Manchester Psoriasis Shout Out 2014

The Review





What is psoriasis?

Psoriasis is a chronic inflammatory disease. It is non-contagious and is characterised by patches of red, flaky skin. The condition is unique to each individual patient – there are many different forms of psoriasis, and the amount of skin involved can range from tiny patches to extensive body coverage. Psoriasis has a genetic component, and flare-ups can be triggered by a variety of factors including stress, anxiety or an infection. Psoriasis is much more than just a simple skin condition.

psoriasis sufferers.

John Thompson, actor, psoriasis patient and Shout Out supporter



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Psoriasis affects over 1.8 million people in the UK. In Greater Manchester this equates to 75,000 people – enough to fill Manchester United's Old Trafford stadium!

Few people, however, talk publically about having the condition as it can be considered embarrassing and unsightly. Because psoriasis is much more than a simple skin complaint. it can have a significant impact upon an individual's quality of life. For some people it can be life ruining.

The first Manchester Psoriasis Shout Out was the vision of Professor Chris Griffiths, Director of the Manchester Centre for Dermatology Research, and was brought to life in April 2014. The Shout Out team's aim was to get people talking about psoriasis (what it is and what it isn't) and to bring psoriasis patients together with professionals working in the field of psoriasis management and research. Through the enthusiasm of staff and patients, what began as a small event soon snowballed into a week-long festival of activities - including high profile project launches, dedicated patient events and even a fashion show! The overarching message was a positive one – it is possible to live well with psoriasis.

We were delighted that the Shout Out attracted the support of local schools, a few celebrities(!) and crucially patients themselves. The week was a roaring success with the Shout Out roadshow attracting over 300 visitors, and the associated films enjoying nearly 3,000 views to date. The feedback from both patients and professionals has been overwhelmingly positive, and many quotes are included in this review.

The week was informative not only for the public and psoriasis patients, but also for us and our colleagues. The message was clear – a lot has been done to improve the lives of people living with psoriasis, but there is still so much more that can, and should, be done.

We hope you enjoy reading this review of the Manchester Psoriasis Shout Out 2014.

LETS TALK PSORIASIS!

Professor Chris Griffiths, Susie Moschogianis (Shout Out Coordinator)



FILMS ---

Let's Talk Psoriasis

The film 'Lets Talk Psoriasis' starred Pippa, Josie and Toby who shared their experience of living with psoriasis.

Comedian and actor Toby Hadoke talks about his psoriasis, how comedy has helped him cope, and how his life has been "completely transformed" by finding a treatment which was right for him.

'Let's Talk Psoriasis' was produced by Haelo (April 2014)

for the Manchester Psoriasis Shout Out.



consuming.

Josie – English Language student

ff I used to fight it, fight it hard... I've got to accept it...Its my skin! We've been together a long time.

Pippa –Teacher and Illustrator





much better as I have got older. I've learned



Psoriasis Flashdance

The musical anthem for Manchester Psoriasis Shout Out 2014 was Pharrell Williams' chart topping hit 'Happy'.

This light-hearted film aimed to raise the profile of the Shout Out initiative and featured the team dancing to 'Happy' in a fun routine professionally choreographed by The University of Manchester's Dr Anna Chisholm. Enthusiasm made up for the 'not quite professional' performance by patients. dermatologists, health psychologists, researchers and University/NHS staff. Special mention must go to the students from New Charter Academy who danced superbly. The Flashdance was performed throughout the week at various sites across Manchester.



Both films, along with celebrity endorsements can be viewed on our You Tube Channel –

Manchester Psoriasis Shout Out

'Flashdance' was produced by Phil Bracegirdle (April 2014) for the Manchester Psoriasis Shout Out.





66 We spent many a time, squashed in an office, practising, until we were all walking around constantly humming the "Happy" tune. "

Catherine Vickers, Dermatology **Outpatient Department Manager**













'Chill out' Zone

The relationship between psoriasis and stress or anxiety is well documented. Many people report that their psoriasis can be triggered or exacerbated during periods of psychosocial stress. Furthermore, having psoriasis can itself have a significant impact on psychological wellbeing. To address this vicious cycle as an aspect of the condition, the roadshow included a dedicated 'chill out' zone where members of the public could take advantage of 'mindfulness' taster sessions and even complimentary messages.



What is mindfulness?

Mindfulness is paying attention, in the present moment, with curiosity, openness and a warm accepting attitude. We can spend time focusing on something in particular, like our breath, body or sounds around us, or we can try and bring mindfulness into any aspect of our daily life like having a conversation or eating a meal.

How can mindfulness help with psoriasis?

Amongst other benefits, practising mindfulness can help to reduce stress levels. There is some evidence to suggest that practising mindfulness can reduce stress for people who experience psoriasis as well as the symptoms of psoriasis themselves. Research conducted here in Manchester has contributed towards this evidence base.

For a brief introduction to mindfulness and some sample practices go to: **www.freemindfulness.org**



'Be Active/Be Calm' events

In conjunction with Sport Manchester, the roadshow included free active (Zumba fitness) and stress reductionsessions

Manchester Psoriasis Shout Out Roadshow

April 28th - 2nd May 2014

Thanks to: Dr Anna Chisholm, Dr Peter Morgan, Dr Pauline Nelson, Sport Manchester Tracy Lambert, Anne Delooze, Eleanor Lawley – Massage Therapists

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See Psoriasis: Look Deeper

On 28th April the See Psoriasis: Look Deeper campaign kicked off the Manchester Psoriasis Shout Out by hosting an event at the Manchester Town Hall to raise awareness of the psychological impact of psoriasis.

See Psoriasis: Look Deeper is a collaboration formed in 2012 to address the psychological impact that psoriasis can have. The campaign's aim is to raise awareness amongst the general public, patients and health care professionals of the full life impact that psoriasis can have, and in doing so encourage healthcare professionals to provide holistic care for their patients with psoriasis to give them the care and support they need.





The collaboration consists of The Psoriasis Association; Mental Health Foundation; Dr Sandy McBride, Consultant Dermatologist at Royal Free Hampstead NHS Trust; Dr Chris Bundy, Senior Lecturer in Behavioural Medicine at The University of Manchester; and Toby Hadoke, actor and comedian living with psoriasis.

The event was attended by patients, academics, clinicians and politicians, who all came to the event to learn about the SPLD campaign and celebrate some of the progress being made in psoriasis treatment across the UK.

Following an introduction by Professor Chris Griffiths, members of the collaboration gave short presentations about the campaign's formation in 2012, work the group are carrying out and an emphasis on the need for whole person care for psoriasis that takes into account both the physical and psychological aspects of the condition. During a Q&A session, guests shared insights on the variable nature of psoriasis, how everyone's journey is different and how

in particular physical severity does not always correlate to the psychological impact experienced by the patient.



A focal point for the event was the group's campaign tree, a life size illuminated tree with messages from patients hung from its branches. The display acted as a powerful visualisation of the emotions caused by psoriasis, highlighting both the positive and negative emotions that many people with the condition experience.

www.SeePsoriasisLookDeeper.co.uk

Look Deeper team

See Psoriasis Look Deeper Monday 28th April 2014, Manchester Town Hall Thanks to: Dr Chris Bundy and The See Psoriasis



Psoriasis Stratification to Optimise Relevant Therapy



The Manchester Psoriasis Shout Out saw the launch of an innovative four-year stratified medicine programme.

Psoriasis Stratification to Optimise Relevant Therapy (PSORT) is a unique consortium formed by world-leading dermatologists comprising five UK universities: Manchester, King's College London, Newcastle, Queen Mary and Liverpool, 10 pharmaceutical and diagnostics companies, NHS Trusts and the National Psoriasis Association. In 2013, led by Professor Chris Griffiths, the consortium was awarded £5million funding from the Medical Research Council and an additional £2million contribution from its industry partners to carry out research into psoriasis which will directly benefit patients.

In the past 10 years there has been a dramatic improvement in clinical outcomes for patients with severe psoriasis due to the introduction of a new class of injectable drugs called biologics. These work by targeting specific parts of the immune system which are important in causing the condition. However, these drugs are very expensive (estimated annual patient cost is £10,000) and it remains the case that a significant number of patients fail to respond adequately.

PSORT aims to use existing knowledge about psoriasis, an unparalleled patient base coupled with the involvement of patient organisations, and state-of-the-art investigative tools, to develop clinical tests to help direct personalised treatments. Rather than the current system of "trial and error" prescribing, this would be of added benefit to society as a whole since it could result in significant cost savings to the NHS and aid the pharmaceutical industry in development of new drugs.

The PSORT programme was launched officially by the President of The University of Manchester, Professor Dame Nancy Rothwell, at the Imperial War Museum North on 29 April 2014. Research teams began work on 1 September.

www.psort.org.uk

PSORT Launch

Tuesday 29th April 2014, Imperial War Museum North Thanks to: Samantha Ryder, PSORT Programme Manager





ne Nancy Rothwell, President of The University of chester speaking at the launch of the PSORT programme.

Patient day at Salford Royal NHS Foundation Trust

The Shout Out roadshow arrived at Salford Royal Hospital on Wednesday 30th April.

In addition to an array of roadshow activities, a dedicated patient event was held in the event marquee led by Professor Chris Griffiths. The interactive discussions provided an opportunity for patients to discuss current medications and cutting edge research. Special guest presenters included fashion blogger Helen Hanrahan and comedian Toby Hadoke who gave honest and often humorous personal accounts of living with psoriasis.







66 Giving people opportunity to engage with professionals and other patients in this way is so important for personal wellbeing and knowing you are not alone. We should support people to come together in this way more often.

Francine Jury, Citizen Scientist Programme Manager





Wednesday 30th April, Salford Royal NHS Foundation Trust Thanks to: Professor Chris Griffiths, Helen Hanrahan, Toby Hadoke, Dr Elise Kleyn, Dr Amy Foulkes, Dr Beth Fordham



impact

PSORIASIS

'PsoWell' Training Launch

Thursday 1st May, The Midland Hotel, Manchester Thanks to: Alison Littlewood, IMPACT Programme Manager

New health professional training package launched

The Identification and Management of Psoriasis Associated ComorbidiTy (IMPACT) research programme is a collaboration between The University of Manchester, Salford Royal NHS Foundation Trust and the Psoriasis Association IMPACT launched in September 2010 with a mission to apply the best quality research knowledge to devise responsive services to improve the care of, and outcomes for, people with psoriasis. The current programme is supported by an award from the National Institute for Health Research in the form of a five year Programme Grant for Applied Research.

The IMPACT team recognise the accruing evidence suggesting that people with psoriasis are at high risk of acquiring a wide range of additional physical and psychological conditions. In response, IMPACT has brought together a multi-disciplinary team of experts to investigate the most likely causal explanations for these comorbidities, and to then identify the best evidence-based interventions to support patients to manage psoriasis, limit the impact of comorbidities and potentially prevent them altogether.

Health professionals vary in their confidence to manage psoriasis as a complex long-term condition, and they recognise that there is an unmet training need. As part of the Manchester Psoriasis Shout Out 2014, the IMPACT team launched their 'Pso Well' training programme. Developed by the IMPACT team and led by Dr Chris Bundy, Health Psychologist at The University of Manchester, this tailored intensive training programme is designed to equip a range of healthcare practitioners to support people to manage their psoriasis more effectively. The emphasis of the training is on enhancing patient involvement in the standard consultation, especially around medicines management and adherence; lifestyle behaviour change and encouraging better selfmanagement. The team introduced this much needed training package to approximately 60 clinical colleagues from across the country at an evening event at Manchester's Midland Hotel. The training package is being assessed prior to national roll out.

www.impactpsoriasis.org.uk



@impactpsoriasis

The Poetry Collection

In the months before the Psoriasis Shout Out. we asked people to write about their experiences of living with psoriasis. We were delighted that many people responded to our advertisements and shared their feelings about psoriasis, its visibility and being made to feel different

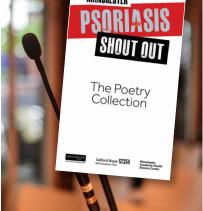
The result was a truly unique spoken word event held at Manchester's Cornerhouse and hosted by local poet copland smith. Professional poets and complete novices came together to showcase their work. The collection of poems have been published in full and can be viewed on the Psoriasis Shout Out. website.

The Centre's fabulous 'Psoriasis Shout Out' week of events in Manchester was brilliantly planned and reached thousands of people in really creative and innovative ways. I had worked with staff at the Centre briefly as part of my time as Writer-in-Residence for the NHS in the North West and was delighted to perform the poems I produced as a result of my time with them at their excellent poetry event. It was very moving to see and hear people with psoriasis read their own poems, and react to the poetry of others.

Char March, Poet







I have psoriasis – I don't "suffer from" it I live with psoriasis I'm not a "victim" of it I am a psoriasis patient not a psoriasis sufferer.

by Salford Psoriasis Support Group

Sometimes it aets me down

I am capable of making my skin erupt volcanoes of plagues that spout pain, my scalp is a fabulous hat of itch, my testicles great balls of fire!

You live in a cold world of perfection your hands smooth, your legs polished, when you swim no-one runs shrieking from the pool, you turn no heads.

We are the Psoriasis Warriors

Char March

I buzz with steroids, clothe myself in the stink of coal tar, I am guttate, pustular, flexular – they try to stun me to normality with their UV rayguns

You complain of slightly the wrong shade of honey blonde highlights. while you cram me into a burka to not offend your world's sight.

But I burst out, scarlet skin-armour gleaming, splitting with pride, raging with the heat of battling this world that loves bland.

© Char March www.charmarch.co.uk Russ Cowper

Its tough it hurts its embarrasing

sometimes it gets me down but I get away with it

because I act the clown

its sore it itches

my hands are a mess

sometimes it gets me down

but I keep smiling

I joke and fool around.

Its messy its flaky

People avoid you

sometimes it gets me down

but I always have the derm team

Salfords the best in town.

its moisturise its moisturise

Moisturise some more

sometimes it gets me down

trying to be happy

4 pints in the Crown.

A cure

relief

a days respite

sometimes it gets me down.

knowing others suffer

keep my feet on the ground

Psoriasoaurus

Poetry Evening

Pippa Farina

Pip is my Psoriasoaurus. Pip is stubborn and irritating antisocial and embarrassing.

But Pip doesn't know this.

Pip just is.

So there's no point getting angry

Pip doesn't know what anger is.

So. I accept Pip. scales and all.

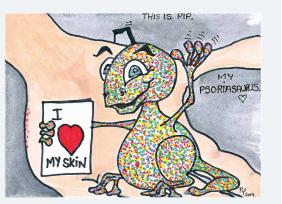
We've been together a long time and I've noticed that the more I treat Pip with care

Wednesday 30th April 7pm, Manchester Cornerhouse

Thanks to: Vaila Mallace, IMPACT Research Assistant

and respect.

the better Pip becomes



44 Your feedback



I have had psoriasis for over fifteen years – but I have never allowed it to define me or to prevent me from living the life I want. This is why I blog – to offer people practical advice; to bring some light-hearted banter to what is essentially a depressing subject; and to try and illustrate that it is still possible to live a full life despite a chronic skin disorder. But the truth is that for some people, this skin disease can have a horrible and detrimental impact on their lives, to the point that they feel completely hopeless. And this is why the Manchester Psoriasis Shout Out was so incredibly important. Because for the woman who said to me "I thought I was the only one", it brought the comfort of knowing that she is not alone. For the sufferer who said "this is the first time in 20 vears I've felt positive about psoriasis", there is now the knowledge that he hasn't been forgotten. And for the patient who said "this has been the best day of my life" after hearing the talks, there was finally hope. And there must always be hope.

Helen Hanrahan aka the 'Flaky Fashionsita'

I did not realise how common psoriasis was before I got involved in the Shout Out week – it opened my eyes. I was really inspired by how our psoriasis patients got involved in our different events, it was great to meet them and understand more about the condition.

Gemma Boswell, Receptionist, The Manchester Centre for Dermatology Research



There were so many wonderful things about the Shout Out, but the best for me was the strong feeling of camaraderie between patients, researchers and health professionals coming together to get people talking about psoriasis. It was one amazing week – bring on the next one!

Dr Pauline Nelson, Researcher in health services for psoriasis It cannot be said that the Researchers, Clinicians and people with psoriasis in Manchester do not go the extra mile in raising awareness of psoriasis. Our understanding of psoriasis and the impact the condition can have on peoples' lives has been greatly increased through the dedication and hard work of those based in Manchester. The Manchester Psoriasis Shout Out not only highlighted the important research that is ongoing in the area, but had people with psoriasis at the heart of it – it gave an opportunity to come together and share our knowledge and experiences, appreciating the difficult intricacies of psoriasis whilst also having fun! Psoriasis should not have to define you, but often can – the Manchester Psoriasis Shout Out placed great value to people with psoriasis.

Helen McAteer, President of the Psoriasis Association

I came to the event at Salford Royal and couldn't believe that all these people were getting up and dancing for psoriasis – it was overwhelming. At this point my whole mental state was a mess. I felt low, ugly, angry and quite hateful – all of which slowly went as the afternoon went on. I met Toby and Helen in person, and I couldn't get my head round how accepting they both were (to a point) of their psoriasis. It was so nice to just be truly honest about how I felt. We also made a few jokes about psoriasis and leaving skin around, which, if you've ever suffered from psoriasis, you will know that you need to maintain some level of humour to keep you sane!

I have since been admitted [as an inpatient] to Salford Royal. The admission was what I needed to finally accept my psoriasis, and embrace it as part of me. With the help of all the wonderful staff and patients I feel I've done just that. I was out of hospital in time for summer – the perfect time to get my legs out in a pair of shorts. Yes I'm flake free for the first time in over 10 years, and it feels amazing.

I truly believe that the Shout Out was my turning point and I would love to be able to help others in the way Toby and Helen helped me. So sign me up for Shout Out 2015!

Rebecca Darwent-Black, psoriasis patient and Shout Out ambassador 2015



As Dermatology nurses, we deal with many patients with psoriasis, and feel it is often a misunderstood condition. We were eager to get involved with the Shout Out and many patients talk to us about it.

Catherine Vickers,
Dermatology Outpatient Manager



I loved the concept of the Shout Out. Psoriasis is such a hidden affliction that anything that raises awareness has to be a good thing... I can always claim I'm a published poet now and I was very pleased with how it was received.

Russ Cowper, psoriasis patient and poet



I will do anything to raise awareness of psoriasis – the care I have had from the Royal Free Hospital is so fantastic that embarrassing my children by dancing like an idiot on the internet is scant recompense. I also know how difficult it is to get the media to cover the disease – eczema clearly has a better agent as that is far more well known and discussed. I also think it helps patients to know they are not alone so the louder we shout the more people will hear.

Toby Hadoke, Actor and comedian

Psoriasis on the catwalk

Manchester Psoriasis Shout Out 2014 ended on a high note with a fashion show at intu Trafford Centre, run by Ireland's fashion blogger and psoriasis patient Helen Hanrahan.

It can be challenging living with a stigmatising and visible skin disease, and many individuals respond by avoiding or limiting social contact. Frustratingly there is a lack of available advice on how to dress fashionably despite the skin condition. This inspired Helen set up her blog, The Flaky Fashionista, in July 2012.

NHS and University staff joined psoriasis patients on the Orient catwalk to model the latest fashions (carefully chosen by Helen) and to share 'top tips' on how to dress with psoriasis during the spring/summer season – often a problematic time of year for people with the condition.









This was a deliberate attempt to challenge the view [of patients] that living with psoriasis means keep a low profile.

Dr Christine Bundy, Senior Lecturer in Behavioural Medicine and Shout Out catwalk model





66 As all psoriasis suffers know, it is sometimes difficult to feel good about how you look, always 'hiding' under clothing and never wanting to take centre stage. By the time I was dressed in my fabulous outfit with lots of eye catching bling, I began to feel excited. Everyone supported each other and we had lots of laughs as well. Instead of being a psoriasis sufferer, I felt totally at ease, and my psoriasis was not my concern at all! With the right attitude and confidence, it is possible to overcome the feeling of being unattractive because you have psoriasis. It has changed the way I see myself, I can look good, in spite of this condition. Psoriasis should not define who you are, it can only do that if you allow it to.



Hazel Pallot, psoriasis patient and

Shout Out fashion model



Hazel with fellow model and psoriasis patient Lauren

Fashion Show

Friday 29th April 2014, Intu Trafford Centre

Thanks to: Helen Hanrahan and all our fashion models Makeup: Bobbi Brown Cosmetics, John Lewis Clothes: BE Lifestyle Boutique (Bramhall), Dorothy Perkins, Burtons, Gap, Warehouse, Wallis

What did the Manchester Psoriasis Shout Out reveal?

There is a lack of understanding about psoriasis – by patients, the public and some of our clinical colleagues

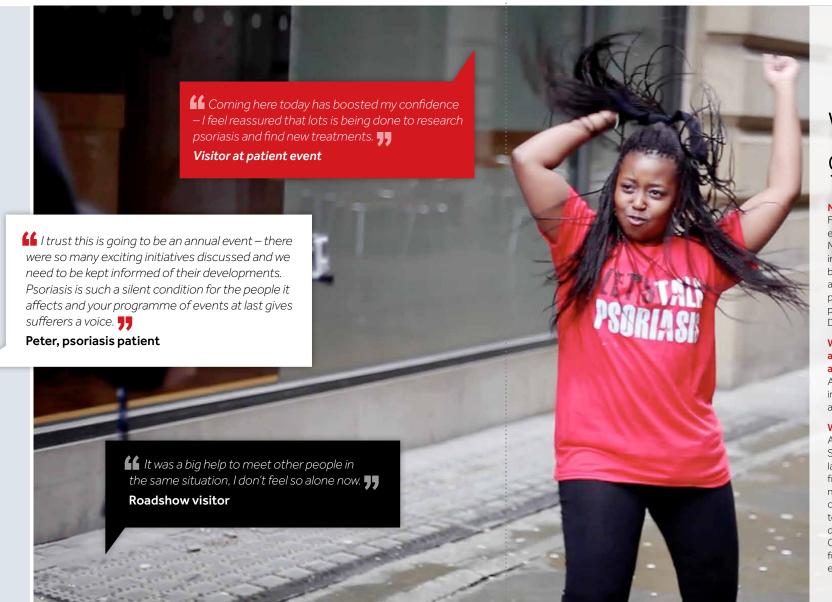
Discussions during the Shout Out indicate that there is a lack of widely available high quality information about psoriasis.

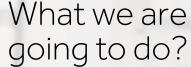
Not all health care professionals know how to best manage psoriasis

Many visitors to the roadshow reported a breakdown in the relationship between themselves and their GP or dermatologist. For example, some people felt 'stuck' in primary care, where they are being prescribed treatments they feel are not right for them and are unable to see a dermatologist if they wanted to. People frequently reported being given inaccurate and unhelpful information about the condition from health care staff, and some talked about having their concerns dismissed in unprofessional ways. Others reported a lack of compassion ("get a grip, it is not life threatening") – often based on a poor knowledge of psoriasis, considering it "just being a skin rash".

Public Engagement is important

Feedback from the Shout Out, from both patients and professionals, has been overwhelmingly positive. There is a real need for events which truly engage and unite members of the public, patients and professionals. The inclusion of patient 'experts' like Toby Hadoke and Helen Harahan was particularly welcomed, and provided huge support and encouragement for others living with the condition. Whilst some people were able to participate in these events in person, the Shout Out message also spread widely through social networking channels.





Messages from the Shout Out will inform our research

Feedback from patients during the roadshow will inform educational and research activities carried out by the Manchester Centre for Dermatology Research. For example, information around the poor quality health care experienced by some will feed into the PsoWell training programme, aimed at developing health care professionals' skills to manage psoriasis as a long-term condition and to produce high quality patient information about psoriasis. This is being developed by Dr Chris Bundy and the IMPACT team (see page 11).

We will share the key messages from the Shout Out widely, and will we support access to high quality information about psoriasis

A new website for the Shout Out is being developed, and the initiative has already received coverage in several publications and conferences.

We are going to Shout again!

Although it will be hard to top the first Manchester Psoriasis Shout Out event, we plan to build on its success with another large scale festival in 2016 where we hope to engage people from the wider Greater Manchester region. Over the next 12 months we will develop our online presence through tweet chats and discussion forums. Patient 'experts' will continue to be a key component of the Shout Out initiative, and we are delighted to welcome Rebecca Darwent-Black (visitor to Shout Out 2014) as a Shout Out ambassador. Rebecca will help plan future Shout Out activities, and will be on hand to share her experiences of living with psoriasis.



To be kept informed of future Manchester Psoriasis Shout Out events, or to get involved as a patient ambassador please contact:

Susie Moschogianis (Shout Out Coordinator) tel: 0161 206 8077 email: info@psoriasisshoutout.co.uk

The Manchester Psoriasis Shout Out 2014 team were:

Staff and students from the Manchester Centre for Dermatology Research

Staff and students from Salford Royal NHS Foundation Trust Representatives from Salford Psoriasis Support Group and the IMPACT Research User Group

Helen Hanrahan Toby Hadoke Salford Citizen Scientist

Many thanks to

Susie Moschogianis (Shout Out Coordinator)
David Webb (Design)
Zoe McClean (Photography)
Patients and members of the public for SHOUTING OUT!

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Salford Royal **NHS NHS Foundation Trust**

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Abbvie have supplied printing costs as part of a medical educational grant but have had no involvement in content.