Scottish Parliament

Cross Party Group on Psoriasis and Psoriatic Arthritis

Annual General Meeting

And ordinary meeting

19th March 2014

DRAFT

Present:

Dave Thompson MSP (Convener), Ken Macintosh MSP, Janice Johnson PSALV, Mairi MacIver PSALV, Pat Evans PSALV, Polly Buchanan NHS, Barbara Page SCCS, Sheila Hannay SCCS, Stewart Douglas SCCS, Hoda al-Mahrouki Southern General Hospital Glasgow, Iain Campbell GP/NHS Education Scotland, Marion Butchart Government Affairs Novartis, Jim Walker, Duncan Bowers, Mary Blackford Secretary

1) Election of officers:

Dave Thompson proposed as Convener by Ken Macintosh, seconded by Stewart Douglas and elected unopposed.

James Dornan proposed as Vice Convener by Dave Thompson, seconded by Barbara Page and elected unopposed.

Mary Blackford proposed as secretary by Dave Thompson, seconded by Barbara Page and elected unopposed.

2) Apologies:

Linda Fabiani MSP, James Dornan MSP, Hilary Wilson, Liz McIvor, Diane Thomson, Dr Girish Gupta, Dr Colin Morton, Dr Colin Fleming, Dr David Bilsland, Ruth Burns, Dr Lorna McHattie, Dr Daniel Kemmett

3) Minutes of the AGM held on 16th January 2013 were proposed as correct by Jim Walker and seconded by Janice Johnson. There were no matters arising.

The AGM ended at this point

"Ordinary" meeting

4) Discussion of the proposal for a CPG on Skin

Dave Thompson - no problem with a new group starting but that it would raise issues regarding the difficulty for people attending, getting the requisite two MSPs for

quorate decision-making. The current CPG would have to be happy with any new arrangement. We struggle to get a quorum.

Sheila Hannay – other groups have similar voices. There is no intention to detract from the work of this group. SCCS has enthusiastic support from its member organisations. Proposal is for 10 meetings a year with this group having some of those.

D T – Mary and I met SCCS and at that meeting I suggested the new group have 10 meetings a year with this group taking 4 of those. Hope is that other MSPs would be interested.

Janice Johnson – SCCS did not canvas its member organisations before putting the proposal forward. CPGs having overlapping interests creates a problem.

Stewart Douglas – There was a consultative email after the (SCCS) AGM. The idea was originally raised at the Dermatology Council of Scotland in October 2013.

JJ – As an ex director I know that very few patients turn up for SCCS meetings. Which patients are you representing?

SH – We need to improve our engagement & explore why patients do not turn up.

JJ – we are not hearing other patients.

DT – Are you saying there was consultation? How SCCS presents and consults with members is its own matter. I fully understand that this group could get lost. However I can see advantages with a larger group. It would be essential for there to be patients from the other member groups. I would need to be reassured of that.

A bigger organisation can mean more clout and more secretarial support

Jim Walker – we are sympathetic to people with other skin conditions. This group relies on dermatology input – we do not need a problem over dermatologists etc being members of this group.

This group is Psoriasis AND Psoriatic Arthritis. They need to be addressed together. The numbers of people involved may be relatively small. A skin CPG would lose the “joints” patients.

Mary Blackford – There is also a question of balance e.g. 2-3% may have psoriasis, but the figure for eczema is much higher (SD – 10%). Psoriasis could get lost.

SD – there is much in common. We do not wish to threaten this group. Other skin conditions also feature problems with joints.

Catherine O’Hara – Behcet’s is a skin disorder but it is also an inflammatory condition. There is greater integration of social care and health…

Hoda Al-Mahrouki – PsA patients can develop the skin disorder first (around 60%). The rheumatology part can be lost.

Ken Macintosh – Most of what I know came from Janice. I came to this group via the CPG on Cancer. Skin conditions have a very low profile in the NHS. I understand why people want to increase that profile. There is much in common. Would it be possible to go away and work it out to agree a way forward?

Iain Campbell – Would all SCCS-affiliated groups be affiliated to a CPG or would SCCS act as an umbrella organisation? If all were represented separately it would be unwieldy

Polly Buchanan – Highlighting all conditions would highlight all need. We are here to secure access and quality. We do not want a mutual admiration society but action taken through MSPs to get better care.

The minutiae and ethos could be easily worked out. We need people to drive forward. The patient voice is the greatest driver.

SH – At present eczema group has no voice & people are very excited at the prospect of a CPG

JW – I believe in collaboration and co-operation. I am a strong supporter of long-term condition management. A lot of effort is expended in this group and want to make sure that we can protect and enhance what has already been achieved.

Pat Evans – I agree with Jim. In a new group PsA will be “swallowed up”

PB – We could look at the English model for a Skin group

JW – The NICE Guideline on Psoriasis excluded PsA & that has let PsA down. We have different approaches.

JJ – The situation is different in England and Wales

PB – We can pick up ideas from England

JJ – Why do we have to copy England?

PB – Not necessarily copy but it is a model that has worked

DT – Who would the members be? In a group there would be individuals, representatives of organisations. We could have a range – individual patients, clinicians and organisations

If there was a burgeoning of interest from other groups there is the probability of getting MSPs to attend. I am also conscious that JW travels from Moray!

A lot of CPGs do get funds for conferences etc. Businesses will fund them. MSPs do like bigger groups.

I would find it difficult to turn down a Skin group as well as a Psoriasis group but I would find it be difficult to be Convener of two groups. These are not “sexy” groups. The new group would have to get its proposal through the Standards Committee. 5 MSPs would need to sign up.

If there were to be a combined group I would make certain Psoriasis/PsA did not lose out but ten meetings a year would be a big time commitment for me.

The Standards Committee will first ask why the proposed group would not be combining with the existing group. We need to do more for psoriasis. We achieved more early on. A new, bigger group might re-invigorate matters.

Mairi MacIver – Would rheumatologists want to come to a skin group?

CO’H – Should that not be an aim to break down barriers between consultants so they talk to one another?

JW – The Glasgow system of joint (i.e. combined) consultation between skin and joint specialists has many advantages. It is a key point for me. Will consideration of joint problems be lost because of a focus on skin – they will be regarded as two, separate conditions.

DT – when we wrote to the RCGP we were told that skin would be considered in the proposed additional year of GP training. How many people are affected altogether by one skin condition or another?

SD – 700,000

PB – Multi-disciplinary treatment is what is needed for complex diseases with co-morbidities – nursing care, psychological help etc

DT – What could a new group be named? The CPG for Skin and Associated Joint Conditions?

(Comments from several members)

Long Term Skin Disorders?

Inflammatory…

Chronic Inflammatory Skin Conditions?

JW – I prefer Skin and Joint

Pat Evans – I have PsA but not psoriasis.

DT – What are people’s thoughts? What shall we do?

JW – We need to protect what we have. There is a need for bi-lateral discussions

SH – Should we go on with the understanding that we should consider how we work together

Iain – Education is a very big consideration

DT – Dermatological and Allied Conditions? We need to think of a name. Joint conditions have to be included. The group purpose would need to set that out very clearly. Safeguards would have to be built in so that PsA issue would not be lost.

BP – I think PsA should appear in the name of the group

DT – I would ask that SCCS look at the title and the purpose of the proposed group and come back to Mary Blackford with their thoughts. I will speak to VC James Dornan about the matter.

JW – This is not a 'done deal'. I recognise what is proposed and am supportive but not convinced. Please convince me.

5) Discussion of the relevance of the Scottish Inflammatory Diseases and Rheumatology Industry Group (SIDRIG) Report and the proposal for a summary chart compiled by expert clinicians on the key features of all the inflammatory arthritis conditions, including Psoriatic Arthritis.

JW – all the recommendations in the SIDRIG report apply to all the inflammatory arthritis conditions but having been told that when I asked to participate in the Rheumatoid Arthritis Multidimensional Project (RAMP) I was told to speak to my consultant.

How is the report to be taken forward? Is it of any relevance to PsA and other conditions? There are similarities between the inflammatory conditions, for example, RA can plateau, peak and burn out whereas PsA is progressive but not as fast as RA. The question is one of management. Should biologics be used early on in the treatment of PsA, rather than other treatments?

Hoda Al-Mahrouki – In Glasgow GPs refer to early inflammatory conditions clinics then on to dedicated, specialised clinics. Treatments are prescribed early, not left for the last resort

JW – There is something to be said for understanding across the board about inflammatory disease. I have had appalling comments from clinicians. I would like to see an A4 sheet setting out the differences between conditions.

DT – it seems very difficult to put this on a chart

JW – I am happy to go into the research and see what I can come up with.

DT – We can bring it back to the group.

What about bringing back the idea of a conference?

BP – It would be useful to bring people together

PB – Lorna and I had feedback that a conference would best be one rather than two days.

MB – agreed to discuss the matter with Lorna McHattie and PB.

DT said he could stay over for a Friday conference which could go from 10am – 4pm. Clinicians would need a long period of notice.

Given that the Referendum will take place in September, we should think about October or November.

6) JJ indicated that the proposal for Quality Indicators for Psoriasis and Psoriatic Arthritis has been accepted onto the Healthcare Improvement Scotland work programme. The work will be carried out by the Standard and Indicators Team, whose lead is Fiona Wardell.

   QIS is a 'step on' from SIGN 121 Guidelines. JJ suggested that Diane Thomson would be able to provide further information. MB will contact Diane.

   PB asked if the QIS standards for dermatology nursing services refer to psoriasis. MB to find out.

   Marion Butchart said she did not think that consideration of PsA issues should become part of the work of the CPG on Arthritis and Musculoskeletal Conditions in whose work she is also involved, but that it should remain with this group.

Date of next meeting Wednesday 11th June