

# Study of impact of psoriasis/psoriatic arthritis on lifestyle choices (SIPPA)

March – July 2005, J E Chandler



## Aims and purpose of the research.

SIPPA, was designed to look at the perceptions held by people with either/or both aspects of the disease particularly on lifestyle choices that were made because of their condition simultaneously and look at how both psoriasis and psoriatic arthritis effect lifestyle choices. There have been studies<sup>1-9</sup> previously but these have looked at psoriasis alone, although a large Nordic country study<sup>10</sup> showed that consideration of arthritis needed to be included in treatment of psoriasis.

SIPPA, looked at some individual case history studies that were submitted together with survey returns, that illustrated the reality of living with a disease, as assessed by the individuals and to see the perceptions held about the condition.

SIPPA is an independent study, (solely funded by the PAA with no funding from the pharmaceutical industry or other sources). It's initial aims were not to compare at the present time, its findings to previous studies. This may of course be done at a later stage, when more evidence is added to the statistical information gathered after the cut off date. This is due to the time restraints imposed by this project at the present time.

## METHODOLOGY

Three groups of psoriatic patients were identified and consisted of:-  
 Group A: PAA subscribers database, active or non-active in seeking professional help for their condition;  
 Group B: Psoriatic patients attending a dermatology clinic – this provided a snapshot view of a limited number of patients, who were actively seeking treatment for their condition;  
 Group C: Unknown recruitment base from an advert placed in a national newspaper – this was to make the survey balanced in its approach to groupings of respondents.

The study took the form of a postal survey and was mailed out with reply envelopes to 1500 individuals selected as above.

## Statement of results

The heart of the report consists of tables, grids, charts and individual case histories, the latter have been extracted from the returned surveys with selection criteria based on more detail given on individual circumstance expressed in free text answers.

## Psoriatic arthritis questionnaires

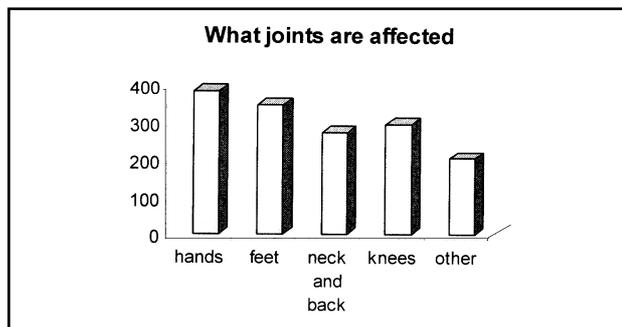
- 432 people completed the psoriatic arthritis study
  - Female = 274
  - Male =124
  - Non stated = 34
- 353 respondents gave their age. Average age is 52 years
- 392 respondents answered the question "how long have

they had psoriatic arthritis". Average time was 15 years

➤ 408 respondents answered the question "what age was your psoriatic arthritis diagnosed". Average age was 39 years

➤ 354 respondents answered the question "how long did you have psoriatic arthritis before it was diagnosed". Average time was 3 1/2 years.

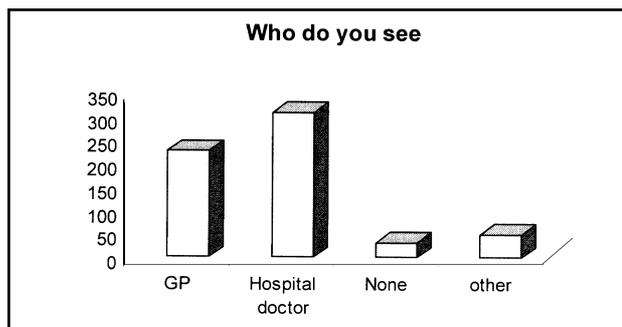
Fig 1



(hands 26%, feet 23%, neck and back 18%, knees 20% and other 13%)

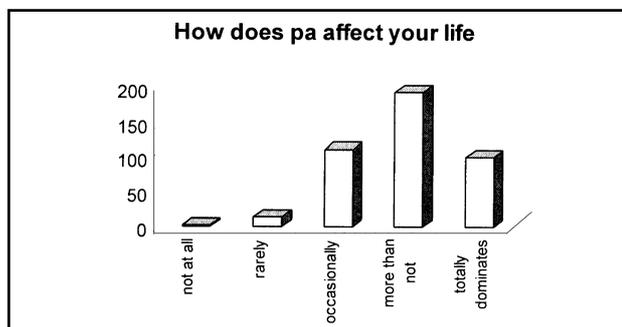
94% of respondents also have psoriasis

Fig 2



(GP 37%, Hospital doctor 50%, none 5% and other 8%) [fig 2].

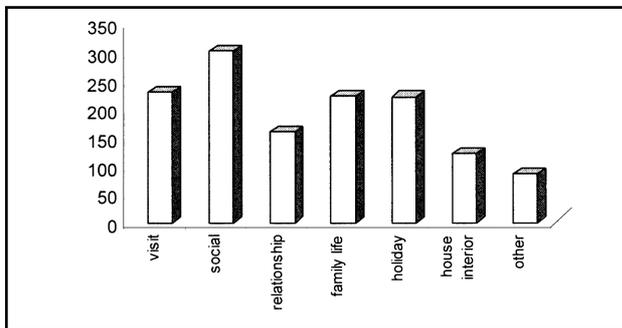
Fig 3



354 (85%) of respondents said their day to day life is affected and 63 (15%) said it was not [fig 3]

(Not at all 0.5%, Rarely 3%, Occasionally 26.5%, more than not 46% and totally dominates 24%)

Fig 4



Places they visit 17%, social activities 23%, relationships 12%, impact on family 17%, choice of holiday 16%, Choice of house interior 9% and other 6%) [fig 4]

108 respondents conceal their psoriatic arthritis. 304 respondents do not. Of the 304 who do not hide it 66% of them talk openly.

**The psoriasis survey**

- 444 people completed the psoriasis study

**126 male, 281 female and 37 didn't state**

- Respondents average age 52 years.
- How long have you had psoriasis?
- Average length of time 26 years,
- Average age when diagnosed 28 years,
- Average length of time before diagnosed 3 years,
- Average % of body covered by psoriasis 23% (by self assessment)
- 92% of respondents also had psoriatic arthritis
- 63% of respondents say psoriasis affects their life. [fig 7]
- 45% of people hid their psoriasis. Of those that did not hide it 74% talk openly about it.
- 58% have their self esteem affected
- 60% have their self confidence affected.
- 128 of the respondents would try anything to get rid of their psoriasis
- 52% of respondents would do the same activities if they didn't have psoriasis
- 86% would like to see more information on psoriasis

Fig 5

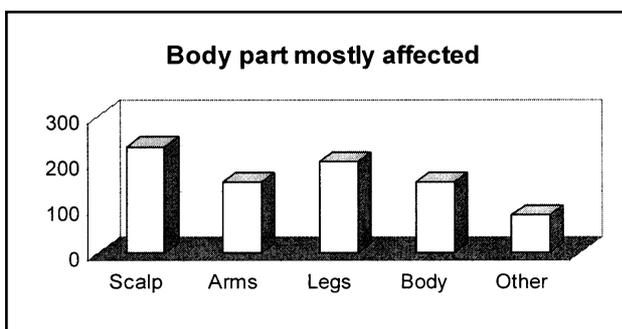


Fig 6

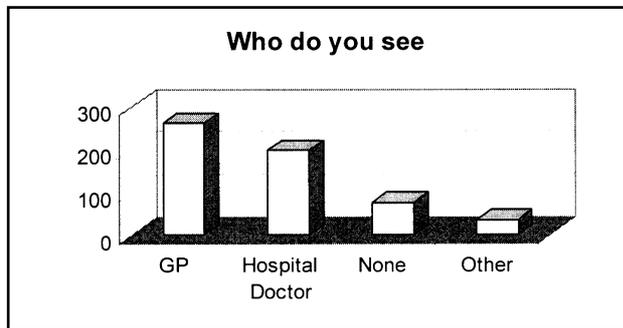


Fig 7

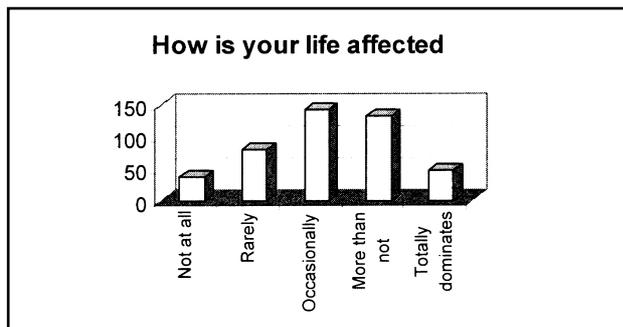


Fig 8

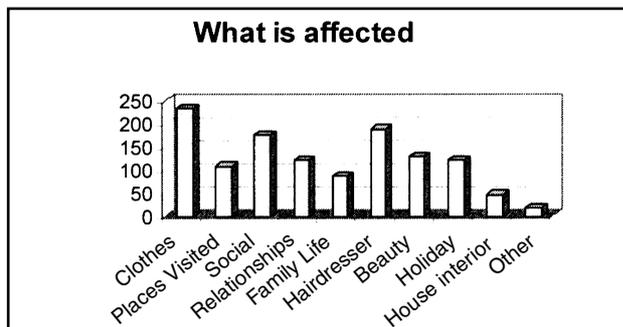


Fig 9

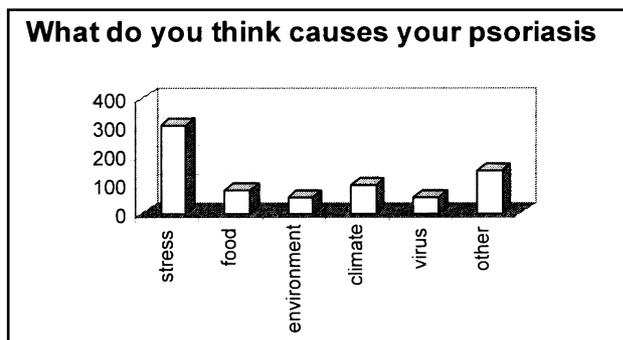


Fig 10

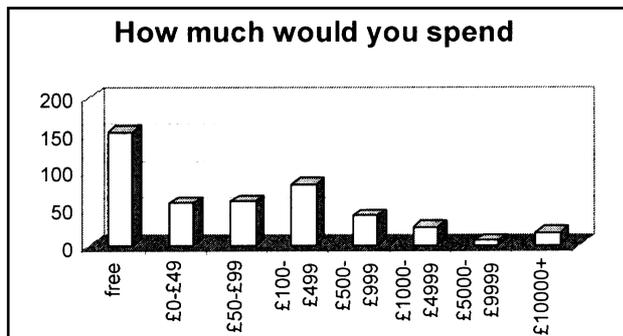
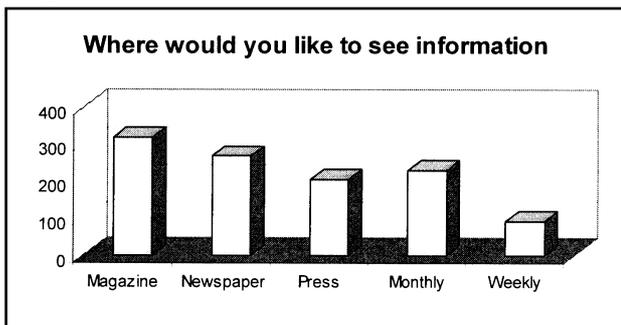


Fig 11

	Yes	No	Don't Know
<b>General Public</b>	63 (14%)	329 (76%)	43 (10%)
<b>Doctors</b>	204 (47%)	183 (42%)	47 (11%)
<b>Nurses</b>	164 (38%)	179 (42%)	87 (20%)
<b>Newspapers</b>	60 (14%)	288 (67%)	83 (19%)
<b>Television</b>	47 (11%)	304 (71%)	80 (18%)

Fig 12



### Perspective of the impact of psoriasis and/or psoriatic arthritis:

Psoriasis and psoriatic arthritis are not discriminatory, affecting both men, women, children, appearing at any age and in varying degrees. However, you have to have a predisposition to psoriasis - i.e. it may run in your close family unit or way back in past generations. Having this predisposition to psoriasis also increases your chance, if you have psoriasis, of developing psoriatic arthritis too.

Over the years psoriasis has had myths built up around it, dating back to the days of leprosy! Many myths are alive today. Many people think Psoriasis is contagious, or people are dirty, their personal hygiene to blame – this is not the case<sup>22</sup>. You will see from some of the information that is to follow, that there is a common thread that runs through many of the case histories, whether it be the misconceptions that psoriasis is contagious, or stress, environmental factors, food intolerances are all major causes of the condition, which can all build up the guilt within a patient. For example, they drink, smoke, eat too much which has brought all this on themselves, which is just not the case, but all contribute to their lifestyle, perceptions of themselves and their self-esteem.

Those living with psoriasis have more than just a skin condition to live with and manage. They have relationships to forge and maintain. There are financial costs involved on a monthly basis regarding prescriptions charges for the amount of topical treatments they have to use.

Family units are affected, children wanting to do everyday things with their affected parent, but are unable to due to the parent's unwillingness to show their skin in public i.e. swimming pools, changing rooms etc.

Normal everyday things can be a challenge down to the colour of clothes they wear – will it show all the shredding skin flakes i.e. black or do they stick to beige. [fig 4]

Discrimination occurs regarding employment issues – denied employment opportunities i.e. restricted from opportunities in the food industry or being a lifeguard. Employment in the leisure industry may be difficult because they have to wear shorts, t-shirts etc.

Children are being bullied at school by kids, encouraged by parental attitudes because they look different.

Normal day-to-day things we all take for granted can be a major challenge for some.

### CASE HISTORIES:-

#### Case History Respondent #008

A 45 year old female has had psoriasis since the age of 10 with most of the body being affected also has had psoriatic arthritis since age 25 with the hands feet and neck being affected. In this case the psoriasis is the dominating element of the disease with it affecting lifestyle more than not, the psoriatic arthritis occasionally affecting social activities. Both conditions affect the daily life style of this individual and her self esteem which has been affected by psoriasis.

Her choice of clothes, social activities, relationships, visits to the hairdressers and beauty therapies were affected by having psoriasis. Her choice of social activity was affected by psoriatic arthritis to due to her limited range of mobility, this person said they would swim and go to the gym if they didn't have psoriasis.

This individual believes that their psoriasis is caused by stress, food, and environment, with psoriatic arthritis being caused by a virus.

When asked about messages that needed to be promoted in the media the respondent said the following "that this is not a disease, not catching not dirty"

In free text the following was written in reply to the question "what would you do to get rid of your psoriasis?":

"Anything - I now realise how much it has influenced my life choice/self-esteem and relationships in a very negative way. I feel depressed about it, and very worried about the future as it is getting worse. Doctors' don't seem interested at all and never ever ask about it at all. Psychological help is needed as well as creams"

#### Case History Respondent #060

A 50 year old female has had psoriasis since the age of 14 and psoriatic arthritis since age of 49. The psoriasis affects mainly nails but most recently has had pustular psoriasis of the face. The psoriatic arthritis affects hands, feet, neck and back, knees. Both conditions affect more than not with flare-ups of psoriatic arthritis totally dominating her life.

Places visited, social activities, relationships and house interior were affected by psoriasis, whilst choice of social activity and choice of motor vehicle was affected by psoriatic arthritis. This person said they would do more exercise, go on long walks, swim and gardening if they didn't have psoriasis and psoriatic arthritis.

This individual believes that the psoriasis is caused by genes, with psoriatic arthritis being caused by a stress, environment and virus.

When asked about messages that needed to be promoted in the media the respondent said the following:

"a more positive approach as opposed to related to death of playwright Dennis Potter"<sup>20</sup>

In free text the following was written in reply to the question "what would you do to get rid of your psoriasis"?:

"...I do not feel enough has been asked about the state of mind

of the sufferer; from deep depression, anxiety, inability to get complete nights of sleep and ability or otherwise to cope with chronic pain” .

### Case History Respondent #081

A 56 year old female has had psoriasis since the age of 12 with most of the body being affected also has had psoriatic arthritis since age 45 with the hands feet and neck being affected. In this case the psoriasis does not affect her life at all only occasionally, but psoriatic arthritis does have an impact on family life daily, including most manual tasks such as cooking, cleaning, bathing and writing life. This individual's self esteem has not been affected by psoriasis or psoriatic arthritis.

This individual, however, believes that the psoriasis and psoriatic arthritis are caused by a heredity predisposition to the disease that could be exacerbated by stress, food, environment and climate.

When asked about messages that needed to be promoted in the media the respondent said the following “basic facts with emphasis that it is not contagious”

In free text the following was written in reply to the question “what would you do to get rid of your psoriasis?”:

“Live in the sun”

And to the same question regarding psoriatic arthritis “Anything if it could be cured, but this would depend on what was involved... I'd rather not have the condition, of course, if only for the long term hassle and possible consequences of taking a cocktail of strong drugs”

### Case History Respondent #094

A 68 year old female has had psoriasis since the age of 13 with most of the body being affected with only nails currently being affected also has had psoriatic arthritis since age 54. In this case the psoriasis does not affect her life, but in the past it has had an impact on the choice of clothing worn.

The psoriatic arthritis rarely affects but is present in hands and feet, but does have an impact on choice of social activities.

Again, this individual believes that the psoriasis is caused by stress, virus and genetics, but does not have a view on what causes psoriatic arthritis.

When asked about messages that needed to be promoted in the media the respondent said the following “that it can be alleviated, so keep on until your GP sends you to see a specialist”.

In response to the question “what would you do if you didn't psoriatic arthritis?” the reply was “tap dancing”.

In free text the following was written in reply to the question “what would you do to get rid of your psoriasis?”:

“I'm fortunate, to me it was an annoyance but not life threatening, so I lived with it. It was short hair washed daily, long sleeves, nail varnish but methotrexate has cleared the lot. I always felt that I was behind the ugliness looking out. So it didn't affect me – in fact it was an excuse to wear extreme clothing styles and bright nail varnish”

In response to the same question for psoriatic arthritis the respondent wrote the following:

“Before methotrexate [disease modifying drug DMARD],

I couldn't go for a walk, knit, peel vegetables, take the handbrake off the car, make pastry, carry a book – though in costume on stage I could forget the pain. Since treatment I can do virtually everything again (though tap dancing hurts!) and as a bonus my skin is clear for the first time since I was 13”.

Clearly from the responses given to the above, demonstrates that the respondent has over the years, despite much pain, developed coping mechanisms that have built up her self-esteem and confidence, enabling her to live with a chronic long-term condition, and regain and sustain, with the help of appropriate drug management for her, some quality of life

### Case History Respondent #101

A 37 year old female has had psoriasis since the age of 4 with most of the body being affected (90% self-assessed). She has had psoriatic arthritis since age 21. The psoriatic arthritis only affected fingers and toes until the age of 34 when it became totally debilitating and dominating of her life.

“Because of my arthritis I couldn't care less about my looks anymore – got past caring, just pain and lack of mobility which doesn't help when I have three kids 14, 11 and 7”.

This individual believes that the psoriasis and psoriatic arthritis are caused by stress and genetics.

In response to “what would you do if things were different?” this individual wrote “walk round shops, walk into school to meet teachers rather than sit in the car all the time, visit places and take the kids out more”

When asked about messages that needed to be promoted in the media the respondent said the following “positive outcomes, causes and treatments”

Clearly, self esteem and self confidence, restrictive mobility have affected this person a lot, with the impact of both aspects of the disease not only affecting the choices she makes but also those that affect her activities with her family, which could have a long term impact on her children. There may be more responsibilities on the children as “carers” for her and so-forth depending on the severity of the respondent's illness.

### Case History Respondent #338

A 63 year old female has had psoriatic arthritis since the age of 15 with neck, hands and jaw affected, currently she does not have any psoriasis but has had patches previously. She is more affected than not by her arthritis “I think carefully about the task I carry out with my hands daily and avoid overuse where possible. I conceal my psoriasis from those who believe that limited hand use would prevent me carrying out work properly and effectively”

Her psoriatic arthritis affects her self confidence “I'm conscious of malformations of my hands when on show. I'm a practising Architect. It is important to me to continue my work, as well as I'm able, as this is of value to my self-esteem. My hands are obviously of prime importance to my work, hence my preoccupation with rationing of hand use”

This individual believes that the psoriasis is caused by stress and climate

In response to the question what would you do if you didn't have psoriatic arthritis the reply was “more craft work and sewing”.

When asked about messages that needed to be promoted in the media the respondent said the following “how psoriatic arthritis

affects sufferers, but emphasis on the fact that these are ordinary people not invalids”

Clearly this condition has a huge impact on the respondent's lifestyle; what she does in her leisure time could seriously have an impact on her working life, as she relies on the use of her hands as her financial income, so employment and discriminatory issues arise too.

### Case History Respondent #387

A 23 year old female has had psoriasis since the age of 7 with scalp being affected, who also has had psoriatic arthritis since age 21 with the hands, feet, neck, back and knees affected.

This individual doesn't feel that her psoriasis or psoriatic arthritis has an impact on day-to-day life and does talk openly about the condition. She believes that the psoriasis is caused by stress and food, with psoriatic arthritis being caused by stress, food, environment and climate.

In free text the following was written in reply to the question "what would you do to get rid of your psoriatic arthritis?":

"I'm now using Humira (adalimumab an anti-TNF drug produced by Abbott Pharmaceuticals) and to be honest have tried to blank out how bleak and desperate things were when things were unbearable. I attempted suicide – that's what I tried to get rid of my psoriatic arthritis"

The last statement clearly reflects this individuals desperation and mental torment she has experienced in learning to deal with her condition, reflecting the impact the illness has had on her. Perhaps in this case, more could have been done by her medical team to spot the signs for more help in helping her to cope.

### Case History Respondent #448

A 51 year old male has had psoriasis since the age of 4 with most of the body being affected at some stage, also has had psoriatic arthritis since age 20 with the hands, feet, neck and back being affected.

In this case both the psoriasis and psoriatic arthritis affected lifestyle more than not.

Both conditions have impacted on self esteem and self confidence with choice of clothes, social activities, relationships, family life, going to the barber and holiday destination being affected by psoriasis, whilst relationships, family life, holiday destination have been affected by psoriatic arthritis "It has affected my life choices, employment, hobbies (playing guitar), sport and fitness"

This individual believes that the psoriasis and psoriatic arthritis can be affected by stress, food, environment, climate and virus but that they are caused by something else.

When asked about messages that needed to be promoted in the media the respondent said the following "positive messages of how people live with the disease, and that people can live good lives"

In free text the following was written in reply to the question "what would you do to get rid of your psoriatic arthritis?":

"I feel it is too late, the damage is done. Still have awful problems with my nails which are unsightly and problematic. Would consider corrective surgery for cosmetic reasons (fingers straightened so guitar playing would be more accessible). Not keen on drugs – have tried most treatment and felt worse.

Also tried diet change, exercise and relaxation"

From this statement, clearly the respondent has tried much to overcome the condition or indeed improve it, and, this statement is tinged perhaps with resignation and accepting of what he has to live with, but again shows the impact the condition has had on his wellbeing.

### Analysis and discussion

The results and analysis of this study need to be placed in context. Charities are often set-up to fulfil a need, usually because the system has failed. In this case the National Health Service which has failed to help or support those with the condition or to support individuals or raise awareness about the cause. In the case of psoriasis awareness is relatively low amongst the general public and where awareness exists it is usually negative and often stigmatising. In the case of psoriatic arthritis lack of awareness amongst people with psoriasis is low and virtually non-existent in wider context.

The response to the survey was high. Total after the analysis cut-off date was 29% (464) returned psoriatic arthritis surveys and 32% (497) returned psoriasis surveys.

The gender split is typical of the database and it was expected that more females would respond, interestingly more females wrote free text answers than males and this is reflected in the selected case histories. The survey aimed to find out about life styles choice was partly fulfilled, but encouragingly enough many were not deeply affected by the condition with only 24% expressing that psoriatic arthritis dominated their life with only 12% of those with psoriasis expressing the same view. It is a well known view that self esteem is affected, but again although it would be expected that those who are members of a self-help charity may be more severe many did not feel that this aspect was affected. It therefore could be argued that either they have benefited from the work of the organisations or have become resigned to the condition and no longer care about what others felt this reflected in case history#101 whose psoriatic arthritis has become so debilitating that she has "got past caring"

The ability of some individuals to cope and not be affected on a daily basis although having extensive disease could be explained again by attaining a certain level of knowledge, education or awareness about the condition although this contradicts the issues as reported in the media with only 8% believing that news stories were positive about psoriasis and only 2% about psoriatic arthritis. This is reflected in the frustration with many free text comments wanting to see more positive messages and better awareness about the disease this was reflected in case history #448

### Conclusion

It is clear that psoriasis and psoriatic arthritis have a major impact on the lifestyles of those who responded to this survey. Other studies have also shown impact on quality of life.

Although, it would be safe to assume that those who are motivated to complete a survey, contact a support organisation or belong to a charity may be at the more severe end of the disease spectrum, these results also included answers from individuals who are not as physically affected but have some form of psychological impact.

- Early diagnosis and appropriate interventions must still be a key to long term positive outcomes

- Education of healthcare providers is still perceived to be low
- Awareness should be more visible but positive
- Encouragingly many people cope well and do not let the conditions affect their lifestyle choices
- Psychological impact should not be underestimated, physical disease severity is only one aspect

Given the range of needs and the way psoriatics cope and manage disease and the way in which it is portrayed within the media, providing positive management and coping mechanisms for individuals that allow individuals to feel comfortable and less stigmatised by disease appears to be a positive approach.

It may be more effective to help individuals than try to change general population attitudes; the medical professional and healthcare providers must play a key role in developing a good communication and management with greater involvement of the patient. The survey also included people who were not being seen by anyone for disease management, given that both diseases are chronic and life long and in the case of psoriatic arthritis potentially disabling, careful consideration needs to be given to helping these individuals to be able to gain access to care as and when needed.

### Contributors and collaborators

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