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# People living with psoriasis require guidance to navigate popular dietary information: a qualitative study of UK adults

Journal:	BMJ Open
Manuscript ID	bmjopen-2024-085536
Article Type:	Original research
Date Submitted by the Author:	19-Feb-2024
Complete List of Authors:	Hawkins, Poppy; University of Hertfordshire, Mason, Sarah; University of Hertfordshire, Life and Medical Sciences Earl, Kate; University of Hertfordshire, Life and Medical Sciences Tektonidis , Athanasios ; Oxford Brookes University, Department of Sport, Health Sciences and Social Work Fallaize, Rosalind; University of Hertfordshire, Life and Medical Sciences
Keywords:	DERMATOLOGY, Psoriasis < DERMATOLOGY, Patient-Centered Care, NUTRITION & DIETETICS





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# PEOPLE LIVING WITH PSORIASIS REQUIRE GUIDANCE TO NAVIGATE POPULAR DIETARY INFORMATION: A QUALITATIVE STUDY OF UK ADULTS

Poppy Hawkins <sup>1</sup>\*, Sarah Mason <sup>1</sup>, Kate Earl <sup>1</sup>, Thanasis G. Tektonidis <sup>2</sup>, Rosalind Fallaize <sup>1</sup>

<sup>1</sup> School of Life and Medical Sciences, University of Hertfordshire, Hatfield, AL10 9AB, UK

<sup>2</sup> Department of Sport, Health Sciences and Social Work, Oxford Brookes University, Oxford,

OX3 0BP, UK

\*Corresponding author

E-mail: <u>p.hawkins@herts.ac.uk</u>

BMJ Open: first published as 10.1136/bmjopen-2024-085536 on 9 April 2025. Downloaded from http://bmjopen.bmj.com/ on June 7, 2025 at Agence Bibliographique de

#### ABSTRACT

#### Introduction

Psoriasis is a chronic inflammatory skin disease associated with significant comorbidities. Emerging evidence suggests people living with psoriasis (PLwP) try self-prescribed restrictive diets to help manage their symptoms. However, there is a lack of research on how PLwP perceive and use dietary modifications in the UK. Following restrictive diets without healthcare professional (HCP) guidance can have detrimental effects on health and well-being. Understanding the experiences and use of diet in PLwP will play a key role in psoriasis care.

#### Methods

Adults living with psoriasis in the UK were recruited and semi-structured individual interviews were conducted. Interviews were transcribed and coded using NVivo software. The data was analysed thematically using a reflexive thematic approach.

#### Results

Nine participants were interviewed for this study. The majority (n=8) perceived that diet had an impact on their psoriasis. Most participants (n=7) reported trying restrictive diets including dairy-free, gluten-free, and "cleansing" diets to help manage their psoriasis with limited success. Psoriasis flare-ups, potential medication side-effects and online dietary recommendations were frequently mentioned as factors that motivated PLwP to make dietary modifications. A perceived lack of dietary support led to participants using social media and online forums for dietary information. Participants highlighted the confusion and burden of not having reliable nutrition guidance and reported that dietary support from HCPs was lacking.

# Conclusions

PLwP largely rely on social media and online forums for dietary information. These often suggest unsubstantiated restrictive diets, that could negatively impact health. Participants often felt overwhelmed by dietary recommendations and perceived that dietary guidance from HCPs was lacking and wanted more dietary support. In the absence of evidence-based dietary

information for psoriasis, HCPs need to be able to provide basic dietary support. To aid this, larger studies aimed at understanding how best to support people with psoriasis are needed.

# **Strengths and limitations**

- To the best of our knowledge, this is the first qualitative study to explore the use and role of diet among PLwP in the UK and provides important novel insights into their experiences.
- The qualitative study design allowed for an in-depth exploration of patient experience regarding diet and enabled the identification of support gaps in psoriasis care, which could assist healthcare professionals in improving patient-centered support for PLwP.
- The study design is exploratory, and the experiences of PLwP presented require further research with a larger and more diverse sample before they can be generalised.

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#### INTRODUCTION

Psoriasis is a chronic, immune-mediated, inflammatory skin disease associated with arthritic, cardiovascular, metabolic, and psychological comorbidities [1–3]. There are an estimated 60 million people living with psoriasis (PLwP) globally and in the UK approximately 2% of the adult population (~ 1.1 million people) are living with psoriasis [4]. The painful and visible symptoms of the disease can have a substantial negative impact on quality of life (QoL) [3,5].

Research indicates that lifestyle can impact psoriasis symptoms [6,7]. Reducing alcohol [8], limiting stress [9] and smoking cessation [10] have all been shown to improve psoriasis symptoms. However, there is limited evidence on the role of diet in the management of psoriasis and there are no evidence-based dietary guidelines for psoriasis. Despite this, emerging data suggests that PLwP trial restrictive diets without guidance from a healthcare professional (HCP), to try and help manage their psoriasis [11]. There is a lack of data on PLwP, however, individuals with other skin conditions report using unregulated platforms including Instagram and online forums for nutritional advice to manage their condition [12]. Following restrictive diets without the guidance of HCPs, can result in micronutrient deficiencies and negatively impact quality of life [13,14].

Research on the experiences of PLwP in the UK and their perceptions regarding the role and use of diet is scarce. No studies in the UK have explored the use of diet in PLwP or their experiences of such dietary modifications, including the sources they rely on for dietary guidance, in the absence of evidence-based dietary guidelines. With an estimated 1.1 million PLwP in the U.K, this represents an important research gap. Exploring how PLwP perceive and use diet will play a key role in understanding the potential impact on both psoriasis and the health and well-being of PLwP, crucial for providing holistic care for patients. This study aims to explore in-depth the experiences and use of diet in psoriasis management among adults with lived experience in the UK through qualitative methods.

#### **METHODS**

The Consolidated criteria for reporting qualitative research (COREQ) a 32-item checklist for interviews and focus groups, was used to guide the reporting of the study findings [15].

#### Study design and participant recruitment

Qualitative semi-structured interviews were conducted with UK adults with psoriasis. Ethical Approval was granted by The University of Hertfordshire, Heath, Science, Engineering & Technology Ethics Committee with Delegated Authority research aLMS/SF/UH/04684(2). Participants were recruited online via Facebook. The study was posted in a private Facebook group for PLwP in the UK, which comprised of over 15000 members at the time of recruitment. The eligibility criteria for this study were aged  $\geq$  18 years, currently living in the UK, English speaking, and a medical diagnosis of psoriasis of any severity. No incentive was advertised on the study recruitment post, however, following participation, participants were offered a £30 renumeration voucher for their time. Participant information and informed consent forms were emailed to each participant prior to undertaking the interview. At the start of the interview the interviewer went through all forms and obtained verbal informed consent. Participants were aware that the research team wanted to explore the perceptions of PLwP on diet.

#### Patient and public involvement

The design of this study was guided by the outcomes of earlier cross-sectional questionnaires asking people living with psoriasis about their diet. The topic guide for the interviews in this study was informed by the responses given in these earlier studies. Patients were not involved in the study's design, recruitment or completion. The results will be shared with the study participants and public through this publication.

# **Data collection**

Semi-structured individual interviews with UK adults with psoriasis were conducted to explore the perceived role of diet in the management of psoriasis. Topic guides were developed by RF and SM (both females). RF is a registered dietitian and Associate Professor in Research at the University of Hertfordshire, with extensive experience in qualitative research. SM was a final

year dietetics student with an interest in diet and psoriasis. The topic guides were used to ensure interviews were consistent, but participants were also encouraged to expand on answers and express their opinions freely. The interviewer asked participants to clarify answers and comments where meaning was unclear and frequently checked with participants whether their understanding of the meaning of their answers was correct. All interviews were conducted by one researcher (SM) with a single participant at a time. Each interview lasted approximately 1 hour, and all were conducted online via remote meeting applications, Microsoft Teams and Zoom. All interviews were audio-recorded and transcribed verbatim.

# **Data Analysis**

Data was analysed using a reflexive thematic approach based on the work of Braun and Clarke[16]. The analysis process began with familiarisation with the data. The researchers PH and SM familiarised themselves with the data through immersion in the audio files and transcripts of the individual interviews of each participant. PH (female) is a PhD student and registered nutritionist, with experience in conducting qualitative research and thematic analysis.

Subsequently, PH and SM independently coded the data using NVivo software. The codes reflected each researcher's own interpretations of patterns and meaning throughout the dataset. PH and SM then independently generated themes for the dataset through organisation of their independent codes. All themes were then discussed together with the wider research team (all authors of this paper) to explore the interpretations of the data using a collaborative and reflexive approach. Through these discussions, four key themes were generated, which were divided into sub-themes.

# RESULTS

# Participants

Overall, 9 participants took part in the study (2 males, 7 females). The demographic information of the participants is summarised in Table 1.

Table 1. Demographics and characteristics of study participants (n=9)

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Variable	Ν		
Sex			
Female	7		
Male	2		
Age, years: mean (range)	39 (25 – 53)		
Psoriasis duration, years: mean (range)	17 (2 – 34)		
Ethnicity			
White British	9		
Medication (current)			
Topical Steroids	5		
Biologicals	3		
Self-reported psoriasis severity			
Mild	2		
Moderate	2		
Severe	5		

#### **Generated Themes**

Four key themes were generated from the collected data: (1) Impact of diet, (2) Dietary modification (3) Dietary information and (4) Dietary support. Each key theme contained multiple sub-themes, which are summarised in figure 1.

#### Key Theme 1: Impact of diet

Participants discussed their thoughts on the role of diet in the management of psoriasis. They described the dietary factors that worsened or improved their psoriasis. A negative difference in psoriasis symptoms was more often experienced by participants than a positive difference to psoriasis symptoms through diet. Participants commonly described negative differences as a "flare" or "flare-up" which is an acute episode of worsened psoriasis symptoms. Additionally, participants also discussed increased itch, redness, and drier skin when describing the negative differences that they experienced.

Sub-theme: Overall diet

All participants (n=9) believed that diet could play a role in the management of psoriasis, and almost all participants (n=8) reported that diet had impacted their own psoriasis in some way. The majority (n=7) stated they notice a negative difference in their psoriasis when they do not eat a healthy, balanced diet.

"....when I eat worse, it is worse. And when I eat healthy, it does get slightly better. [Recently] I haven't been eating very well and it is getting a lot worse than it used to be..." (Participant 4)

"I know that when I'm eating healthier, it is... it doesn't clear up, but it does fade and it is better." (Participant 9)

"I don't need the Methotrexate anymore and I put so much down to not needing it because I've got a much better diet than I ever had." (Participant 2)

Sub-theme: Impact of specific foods and drink

The majority (n=7) stated they notice a negative difference in their psoriasis when they eat certain "trigger" foods. The most reported "trigger" foods and drink for psoriasis were alcohol, dairy, and sugar. Participants also reported that not eating enough fruit and vegetables had a negative impact on their psoriasis.

"I guess the things we eat as well, do have an impact because there are times when I do eat some things and I seem to be more itchy with other things that don't make me itchy." (Participant 8)

"I don't eat anything that I know triggers [my psoriasis]" (Participant 3)

"Dairy and alcohol are the big offenders [for making my psoriasis worse]" (Participant 5)

"...if I have a lot of alcohol, that's really bad. It takes... it's not immediate - not like the next day but within the week. I know my... my face is a lot drier... it's a lot redder" (Participant 9)

"I've noticed that red wine will have a massive flare with me." (Participant 2)

"...not eating enough fruit and vegetables... eating too much sugar [are dietary triggers for my psoriasis]". (Participant 4)

# Key Theme 2: Dietary modifications

Dietary modifications involve intentional changes in the food and drinks consumed. Dietary modifications were commonly discussed by participants alongside the impact these had on their psoriasis symptoms. Almost all of the dietary modifications were restrictive. Only one participant had tried adding supplements, but found they had no impact on their psoriasis.

"primrose oil was one thing that was suggested and cod liver oil. So, I did start taking both of those, um... but they didn't have an effect." (Participant 9)

Sub-theme: Restrictive diets

Most participants (n=7) had tried following at least one restrictive diet to try and help their psoriasis symptoms. A restrictive diet refers to an eating pattern that reduces or cuts-out certain foods, food groups or energy intake. The most common restrictive diets tried by participants were reducing or removing dairy, cutting out nightshades and following gluten-free diets. Dietary "cleanses" were also mentioned and involved numerous different restrictions.

"I've not had any dairy at all... [for 3 months]" and "[I tried going] completely gluten-free for three months" (Participant 1)

"[I am] actively avoiding nightshades" (Participant 2)

"I've done lots of cleansing diets..." (Participant 5)

"[I tried a diet] where you had to eat [...] just apples for like 2 weeks. And that was supposed to be some, like sort of... cleanse." (Participant 6)

Participants reported mixed results from restricting dairy, 2 of the 4 participants that had tried reducing or removing dairy reported no difference to symptoms and 2 reported an alleviation of psoriasis symptoms. Weight-loss was also reported as a consequence of following a dairy-free diet.

"I found that cutting out milk made a bit of a [positive] impact" (Participant 9) "I have noticed that I've lost weight during the dairy-free diet because obviously... you can't eat so many things". (Participant 1)

Following a gluten-free diet and avoiding nightshades was frequently reported to have no impact on psoriasis symptoms by those that had tried these, and following overly restrictive low-fat diets were believed to have worsened one participants' psoriasis.

*"I did follow it for quite a while and was having like, gluten-free bread and other things ....] I didn't see a difference."* (Participant 9)

"Tried a gluten free diet for three months. And it made absolutely no difference whatsoever. And when I went back to eating copious amounts of gluten again, I didn't notice it got worse either." (Participant 1)

"[I tried] nightshades... trying to avoid them. Um, and... but I didn't find that it worked" (Participant 6)

"When I was restricted and going down the complete healthy route of eating like, healthy as in eating disordered healthy - it would be low-fat this, low-fat that. Like completely skinny milk - and that's when my skin was the worst." (Participant 2)

# Sub-theme: Experience of dietary modifications

Those that had tried following a specific dietary modification to help their psoriasis, frequently reported that it was difficult to adhere to. Preparing separate meals was a barrier for those who cooked for others, and cutting-out foods or whole food groups meant that it was difficult to know what to replace them with. Restrictive diets also reported to provide little enjoyment and limited reward. Participants often reported that the restrictive diets had not made any or much difference to their psoriasis symptoms which was demotivating, or they had not been able to keep following them due to some requiring extremely strict exclusions.

"I just think I don't want to make myself miserable either. And to take over my life to that extent, either without really thinking that that would work. And there's a huge commitment, especially when you then cook for a family of five too... I don't want to take it out of their diets, so it will be quite difficult to do." (Participant 1)

"I'm quite happy to kind of - give up things and try new things. And I'm... but yeah, I find I find it really hard to kind of... because when you've got kids and you're like, doing different meals and different... all the different things, so it is difficult to sustain. That's... that's the thing. I think I'm happy to do it for a week or two but then life gets in the way" (Participant 9)

"... I had a lot of dairy. So, it's a lot to cut out." (Participant 1)

Sub-theme: Motivations for using dietary modifications

The main reason that participants reported wanting to try dietary modifications for their psoriasis were: 1) wanting a natural way to help manage the condition, 2) as a potential way to avoid starting or going back on medication that was perceived to be strong or associated with undesirable side effects (e.g., immunosuppressants) and 3) having autonomy and a sense of empowerment by being able to do something to help themselves, rather than being completely reliant on referrals to healthcare professionals and dermatologists.

*"I've* [always] *looked for the more natural ways to control it."* (Participant 5)

"I'm so reluctant to go on something as strong as Methotrexate I have tried a gluten free diet for three months." (Participant 1)

"I'm always looking for ways in which I myself can help the condition without always being referred ... If there's anything... natural ways that it can be better, then I'm always up for doing it that way." (Participant 8)

# **Key Theme 3: Dietary information**

Participants discussed where they obtained dietary information from, their experiences of navigating dietary information from different sources and gave insights into the factors that influenced their decisions to make certain dietary modifications.

Sub-theme: Dietary information Sources

The participants often reported that online patient forums and groups, as well as social media and Google were their main source of dietary information for psoriasis. This was often due to a lack of information from trusted sources such as healthcare professionals, health charities and organisations, and a lack of evidence-based information readily available to them. The dietary modifications recommended online and in the patient forums and social media groups were often restrictive.

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"...every diet you could possibly suggest. No nightshades, no gluten, no meat, no read meat, no sugar, no dairy and no alcohol, and pretty much any combination of those" diets suggested on forums and trialled by forum members]. (Participant 1)

*"If you listen to this doctor* [an American doctor found online], *I might as well just not eat because he's going, "Nightshades, milk, cheese…" and I'm thinking, "Well, what can I eat?" "Chicken." That was all what he was saying. And I thought, "No." I couldn't live like that. I couldn't live with cutting all of them things out." (Participant 7)* 

However, participants also frequently reported that the online psoriasis forums were useful for general support, even if the dietary information was perceived by some to be misleading or unfounded. They reported that the groups gave them a chance to feel understood, a place to ask questions about psoriasis without judgment and hearing coping strategies other PLwP had used. Overall, the online groups were perceived in a positive light and provided participants with psychosocial support.

"....it's good to be around... or have access to people who have gone through the same kind of things." (Participant 6)

"I find it helpful to know that there's other people that are going through similar things to what I've done in the past [....] but there's a lot of mis-led information out there as well." (Participant 2)

Sub-theme: Navigating dietary information

Participants often reported that when looking for dietary advice they felt overwhelmed by the amount of information available. The information was often contradictory and went against their better judgment. This caused uncertainty, and added to the cognitive burden of

participants, alongside resulting in them trialling diets even when they were sceptical about the reliability and health impacts of the dietary changes recommended.

"... there are too many websites and too many pages with too many different conflicting things on and I get mind boggled [.....] one will say, don't eat that and then one will say, do eat that." (Participant 7)

"...as soon as you put in Google [diet and psoriasis] all this information comes out and... You'll try anything." (Participant 7)

"You're not meant to remove whole food groups... [...] So, I kind of question whether that is a good move." (Participant 1)

Sub-theme: Making dietary decisions

Participants reported that their decisions to try certain dietary modifications were influenced by before and after photos posted online by forum members who had changed their diets, anecdotal experience of dietary changes of other PLwP and popular wellness figures, even when they were sceptical. Participants reported trying dietary changes just to see if it would work for them, like it had for other people they had seen online.

"[Those who] post pictures of before and after, who'd done the Hannah Sillitoe diet. And that is, I think, probably what made me do this dairy-free diet and if I'm honest, that is probably from seeing the difference in her skin on the pictures. I don't know her... I've never had a conversation with her, but just thinking... if, if that is real, then I'd be silly to keep my mind closed to that as well. So, I'm willing to try it. Um, so... so it does influence me even if I take it with a pinch of salt." (Participant 1) "I've been following, you know, Hannah Sillitoe who cleared her psoriasis by having a very vegan healthy lifestyle? And it's one of the reasons why I've become a vegan." (Participant 9)

# Key Theme 4: Dietary Support

Participants discussed their experiences of the dietary support they had sought and received.

Sub-theme: Support available

All participants (n=9) perceived there to be a lack of dietary support available to them and that HCPs were reluctant to discuss diet during appointments. Participants recognised that this may be because there is a lack of evidence of a relationship between diet and psoriasis. However, the absence of discussion about anything to do with diet was deemed unhelpful and left participants felling frustrated. Additionally, suggesting a vague varied healthy diet without any specific information was also perceived to be unhelpful and presumed dietary knowledge.

"[The Doctor] just kept on saying, "Oh, there's no cure. There's nothing that you can do." (Participant 9)

[when trying to discuss diet with HCPS] "they're a little bit nervous. Um, I don't think they ever like to comment [..] they're very much like, um, "Just keep it varied." (Participant 2)

*"I think that expecting people to have like, a good knowledge of food, and what things can be replaced with, is... it's just quite unfair."* (Participant 3)

Sub-theme: Support needs

Most participants (n=8) stated that they would benefit from dietary support from a healthcare professional with nutritional expertise, to help them to navigate the overwhelming amount of

often contradictory dietary advice available, and the cognitive burden of trying to decide what was safe. Participants stressed the importance of evidence-based advice. Recognising that although there was limited evidence on the relationship between diet and psoriasis, they were still willing to try diets suggested online, by friends and family or from popular wellness figures in case they did work for them. As a result, they wanted support to be able to try these diets safely and better understand the potential health implications, particularly for elimination diets.

*"Just knowing what is safe, what will be a good move, where I can start...."* Participant 8)

"..... I didn't know how to do it properly. Like I don't know what gluten's in [...] it's everywhere, isn't it?" (Participant 2)

"Because such huge amounts of your food groups you're cutting out, I think I'd want to know that I was not depriving myself." (Participant 1)

"...when someone's expecting you to cut something... that might make up quite a big part of your diet, then you need to know what you can be using instead." (Participant 3)

There was no observed difference in perception or experience across different age groups, severities, or sexes under any theme. However, the sample size was too small to conduct any comparative analysis and the sample size may also be the reason that no differences were observed.

#### DISCUSSION

Despite a growing interest in the role of diet in psoriasis management, there has been limited research exploring the perceptions of PLwP on the use and role of diet. To the best of our knowledge this is the first study to explore this topic in PLwP in the UK. The findings of this

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> study have identified the challenges PLwP face and have highlighted potential gaps in support for PLwP regarding diet, alongside areas for further research to improve psoriasis care.

Most participants in this study perceived that diet had an impact on their psoriasis and took proactive measures to avoid foods known to trigger psoriasis flare-ups or worsen symptoms. The most common dietary triggers perceived to negatively affect psoriasis in this study were alcohol, dairy, and sugar. This mirrors findings from previous studies [11,17]. Additionally, participants also perceived that eating a "generally healthy diet" characterised by consuming plenty of fruit and vegetables had a positive impact on their psoriasis. Previous studies have found that fruit and vegetable consumption was reported to alleviate symptoms by PLwP [17] and that higher fruit and vegetable intake was associated with lower psoriasis severity [18,19].

Specific diets were also commonly trialled by participants to try and help manage their psoriasis, all of which were restrictive. The most trialled diets were dairy restriction, gluten-free, avoiding nightshades and a range of different cleanses, with limited or no perceived impact on psoriasis symptoms.

Dairy restriction was reported as a dietary modification trialled by 4 of the participants in this study, with mixed results. Previous research has also reported that dairy elimination or restriction was common in PLwP in the US and provided alleviation of psoriasis symptoms in almost 50% of people that removed it [11]. However, there is limited research investigating the impact of dairy consumption on psoriasis severity. The reasoning behind eliminating dairy may be attributed to concerns about the pro-inflammatory effect of saturated fat, which is high in certain dairy products [20,21]. However, research indicates that dairy may have neutral to favourable effects on inflammation [20]. Furthermore, low-fat fermented dairy products such as yogurt have been shown to have anti-inflammatory effects attributed to the presence of probiotics [20,22]. Dairy products are also key sources of high-quality protein and essential micronutrients, including vitamin B12, calcium, magnesium, and zinc [23]. Eliminating or restricting dairy may negatively impact the intake of essential nutrients [24]. There is an absence of research on the type of dairy product perceived to have a negative impact on psoriasis symptoms, and this warrants further investigation. Additionally, one of the

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participants who reported removing diary, also reported losing weight whilst following a dairyfree diet. Weight-loss in PLwP who are also living with obesity or overweight has been shown to improve psoriasis symptoms [25,26].

Avoiding nightshades was a common dietary modification reported by participants. Nightshades are a family of plants that include potatoes, tomatoes, peppers, and aubergines, they contain solanine and alkaloids which have been linked to inflammation in mouse models [11,27]. However, no human studies support this association; furthermore, nightshades are high in fibre and a rich source of antioxidants. Additionally, participants in this study and others have reported that eating fruit and vegetables improved psoriasis symptoms [18,19].

Gluten-free diets were also commonly trialled by PLwP, and research suggests that it could alleviate psoriasis symptoms, but only in PLwP who have coeliac disease or a sensitivity to gluten, otherwise, it is not recommended [25]. Previous research has also indicated that PLwP trial a GFD with mixed effects [11]. It is unclear whether PLwP recognise that the evidence only suggests following a GFD for those PLwP who are coeliac or have a diagnosed gluten sensitivity. Psoriasis is associated with numerous other autoimmune diseases, including coeliac disease [28]. However, greater awareness may be needed regarding who this type of diet is appropriate for, as gluten-free diets have been shown to be low in dietary fibre [29]. Greater dietary fibre intake is associated with a lower risk of cardiovascular disease and coronary heart disease, as well as lower systemic inflammation [30,31]. Dietary fibre also has appetite regulating and antiobesogenic properties [30]. This is relevant to PLwP considering the associated comorbidities.

The combination of the prebiotic properties of dietary fibre consumption, alongside the probiotics found in fermented dairy products, may exert a moderating influence on the pathogenesis of psoriasis [32], by promoting gut health and subsequently regulating the innate and adaptive immune responses [32]. Therefore, the health benefits of these commonly eliminated foods are important considerations, as well as understanding the substitutions that may be consumed in place of the eliminated foods. Following restrictive diets without the guidance of a HCP, can lead to micronutrient deficiencies and disordered eating [14,33].

The main motivations for participants wanting to trial dietary modifications was to find a natural way to help manage the condition, avoid medication side effects, and wanting autonomy over their condition. These findings echo previous studies which found that PLwP mainly use complimentary or alternatives to conventional medication due to treatment failures or unwanted side effects [34].

This study found that there was a perceived lack of dietary support available for PLwP from HCPs. Despite recognising the shortage of evidence-based information on diet and psoriasis, participants often felt that HCPs were reluctant to discuss diet at all, and if dietary information was given it was perceived to be vague and lacking useful instruction. This led to individuals seeking dietary advice from alternative sources, primarily wellness figures and other PLwP on online forums or social media. Previous research has highlighted the amount of health misinformation on social media [35] especially regarding psoriasis [36,37]. Which further highlights the importance of providing dietary support to this group.

Most participants felt overwhelmed with the number of dietary recommendations available online and did not feel as though they had the knowledge to be able to navigate them safely. This led to people trying restrictive diets, often against their better judgement and without the knowledge of how to do so safely. Participants were often influenced to try different diets by before and after pictures posted on social media and wellness figures.

The findings of this study highlight the unmet demand for dietary support for PLwP. A recent study exploring dermatology professionals' experiences of dietary habits of outpatients (n=159) found that psoriasis patients were one of the patient groups reported to ask about nutrition most often [38]. However, 73.1% of dermatologists did not feel confident in answering these questions and over 90% felt that additional nutrition training and access to specialist dietician support would be of benefit to dermatology practice [38]. This suggests, alongside previous research [11], that there is a high demand for dietary support from both a patient and healthcare professional perspective. Considering patients' values and preferences alongside their physical, social and emotional needs is a core part of patient-centred care [39]. All of which further highlights the need for research in this area. Furthermore, many of the psoriasis

#### **BMJ** Open

associated co-morbidities are widely recognised to be related to diet [31,40]. As a result, engaging in discussions about dietary considerations with HCPs with nutritional expertise, or having access to evidence-based dietary support, could improve comprehensive care for PLwP. Whilst also lessening the reliance on unsubstantiated online sources of dietary information.

#### Limitations

The small sample size of this study, that comprised of all white British and predominantly female participants means that further research is required to establish whether these findings are generalisable to PLwP across the UK. Furthermore, participants were recruited via an online psoriasis support group, which could have influenced the answers given by participants regarding sources of dietary information. The nature of the study may have led to a sample that perceived there to be a role for diet in managing psoriasis. Additionally, all dietary information and impact on psoriasis was self-reported. Despite the limitations of this study, the findings provide an insight into the experience of PLwP regarding diet and potential support gaps in psoriasis care.

#### CONCLUSION

People living with psoriasis feel overwhelmed with the number of dietary recommendations claiming to help psoriasis and require more support to be able to navigate them. From the patient perspective, current dietary support provided by HCPs is lacking. As a result, PLwP turn to unregulated online platforms shown to be full of health misinformation [36,37]. This could have detrimental implications on the health and well-being of PLwP and therefore HCPs need to be able to confidently discuss diet and provide basic dietary support to PLwP until evidence-based dietary guidance for psoriasis is available. Understanding dietary support needs in psoriasis care from a HCP perspective warrants further investigation. Alongside, further studies on the perceptions and experience of a larger group of PLwP in the UK to be able to better understand the use of diet, dietary support needs and opportunities to provide tailored support.

#### Acknowledgments

BMJ Open: first published as 10.1136/bmjopen-2024-085536 on 9 April 2025. Downloaded from http://bmjopen.bmj.com/ on June 7, 2025 at Agence Bibliographique de l Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

The authors would like to thank the participants of this study for giving their time and discussing their experiences for this research. The preliminary findings of this research were presented at the Nutrition Society Conference. *Citation:* Hawkins P, Mason S, Earl K, *et al.* The perceived role of diet in the management of psoriasis in UK adults with psoriasis: a qualitative study. *Proc Nutr Soc* 2023;**82**:E365.

#### **Author Contributions**

All authors contributed to this article, and all have reviewed and approved the final manuscript. PH was involved in the methodology and design of the study, data analysis, and drafted the manuscript. SM was involved in methodology, data collection and data analysis. RF, KE and AT were involved in the methodology and design of the study, data analysis and research supervision.

# **Competing Interests**

The authors have declared that no competing interests exist

#### Funding

Poppy Hawkins received funding from the University of Hertfordshire, QR-funded PhD Studentship, titled 'The role of diet in the management of psoriasis' 2021–2024, supervised by Dr Rosalind Fallaize (<u>r.fallaize@herts.ac.uk</u>), Dr Kate Earl (<u>k.earl@herts.ac.uk</u>) and Dr Athanasios Tektonidis (<u>atektonidis@brookes.ac.uk</u>). Sarah Mason was awarded a Centre for Health Services and Clinical Research (CHSCR), University of Hertfordshire, QR-funded Research Grant for this research.

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	Perceived Use ar	nd Role of Diet in Psoriasis Experier		dults with Lived
Key Themes	Impact of Diet	Dietary Modifications	Dietary Information	Dietary Support
Sub-themes	Overall diet     "Trigger" foods     and drinks	<ul> <li>Restrictive diets</li> <li>Experiences of dietary modifications</li> <li>Motivations for using dietary modifications</li> </ul>	<ul> <li>Dietary information sources</li> <li>Navigating dietary information</li> <li>Dietary decisions</li> </ul>	<ul> <li>Dietary support needs</li> <li>Dietary support available</li> </ul>

Figure 1. Key themes and sub-themes generated through reflexive thematic analysis for the dataset of individual interviews exploring the experiences of people living with psoriasis, on the use and role of diet in psoriasis management.

338x190mm (96 x 96 DPI)

# People living with psoriasis require guidance to navigate popular dietary information: a qualitative study of UK adults

Journal:	BMJ Open
Manuscript ID	bmjopen-2024-085536.R1
Article Type:	Original research
Date Submitted by the Author:	06-Dec-2024
Complete List of Authors:	Hawkins, Poppy; University of Hertfordshire, Mason, Sarah; University of Hertfordshire, Life and Medical Sciences Earl, Kate; University of Hertfordshire, Life and Medical Sciences Tektonidis , Athanasios ; Oxford Brookes University, Department of Sport, Health Sciences and Social Work Fallaize, Rosalind; University of Hertfordshire, Life and Medical Sciences
<b>Primary Subject Heading</b> :	Nutrition and metabolism
Secondary Subject Heading:	Dermatology
Keywords:	Psoriasis < DERMATOLOGY, Patient-Centered Care, NUTRITION & DIETETICS, DERMATOLOGY, QUALITATIVE RESEARCH





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# PEOPLE LIVING WITH PSORIASIS REQUIRE GUIDANCE TO NAVIGATE POPULAR DIETARY INFORMATION: A QUALITATIVE STUDY OF UK ADULTS

- Poppy Hawkins <sup>1</sup><sup>\*</sup>, Sarah Mason <sup>1</sup>, Kate Earl <sup>1</sup>, Thanasis G. Tektonidis <sup>2</sup>, Rosalind Fallaize <sup>1</sup>

- <sup>1</sup> School of Life and Medical Sciences, University of Hertfordshire, Hatfield, AL10 9AB, UK
- <sup>2</sup> Department of Sport, Health Sciences and Social Work, Oxford Brookes University, Oxford,
- 8 OX3 OBP, UK
- 9 \*Corresponding author
- 1 E-mail: <u>p.hawkins@herts.ac.uk</u>

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2 3 4	12	3.1 ABSTRACT
5 6	13	Introduction
7 8	14	Psoriasis is a chronic inflammatory skin disease associated with significant comorbidities.
9 10	15	Emerging evidence suggests people living with psoriasis (PLwP) try self-prescribed restrictive
11 12	16	diets to help manage their symptoms. However, there is a lack of research on use and
13 14	17	perceptions of diet among PLwP in the UK. Following restrictive diets without professional
15	18	guidance can negatively impact health and well-being, highlighting the need for exploration into
16 17 18	19	this.
19 20	20	Objective
21 22	21	This study aimed to explore the use, experiences and perceptions of diet in psoriasis
23 24	22	management among adults with lived experience in the UK.
25 26	•••	
27	23	Methods
28 29	24	Semi-structured individual interviews were conducted with adults living with psoriasis in the
30 31	25	UK. The data was analysed thematically using a reflexive thematic approach.
32 33 34	26	Results
35 36	27	Nine participants were interviewed for this study. The majority (n=8) perceived that diet had an
37 38	28	impact on their psoriasis. Most participants (n=7) reported trying restrictive diets including
39 40	29	dairy-free, gluten-free, and "cleansing" diets to help manage their psoriasis with limited
41	30	success. Psoriasis flare-ups, potential medication side-effects and online dietary
42 43	31	recommendations were frequently mentioned as factors that motivated PLwP to make dietary
44 45	32	modifications. A perceived lack of dietary support led to participants using social media and
46 47	33	online forums for dietary information. Participants highlighted the confusion and burden of not
48 49	34	having reliable nutrition guidance and reported that dietary support from HCPs was lacking.
50 51 52	35	Conclusions
53 54	36	PLwP largely rely on social media and online forums for dietary information. These often
55 56	37	suggest unsubstantiated restrictive diets, that could negatively impact health. Participants often
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59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

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felt overwhelmed by dietary recommendations and perceived that dietary guidance from HCPs .a , suppor. .ed to be able . .standing how best to was lacking and wanted more dietary support. In the absence of evidence-based dietary information for psoriasis, HCPs need to be able to provide basic dietary support. To aid this, larger studies aimed at understanding how best to support people with psoriasis are needed. 

1 2		
2 3 4	43	Journal submission title page
5 6 7	44	Strengths and limitations
	45	• To the best of our knowledge, this is the first study to explore the use and experiences
8 9	46	of dietary modification among PLwP in the UK.
10 11	47	• The qualitative study design allowed for an in-depth exploration of patient experience
12 13	48	regarding diet and enabled the identification of support gaps in psoriasis care, which
14 15	49	could assist healthcare professionals in improving patient-centred support for PLwP.
16 17	50	• The study design is exploratory, and the experiences of PLwP presented require further
18 19	51	research with a larger and more diverse sample before they can be generalised.
20 21 22	52	Acknowledgments
23 24	53	The authors would like to thank the participants of this study for giving their time and
25	54	discussing their experiences for this research. The preliminary findings of this research were
26 27	55	presented at the Nutrition Society Conference. Citation: Hawkins P, Mason S, Earl K, et al. The
28 29	56	perceived role of diet in the management of psoriasis in UK adults with psoriasis: a qualitative
30 31	57	study. Proc Nutr Soc 2023; <b>82</b> :E365.
32 33 34	58	Author Contributions
35 36	59	All authors contributed to this article, and all have reviewed and approved the final manuscript.
37	60	PH was involved in the methodology and design of the study, data analysis, and drafted the
38 39	61	manuscript. SM was involved in methodology, data collection and data analysis. RF, KE and AT
40	62	were involved in the methodology and design of the study, data analysis and research
41 42	63	supervision. Poppy Hawkins (PH) is the primary researcher and contact. Guarantor is Rosalind Fallaize (RF).
43 44	64	Competing Interests
45 46	65	The authors have declared that no competing interests exist
47 48 49	66	Funding
50 51	67	Poppy Hawkins received funding from the University of Hertfordshire, QR-funded PhD
52 53 54 55	68	Studentship, titled 'The role of diet in the management of psoriasis' 2021–2024, supervised by
	69	Dr Rosalind Fallaize ( <u>r.fallaize@herts.ac.uk</u> ), Dr Kate Earl ( <u>k.earl@herts.ac.uk</u> ) and Dr Athanasios
56	70	Tektonidis (atektonidis@brookes.ac.uk). Sarah Mason was awarded a Centre for Health
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for this research.

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# 74 3.2 INTRODUCTION

Psoriasis is a chronic, immune-mediated, inflammatory skin disease associated with arthritic,
cardiovascular, metabolic, and psychological comorbidities [1,2]. There are an estimated 60
million people living with psoriasis (PLwP) globally and in the UK approximately 2% of the adult
population are living with psoriasis [3]. The chronic, painful and visible symptoms of the disease
can have a substantial negative impact on quality of life (QoL) [4].

80 Research indicates that lifestyle can impact psoriasis symptoms [5,6]. Reducing alcohol [7],

81 limiting stress [8] and smoking cessation [9] have been shown to improve psoriasis symptoms.

82 Furthermore, obesity is more common in PLwP compared to controls, and a higher body mass

83 index (BMI) is associated with increased psoriasis severity, attributed to adipose-driven

84 inflammatory activity [10]. Current evidence on the role of diet in the management of psoriasis

is limited to weight-loss in those living with overweight or obesity and a gluten-free diet (GFD)
 in those with coeliac or a gluten sensitivity [11,12]. There are no dietary guidelines for psoriasis,

87 and there is high demand for information on diet from both HCPs and PLwP. The question 'Do

88 lifestyle factors such as diet, dietary supplements, alcohol, smoking, weight loss and exercise

89 play a part in treating psoriasis?' was identified as the top research priority for psoriasis by The

James Lind Alliance Priority Setting Partnership [13]. However, research on the experiences of
 PLwP and their use and perceptions on the role of diet is scarce globally [11]. Emerging data

suggests that PLwP trial restrictive diets without guidance from a healthcare professional (HCP),
 to try and help manage their psoriasis [14], which could lead to micronutrient deficiencies and
 negatively impact QoL [15,16]. There is a lack of data on the practices of PLwP, individuals with
 other skin conditions report using unregulated platforms including Instagram and online forums
 for nutritional advice to manage their condition [17].

No studies in the UK have explored the use of diet in PLwP, their experiences of dietary modifications, or sources they rely on in the absence of evidence-based dietary guidelines. With 49 99 an estimated 1.1 million PLwP in the UK, this represents an important research gap. Exploring 50 51 100 how PLwP use and perceive the impact of diet will play a key role in understanding the 52 53 potential effect on both psoriasis and the health and well-being of PLwP, crucial for providing 101 54 55 102 holistic care for patients. This study aims to explore in-depth the experiences and use of diet in 56

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3 4	103	psoriasis management among adults with lived experience in the UK through qualitative
5 6	104	methods.
7 8	105	
9 10	106	3.3 METHODS
11 12	107	Due to the scarcity of literature on this topic among a UK population, an explorative qualitative
13 14	108	study was undertaken to enhance understanding and provide in-depth insights. Consolidated
15 16	109	Criteria for Reporting Qualitative Research (COREQ) a 32-item checklist for interviews and focus
17 18	110	groups, was used to guide the reporting of the study findings [18].
19 20 21	111	Study design and participant recruitment
22 23	112	Qualitative semi-structured interviews were conducted with UK adults with psoriasis. Ethical
24	113	Approval was granted by The University of Hertfordshire, Heath, Science, Engineering &
25 26 27 28	114	Technology Ethics Committee with Delegated Authority research aLMS/SF/UH/04684(2).
	115	Participants were recruited online via Facebook. The study was posted in a private Facebook
29 30	116	group for PLwP in the UK, which comprised of over 15000 members at the time of recruitment.
31 32	117	Purposive sampling was employed to recruit participants. The eligibility criteria for this study
33 34	118	were aged $\geq$ 18 years, currently living in the UK, English speaking, and a medical diagnosis of
35 36	119	psoriasis of any severity. No incentive was advertised on the study recruitment post, however,
37	120	following participation, participants were offered a £30 renumeration voucher for their time.
38 39	121	Participant information and informed consent forms were emailed to each participant prior to
40 41	122	undertaking the interview. At the start of the interview the interviewer went through all forms
42 43	123	and obtained verbal informed consent. Participants were aware that the research team wanted
44 45 46 47 48 49 50 51	124	to explore the perceptions of PLwP on diet.
	125	Patient and public involvement
	126	The design of this study was guided by the outcomes of previous cross-sectional questionnaires
	127	asking PLwP about their diet. The topic guide for the interviews in this study was informed by
52 53 54	128	the responses given in these earlier studies. Patients were not involved in the study's design,
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3 4	129	recruitment or completion. The results will be shared with the study participants and public
5 6	130	through this publication.
7 8 9	131	Data collection
9 10 11	132	Semi-structured individual interviews with UK adults with psoriasis were conducted to explore
12	133	the perceived role of diet in the management of psoriasis. Topic guides were developed by RF
13 14	134	and SM (both females). RF is a registered dietitian and Associate Professor in Research at the
15 16	135	University of Hertfordshire, with extensive experience in qualitative research. SM was a final
17 18	136	year dietetics student with an interest in diet and psoriasis. The topic guides were used to
19 20	137	ensure interviews were consistent, but participants were also encouraged to expand on
21 22	138	answers and express their opinions freely. The topic guide can be found in the supplementary
23	139	material. The interviewer asked participants to clarify answers and comments where meaning
24 25	140	was unclear and frequently checked with participants whether their understanding of the
26 27	141	meaning of their answers was correct. All interviews were conducted by one researcher (SM)
28 29	142	with a single participant at a time. Each interview lasted approximately 1 hour, and all were
30 31	143	conducted online via remote meeting applications, Microsoft Teams and Zoom. All interviews
32 33	144	were audio-recorded and transcribed verbatim.
34 35	145	Psoriasis severity was self-reported by participants during interviews, as formal PASI scores or
36 37	146	clinician assessments were not available. Participants were asked to describe their perceived
38 39	147	severity, body surface area affected, and were asked about any PASI scores provided by their
40 41	148	healthcare providers, to ascertain severity scores based on mild, moderate and severe [19].
42 43 44	149	Data Analysis
45	150	Data was analysed using a reflexive thematic approach based on the work of Braun and Clarke
46 47	151	[20]. The analysis process began with familiarisation with the data. The researchers PH and SM
48 49	152	familiarised themselves with the data through immersion in the audio files and transcripts of
50 51	153	the individual interviews of each participant. PH (female) is a PhD student and registered

- $\frac{52}{53}$  154 nutritionist, with experience in conducting qualitative research and thematic analysis.
- Subsequently, PH and SM independently coded the data using NVivo software. The codes
   reflected each researcher's own interpretations of patterns and meaning throughout the

dataset. PH and SM then independently generated themes for the dataset through organisation
of their independent codes. All themes were then discussed together with the wider research
team (all authors of this paper) to explore the interpretations of the data using a collaborative
and reflexive approach. Through these discussions, four key themes were generated, which
were divided into sub-themes.

### **3.4 RESULTS**

163 Participants

Seventeen individuals expressed interest in taking part, with ten consenting to participate in the interviews. One participant dropped out prior to interview with no disclosed reason. Data saturation was achieved during these interviews, meaning that data replication was observed, and no new themes or insights were generated from the interviews [21]. Overall, 9 participants took part in the study (2 males, 7 females). The demographic information of the participants is summarised in **Table 1**.

170 Table 1. Demographics and characteristics of study participants (n=9)

Variable	N
Sex	
Female	7
Male	2
Age, years: mean (range)	39 (25 – 53)
Psoriasis duration, years: mean (range)	17 (2 – 34)
Ethnicity	
White British	9
Medication (current)	
Topical Steroids	5
Biologicals	3
Self-reported psoriasis severity	
Mild	2
Moderate	2
Severe	5

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1 2		
3 4	171	
5 6	172	Generated Themes
7 8	173	Four key themes were generated from the collected data: (1) Impact of diet, (2) Dietary
9 10	174	modification (3) Dietary information and (4) Dietary support. Each key theme contained
11 12	175	multiple sub-themes, which are summarised in Figure 1.
13 14 15	176	
16 17	177	Key Theme 1: Impact of diet
18 19	178	Participants discussed their thoughts on the role of diet in the management of psoriasis. They
20 21	179	described the dietary factors that worsened or improved their psoriasis. A negative difference
22 23	180	in psoriasis symptoms was more often experienced by participants than a positive difference to
24	181	psoriasis symptoms through diet. Participants commonly described negative differences as a
25 26	182	"flare" or "flare-up" which is an episode of worsened psoriasis symptoms. Additionally,
27 28	183	participants also discussed increased itch, redness, and drier skin when describing the negative
29 30	184	differences that they experienced.
31 32	185	
33 34	186	Sub-theme: Overall diet
35 36	187	All participants (n=9) believed that diet could play a role in the management of psoriasis, and
37 38	188	most (n=8) reported that diet had impacted their psoriasis in some way. The majority (n=7)
39 40	189	stated they notice a negative difference in their psoriasis when they do not eat a healthy,
41 42 43	190	balanced diet.
43 44 45	191	
46 47	192	"when I eat worse, it is worse. And when I eat healthy, it does get slightly better.
48 49	193	[Recently] I haven't been eating very well and it is getting a lot worse than it used to
50 51	194	<i>be"</i> (Participant 4)
52 53	195	"I know that when I'm eating healthier, it is it doesn't clear up, but it does fade and it is
54 55	196	better." (Participant 9)
56 57		
58 59		10
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3	197	"I don't need the Methotrexate anymore and I put so much down to not needing it
4 5 6	198	because I've got a much better diet than I ever had." (Participant 2)
7 8 9	199	Sub-theme: Weight-loss
10 11	200	Regarding weight-loss, one of the few evidence-based dietary recommendations for psoriasis,
12	201	those whose weight had fluctuated in their adult life (n=4), reported mixed impact of weight-
13 14 15	202	loss or gain on their psoriasis.
16 17	203	"if I'm eating worse, I'm putting weight on - which then is making it worse."
18 19	204	(Participant 4)
20 21	205	"I haven't sort of, noticed that it's [losing weight] made any difference, positive or
22 23	206	negative on the psoriasis." (Participant 6)
24 25 26	207	Sub-theme: Impact of specific foods and drink
27 28	208	The majority (n=7) stated they notice a negative difference in their psoriasis when they eat
29 30	209	certain "trigger" foods. The most reported "trigger" foods and drink for psoriasis were alcohol,
31	210	dairy, and sugar. Participants also reported that not eating enough fruit and vegetables had a
32 33 34	211	negative impact on their psoriasis.
35 36	212	"I guess the things we eat as well, do have an impact because there are times when I do
37 38	213	eat some things and I seem to be more itchy with other things that don't make me
39 40	214	itchy." (Participant 8)
41 42	215	"I don't eat anything that I know triggers [my psoriasis]." (Participant 3)
43 44 45	216	"Dairy and alcohol are the big offenders [for making my psoriasis worse]." (Participant 5)
46 47	217	if I have a lot of alcohol, that's really bad. It takes it's not immediate - not like the
48 49	218	next day but within the week. I know my my face is a lot drier it's a lot redder."
50 51	219	(Participant 9)
52 53 54 55 56	220	"I've noticed that red wine will have a massive flare with me." (Participant 2)
57 58		11
59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1 2		
2 3 4	221	"not eating enough fruit and vegetables eating too much sugar [are dietary triggers
5 6 7	222	for my psoriasis]." (Participant 4)
	223	
8 9	225	
10 11	224	Key Theme 2: Dietary modifications
12 13	225	Dietary modifications involved intentional changes in the food and drinks consumed. Dietary
14 15	226	modifications were commonly discussed by participants alongside the impact these had on
16 17	227	their psoriasis symptoms. Almost all of the dietary modifications were restrictive. Only one
18 19	228	participant had tried adding supplements, but found they had no impact on their psoriasis.
20 21	229	primrose oil was one thing that was suggested and cod liver oil. So, I did start taking both of
22 23	230	those, um but they didn't have an effect." (Participant 9)
24 25 26	231	Sub-theme: Restrictive diets
27 28 29 30 31 32 33 34 35	232	Most participants (n=7) had tried following at least one restrictive diet to try and help their
	233	psoriasis symptoms. A restrictive diet refers to an eating pattern that reduces or cuts-out
	234	certain foods, food groups or energy intake. The most common restrictive diets tried by
	235	participants were reducing or removing dairy, cutting out nightshades and following gluten-free
	236	diets. Nightshades are plants from the Solanaceae family, which include potatoes, tomatoes,
36 37	237	peppers and aubergines [14]. Dietary "cleanses" were mentioned and involved numerous
38 39	238	different restrictions. The "cleanses" that participants attempted in this study were typically
40 41	239	highly restrictive, involving either the consumption of only specific types of foods or juice-based
42 43	240	diets, where participants drank only juice and water for a set number of days.
44 45 46	241	
47	242	"I've not had any dairy at all [for 3 months]" and "[I tried going] completely gluten-free
48 49 50	243	for three months" (Participant 1)
51 52	244	"[I am] actively avoiding nightshades" (Participant 2)
53 54 55	245	"I've done lots of cleansing diets" (Participant 5)
56 57		12
58 59		12 For peer review only - http://bmiopen.bmi.com/site/about/quidelines.xhtml
60		FOLDERLEVIEW ONLY - HTTP://DHTODEN.DHTCOM/SITE/9DOUT/QUIDENDES.XHTML

1 2		
3 4	246	"[I tried a diet] where you had to eat [] just apples for like 2 weeks. And that was
5 6	247	supposed to be some, like sort of cleanse." (Participant 6)
7 8 9	248	
10 11	249	Participants reported mixed results from restricting dairy, 2 of the 4 participants that had tried
12	250	reducing or removing dairy reported no difference to symptoms and 2 reported an alleviation
13 14	251	of psoriasis symptoms. Weight-loss was also reported as a consequence of following a dairy-
15 16 17	252	free diet.
18 19 20	253	
20 21 22	254	<i>"I found that cutting out milk made a bit of a [positive] impact" (Participant 9)</i>
23 24	255	"I have noticed that I've lost weight during the dairy-free diet because obviously you
25 26	256	can't eat so many things". (Participant 1)
27 28 29	257	
30 31	258	Following a gluten-free diet and avoiding nightshades was frequently reported to have no
32	259	impact on psoriasis symptoms by those that had tried these, and following overly restrictive
33 34 35	260	low-fat diets were believed to have worsened one participants' psoriasis.
36 37 28	261	
38 39	262	"I did follow it for quite a while and was having like, gluten-free bread and other things
40 41 42	263	] I didn't see a difference." (Participant 9)
43 44	264	"Tried a gluten free diet for three months. And it made absolutely no difference
45	265	whatsoever. And when I went back to eating copious amounts of gluten again, I didn't
46 47 48	266	notice it got worse either." (Participant 1)
49 50	267	"[I tried] nightshades trying to avoid them. Um, and but I didn't find that it worked"
51 52 53 54 55 56	268	(Participant 6)
57 58		13
59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

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1 2		
2 3 4	269	"When I was restricted and going down the complete healthy route of eating like,
5	270	healthy as in eating disordered healthy - it would be low-fat this, low-fat that. Like
6 7	271	completely skinny milk - and that's when my skin was the worst." (Participant 2)
8 9	272	
10 11		
12 13	273	Sub-theme: Experience of dietary modifications
14 15	274	Those that had tried following a specific dietary modification to help their psoriasis, frequently
16	275	reported that it was difficult to adhere to (n=6). Preparing separate meals was a barrier for
17 18	276	those who cooked for others, and cutting-out foods or whole food groups meant that it was
19 20	277	difficult to know what to replace them with. Restrictive diets also reported to provide little
21 22	278	enjoyment and limited reward. Participants often reported that the restrictive diets had not
23	279	made any or much difference to their psoriasis symptoms which was demotivating, or they had
24 25	280	not been able to keep following them due to some requiring extremely strict exclusions.
26 27	281	
28 29	201	
30 31	282	"I just think I don't want to make myself miserable either. And to take over my life to
32	283	that extent, either without really thinking that that would work. And there's a huge
33 34	284	commitment, especially when you then cook for a family of five too I don't want to
35 36	285	take it out of their diets, so it will be quite difficult to do." (Participant 1)
37 38	286	
39 40		
41	287	"I'm quite happy to kind of - give up things and try new things. And I'm but yeah, I find
42 43	288	I find it really hard to kind of because when you've got kids and you're like, doing
44 45	289	different meals and different all the different things, so it is difficult to sustain. That's
46 47	290	that's the thing. I think I'm happy to do it for a week or two but then life gets in the way"
48	291	(Participant 9)
49 50	292	"I had a lot of dairy. So, it's a lot to cut out." (Participant 1)
51 52		
53 54	293	
55 56	294	Sub-theme: Motivations for using dietary modifications
57		4 A
58 59		14
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The main reason that participants reported wanting to try dietary modifications for their psoriasis were: 1) wanting a natural way to help manage the condition (n=4), 2) as a potential way to avoid starting or going back on medication that was perceived to be strong or associated with undesirable side effects (e.g., immunosuppressants) (n=4), and 3) having autonomy and a sense of empowerment by being able to do something to help themselves, rather than being completely reliant on referrals to healthcare professionals and dermatologists (n=5).

- "I've [always] looked for the more natural ways to control it." (Participant 5)
- *"I'm so reluctant to go on something as strong as Methotrexate I have tried a gluten free diet for three months."* (Participant 1)
- 305 *"I'm always looking for ways in which I myself can help the condition without always*306 *being referred ... If there's anything... natural ways that it can be better, then I'm always*307 *up for doing it that way."* (Participant 8)
- 309 Key Theme 3: Dietary information
- Participants discussed where they obtained dietary information from, their experiences of
   navigating dietary recommendations from different sources, and gave insights into the factors
   that influenced their decisions to make certain dietary modifications.
- <sup>1</sup> 313 Sub-theme: Information Sources

The participants frequently reported that online patient forums and groups, as well as social media and Google were their main source of dietary information for psoriasis (n=8). This was primarily due to a lack of information from trusted sources such as healthcare professionals and organisations, and a lack of evidence-based information readily available to them. The dietary modifications recommended online and in the patient forums and social media groups were often restrictive. The restrictive dietary modifications often recommend eliminating certain

1 2		
- 3 4	320	food groups, or specific foods and drinks from the diet, and often had strict rules on what can
5 6	321	and can't be eaten.
7 8 9	322	
10 11	323	every diet you could possibly suggest. No nightshades, no gluten, no meat, no red.
12	324	meat, no sugar, no dairy and no alcohol, and pretty much any combination of those"
13 14 15	325	diets suggested on forums and trialled by forum members]. (Participant 1)
16 17	326	"If you listen to this doctor [an American doctor found online], I might as well just not
18	327	eat because he's going, "Nightshades, milk, cheese" and I'm thinking, "Well, what can I
19 20	328	eat?" "Chicken." That was all what he was saying. And I thought, "No." I couldn't live like
21 22 23	329	that. I couldn't live with cutting all of them things out." (Participant 7)
24 25	330	
26 27	331	However, participants also frequently reported that the online psoriasis forums were useful for
28 29	332	general support, even if the dietary information was perceived by some to be misleading or
30 31	333	unfounded. They reported that the groups gave them a chance to feel understood, a place to
32 33	334	ask questions about psoriasis without judgment and hearing coping strategies other PLwP had
34	335	used. Overall, the online groups were perceived in a positive light and provided participants
35 36 27	336	with psychosocial support.
37 38 39	337	
40 41	338	"it's good to be around or have access to people who have gone through the same
42 43 44	339	kind of things." (Participant 6)
45 46	340	"I find it helpful to know that there's other people that are going through similar things
47	341	to what I've done in the past [] but there's a lot of mis-led information out there as
48 49 50	342	well." (Participant 2)
51 52 53	343	
53 54 55	344	Sub-theme: Navigating dietary information
56 57		16
58 59		
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1 2		
2 3 4	345	Participants often reported that when looking for dietary advice they felt overwhelmed by the
5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	346	amount of information available (n=7). The information was often contradictory and went
	347	against their better judgment. This caused uncertainty, and added to the cognitive burden of
	348	participants, alongside resulting in them trialling diets even when they were sceptical about the
	349	reliability and health impacts of the dietary changes recommended.
	350	
	351	" there are too many websites and too many pages with too many different conflicting
	352	things on and I get mind boggled [] one will say, don't eat that and then one will say,
	353	do eat that." (Participant 7)
21 22	354	"as soon as you put in Google [diet and psoriasis] all this information comes out and
23 24 25	355	You'll try anything." (Participant 7)
25 26 27	356	"You're not meant to remove whole food groups [] So, I kind of question whether that
28 29	357	is a good move." (Participant 1)
30 31	358	
32 33 34	359	Sub-theme: Making dietary decisions
35 36	360	Participants reported that their decisions to try certain dietary modifications were influenced
37 38	361	by before and after photos posted online by forum members who had changed their diets,
39 40	362	anecdotal experience of dietary changes of other PLwP and popular wellness figures, even
41 42	363	when they were sceptical (n=6). Participants reported trying dietary changes just to see if it
42 43 44	364	would work for them, like it had for other people they had seen online.
45 46	365	
47 48	366	"[Those who] post pictures of before and after, who'd done the Hannah Sillitoe diet. And
49 50	367	that is, I think, probably what made me do this dairy-free diet and if I'm honest, that is
51 52	368	probably from seeing the difference in her skin on the pictures. I don't know her I've
53 54 55 56	369	never had a conversation with her, but just thinking if, if that is real, then I'd be silly to
57 58		17
59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1 2		
2 3 4	370	keep my mind closed to that as well. So, I'm willing to try it. Um, so so it does influence
4 5 6	371	me even if I take it with a pinch of salt." (Participant 1)
7 8 9	372	
10 11	373	"I've been following, you know, Hannah Sillitoe who cleared her psoriasis by having a
12	374	very vegan healthy lifestyle? And it's one of the reasons why I've become a vegan."
13 14 15	375	(Participant 9)
16 17	376	
18 19 20	377	Key Theme 4: Dietary Support
20 21 22	378	Participants discussed their experiences of the dietary support they had sought and received.
23 24 25	379	Sub-theme: Support available
26 27	380	All participants (n=9) perceived there to be a lack of dietary support available to them and that
28 29 30	381	HCPs were reluctant to discuss diet during appointments. Participants recognised that this may
	382	be due to a lack of evidence of a relationship between diet and psoriasis. However, the lack of
31 32	383	discussion about anything to do with diet was deemed unhelpful and left participants feeling
33 34	384	frustrated. Additionally, if dietary advice was given by HCPs, it was reported to be vague
35 36 37 38	385	healthy diet or weight-loss suggestions, without any specific information or support. This was
	386	perceived to be unhelpful and presumed dietary knowledge.
39 40	387	"[The Doctor] just kept on saying, "Oh, there's no cure. There's nothing that you can do."
41 42 43	388	(Participant 9)
44	389	[when trying to discuss diet with HCPS] "they're a little bit nervous. Um, I don't think
45 46	390	they ever like to comment [] they're very much like, um, "Just keep it varied."
47 48 49	391	(Participant 2)
50 51	392	"I think that expecting people to have like, a good knowledge of food, and what things
52 53	393	can be replaced with, is it's just quite unfair." (Participant 3)
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3 4	394	"dermatology and rheumatology, have both told me to, sort of lose weight and
5 6 7 8	395	that'll help with the psoriasis and the psoriatic arthritis. But, um that's it and I
	396	haven't noticed any improvement." (Participant 6)
9 10 11	397	Sub-theme: Dietary support needs
12	398	Most participants (n=8) stated that they would benefit from dietary support from a healthcare
13 14	399	professional with nutritional expertise, to help them to navigate the overwhelming amount of
15 16	400	often contradictory dietary advice available, and the cognitive burden of trying to decide what
17 18	401	was safe. Participants stressed the importance of evidence-based advice. Recognising that
19 20	402	although there was limited evidence on the relationship between diet and psoriasis, they were
21	403	still willing to try diets suggested online, by friends and family or from popular wellness figures
22 23	404	in case they did work for them. As a result, they wanted support to be able to try these diets
24 25	405	safely and better understand the potential health implications, particularly for elimination
26 27	406	diets.
28 29 30	407	
31 32	408	"Just knowing what is safe, what will be a good move, where I can start"
33 34	409	Participant 8)
35 36	410	I didn't know how to do it properly. Like I don't know what gluten's in [] it's.
37 38	411	everywhere, isn't it?" (Participant 2)
39 40 41	412	"Because such huge amounts of your food groups you're cutting out, I think I'd want to
42 43	413	know that I was not depriving myself." (Participant 1)
44 45	414	"when someone's expecting you to cut something that might make up quite a big
46 47	415	part of your diet, then you need to know what you can be using instead." (Participant 3)
48 49 50	416	
50 51 52	417	There was no observed difference in perception or experience across any demographic
53 54	418	characteristics. However, the sample size was too small to conduct any comparative analysis
55 56	419	and the sample size may also be the reason that no differences were observed.
57		19
58 59		
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2 3	420	
4 5	421	3.5 DISCUSSION
6 7 8	422	Despite a growing interest in the role of diet in psoriasis management, there has been limited
9	423	research exploring the perceptions of PLwP on the use and role of diet. To the best of our
10 11	424	knowledge this is the first study to explore this topic in PLwP in the UK. The findings of this
12 13	425	study have identified the challenges PLwP face and have highlighted potential gaps in support
14 15	426	for PLwP regarding diet, alongside areas for further research to improve psoriasis care.
16 17 18	427	Most participants in this study perceived that diet had an impact on their psoriasis and took
19	428	proactive measures to avoid foods known to trigger psoriasis flare-ups or worsen symptoms.
20 21	429	The most common dietary triggers perceived to negatively affect psoriasis in this study were
22 23	430	alcohol, dairy, and sugar. This mirrors findings from previous studies [14]. Additionally,
24 25	431	participants also perceived that eating a "generally healthy diet" characterised by consuming
26 27	432	plenty of fruit and vegetables had a positive impact on their psoriasis. Previous studies have
28	433	found that fruit and vegetable consumption was reported to alleviate symptoms by PLwP [22],
29 30 31	434	and that higher fruit and vegetable intake was associated with lower psoriasis severity [23,24].
32 33	435	Specific diets were also commonly trialled by participants to try and help manage their
34 35	436	psoriasis, all of which were restrictive. The most trialled diets were dairy restriction, gluten-
36 37	437	free, avoiding nightshades and a range of different cleanses, with limited or no perceived
38 39	438	impact on psoriasis symptoms.
40 41	439	Dairy restriction was reported as a dietary modification trialled by 4 of the participants in this
42 43	440	study, with mixed results. Previous research has reported that dairy elimination or restriction is
44	441	common in PLwP in the US and provided alleviation of psoriasis symptoms in almost 50% of
45 46	442	people that removed it [14]. However, there is limited research investigating the impact of
47 48	443	dairy consumption on psoriasis severity. The reasoning behind eliminating dairy may be
49 50	444	attributed to concerns about the pro-inflammatory effect of saturated fat, which is high in
51 52	445	certain dairy products [25]. However, research indicates that dairy may have neutral to
53 54	446	favourable effects on inflammation [25]. Furthermore, low-fat fermented dairy products such
55 56	447	as yogurt have been shown to have anti-inflammatory effects attributed to the presence of
50 57		20

probiotics [25,26]. Dairy products are also key sources of high-quality protein and essential micronutrients, including vitamin B12, calcium, magnesium, and zinc [27]. Eliminating or restricting dairy may negatively impact the intake of essential nutrients [28]. There is an absence of research on the type of dairy product perceived to have a negative impact on psoriasis symptoms, and this warrants further investigation. Additionally, one of the participants who reported removing diary, also reported losing weight whilst following a dairy-free diet. Weight-loss in PLwP who are also living with obesity or overweight has been shown to improve psoriasis symptoms [12]. Avoiding nightshades was a common dietary modification reported by participants. Nightshades are a family of plants that include potatoes, tomatoes, peppers, and aubergines, they contain solanine and alkaloids which have been linked to inflammation in mouse models [14,29]. However, no human studies support this association; furthermore, nightshades are high in fibre and a rich source of antioxidants. Additionally, participants in this study and others have reported that eating fruit and vegetables improved psoriasis symptoms [23,24]. Gluten-free diets were also commonly trialled by PLwP, and research suggests that it could alleviate psoriasis symptoms, but only in PLwP who have coeliac disease or a sensitivity to gluten, otherwise, it is not recommended [12]. Previous research has also indicated that PLwP trial a GFD with mixed effects [14]. It is unclear whether PLwP recognise that the evidence only suggests following a GFD for those PLwP who are coeliac or have a diagnosed gluten sensitivity. Psoriasis is associated with numerous other autoimmune diseases, including coeliac disease [30]. However, greater awareness may be needed regarding who this type of diet is appropriate for, as gluten-free diets have been shown to be low in dietary fibre [31]. Greater dietary fibre intake is associated with a lower risk of cardiovascular disease and coronary heart disease, as well as lower systemic inflammation [32,33]. Dietary fibre also has appetite regulating and anti-obesogenic properties [32]. This is relevant to PLwP considering the associated comorbidities. The combination of the prebiotic properties of dietary fibre consumption, alongside the probiotics found in fermented dairy products, may exert a moderating influence on the pathogenesis of psoriasis [34], by promoting gut health and subsequently regulating the innate 

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and adaptive immune responses [34]. Therefore, the health benefits of these commonly eliminated foods are important considerations, as well as understanding the substitutions that may be consumed in place of the eliminated foods. Most participants felt overwhelmed with the number of dietary recommendations available online and did not feel as though they had the knowledge to be able to navigate them safely. This led to people trying restrictive diets, often against their better judgement and without the knowledge of how to do so safely. Following restrictive diets without the guidance of a HCP, can lead to micronutrient deficiencies [15] and studies show that individuals who follow restrictive diets, report significantly lower QoL and negatively impact mental well-being [35]. The restrictive dietary practices that PLwP adopt could therefore have detrimental impacts on both physical and mental health. To build on the findings of this study, future research should further investigate the diets commonly trialled by PLwP to better understand the potential impacts of these on both physical and mental health.

This study found that there was a perceived lack of dietary support available for PLwP from HCPs. Despite recognising the shortage of evidence-based information on diet and psoriasis, participants often felt that HCPs were reluctant to discuss diet at all, and if dietary information was given it was perceived to be vague and lacking useful instruction. This led to individuals seeking dietary advice from alternative sources, primarily wellness figures and other PLwP on online forums or social media. The main motivations for participants wanting to trial dietary modifications was to find a natural way to help manage the condition, avoid medication side effects, and wanting autonomy over their condition. These findings echo previous studies which found that PLwP mainly use complimentary or alternatives to conventional medication due to treatment failures or unwanted side effects [36]. Previous research has highlighted the amount of dietary misinformation on social media [37]. Which further highlights the importance of providing dietary support to this group. 

Moreover, a recent study exploring dermatology professionals' experiences of dietary habits of
 outpatients (n=159) found that psoriasis patients were one of the patient groups reported to
 ask about nutrition most often [38]. However, 73.1% of dermatologists did not feel confident in
 answering these questions and over 90% felt that additional nutrition training and access to

### specialist dietician support would be of benefit to dermatology practice [38]. This suggests that not only is there a high demand for dietary support patients, but that HCPs may require further training and resources to be able to provide this type of support. Considering patients' values and preferences alongside their physical, social and emotional needs is a core part of patient-centred care [39]. All of which further highlights the need for research in this area. Furthermore, many of the psoriasis associated co-morbidities are widely recognised to be related to diet [33,40]. As a result, engaging in discussions about dietary considerations with HCPs with nutritional expertise, or having access to evidence-based dietary support, could improve comprehensive care for PLwP. Whilst also lessening the reliance on unsubstantiated online sources for dietary information.

### 515 Limitations

The small sample size of this study, that comprised of all white British and predominantly female participants means that further research is required to establish whether these findings are generalisable to PLwP across the UK. Furthermore, participants were recruited via an online psoriasis support group, which could have influenced the answers given by participants regarding sources of dietary information. The topic of the study may have led to a sample that perceived there to be a role for diet in managing psoriasis. Additionally, all dietary information and impact on psoriasis was self-reported. However, this was an initial exploratory study into a previously unexplored population and despite the limitations of this study, the findings provide novel and in-depth insight into the experience of PLwP regarding diet and potential support gaps in psoriasis care, which has the potential to inform subsequent larger research studies. 

### **3.6 CONCLUSION**

People living with psoriasis feel overwhelmed with the number of dietary recommendations
 claiming to help psoriasis and require more support to be able to navigate them. From the
 patient perspective, current dietary support provided by HCPs is lacking. As a result, PLwP turn
 to unregulated online platforms. This could have detrimental implications on the health and
 well-being of PLwP and therefore HCPs need to be able to confidently discuss diet and provide
 basic dietary support to PLwP until evidence-based dietary guidance for psoriasis is available.

1 2		
2 3 4	533	Understanding dietary support needs in psoriasis care from a HCP perspective warrants further
5 6	534	investigation. The findings of this exploratory qualitative study will inform larger quantitative
7	535	investigations of dietary practices of PLwP in the UK. This will enable better understanding of
8 9 10	536	the use of diet, dietary support needs and opportunities to provide tailored support.
9 10 11 12 13 14 15 16 17 18 19 20 21 22 32 4 25 26 27 28 29 30 31 22 33 34 35 36 37 38 9 40 41 42 43 44 55 56 57	536	
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49 50	630		
51 52 53	631	Figu	ure Legends
55 54	632	Figu	are 1. Key themes and sub-themes generated during interviews with UK adults living with
55 56 57	633	-	riasis, regarding the use and experience of dietary modifications.
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1 2 3 <b>Perce</b> 4	ved use and role	of diet in psoria with lived expe		t among adults
<ol> <li>Key</li> <li><sup>6</sup> Themes</li> <li>7</li> </ol>	Impact of Diet	Dietary Modifications	Dietary Information	Dietary Support
8 Sub- 9 themes 10 11 12 13 14 15 16	<ul> <li>Overall diet</li> <li>Weight-loss</li> <li>Impact of specific foods and drink</li> </ul>	<ul> <li>Restrictive diets</li> <li>Experience of dietary modifications</li> <li>Motivations for using dietary modifications</li> </ul>	<ul> <li>Information sources</li> <li>Navigating dietary information</li> <li>Making dietary decisions</li> </ul>	<ul> <li>Support available</li> <li>Support needs</li> </ul>
17 18 19 20 21 22 23 24 25 For p 26 27	eer review only - htt	p://bmjopen.bmj.co	om/site/about/guid	delines.xhtml

# **Topic Guide for Individual Interviews INTRODUCTION**

Thank you for agreeing to take part in our study on perceptions and experiences of nutrition in the progression and management of psoriasis. The study aims to explore to what extent individuals with psoriasis perceive that diet is important and/or plays a role in the development/progression and management of their condition.

We will ask some general health background questions first then specific questions about your perceptions and experience of the impact of nutrition in the progression (e.g., flares) and management of your plaque psoriasis. The experience of the impact of nutrition in the progression (e.g., flares) and management of your plaque psoriasis. The progression will last around 45 minutes or longer, but it depends how much you have to say. If we ask something that's not relevant just let us know and we will move on. We are really interested in your experiences so feel free to give us as much detail as you'd like to. When we analyse all the interviews, we will write up the findings without referring to your name or anything that identifies others in your household or family.
So that we can accurately type up what you say today I'd like to audio record the interview. The recording will be deleted once the transcript has been written up. Is that OK with you?
Do you have any questions before we start?
Confirm answers have been understood and recorded correctly by checking with participants. Ask participants to expand if needed.
PART A: Demographics

Age of participant Do you have psoriasis? If yes, what type, & how severe? Use PASI Index How long have you had psoriasis/ when were you diagnosed? Did anything trigger your initial symptoms/diagnosis? (i.e., Infection/illness?) Have you noticed any pattern in your symptoms?

## PART B: ROLE OF DIET IN MANAGING PSORIASIS

What factors do you think contribute most to your flare ups and/or condition (i.e., development)? Does stress impact your condition? How would you describe your stress levels? Does what you eat and/or drink impact your condition? Have you ever suffered from pain/wind/bloating? How frequent are your bowel movements? Are your bowel movements often soft and/or hard and difficult to pass? Do you think family history and/or genetics impacts your condition? Does Illness or infection, including testing positive for Covid-19, impact your condition?

2	
3	Do you think weight impacts your psoriasis?
4	Do other conditions and/or co-morbidities impact your condition?
5	Do other conditions and of completentics impact your condition.
6	What factors do you think play a rale in managing a flage up and/on your condition?
7	What factors do you think play a role in <b>managing a flare up and/or your condition</b> ?
8	(As above for probing about known factors – including medication)
9	
10 11	Have you identified any dietary triggers related to your condition?
12	What are these?
13	How did you identify these? (e.g., using a symptoms diary)
14	Did you and/or are you still changing your diet are a result of this?
15	Did you and/or are you still endinging your diet are a result of this:
16	
17	Have you ever <b>excluded</b> anything from your diet?
18	What did you exclude?
19	Was this helpful/ beneficial and in what way?
20	CHECK if related to another condition
21	Did you and/or are you still changing your diet are a result of this?
22	Dia you and of all you officially your allot all a result of allo.
23	
24	Have you ever added anything to your diet?
25	What did you exclude?
26	
27	Was this helpful/ beneficial and in what way?
28	CHECK if related to another condition
29 30	Did you and/or are you still changing your diet are a result of this?
30 31	
32	Have you received any dietary advice in relation to managing your psoriasis?
33	From whom?
34	Did you follow it?
35	
36	How useful was it?
37	Which lifestyle/dietary factors were targeted by the person who gave you advice? [If
38	mentioned prompt for weight re: weight stigma]
39	
40	Would you consider making changes to your diet in the future?
41	If not tried previously, what are the barriers that have prevented you from making dietary
42	changes? (E.g., lack of evidence, cooking skills, motivation etc.)
43	changes? (E.g., lack of evidence, cooking skins, motivation etc.)
44	
45	What support would be useful to help you make changes to your diet? (If perceived as
46	useful/beneficial)
47	
48 49	Are you aware of anyone that has successfully managed their psoriasis with diet?
49 50	
51	
52	PART C: CURRENT DIETARY HABITS
53	
54	How would you describe your diet? (Healthy/unhealthy? Vegetarian? Cooked/convenience?
55	Restrictive? Varied? Ketogenic? Carnivorous?)
56	
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Do you drink alcohol? (If so, what pattern? How many units? What type?)

### PART C: PERCEPTIONS OF RECEIVING NUTRITION ADVICE

- Are you a member of any patient support groups? If so, which do you find most helpful & for what reasons?
- Re: diet, do you think it would be beneficial to have access to a dietitian and/or nutritionist as part of your management? (I.e., freely available on the NHS).

# THAT'S THE END OF THE INTERVIEW, thank you for your time. Is there anything else you'd like to tell me or add?

# **BMJ Open**

### A QUALITATIVE EXPLORATION OF THE EXPERIENCES AND PERCEPTIONS OF DIET IN PSORIASIS MANAGEMENT AMONG UK ADULTS

Journal:	BMJ Open
Manuscript ID	bmjopen-2024-085536.R2
Article Type:	Original research
Date Submitted by the Author:	25-Jan-2025
Complete List of Authors:	Hawkins, Poppy; University of Hertfordshire, Mason, Sarah; University of Hertfordshire, Life and Medical Sciences Earl, Kate; University of Hertfordshire, Life and Medical Sciences Tektonidis , Athanasios ; Oxford Brookes University, Department of Sport, Health Sciences and Social Work Fallaize, Rosalind; University of Hertfordshire, Life and Medical Sciences
<b>Primary Subject Heading</b> :	Nutrition and metabolism
Secondary Subject Heading:	Dermatology, Qualitative research
Keywords:	Psoriasis < DERMATOLOGY, Patient-Centered Care, NUTRITION & DIETETICS, DERMATOLOGY, QUALITATIVE RESEARCH





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# A QUALITATIVE EXPLORATION OF THE EXPERIENCES AND PERCEPTIONS OF DIET IN PSORIASIS MANAGEMENT AMONG UK ADULTS

- Poppy Hawkins <sup>1</sup><sup>\*</sup>, Sarah Mason <sup>1</sup>, Kate Earl <sup>1</sup>, Thanasis G. Tektonidis <sup>2</sup>, Rosalind Fallaize <sup>1</sup>

- <sup>1</sup> School of Life and Medical Sciences, University of Hertfordshire, Hatfield, AL10 9AB, UK
- <sup>2</sup> Department of Sport, Health Sciences and Social Work, Oxford Brookes University, Oxford,
- 8 OX3 OBP, UK
- 9 \*Corresponding author
- 10 E-mail: <u>p.hawkins@herts.ac.uk</u>

Page 3 of 32

1 2			
3 4	12	ABSTRACT	
5 6 7 8	13	Objective	
	14	This study aimed to explore the use, experiences and perceptions of diet in psoriasis	
9 10 11	15	management among adults with lived experience in the UK.	
12 13	16	Design	
14 15	17	Qualitative. Data was analysed thematically using a reflexive thematic approach.	
16 17 18	18	Setting	
19 20	19	Online discussions with adults living with psoriasis in the UK.	
21 22 23	20	Participants	
24 25 26 27 28 29 30 31 32 33 34 35	21	Nine adults (two males, seven females) ≥ 18 years of age, living in the UK, English speaking, w	ith
	22	a diagnosis of psoriasis of any severity.	
	23	Results	
	24	Four key themes were generated: (1) Impact of diet, (2) Dietary modification (3) Dietary	
	25	information and (4) Dietary support. Overall, the majority (n=8) perceived that diet had an	
	26	impact on their psoriasis. Most participants (n=7) reported trying restrictive diets including	
36 37	27	dairy-free, gluten-free, and "cleanses" to help manage their psoriasis with limited success. A	
38 39	28	perceived lack of dietary support led to participants using social media and online forums for	
40 41	29	dietary information. Participants reported a high cognitive burden due to the lack of reliable	
42 43	30	nutrition guidance and insufficient dietary support from healthcare professionals.	
44 45 46	31	Conclusions	
40 47 48	32	Participants rely on social media and online forums for dietary information, which suggest	
49 50	33	unsubstantiated restrictive diets, that could negatively impact health. Participants felt	
51	34	overwhelmed by dietary recommendations and wanted more relevant dietary support. In the	
52 53 54	35	absence of evidence-based dietary information for psoriasis, HCPs need to be able to provide	
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57 58 59			~

1 2		
3 4	36	basic dietary support. Larger studies aimed at understanding how best to support people with
5 6	37	psoriasis are needed.
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2				
3 4	39	Journal submission title page		
5 6	40	Strengths and limitations		
7 8 9 10 11 12 13 14 15 16 17 18 19 20	41	The qualitative design of the study allowed for in-depth exploration and rich insight into		
	42	the participant's experience.		
	43	This study employed Braun and Clarke's reflexive thematic analysis, a flexible approach		
	44	that allowed researchers to effectively capture and represent participants' reported		
	45	experiences.		
	46	Adherence to the Consolidated Criteria for Reporting Qualitative Research (COREQ)		
	47	checklist enhanced the quality, rigor and transparency of the study.		
21 22	48	The study provides valuable insights, but the findings are based on a small		
23 24	49	homogeneous sample, which may limit generalisability.		
25 26	50			
27 28 29 30 31 32 33 34 35 36 37 38 39 40 41	51	Acknowledgments		
	52	The authors would like to thank the participants of this study for giving their time and		
	53	discussing their experiences for this research. The preliminary findings of this research were		
	54	presented at the Nutrition Society Conference. Citation: Hawkins P, Mason S, Earl K, et al. The		
	55	perceived role of diet in the management of psoriasis in UK adults with psoriasis: a qualitative		
	56	study. <i>Proc Nutr Soc</i> 2023; <b>82</b> :E365.		
	57	Author Contributions		
42 43 44	58	All authors contributed to this article, and all have reviewed and approved the final manuscript.		
45	59	PH was involved in the methodology and design of the study, data analysis, and drafted the		
46 47	60	manuscript. SM was involved in methodology, data collection and data analysis. RF, KE and AT		
48 49	61	were involved in the methodology and design of the study, data analysis and research		
50 51	62	supervision. Poppy Hawkins (PH) is the primary researcher and contact. Guarantor is Rosalind		
52 53	63	Fallaize (RF).		
54 55 56 57	64	Competing Interests 4		
58 59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml		

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The authors have declared that no competing interests exist 

Funding 

- Poppy Hawkins received funding from the University of Hertfordshire, QR-funded PhD
- Studentship, titled 'The role of diet in the management of psoriasis' 2021–2024, supervised by
- Dr Rosalind Fallaize (r.fallaize@herts.ac.uk), Dr Kate Earl (k.earl@herts.ac.uk) and Dr Athanasios
- Tektonidis (atektonidis@brookes.ac.uk). Sarah Mason was awarded a Centre for Health
- earch Services and Clinical Research (CHSCR), University of Hertfordshire, QR-funded Research Grant

### for this research.

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74	INTRODUCTION
75	Psoriasis is a chro
76	cardiovascular, n
77	million people liv
78	population are liv
79	can have a substa
80	Research indicate
81	limiting stress [8]
82	Furthermore, ob
83	index (BMI) is ass
84	inflammatory act
85	is limited to weig
86	in those with coe
87	and there is high
88	lifestyle factors s
89	play a part in trea
90	James Lind Allian
91	PLwP and their u
92	suggests that PL
93	to try and help m
94	negatively impac
95	other skin condit
96	for nutritional ad
97	No studies in the
98	modifications, or
99	an estimated 1.1
100	how PLwP use ar
101	potential effect o
102	holistic care for p
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	75 76 77 78 79 80 81 82 83 84 85 86 87 88 89 90 91 90 91 92 93 90 91 92 93 94 95 96 97 95 96 97 98 99 100 101

onic, immune-mediated, inflammatory skin disease associated with arthritic, netabolic, and psychological comorbidities [1,2]. There are an estimated 60 ving with psoriasis (PLwP) globally and in the UK approximately 2% of the adult ving with psoriasis [3]. The chronic, painful and visible symptoms of the disease antial negative impact on quality of life (QoL) [4].

es that lifestyle can impact psoriasis symptoms [5,6]. Reducing alcohol [7],

] and smoking cessation [9] have been shown to improve psoriasis symptoms.

esity is more common in PLwP compared to controls, and a higher body mass

sociated with increased psoriasis severity, attributed to adipose-driven

tivity [10]. Current evidence on the role of diet in the management of psoriasis

ght-loss in those living with overweight or obesity and a gluten-free diet (GFD) eliac or a gluten sensitivity [11,12]. There are no dietary guidelines for psoriasis,

demand for information on diet from both HCPs and PLwP. The question 'Do

such as diet, dietary supplements, alcohol, smoking, weight loss and exercise

ating psoriasis?' was identified as the top research priority for psoriasis by The

nce Priority Setting Partnership [13]. However, research on the experiences of se and perceptions on the role of diet is scarce globally [11]. Emerging data wP trial restrictive diets without guidance from a healthcare professional (HCP),

nanage their psoriasis [14], which could lead to micronutrient deficiencies and ct QoL [15,16]. There is a lack of data on the practices of PLwP, individuals with tions report using unregulated platforms including Instagram and online forums dvice to manage their condition [17].

e UK have explored the use of diet in PLwP, their experiences of dietary r sources they rely on in the absence of evidence-based dietary guidelines. With million PLwP in the UK, this represents an important research gap. Exploring nd perceive the impact of diet will play a key role in understanding the on both psoriasis and the health and well-being of PLwP, crucial for providing patients. This study aims to explore in-depth the experiences and use of diet in

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psoriasis management among adults with lived experience in the UK through qualitative methods. **METHODS** Due to the scarcity of literature on this topic among a UK population, an explorative qualitative study was undertaken to enhance understanding and provide in-depth insights. Consolidated Criteria for Reporting Qualitative Research (COREQ) a 32-item checklist for interviews and focus groups, was used to guide the reporting of the study findings [18]. Study design and participant recruitment Qualitative semi-structured interviews were conducted with UK adults with psoriasis. Ethical Approval was granted by The University of Hertfordshire, Heath, Science, Engineering & Technology Ethics Committee with Delegated Authority research aLMS/SF/UH/04684(2). Participants were recruited online via Facebook. The study was posted in a private Facebook group for PLwP in the UK, which comprised of over 15000 members at the time of recruitment. Purposive sampling was employed to recruit participants. The eligibility criteria for this study were aged  $\geq$  18 years, currently living in the UK, English speaking, and a medical diagnosis of psoriasis of any severity. No incentive was advertised on the study recruitment post, however, following participation, participants were offered a £30 renumeration voucher for their time. Participant information and informed consent forms were emailed to each participant prior to undertaking the interview. At the start of the interview the interviewer went through all forms and obtained verbal informed consent. Participants were aware that the research team wanted to explore the perceptions of PLwP on diet. Patient and public involvement The design of this study was guided by the outcomes of previous cross-sectional questionnaires asking PLwP about their diet. The topic guide for the interviews in this study was informed by the responses given in these earlier studies. Patients were not involved in the study's design, recruitment or completion. The results will be shared with the study participants and public through this publication. 

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### 130 Data collection

Semi-structured individual interviews with UK adults with psoriasis were conducted to explore the perceived role of diet in the management of psoriasis. Topic guides were developed by RF and SM (both females). RF is a registered dietitian and Associate Professor in Research at the University of Hertfordshire, with extensive experience in qualitative research. SM was a final year dietetics student with an interest in diet and psoriasis. The topic guides were used to ensure interviews were consistent, but participants were also encouraged to expand on answers and express their opinions freely. The topic guide is provided as a supplementary file. The interviewer asked participants to clarify answers and comments where meaning was unclear and frequently checked with participants whether their understanding of the meaning of their answers was correct. All interviews were conducted by one researcher (SM) with a single participant at a time. Each interview lasted approximately 1 hour, and all were conducted online via remote meeting applications, Microsoft Teams and Zoom. All interviews were audio-recorded and transcribed verbatim. Data saturation guided the sample size, interviews were conducted until saturation was reached. 

Psoriasis severity was self-reported by participants during interviews, as formal PASI scores or
 clinician assessments were not available. Participants were asked to describe their perceived
 severity, body surface area affected, and were asked about any PASI scores provided by their
 healthcare providers, to ascertain severity scores based on mild, moderate and severe [19].

### <sup>0</sup> 149 **Data Analysis**

Data was analysed using a reflexive thematic approach based on the work of Braun and Clarke [20]. The analysis process began with familiarisation with the data. The researchers PH and SM familiarised themselves with the data through immersion in the audio files and transcripts of the individual interviews of each participant. PH (female) is a PhD student and registered nutritionist, with experience in conducting qualitative research and thematic analysis. Subsequently, PH and SM independently coded the data using NVivo software. The codes reflected each researcher's own interpretations of patterns and meaning throughout the dataset. PH and SM then independently generated themes for the dataset through organisation 

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of their independent codes. All themes were then discussed together with the wider research
team (all authors of this paper) to explore the interpretations of the data using a collaborative
and reflexive approach. Through these discussions, four key themes were generated, which

**RESULTS** 

### 163 Participants

Seventeen individuals expressed interest in taking part, with ten consenting to participate in the interviews. One participant dropped out prior to interview with no disclosed reason. Data saturation was achieved during these interviews, meaning that data replication was observed, and no new themes or insights were generated from the interviews [21] and no further recruitment was deemed necessary. Overall, 9 participants took part in the study (2 males, 7

169 females). The demographic information of the participants is summarised in **Table 1**.

### 3 170 Table 1. Demographics and characteristics of study participants (n=9)

were divided into sub-themes.

Variable	N
Sex	
Female	7
Male	2
Age, years: mean (range)	39 (25 – 53)
Psoriasis duration, years: mean (range)	17 (2 – 34)
Ethnicity	
White British	9
Medication (current)	
Topical Steroids	5
Biologicals	3
Self-reported psoriasis severity	
Mild	2
Moderate	2
Severe	5

1		
2 3 4	172	Generated Themes
5 6	173	Four key themes were generated from the collected data: (1) Impact of diet, (2) Dietary
7 8	174	modification (3) Dietary information and (4) Dietary support. Each key theme contained
9 10	175	multiple sub-themes, which are summarised in Figure 1.
11 12 13	176	
14 15	177	Key Theme 1: Impact of diet
16 17	178	Participants discussed their thoughts on the role of diet in the management of psoriasis. They
18	179	described the dietary factors that worsened or improved their psoriasis. A negative difference
19 20	180	in psoriasis symptoms was more often experienced by participants than a positive difference to
21 22	181	psoriasis symptoms through diet. Participants commonly described negative differences as a
23 24	182	"flare" or "flare-up" which is an episode of worsened psoriasis symptoms. Additionally,
25 26	183	participants also discussed increased itch, redness, and drier skin when describing the negative
27 28	184	differences that they experienced.
29 30 31	185	
32 33	186	Sub-theme: Overall diet
34	187	All participants (n=9) believed that diet could play a role in the management of psoriasis, and
35 36	188	most (n=8) reported that diet had impacted their psoriasis in some way. The majority (n=7)
37 38	189	stated they notice a negative difference in their psoriasis when they do not eat a healthy,
39 40	190	balanced diet.
41 42 43	191	
44 45	192	"when I eat worse, it is worse. And when I eat healthy, it does get slightly better.
46	193	[Recently] I haven't been eating very well and it is getting a lot worse than it used to
47 48	194	<i>be"</i> (Participant 4)
49 50 51	195	"I know that when I'm eating healthier, it is it doesn't clear up, but it does fade and it is
52 53	196	<i>better."</i> (Participant 9)
54 55		
56 57		10
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3 4	197	"I don't need the Methotrexate anymore and I put so much down to not needing it
5 6	198	because I've got a much better diet than I ever had." (Participant 2)
7 8 9	199	Sub-theme: Weight-loss
) 10 11	200	Regarding weight-loss, one of the few evidence-based dietary recommendations for psoriasis,
12	201	those whose weight had fluctuated in their adult life (n=4), reported mixed impact of weight-
13 14 15	202	loss or gain on their psoriasis.
16 17	203	"if I'm eating worse, I'm putting weight on - which then is making it worse."
18 19	204	(Participant 4)
20 21	205	"I haven't sort of, noticed that it's [losing weight] made any difference, positive or
22 23 24	206	negative on the psoriasis." (Participant 6)
24 25 26	207	Sub-theme: Impact of specific foods and drink
27 28	208	The majority (n=7) stated they notice a negative difference in their psoriasis when they eat
29 30	209	certain "trigger" foods. The most reported "trigger" foods and drink for psoriasis were alcohol,
31 32	210	dairy, and sugar. Participants also reported that not eating enough fruit and vegetables had a
32 33 34	211	negative impact on their psoriasis.
35 36	212	"I guess the things we eat as well, do have an impact because there are times when I do
37 38	213	eat some things and I seem to be more itchy with other things that don't make me
39 40	214	itchy." (Participant 8)
41 42 43	215	"I don't eat anything that I know triggers [my psoriasis]." (Participant 3)
44 45	216	"Dairy and alcohol are the big offenders [for making my psoriasis worse]." (Participant 5)
46 47	217	if I have a lot of alcohol, that's really bad. It takes it's not immediate - not like the
48 49	218	next day but within the week. I know my my face is a lot drier it's a lot redder."
50 51	219	(Participant 9)
52 53 54	220	"I've noticed that red wine will have a massive flare with me." (Participant 2)
55 56		
57 58		11
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2 3	221	"not eating enough fruit and vegetables eating too much sugar [are dietary triggers
4 5	222	for my psoriasis]." (Participant 4)
6 7	223	
8 9	225	
10 11	224	Key Theme 2: Dietary modifications
12 13	225	Dietary modifications involved intentional changes in the food and drinks consumed. Dietary
14 15	226	modifications were commonly discussed by participants alongside the impact these had on
16 17	227	their psoriasis symptoms. Almost all of the dietary modifications were restrictive. Only one
18 19	228	participant had tried adding supplements, but found they had no impact on their psoriasis.
20 21	229	primrose oil was one thing that was suggested and cod liver oil. So, I did start taking both of
22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37	230	those, um but they didn't have an effect." (Participant 9)
	231	Sub-theme: Restrictive diets
	232	Most participants (n=7) had tried following at least one restrictive diet to try and help their
	233	psoriasis symptoms. A restrictive diet refers to an eating pattern that reduces or cuts-out
	234	certain foods, food groups or energy intake. The most common restrictive diets tried by
	235	participants were reducing or removing dairy, cutting out nightshades and following gluten-free
	236	diets. Nightshades are plants from the Solanaceae family, which include potatoes, tomatoes,
	237	peppers and aubergines [14]. Dietary "cleanses" were mentioned and involved numerous
38 39	238	different restrictions. The "cleanses" that participants attempted in this study were typically
40 41	239	highly restrictive, involving either the consumption of only specific types of foods or juice-based
42 43	240	diets, where participants drank only juice and water for a set number of days.
44 45 46	241	
47	242	"I've not had any dairy at all [for 3 months]" and "[I tried going] completely gluten-free
48 49	243	for three months" (Participant 1)
50 51 52	244	"[I am] actively avoiding nightshades" (Participant 2)
53 54 55	245	"I've done lots of cleansing diets" (Participant 5)
56 57		12
58 59		
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2 3	246	"[I tried a diet] where you had to eat [] just apples for like 2 weeks. And that was
4 5		
6	247	supposed to be some, like sort of cleanse." (Participant 6)
7 8 9	248	
) 10 11	249	Participants reported mixed results from restricting dairy, 2 of the 4 participants that had tried
12	250	reducing or removing dairy reported no difference to symptoms and 2 reported an alleviation
13 14	251	of psoriasis symptoms. Weight-loss was also reported as a consequence of following a dairy-
15 16 17	252	free diet.
18 19	253	
20 21 22	254	"I found that cutting out milk made a bit of a [positive] impact" (Participant 9)
23 24	255	"I have noticed that I've lost weight during the dairy-free diet because obviously you
24 25 26	256	can't eat so many things". (Participant 1)
27 28 29	257	
30	258	Following a gluten-free diet and avoiding nightshades was frequently reported to have no
31 32	259	impact on psoriasis symptoms by those that had tried these, and following overly restrictive
33 34 35	260	low-fat diets were believed to have worsened one participants' psoriasis.
36 37	261	
38 39	262	"I did follow it for quite a while and was having like, gluten-free bread and other things
40 41 42	263	] I didn't see a difference." (Participant 9)
43	264	"Tried a gluten free diet for three months. And it made absolutely no difference
44 45	265	whatsoever. And when I went back to eating copious amounts of gluten again, I didn't
46 47 48	266	notice it got worse either." (Participant 1)
49 50	267	"[I tried] nightshades trying to avoid them. Um, and but I didn't find that it worked"
51 52	268	(Participant 6)
53 54		
55 56		
57		13
58 59		

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1 2		
3 4	269	"When I was restricted and going down the complete healthy route of eating like,
5	270	healthy as in eating disordered healthy - it would be low-fat this, low-fat that. Like
6 7	271	completely skinny milk - and that's when my skin was the worst." (Participant 2)
8 9	272	
10 11		
12 13	273	Sub-theme: Experience of dietary modifications
14 15	274	Those that had tried following a specific dietary modification to help their psoriasis, frequently
16 17	275	reported that it was difficult to adhere to (n=6). Preparing separate meals was a barrier for
18	276	those who cooked for others, and cutting-out foods or whole food groups meant that it was
19 20	277	difficult to know what to replace them with. Restrictive diets also reported to provide little
21 22	278	enjoyment and limited reward. Participants often reported that the restrictive diets had not
23 24	279	made any or much difference to their psoriasis symptoms which was demotivating, or they had
25	280	not been able to keep following them due to some requiring extremely strict exclusions.
26 27	281	
28 29		
30 31	282	"I just think I don't want to make myself miserable either. And to take over my life to
32 33	283	that extent, either without really thinking that that would work. And there's a huge
34	284	commitment, especially when you then cook for a family of five too… I don't want to
35 36	285	take it out of their diets, so it will be quite difficult to do." (Participant 1)
37 38	286	
39 40	207	(line quite how we hind of airs we things and the new things find line but work I find
41 42	287	"I'm quite happy to kind of - give up things and try new things. And I'm but yeah, I find
43	288	I find it really hard to kind of because when you've got kids and you're like, doing
44 45	289	different meals and different all the different things, so it is difficult to sustain. That's
46 47	290	that's the thing. I think I'm happy to do it for a week or two but then life gets in the way"
48 49	291	(Participant 9)
50 51	292	"I had a lot of dairy. So, it's a lot to cut out." (Participant 1)
52	202	
53 54	293	
55 56	294	Sub-theme: Motivations for using dietary modifications
57 58		14
58 59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml
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295 The main reason that participants reported wanting to try dietary modifications for their 296 psoriasis were: 1) wanting a natural way to help manage the condition (n=4), 2) as a potential 297 way to avoid starting or going back on medication that was perceived to be strong or associated with undesirable side effects (e.g., immunosuppressants) (n=4), and 3) having autonomy and a 298 299 sense of empowerment by being able to do something to help themselves, rather than being 300 completely reliant on referrals to healthcare professionals and dermatologists (n=5). 301 "I've [always] looked for the more natural ways to control it." (Participant 5) 302 303 "I'm so reluctant to go on something as strong as Methotrexate I have tried a gluten free 304 *diet for three months."* (Participant 1) "I'm always looking for ways in which I myself can help the condition without always 305 being referred ... If there's anything... natural ways that it can be better, then I'm always 306 307 up for doing it that way." (Participant 8) 308 **Key Theme 3: Dietary information** 309 Participants discussed where they obtained dietary information from, their experiences of 310 311 navigating dietary recommendations from different sources, and gave insights into the factors 312 that influenced their decisions to make certain dietary modifications. Sub-theme: Information Sources 313 The participants frequently reported that online patient forums and groups, as well as social 314 media and Google were their main source of dietary information for psoriasis (n=8). This was 315 primarily due to a lack of information from trusted sources such as healthcare professionals and 316 organisations, and a lack of evidence-based information readily available to them. The dietary 317 modifications recommended online and in the patient forums and social media groups were 318 often restrictive. The restrictive dietary modifications often recommend eliminating certain 319 15

1 2		
3 4	320	food groups, or specific foods and drinks from the diet, and often had strict rules on what can
5 6	321	and can't be eaten.
7 8 9	322	
10 11	323	"every diet you could possibly suggest. No nightshades, no gluten, no meat, no red
12	324	meat, no sugar, no dairy and no alcohol, and pretty much any combination of those"
13 14 15	325	diets suggested on forums and trialled by forum members]. (Participant 1)
16 17	326	<i>"If you listen to this doctor</i> [an American doctor found online], I might as well just not
18	327	eat because he's going, "Nightshades, milk, cheese" and I'm thinking, "Well, what can I
19 20	328	eat?" "Chicken." That was all what he was saying. And I thought, "No." I couldn't live like
21 22 23	329	that. I couldn't live with cutting all of them things out." (Participant 7)
24 25 26	330	
27	331	However, participants also frequently reported that the online psoriasis forums were useful for
28 29	332	general support, even if the dietary information was perceived by some to be misleading or
30 31	333	unfounded. They reported that the groups gave them a chance to feel understood, a place to
32 33	334	ask questions about psoriasis without judgment and hearing coping strategies other PLwP had
34 35	335	used. Overall, the online groups were perceived in a positive light and provided participants
36	336	with psychosocial support.
37 38 39	337	
40 41	338	"it's good to be around or have access to people who have gone through the same
42 43 44	339	kind of things." (Participant 6)
45 46	340	"I find it helpful to know that there's other people that are going through similar things
47	341	to what I've done in the past [] but there's a lot of mis-led information out there as
48 49 50	342	<i>well."</i> (Participant 2)
51 52 53	343	
54 55	344	Sub-theme: Navigating dietary information
56 57 58		16
59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

1 2		
2 3 4	345	Participants often reported that when looking for dietary advice they felt overwhelmed by the
5	346	amount of information available (n=7). The information was often contradictory and went
6 7	347	against their better judgment. This caused uncertainty, and added to the cognitive burden of
8 9	348	participants, alongside resulting in them trialling diets even when they were sceptical about the
10 11	349	reliability and health impacts of the dietary changes recommended.
12 13 14 15	350	
15 16	351	" there are too many websites and too many pages with too many different conflicting
17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39	352	things on and I get mind boggled [] one will say, don't eat that and then one will say,
	353	do eat that." (Participant 7)
	354	"as soon as you put in Google [diet and psoriasis] all this information comes out and
	355	You'll try anything." (Participant 7)
	356	"You're not meant to remove whole food groups [] So, I kind of question whether that
	357	is a good move." (Participant 1)
	358	
	359	Sub-theme: Making dietary decisions
	360	Participants reported that their decisions to try certain dietary modifications were influenced
	361	by before and after photos posted online by forum members who had changed their diets,
	362	anecdotal experience of dietary changes of other PLwP and popular wellness figures, even
40 41	363	when they were sceptical (n=6). Participants reported trying dietary changes just to see if it
42 43	364	would work for them, like it had for other people they had seen online.
43 44 45 46	365	
47 48	366	"[Those who] post pictures of before and after, who'd done the Hannah Sillitoe diet. And
49 50	367	that is, I think, probably what made me do this dairy-free diet and if I'm honest, that is
51 52 53 54	368	probably from seeing the difference in her skin on the pictures. I don't know her I've
	369	never had a conversation with her, but just thinking if, if that is real, then I'd be silly to
55 56 57 58 59		17
59 60		For peer review only - http://bmiopen.bmi.com/site/about/guidelines.xhtml

1 2		
3	370	keep my mind closed to that as well. So, I'm willing to try it. Um, so so it does influence
4 5 6	371	me even if I take it with a pinch of salt." (Participant 1)
7 8 9	372	
9 10 11	373	"I've been following, you know, Hannah Sillitoe who cleared her psoriasis by having a
12	374	very vegan healthy lifestyle? And it's one of the reasons why I've become a vegan."
13 14 15	375	(Participant 9)
16 17	376	
18 19 20	377	Key Theme 4: Dietary Support
20 21 22	378	Participants discussed their experiences of the dietary support they had sought and received.
23 24 25	379	Sub-theme: Support available
26 27	380	All participants (n=9) perceived there to be a lack of dietary support available to them and that
28	381	HCPs were reluctant to discuss diet during appointments. Participants recognised that this may
29 30	382	be due to a lack of evidence of a relationship between diet and psoriasis. However, the lack of
31 32	383	discussion about anything to do with diet was deemed unhelpful and left participants feeling
33 34	384	frustrated. Additionally, if dietary advice was given by HCPs, it was reported to be vague
35 36	385	healthy diet or weight-loss suggestions, without any specific information or support. This was
37 38	386	perceived to be unhelpful and presumed dietary knowledge.
39 40	387	"[The Doctor] just kept on saying, "Oh, there's no cure. There's nothing that you can do."
41 42 43	388	(Participant 9)
44	389	[when trying to discuss diet with HCPS] "they're a little bit nervous. Um, I don't think
45 46	390	they ever like to comment [] they're very much like, um, "Just keep it varied."
47 48 49	391	(Participant 2)
50 51	392	"I think that expecting people to have like, a good knowledge of food, and what things
52 53 54	393	can be replaced with, is it's just quite unfair." (Participant 3)
54 55 56		
57 58		18
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- 3 4	394	"dermatology and rheumatology, have both told me to, sort of lose weight and
5	395	that'll help with the psoriasis and the psoriatic arthritis. But, um that's it and I
6 7 8	396	haven't noticed any improvement." (Participant 6)
9 10 11	397	Sub-theme: Dietary support needs
12 13	398	Most participants (n=8) stated that they would benefit from dietary support from a healthcare
14	399	professional with nutritional expertise, to help them to navigate the overwhelming amount of
15 16	400	often contradictory dietary advice available, and the cognitive burden of trying to decide what
17 18	401	was safe. Participants stressed the importance of evidence-based advice. Recognising that
19 20	402	although there was limited evidence on the relationship between diet and psoriasis, they were
21	403	still willing to try diets suggested online, by friends and family or from popular wellness figures
22 23	404	in case they did work for them. As a result, they wanted support to be able to try these diets
24 25	405	safely and better understand the potential health implications, particularly for elimination
26 27	406	diets.
28 29 30	407	
31 32	408	"Just knowing what is safe, what will be a good move, where I can start"
33 34	409	Participant 8)
35 36	410	I didn't know how to do it properly. Like I don't know what gluten's in [] it's.
37 38	411	everywhere, isn't it?" (Participant 2)
39 40 41	412	"Because such huge amounts of your food groups you're cutting out, I think I'd want to
42 43	413	know that I was not depriving myself." (Participant 1)
44 45	414	"when someone's expecting you to cut something that might make up quite a big
46 47	415	part of your diet, then you need to know what you can be using instead." (Participant 3)
48 49 50	416	
50 51 52	417	There was no observed difference in perception or experience across any demographic
53 54	418	characteristics. However, the sample size was too small to conduct any comparative analysis
55 56	419	and the sample size may also be the reason that no differences were observed.
57 58		19
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2 3	420	
4 5	421	DISCUSSION
6 7	422	Despite a growing interest in the role of diet in psoriasis management, there has been limited
8 9	423	research exploring the perceptions of PLwP on the use and role of diet. To the best of our
10 11	424	knowledge this is the first study to explore this topic in PLwP in the UK. The findings of this
12 13	425	study have identified the challenges PLwP face and have highlighted potential gaps in support
14 15	426	for PLwP regarding diet, alongside areas for further research to improve psoriasis care.
16 17	427	Most participants in this study perceived that diet had an impact on their psoriasis and took
18 19	428	proactive measures to avoid foods known to trigger psoriasis flare-ups or worsen symptoms.
20 21	429	The most common dietary triggers perceived to negatively affect psoriasis in this study were
22 23	430	alcohol, dairy, and sugar. This mirrors findings from previous studies [14]. Additionally,
24 25	431	participants also perceived that eating a "generally healthy diet" characterised by consuming
26 27	432	plenty of fruit and vegetables had a positive impact on their psoriasis. Previous studies have
28	433	found that fruit and vegetable consumption was reported to alleviate symptoms by PLwP [22],
29 30 31	434	and that higher fruit and vegetable intake was associated with lower psoriasis severity [23,24].
32 33	435	Specific diets were also commonly trialled by participants to try and help manage their
34 35	436	psoriasis, all of which were restrictive. The most trialled diets were dairy restriction, gluten-
36	437	free, avoiding nightshades and a range of different cleanses, with limited or no perceived
37 38 39	438	impact on psoriasis symptoms.
40 41	439	Dairy restriction was reported as a dietary modification trialled by 4 of the participants in this
42 43	440	study, with mixed results. Previous research has reported that dairy elimination or restriction is
44 45	441	common in PLwP in the US and provided alleviation of psoriasis symptoms in almost 50% of
46	442	people that removed it [14]. However, there is limited research investigating the impact of
47 48	443	dairy consumption on psoriasis severity. The reasoning behind eliminating dairy may be
49 50	444	attributed to concerns about the pro-inflammatory effect of saturated fat, which is high in
51 52	445	certain dairy products [25]. However, research indicates that dairy may have neutral to
53 54	446	favourable effects on inflammation [25]. Furthermore, low-fat fermented dairy products such
55 56	447	as yogurt have been shown to have anti-inflammatory effects attributed to the presence of
57		20
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probiotics [25,26]. Dairy products are also key sources of high-quality protein and essential micronutrients, including vitamin B12, calcium, magnesium, and zinc [27]. Eliminating or restricting dairy may negatively impact the intake of essential nutrients [28]. There is an absence of research on the type of dairy product perceived to have a negative impact on psoriasis symptoms, and this warrants further investigation. Additionally, one of the participants who reported removing diary, also reported losing weight whilst following a dairy-free diet. Weight-loss in PLwP who are also living with obesity or overweight has been shown to improve psoriasis symptoms [12]. Avoiding nightshades was a common dietary modification reported by participants. Nightshades are a family of plants that include potatoes, tomatoes, peppers, and aubergines, they contain solanine and alkaloids which have been linked to inflammation in mouse models [14,29]. However, no human studies support this association; furthermore, nightshades are high in fibre and a rich source of antioxidants. Additionally, participants in this study and others have reported that eating fruit and vegetables improved psoriasis symptoms [23,24]. Gluten-free diets were also commonly trialled by PLwP, and research suggests that it could alleviate psoriasis symptoms, but only in PLwP who have coeliac disease or a sensitivity to gluten, otherwise, it is not recommended [12]. Previous research has also indicated that PLwP trial a GFD with mixed effects [14]. It is unclear whether PLwP recognise that the evidence only suggests following a GFD for those PLwP who are coeliac or have a diagnosed gluten sensitivity. Psoriasis is associated with numerous other autoimmune diseases, including coeliac disease [30]. However, greater awareness may be needed regarding who this type of diet is appropriate for, as gluten-free diets have been shown to be low in dietary fibre [31]. Greater dietary fibre intake is associated with a lower risk of cardiovascular disease and coronary heart disease, as well as lower systemic inflammation [32,33]. Dietary fibre also has appetite regulating and anti-obesogenic properties [32]. This is relevant to PLwP considering the associated comorbidities. The combination of the prebiotic properties of dietary fibre consumption, alongside the probiotics found in fermented dairy products, may exert a moderating influence on the pathogenesis of psoriasis [34], by promoting gut health and subsequently regulating the innate 

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and adaptive immune responses [34]. Therefore, the health benefits of these commonly eliminated foods are important considerations, as well as understanding the substitutions that may be consumed in place of the eliminated foods. Most participants felt overwhelmed with the number of dietary recommendations available online and did not feel as though they had the knowledge to be able to navigate them safely. This led to people trying restrictive diets, often against their better judgement and without the knowledge of how to do so safely. Following restrictive diets without the guidance of a HCP, can lead to micronutrient deficiencies [15] and studies show that individuals who follow restrictive diets, report significantly lower QoL and negatively impact mental well-being [35]. The restrictive dietary practices that PLwP adopt could therefore have detrimental impacts on both physical and mental health. To build on the findings of this study, future research should further investigate the diets commonly trialled by PLwP to better understand the potential impacts of these on both physical and mental health.

This study found that there was a perceived lack of dietary support available for PLwP from HCPs. Despite recognising the shortage of evidence-based information on diet and psoriasis, participants often felt that HCPs were reluctant to discuss diet at all, and if dietary information was given it was perceived to be vague and lacking useful instruction. This led to individuals seeking dietary advice from alternative sources, primarily wellness figures and other PLwP on online forums or social media. The main motivations for participants wanting to trial dietary modifications was to find a natural way to help manage the condition, avoid medication side effects, and wanting autonomy over their condition. These findings echo previous studies which found that PLwP mainly use complimentary or alternatives to conventional medication due to treatment failures or unwanted side effects [36]. Previous research has highlighted the amount of dietary misinformation on social media [37]. Which further highlights the importance of providing dietary support to this group.

501 Moreover, a recent study exploring dermatology professionals' experiences of dietary habits of 502 outpatients (n=159) found that psoriasis patients were one of the patient groups reported to 503 ask about nutrition most often [38]. However, 73.1% of dermatologists did not feel confident in

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answering these questions and over 90% felt that additional nutrition training and access to specialist dietician support would be of benefit to dermatology practice [38]. This suggests that not only is there a high demand for dietary support patients, but that HCPs may require further training and resources to be able to provide this type of support. Considering patients' values and preferences alongside their physical, social and emotional needs is a core part of patient-centred care [39]. All of which further highlights the need for research in this area. Furthermore, many of the psoriasis associated co-morbidities are widely recognised to be related to diet [33,40]. As a result, engaging in discussions about dietary considerations with HCPs with nutritional expertise, or having access to evidence-based dietary support, could improve comprehensive care for PLwP. Whilst also lessening the reliance on unsubstantiated online sources for dietary information.

### 515 Limitations

The small sample size of this study, that comprised of all white British and predominantly female participants means that further research is required to establish whether these findings are generalisable to PLwP across the UK. Furthermore, participants were recruited via an online psoriasis support group, which could have influenced the answers given by participants regarding sources of dietary information. The topic of the study may have led to a sample that perceived there to be a role for diet in managing psoriasis. Additionally, all dietary information and impact on psoriasis was self-reported. However, this was an initial exploratory study into a previously unexplored population and despite the limitations of this study, the findings provide novel and in-depth insight into the experience of PLwP regarding diet and potential support gaps in psoriasis care, which has the potential to inform subsequent larger research studies.

### **CONCLUSION**

People living with psoriasis feel overwhelmed with the number of dietary recommendations claiming to help psoriasis and require more support to be able to navigate them. From the patient perspective, current dietary support provided by HCPs is lacking. As a result, PLwP turn to unregulated online platforms. This could have detrimental implications on the health and well-being of PLwP and therefore HCPs need to be able to confidently discuss diet and provide

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2 3	532	basic dietary support to PLwP until evidence-based dietary guidance for psoriasis is available.
4 5	533	Understanding dietary support needs in psoriasis care from a HCP perspective warrants further
6 7	534	investigation. The findings of this exploratory qualitative study will inform larger quantitative
8 9	535	investigations of dietary practices of PLwP in the UK. This will enable better understanding of
10	536	the use of diet, dietary support needs and opportunities to provide tailored support.
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49 50	630					
51 52	631	Figure Legends				
53 54	632	Figure 1. Key themes and sub-themes generated during interviews with UK adults living with				
55 56	633	psoriasis, regarding the use and experience of dietary modifications.				
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1 2 3 <b>Perce</b> 4	ved use and role	of diet in psoria with lived expe		t among adults
<ol> <li>Key</li> <li><sup>6</sup> Themes</li> <li>7</li> </ol>	Impact of Diet	Dietary Modifications	Dietary Information	Dietary Support
8 Sub- 9 themes 10 11 12 13 14 15 16	<ul> <li>Overall diet</li> <li>Weight-loss</li> <li>Impact of specific foods and drink</li> </ul>	<ul> <li>Restrictive diets</li> <li>Experience of dietary modifications</li> <li>Motivations for using dietary modifications</li> </ul>	<ul> <li>Information sources</li> <li>Navigating dietary information</li> <li>Making dietary decisions</li> </ul>	<ul> <li>Support available</li> <li>Support needs</li> </ul>
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# **Topic Guide for Individual Interviews INTRODUCTION**

Thank you for agreeing to take part in our study on perceptions and experiences of nutrition in the progression and management of psoriasis. The study aims to explore to what extent individuals with psoriasis perceive that diet is important and/or plays a role in the development/progression and management of their condition.

We will ask some general health background questions first then specific questions about your perceptions and experience of the impact of nutrition in the progression (e.g., flares) and management of your plaque psoriasis. The experience of the impact of nutrition in the progression (e.g., flares) and management of your plaque psoriasis. The progression will last around 45 minutes or longer, but it depends how much you have to say. If we ask something that's not relevant just let us know and we will move on. We are really interested in your experiences so feel free to give us as much detail as you'd like to. When we analyse all the interviews, we will write up the findings without referring to your name or anything that identifies others in your household or family.
So that we can accurately type up what you say today I'd like to audio record the interview. The recording will be deleted once the transcript has been written up. Is that OK with you?
Do you have any questions before we start?
Confirm answers have been understood and recorded correctly by checking with participants. Ask participants to expand if needed.
PART A: Demographics

Age of participant Do you have psoriasis? If yes, what type, & how severe? Use PASI Index How long have you had psoriasis/ when were you diagnosed? Did anything trigger your initial symptoms/diagnosis? (i.e., Infection/illness?) Have you noticed any pattern in your symptoms?

# PART B: ROLE OF DIET IN MANAGING PSORIASIS

What factors do you think contribute most to your flare ups and/or condition (i.e., development)? Does stress impact your condition? How would you describe your stress levels? Does what you eat and/or drink impact your condition? Have you ever suffered from pain/wind/bloating? How frequent are your bowel movements? Are your bowel movements often soft and/or hard and difficult to pass? Do you think family history and/or genetics impacts your condition? Does Illness or infection, including testing positive for Covid-19, impact your condition?

2	
3	Do you think weight impacts your psoriasis?
4	Do other conditions and/or co-morbidities impact your condition?
5	Do other conditions and/or comorbitation impact your condition.
6	What factors do you think play a rale in managing a flave up and/or your condition?
7	What factors do you think play a role in <b>managing a flare up and/or your condition</b> ?
8	(As above for probing about known factors – including medication)
9	
10 11	Have you identified any dietary triggers related to your condition?
12	What are these?
13	How did you identify these? (e.g., using a symptoms diary)
14	Did you and/or are you still changing your diet are a result of this?
15	Did you and/or are you still endiging your aret are a result of this:
16	Hannen and the transformation from an and the form
17	Have you ever <b>excluded</b> anything from your diet?
18	What did you exclude?
19	Was this helpful/ beneficial and in what way?
20	CHECK if related to another condition
21	Did you and/or are you still changing your diet are a result of this?
22	Dia you and of all you officially your allot all a result of and.
23	
24	Have you ever added anything to your diet?
25	What did you exclude?
26	
27	Was this helpful/ beneficial and in what way?
28 29	CHECK if related to another condition
30	Did you and/or are you still changing your diet are a result of this?
31	
32	Have you received any dietary advice in relation to managing your psoriasis?
33	From whom?
34	Did you follow it?
35	How useful was it?
36	
37	Which lifestyle/dietary factors were targeted by the person who gave you advice? [If
38	mentioned prompt for weight re: weight stigma]
39	
40	Would you consider making changes to your diet in the future?
41	If not tried previously, what are the barriers that have prevented you from making dietary
42	changes? (E.g., lack of evidence, cooking skills, motivation etc.)
43	enunges: (E.g., new of evidence, cooking skins, notivation etc.)
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45	What support would be useful to help you make changes to your diet? (If perceived as
46 47	useful/beneficial)
48	
49	Are you aware of anyone that has successfully managed their psoriasis with diet?
50	
51	
52	PART C: CURRENT DIETARY HABITS
53	
54	How would you describe your diet? (Healthy/unhealthy? Vegetarian? Cooked/convenience?
55	Restrictive? Varied? Ketogenic? Carnivorous?)
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Do you drink alcohol? (If so, what pattern? How many units? What type?)

## PART C: PERCEPTIONS OF RECEIVING NUTRITION ADVICE

- Are you a member of any patient support groups? If so, which do you find most helpful & for what reasons?
- Re: diet, do you think it would be beneficial to have access to a dietitian and/or nutritionist as part of your management? (I.e., freely available on the NHS).

# THAT'S THE END OF THE INTERVIEW, thank you for your time. Is there anything else you'd like to tell me or add?