

Minutes of the  
Cross Party Group on Psoriasis and Psoriatic Arthritis meeting  
11<sup>th</sup> June 2014

1. Present: Dave Thompson MSP, Margaret Mitchell MSP, Janice Johnson PSALV, Mairi MacIver PSALV, Pat Evans PSALV, Lorna McHattie academic, Dr Hoda al Mahrouki Southern General Hospital, Dr Hilary Wilson Glasgow Royal Infirmary, Jennifer Stewart, Aileen Bryson RPS, Sheila Hannay SCCS, Catherine O'Hara SCCS, Stewart Douglas SCCS, Barbara Page SCCS, Pauline Buchanan SCCS, Steven Fenwick Novartis, Marion Butchart Novartis, Lesley Ferguson, Iain Campbell, Irene Clayton, Duncan Bowers, Jim Walker, Jennifer Stewart, Polly Buchanan Ind Nurse Consultant, Andrew Dempsey UCB, Mary Blackford Secretary
2. Apologies from Linda Fabiani MSP, Ken Macintosh MSP, Phil Atkinson, Margo Arnott, Carol Bodwick Abbvie, Gill Westwater Abbvie, Amanda Simonds, Colin Morton, John Hunter, Stefan Siebert, Ruth Burns, Joyce Leman
3. Matters arising from the minutes. Catherine O'Hara requested that her name be added to the list of those who attended the meeting on 19<sup>th</sup> March 2014. Jim Walker indicated that Item 5 on page 5 should mention the Rheumatoid Arthritis Management Programme rather than Multidimensional Project.

Minutes proposed as correct by Barbara Page, seconded by Stewart Douglas

4. Proposal for the formation of a Cross party Group on Skin. SCCS had been asked to undertake further research on the proposal and report back to the meeting. A survey presenting feedback from SCCS members had been carried out since the last CPG meeting. The survey revealed that skin conditions take up around 25% of a GP's time and that they are the fastest growing category of referrals from primary care. SCCS members of the CPG re-affirmed that they have no intention of "diminishing" the existing group.

Possible titles for a new group might be Dermatological and Allied Conditions or Skin and Associated Joint Conditions

The purpose of a new group might be to raise awareness, improve self-management, provide a discussion forum, make recommendations to the Scottish Government and provide an unbiased means for responses to changes in care.

Most replies were positive regarding the new group which could be seen as an opportunity for co-operative working.

Dave Thompson acknowledged the concerns of some members of the existing CPG and stressed that they would have to be dealt with and

assurances made. He also said that any group would need to consider broad principles and recurrent themes, for example GP training.

Jim Walker asked about the Standards Committee Procedure with regard to the formation of a new group. This would comprise a request to the committee for the new name and purpose of the group to be registered. Any such application would have to give assurances that the purpose of the existing group would be included. The proposal is for a new group whose concerns would include those of the existing CPG. Dave is not aware that such a move has been accomplished before and will consult the Standards Committee Clerks and Convener, Stewart Stevenson MSP.

Margaret Mitchel indicated she would very soon have to leave the meeting. She said that events held in the Parliament were well-attended before the CPG had been formed but that once that had taken place attendance had become an issue. She urged the group to consider what benefit a new group would have and emphasised that MSP support for a new group would have to be genuine i.e. active.

Dave T acknowledged the problem for MSPs who wish to belong to groups but cannot always commit to attending meetings. He said we do not know if other MSPs would be attracted to join a group with the new remit.

Jim W said he could see practical difficulties with getting quorums for ten meetings a year and said the proposal sometimes delivered insensitively, feels like, 'a takeover' of a group that has been working for four years and. Mairi MacIver from PSALV agreed.

Margaret M then said that it would not be at all realistic to hold meetings every three months – MSPs have too much else to cover.

Lorna McHattie said she could see Jim's point but that there might be MSPs willing to come if the remit was expanded. She also said she felt that the group had not accomplished much in improving patient care – no conference, no action taken to further the information put forward by the Ninewells Home Phototherapy team.

Pat Evans said she felt the concerns of such a new group would be too big and too diverse with the number of skin conditions.

Janice Johnson said she felt that rheumatology could get pushed out and also expressed her concern that the group should not go into areas that are England-orientated.

Sheila Hannay spoke of the recent investigation by the All Party Parliamentary Group to find out what training had been given to GPs. She said such a study would always be relevant.

Jim Walker said he did not necessarily agree that 'things have not been achieved.

Dave T said that in the last year there was less enthusiasm and fewer attending. If, when Stewart D, Sheila H and Catherine O'H came to see him,

he had agreed that a new group should be formed, the Standards Committee would have asked for the new and old groups to be combined. Instead he decided to see if there was agreement to a change in remit. He concurred that 11 meetings a year would be too many. He also said that, because of recess etc, 'monthly' meetings would be, effectively, eight per annum. He also said that even seemingly narrow –interest CPGs such as Crofting were able to hold quorate meetings.

Hilary said she felt a bigger group would attract more dermatologists.

Dave indicated the larger than usual attendance at this meeting, even if only two MSPs had attended. MSPs definitely do not want to attend groups that attract only a few people.

Margaret M said that the possibility of scrutiny of psoriasis and PSA care by Healthcare Improvement Scotland had been brought about by the efforts of Janice Johnson, not by the CPG (she then left the meeting)

Hilary suggested a show of hands but Dave T said he did not wish to risk divisions and alienating some members who fear a takeover rather than an invigoration and expansion of remit. He also said that a three month gap between meetings is too long to facilitate correspondence with Ministers and professional bodies. Dave then said he could not speak to MSPs to ask if they would attend a group with a bigger remit without some concrete proposals.

Aileen Bryson said the group must have clear ideas about remit and what it would want to achieve.

Jim W said that if the group goes for a wider remit there would need to be a considered, empathetic discussion and that it would be a good thing if there could be more dermatology and rheumatology input to the group's work. It should then be considered how the change is taken forward and how MSPs would receive it.

With regard to the SCCS survey, Dave saw in it a lot of information that would need to be distilled into a group name and purpose for presentation to the Standards Committee. He stressed there was no need to make a decision here and now and that there is implacable opposition from some members and there might be a danger of losing them. Or, a small, remaining Psoriasis group would not be viable as people supporting expansion might then not attend. He said we might consider having six meetings a year with psoriasis and psoriatic arthritis on every agenda. He also said that some CPGs have folded amidst acrimony or just simply died and that he wanted to pull everyone together.

Pat Evans foresaw that even more skin groups would want to join.

Barbara Page reminded members that she and Stewart have attended every group meeting and have also supported PSALV. She said she could not accept that the proposal is for a takeover and that as a professional she would not support such a move.

Iain Campbell, speaking from the education angle said that it would be easier to push for changes from the perspective of broader issues.

Lorna McH said we should get past perceptions of what is happening behind the scenes and consider the issue of going on with a group.

Polly Buchanan agreed and said that people living with P and PSA need a group which would provide an opportunity for them to have a voice about the right care and the right training. SCCS has represented the views of a number of groups. It (the proposal) would be a huge benefit and that the group should take a next step.

Hilary W acknowledged there are generic issues that affect many conditions and which would be considered by an expanded group.

Dave T said he expects that patient groups would be invited to join a new group. It could be guaranteed that psoriasis would be on the agenda for meetings six times a year. Members of those groups could be asked to contact their local MSPs to ask them to join the CPG.

Polly B felt such local engagement would build momentum

Dave T said that if all groups writing to MSPs might encourage them to join and attend CPG meetings. Janice J said this would be a good idea.

Andrew Dempsey, attending his first CPG meeting, said there were genuine concerns but that there seemed to be a consensus developing that an expanded group might be a good way to go.

Sheila H asked if it might be possible to hold one generic meeting as a test, before the end of the year.

Dave T proposed that he could put down some suggestions on paper or asked if the group feels we should move more quickly to tighten the remit and purpose and move on to the next stage. He is reluctant to consult MSPs without more constructive proposals on the table but with good agenda items he feels we would attract MSPs.

Polly B said that there would have to be sensitivity and support and that a larger group would have to listen to all concerns. Janice J repeated what a good idea it would be for local groups to write to MSPs.

Jim W recognised that there could be sub groups. Sheila H said that some groups might be based in England but have members in Scotland. Dave T said there are no restrictions on individuals joining. Thinking of a name – Skin and Associated Conditions?

Hoda Al Mahrouki – Skin and Rheumatic Conditions?

Jim W - Skin and Associated Rheumatic Conditions (SARC)? Perhaps the proposals should be discussed by three or four people. PSALV could be approached on how best to present items on the agenda.

Janice J remained concerned about rheumatology concerns being lost

Dave T agreed to go away and give thought to the group purpose which, as stated in the survey would need to be tightened. (Part of the survey section on the subject of purpose is stated at Appendix 1 of these minutes but for information only, not as any statement of firm proposals to be adopted by the group).

He suggested some of the content might cover raising awareness, influencing improvements in treatment, advising and making recommendations on skin and associated rheumatic conditions to the Scottish Government and the NHS in Scotland, providing a forum for discussion.

Lorna McH said that she felt some of those to be objectives but others (e.g. a forum) are about process.

Dave T and Mary Blackford agreed to go away on work on the statement of purpose. Dave asked if members are happy to move down this road of considering a new group. He will consult the Standards Committee clerks re the best way forward i.e. if the existing arrangement can be amended or if there should be a completely new group.

5. Adoption of the WHO resolution on psoriasis as a, 'chronic, non-communicable, painful, disfiguring and disabling disease for which there is no cure.' Janice spoke about this historic and positive step. A letter on the subject sent to PSALV by the Minister for Public Health, Michael Matheson, forms Appendix 2 to these minutes. The International Federation of Psoriasis Associations pushed WHO for this recognition.

Janice also informed the group that The British Association of Dermatology (BAD) says it is unable to reach health ministers and has ignored Mr Matheson's letter and Scottish Government support.

Dave suggested that the group could, when it is quorate, write to BAD on the subject but in the meantime asked Stewart Douglas to take concerns about the resolution to BAD. Stewart agreed to do so and also to raise the issue of BAD's non-consultation with the CPG.

6. Presentation by Jim Walker on his research into inflammatory arthritis treatment from a patient's perspective, with reference to the Scottish Inflammatory Diseases and Rheumatology Industry Group (SIDRIG) report on the delivery of Rheumatoid Arthritis services in Scotland: The View of the Health Professionals.

Jim feels that it is not clear SIDRIG is working equally for all inflammatory disease patients – conditions other than rheumatoid arthritis seem to be being 'left behind.'

From the sources available Jim estimates there are possibly 1 million sufferers from forms of inflammatory arthritis (IA) in the UK. There are around 200 forms of IA. NHS Inform mentions only the more common forms such as RA, Osteo and Juvenile. (RA is diagnosed by a positive rheumatoid blood test which is unique to RA, although not 100% full proof. For the other inflammatory arthritis conditions there is no specific blood test for diagnosis, it

relies on clinician assessment of the patients' presentation and symptoms. There are blood test elements e.g. Creatine Reactive Protein (CRP) and ESR which can evidence inflammatory activity but not the specific type of inflammatory arthritis)

Andrew Dempsey, Chair of SIDRIG, attending the CPG for the first time, said he would make sure PSA is on the agenda. He added that within the industry some companies manufacture drugs for PSA and some do not, leading to different emphasis.

Jim's recommendation:

To make sure that NHS Inform NHS Choices provide adequate information for patients on all rheumatology issues, currently that which is provided is not even-handed. The diagnosis and treatment of PSA is variable. Jim has communicated his own experiences to the Patient Feedback Co-ordinator for NHS Grampian to help the encouragement more patient-centred care.

Jim also feels we should contribute to the work of and encourage NICE, even though it applies to England. If NICE comes up with better treatment etc, faster than SIGN etc, Mr Salmond could put his stamp on it.

Consideration of what is published by NHS Inform on RA will be put on the agenda for the next meeting.

Pat Evans said that treatment is subject to a postcode lottery (Fife has an interdisciplinary approach where other areas such as Grampian and Ayrshire do not)

Stewart D said that NHS Inform publishes articles from clinicians which are then reviewed by their peers and patients. There is a lot of editorial control.

Polly Buchanan said that Patient Reported Experience Measures (PREMS) and Patient Reported Outcome Measures (PROMS) applying to both clinicians and patients are now part of clinical and quality audit in the NHS.

Dave T spoke about the Patient Opinion website – when patients in his constituency contact that site with details of their cases and experiences he can see how NHS Highland is reacting. The Chief Executive and other senior people can respond directly to patients.

It was said that such details opportunities for patients to respond should be put up in every GP's surgery.

**Date of next meeting – Wednesday 24<sup>th</sup> September 2014, 6pm**

## Appendix 1

Group purpose section of the e-Survey appended here for ease of reference and information only,

<b>Purpose</b>	<b>% - agree</b>	<b>% - disagree</b>
To raise awareness of skin related issues within the Scottish Parliament	50	50
To influence improvement in treatment and self-management for people with skin and associated joint conditions in Scotland	75	25
To provide a forum within the Scottish Parliament for all skin-	50	50

interested stakeholders		
To advise and make recommendations to the Scottish Government on options for care and choices for people with skin and associated joint conditions in Scotland	75	25
To provide an unbiased means of responding to opportunities or threats for dermatology in Scotland	25	75

## Appendix 2

Ministear airson Slàinte Poblach

Minister for Public Health

Micheal Matheson BPA

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Ar faidhle/Our ref: 2014/0005032

11 March 2014

*Dear Mairi,*

Thank you for your email of 6 February 2014 regarding the WHO Executive Board's resolution on psoriasis and a World Psoriasis Day.

I was very pleased to hear that the resolution will now be put to all Member States to vote on at the World Health Assembly in May 2014. This is a welcome and important step towards increasing awareness and recognition of psoriasis and psoriatic arthritis, and I trust that it will pass the vote and serve to highlight these conditions worldwide.

The Scottish Government is committed to ensuring that all people living with psoriasis and psoriatic arthritis in Scotland are able to access the best quality treatment, care and support. As you know, the publication in 2010 of the SIGN guideline 121 on the Diagnosis and management of psoriasis and psoriatic arthritis in adults has been a key development in Scotland. The successful implementation of this guideline has of course been partly due to the efforts of PSALV, and I would like to offer a note of thanks for this and for all of your other work to date to raise awareness of psoriasis and psoriatic arthritis in Scotland.

The Scottish Government has had a good working relationship with PSALV in recent years and I am pleased that we have been able to support your efforts. May I offer my best wishes for the future, and thank you again for writing to highlight the WHO resolution.

*Best wishes*  
  
**Michael Matheson**

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