice for an appointment, and,
33 for a few busy people, this problem was exacerbated by having competing priorities.
34

35 *'Trying to get an appointment with the GP here can just be horrific and because I'm out on*
36 *the road.. I have to plan these things a couple of weeks ahead.'* [F, 40, thinner, SSM, 3w]
37

38 A few people with thicker melanomas also mentioned a dislike of seeing doctors, either in
39 general practices or hospitals, so this might have delayed help-seeking.
40

41 *'I'm just not a hospital person or a doctor person. If I'm really ill, I ken I'll have to go, but I*
42 *have to be that way.'* [M, 52, thicker, SSM, 42w]
43

44 Patients' concerns about 'wasting their GP's time' are well known, but this concern
45 appeared to be exacerbated by the small size of the skin changes, and the lack of pain or
46 other features which could signify more serious conditions. Again, this concern appeared
47 more prevalent among people with thicker than thinner melanomas.
48
49

50 *'My decisions on going to the GP are always influenced to some extent by a knowledge of*
51 *how busy they are and not wanting to waste their time.'* [F, 48, thicker, other, 4w/78w]
52

53 *'I think most people that I know would be afraid of the doctor saying to himself or herself,*
54 *you know, there's people just coming for nothing at all.'* [M, 93, thicker, LMM, 22w]
55

56 A 56 year old woman diagnosed with a stage IIIA nodular melanoma on her lower leg
57 described her pathway over six months as follows:
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3 Appraisal (10w): *'I've always had a mole on my leg.. it was there from birth.. it never*
4 *bothered me because it was just flat and dark brown... It was possibly about six months ago I*
5 *noticed it was just a little bit raised when it had always been flat.. as if like maybe something*
6 *was stuck in there..'*

7
8 Help-seeking: *'I was due to have a smear and.. I asked the nurse to look at it.. and she said,*
9 *"Oh no, there's nothing to worry about, that's... I can tell these things," so she just sort of put*
10 *my mind at rest... I thought, "Well, she knows what she's talking about."*

11
12 Re-appraisal- 16 weeks: *'It just started obviously getting bigger and bigger. What was the*
13 *worst was every time I knocked it, it bled.. like a tick on you, because it was big and bulbous.'*

14
15 Help-seeking: *'I realised it was getting bigger and my friend and I had talked about it and [I*
16 *returned to the surgery] .. it was a different nurse more senior, I have known her for years..*
17 *she sort of panicked me ..saying.. I need to get that looked at straight away.'*
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24 DISCUSSION

25 Main findings

26
27 This is the first study of detailed patient descriptions of their symptom experience and
28 pathways to diagnosis of thinner and thicker melanomas in the UK. Addressing the policy
29 agenda to diagnose melanoma earlier, the findings provide a number of novel insights
30 **suggesting** where future interventions may be targeted. The key finding is that there appear
31 to be subtly different patterns of symptoms experienced by those with thicker and thinner
32 melanomas. In particular, descriptions of vertical growth, bleeding, oozing and itch were
33 features of thicker melanomas irrespective of pathological type. Furthermore, they did not
34 appear to occur subsequent to changes in size, shape and colour, nor just be due to location
35 on the body, for example, not all thicker lesions were nodular melanomas on the backs of
36 older men. There was no clear distinction between time to presentation and melanoma
37 thickness. It also does not appear that those with thicker melanomas have different
38 cognitive, emotional or behavioural responses to skin changes compared to those with
39 thinner melanomas, or have different pathways to or through the healthcare system. Whilst
40 help-seeking was often postponed because of other life concerns, most decisions to seek
41 help were triggered by common factors such as advice from family and friends.
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48 We also found a mismatch between the textual information and published images currently
49 available, and the skin changes that were noticed **by our participants**. This provides
50 opportunities to incorporate more appropriate lay vocabulary and photographic images into
51 targeted community NHS and charity-run awareness campaigns such as 'Be Clear on Cancer'
52 and 'Detect Cancer Early' [27]. A small but important minority of participants did not have
53 their developing melanomas recognised during their first primary care consultation, and
54 were not provided with enough information about on-going assessment of further skin
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3 changes or when to return to their clinician. These 'safety-netting' opportunities could be
4 improved by more systematic approaches by GPs.
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8 **Strengths and weaknesses**

9
10 Our methodological approaches have a number of strengths. We do not know of any other
11 studies worldwide which have compared the patient experience across the appraisal and
12 help-seeking intervals between people with thinner and thicker melanomas. We recruited
13 participants systematically from dermatology clinics in two contrasting regions over 12
14 months, and interviewed all the consenting patients diagnosed with the much less common
15 melanomas $\geq 2\text{mm}$ thickness with a poorer prognosis. The thicker melanoma group included
16 equal numbers of NMs, SSMs, and other rare and unclassified types although no amelanotic
17 lesions; the diversity of types in this group suggest that the differences identified between
18 the thinner and thicker groups cannot simply be considered due to the biological differences
19 between SSMs and NMs. Furthermore, using semi-structured interviews soon after
20 diagnosis reduced recall bias, and allowed participants to speak freely about the period
21 leading up to their diagnosis.
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27 **We used novel and rigorous approaches to data collection, with the Model of Pathways to**
28 **Treatment to underpin the interview schedule, and four different data collection methods**
29 **including the use of patient drawings.** Asking people to draw their skin changes and
30 developing melanomas was of value to a number of participants, allowing them to describe
31 subtle changes in more detail, and also to corroborate the accuracy of their recall of timing
32 and events. Calendar-landmarking was also of value to a large minority of participants, who
33 were able to refine their recall of events and time intervals along their time to presentation
34 [28]. Data saturation was reached before the total sample had been interviewed, suggesting
35 that our findings are robust and representative of people diagnosed with melanoma in
36 these regions of England and Scotland. As recommended in a 2006 review of symptom
37 interpretation as a source of delay in melanoma presentation [29], we increased the rigour
38 of our research by applying a theoretical approach (the Pathways to Treatment model,
39 [17,18]) to frame our data collection and analysis. We conducted and reported this study
40 according to the Aarhus statement guidelines on early cancer diagnosis research [23].
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46 The main weakness is that the interviews are necessarily retrospective and subject to recall
47 and framing bias. As a result, the accounts cannot be regarded as an exact description of
48 what happened. Instead, they are narratives that allowed people to describe their
49 experiences and reflect a post-hoc rationalisation of events framed by their subsequent
50 encounters with HCPs and increased knowledge since the diagnosis. **Although we recruited**
51 **all patients with thicker melanomas compared with purposive recruitment for thinner**
52 **melanomas we believe the groups were similar as the latter group were matched for**
53 **gender, age, geographic location and season.** Furthermore, people from these two UK
54 regions may have different beliefs and experiences of the pathway to melanoma diagnosis
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3 from people in other UK regions, and patients who did not agree to take part in the study
4 **may have affected the representativeness of the sample.**
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8 **Comparison with existing literature**

9
10 While there is a paucity of qualitative studies undertaken with people soon after their
11 melanoma diagnosis, our findings resonate with a grounded theory study undertaken in
12 northern England that explored the meaning to people treated for melanoma of shorter and
13 longer time-lapses between detecting signs and receiving treatment [30], and those from an
14 interview study about factors influencing presentation in primary care, undertaken with
15 patients with suspicious pigmented lesions (only 4/40 interviewees were later diagnosed
16 with melanoma) [15]. A French questionnaire study set among 590 people with melanomas
17 also showed that relatives were involved in the detection of half of the melanomas, with
18 median delays of 4 months before the patient realized they had a suspicious lesion, and
19 further median delays of 2 months before this lesion was seen by a doctor [31]. Other
20 evidence around time to diagnosis, but not comparing thinner and thicker melanomas,
21 comes mainly from retrospective review of medical records or dermatologist experience,
22 and suggests similar times to presentation and diagnosis [32].
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30 **Implications for clinicians and policymakers**

31
32 Policymakers continue to face the challenge of a widespread lack of awareness of cancer
33 symptoms among the UK general population [33], and that there are significant barriers to
34 help-seeking [34]. Policy responses have included campaigns to raise symptom awareness,
35 with major investment in the new 'Be Clear on Cancer' melanoma campaign. Our findings
36 clearly demonstrate that the words and images in current use may not meet the needs of
37 the population who are likely to be assessing their skin changes at an early stage in tumour
38 development. Current images tend to represent more extreme changes which may not
39 always be present. Future melanoma awareness campaigns, as well as NHS and charity
40 websites giving information about skin checks, would be advised to provide more evidence
41 around the features of early skin changes using lay vocabulary [35], to consider their
42 selection of images of early melanomas for a better 'match' with people's observations, and
43 to provide more evidence around prompts to encourage timely help-seeking. They should
44 also consider more targeted approaches such as focusing on: higher risk groups such as
45 older men, with tailored information, lay vocabulary and images; families and friends with
46 advice on how to check each other's skin regularly; and professional groups from the hair,
47 beauty, and exercise industries who also undertake informal skin checks.
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54 Several participants reported visiting their GP or other HCP on more than one occasion and
55 some were given false reassurance. The average GP working in the UK will only diagnose a
56 melanoma every 2-3 years but will commonly be consulted about a pigmented skin lesion,
57 often after other health issues have already been discussed in the consultation. While we
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3 recognise the challenges facing GPs when differentiating potentially rare and serious
4 conditions such as melanoma from common and benign conditions, this study suggests that
5 some patients are not being provided with adequate information either about monitoring
6 their skin changes or what changes should prompt another consultation. The principles of
7 'safety-netting' have been disseminated by the RCGP and could be applied more effectively;
8 they include recommendations for appropriate advice and written information for patients
9 about the warning symptoms, monitoring symptoms, when to make a follow-up
10 appointment, and reassurance to patients that symptoms like skin changes warrant GP
11 attention, thus 'legitimising' a follow-up visit [36].
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17 **Unanswered questions and future research**

18
19 While the findings of this qualitative study are of immediate importance to primary care
20 clinicians and policymakers, there are also suggestions of subtly different patterns of
21 symptoms experienced by those with thicker and thinner melanomas, irrespective of
22 pathological type. The descriptions of vertical as well as horizontal growth, and bleeding,
23 oozing or itch were particular features of thicker melanomas but not only NMs.
24 Furthermore, they did not appear to occur subsequent to changes in size, shape or colour so
25 may not necessarily be later features of melanoma. Although these symptom clusters may
26 be more related to tumour biology than differences in symptom appraisal and help-seeking,
27 these interesting differences need further exploration with bigger and more diverse
28 populations and quantitative as well as qualitative study designs.
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33 Alternative approaches to raising symptom awareness and supporting monitoring of skin
34 changes to prompt earlier help seeking may be needed. There is a growing interest in the
35 application of smartphone technology as one such approach but concerns remain around
36 their safety and utility, and is clearly an area for further research [37].
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ACKNOWLEDGEMENTS

We particularly thank all the patients who kindly gave up their time and shared their personal accounts with us. We also thank Vicky McMorrnan and Sheena Dryden, melanoma/skin cancer nurse specialists at Cambridge University Hospitals NHS Foundation Trust and the Edinburgh Royal Infirmary NHS Lothian respectively, for their enthusiastic help with recruitment. We are also grateful to our two patients who gave us insights and feedback throughout the study, to Anna Barford for her early contribution to study set-up and data collection, to James Brimicombe for advice on data management and for developing the research database, and to Mr Per Hall for his support and encouragement throughout the study and comments on the final manuscript.

Contributors

This study arose from collaboration between members of the National Cancer Research Institute (NCRI) Primary Care and Melanoma Clinical Studies Groups. FW, CC, RM, SS and DW were involved in the design of the study. LB and DC performed all the interviews and led the analysis, contributing to the core study team together with FW, SS and CC. FW wrote the first draft of the manuscript; all authors reviewed and edited the manuscript.

Funding

Thanks to our funding organisation the National Awareness and Early Diagnosis Initiative (NAEDI), and to their funding partners: Cancer Research UK; Department of Health, England; Economic and Social Research Council; Health and Social Care Research and Development Division; Public Health Agency, Northern Ireland, National Institute for Social Care and Health Research, Wales and the Scottish Government. All researchers were independent of the funding body and the study sponsors and funder had no role in study design; data collection, analysis and interpretation of data; in the writing of the report; or decision to submit the article for publication.

FW was supported by an NIHR Clinical Lectureship followed by a NIHR Clinician Scientist award at the time of this study. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health.

Ethics and governance approvals

The study obtained ethical approval from the Cambridgeshire 4 Research Ethics Committee (11/EE/0076). Patients gave informed written consent for participation. The study was CKCRN approved (ID number 10310), and obtained NHS governance approvals from Cambridge University Hospitals NHS Foundation Trust's Research & Development Department, and NHS Lothian (Lothian R&D Project No: 2011/R/DER/04).

Data sharing

No additional data available

Competing Interests

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) they have no support from or relationships with companies that might have an interest in the submitted work in the previous 3 years; (2) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (3) they have no non-financial interests that may be relevant to the submitted work.

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All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis

The corresponding author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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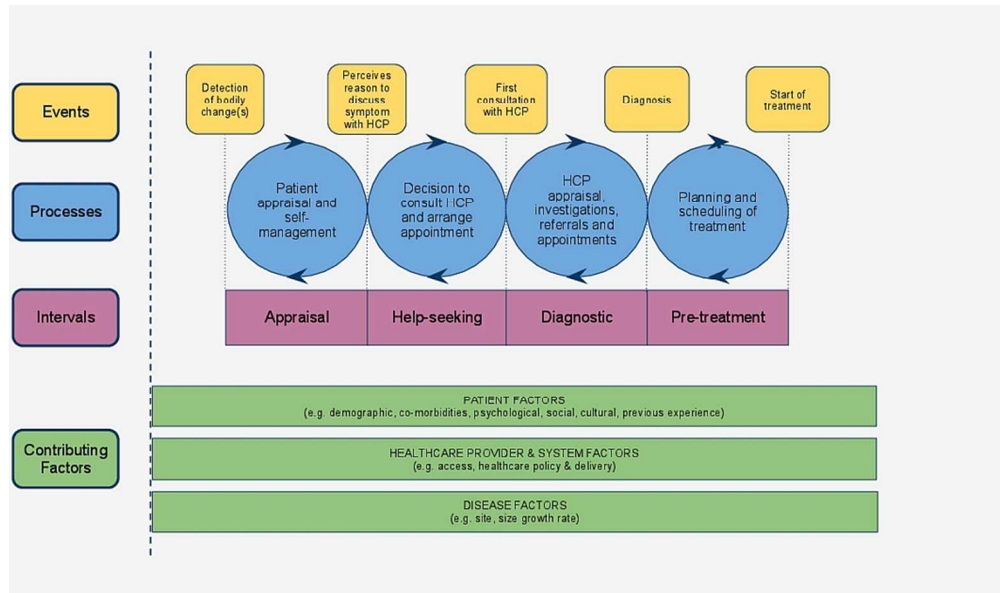


Figure 1 Model of Pathways to Treatment
90x53mm (300 x 300 DPI)

review only

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