

North Wales Arthritis & Musculoskeletal Alliance ( NW ARMA)

 Local Network Group Report January 2016 - December 2016

**Summary.**

* The ‘Memorandum of Understanding’ ( MoU) between North Wales Arthritis and Musculoskeletal Network Group ( NWARMA) and Betsi Cadwaladr University Health Board (BCUHB) was formally replaced by a Musculoskeletal Joint Service Advisory Group ( MSK JSAG ). The inaugural meeting took place on 29th. November 2016.
* Positive links continue to be forged with key BCU HB Managers, professionals and personnel. An up - to - date baseline audit of progress towards achieving the 23 Key Actions (KA) detailed in the 2007 Welsh Government Arthritis and Chronic Musculoskeletal Conditions Service Commissioning Directives will be undertaken by BC UHB.
* The ‘Signposting’ initiative has shown how productively and positively NW ARMA and BCU HB can work together for the benefit of service users, support organisations and professionals users alike.
* The quest to ensure a comprehensive membership to promote the voice of the MSK community is ongoing, encouraging participation of service users who do not necessarily ‘belong’ to an ARMA support group. The Signposting initiative aims to create greater awareness of NW ARMA and MSK support organisations.
* Unfortunately NW ARMA has not yet been successful in receiving funds from which to support the group although a small bid to NHS Charity Awyr Las administered through BCU HB has been resubmitted.
* Key Objectives agreed by NW ARMA in 2014 continue to be pursued.

**It is hoped that the following report provides an overview of the achievements and the challenges facing the group.**

1) How many times did your network meet in the last 12 months from January 2016 toDecember 2016?

Four ‘Ordinary’ meetings with Minutes and copies sent to ARMA UK for reference.

2) What local issues did you group choose to work on?

See Key Objectives for the years 2014-2016.

2.1. **Achieve the Key Actions (KA) 2, 12 and 23 highlighted within the Welsh Government Service Development and Commissioning Directives: Arthritis and Chronic Musculoskeletal Conditions( 2007)**.

2.1.1. The group’s continued perseverance has proven successful and the development of the Signposting initiative ( KA 12 ), will enable the public to access information through the BCU HB public website ( <http://www.wales.nhs.uk/sitesplus/861/page/80614> ) and by NHS professionals locally via the NHS ‘ Howis’ Intranet available at NHS Clinics / GP Practices. The NW ARMA webpage on the BCU HB Public Access website is fully operational. The process has enabled the development of constructive and positive bonds between NW ARMA and BCU HB personnel.

2.1.2 The BCU HB Chairperson maintains key links and presents a vision of a positive and supportive working relationship between BCU HB and NW ARMA.

2.1.3. The ‘Memorandum of Understanding’( MoU) between North Wales Arthritis and Musculoskeletal Network Group and Betsi Cadwaladr University Health Board has been formally replaced by a Musculoskeletal Joint Service Advisory Group (MSK JSAG ). The inaugral meeting took place on 29th. November 2016.

3) What specific activities did you do to address these issues?

3.1. See 2.1 above.

Arthritis Care through its ‘Get Active for Arthritis’ project held a successful ‘Open Event’ in Wrexham on October 12th. NW ARMA members were kindly invited to participate and stands were available. Many thanks to Arthritis Care

4) What, if any, of your own evaluation did you carry out regarding your networks’ work?

A general view of progress was undertaken at each meeting and Objectives reviewed yearly.

5) What impact have these activities had on local issues and services? Please tell us about any successes and what factors you think contributed to them.

5.1. The important key service user / support organisation involvement in the overall BC UHB planning, development, operation and evaluation of MSK services is slowly being realised. Real progress has been made since July 2014 with the initial agreement of the MoU and latterly the MSK JSAG.

5.2. The positive impact of the ‘ Signposting ‘ initiative should be become more evident in 2017/ 2018.

5.3. A key challenge remains to ensure that not only ARMA members have a voice but together BCU HB and NW ARMA encourage a contribution from the wider NW MSK community as was envisaged in the Wilson Sherriff Report dated June 2010.

6) In addition to working on the issues above, how did you develop the network and its membership?

6.1 The development of ARMA Local Network Groups throughout Wales and the re-institution of ARMA Cymru is being explored again and it is hoped that the good practice developed in North Wales may influence positive development across Wales.

6.2. The quest for funding for the North Wales ARMA Local Network Group continues It has still not yet been successful in bids to a variety of charitable sources. However a small bid to NHS Charity Awyr Las, to be administered through BCU HB, which had initially been submitted in October 2015 is again being revisited.

6.3 The Ehlers Danlos Support UK has joined the Network group.

7) Which local stakeholders have you been able to develop relationships with (for example, commissioners, planners, PPI Forums, etc)?

7.1. The ground- breaking MSK JSAG development, the first in Wales within the Musculoskeletal arena is a major achievement.

7.2. However, critically, the involvement of many key service users is more difficult to achieve on a regular basis and it is not for the want of trying! It is hoped that once the ‘Signposting initiative’ is fully established more interest from a wide range of service users across north Wales will be forthcoming. The use of technology / media to ensure a service user voice and opinion, not necessarily requiring physical presence at meetings, is continually being explored. Email and telephone contact are currently utilised. Trust and credibility in Agencies should produce service users willing to participate in the long term. The ‘Paper’ of 2014 relating to Service User Perspectives on participation remains relevant.

Group Membership now includes: service user / BackCare service user member (convener & Chair); Vice President of British Chiropractic Association; Chiropractor; Professional member of BackCare; Chairperson of Lupus UK North Wales; Arthritis Research UK; Policy and Engagement Manager Arthritis Care Wales; Health & Social Care Facilitator, Conwy, representing also Ynys Môn & Gwynedd; National Osteoporosis Society, Chairman- Representative from the Vale of Clwyd Osteoporosis Support Group; Consultant Rheumatologists Medical Consultant Anaesthetist (Pain Management); Senior Physiotherapist; Senior General Manager (BCUHB); Fibromyalgia Action UK; Ehlers Danlos Support UK; Arthritis Care, Change Maker.

Where no ARMA umbrella group is represented, Minutes and relevant documents are provided for its Head Office to circulate to its north Wales Members.

North Wales, National Assembly of Wales Members are on the mailing list and some have been very supportive.

8) What, if any, other issues were you aware of this year (including issues that may have been raised partway through the year)?

 Waiting lists for Pain Management are long. ‘Orthopaedic’ waiting lists have been described as ‘huge’ and general Rheumatology Waiting lists as reported previously continue to remain matters of concern in areas of North Wales. The problem of recruiting suitably trained / qualified professionals to work in north Wales is much discussed but remains unresolved at the time of this report.

 The potential for ‘ burn out’ symptoms occurring in the current workforce cannot be ignored as can the effect of delays on patients who have to learn to ‘ manage their condition’ longer, highlighting again the important role of appropriate MSK support organisations and the direction to them by professionals!

Clear unambiguous data on waiting lists for diagnostic scans requested, is still proving difficult to obtain. Anecdotal evidence also suggests delays for physiotherapy and occupational therapy.

 **Many NHS services catering for people with chronic pain, MSK (non -malignant) conditions appear to be grossly overstretched and seemingly under-funded! When received, the services are reported as very good.**

It is hoped that an initiative with BCU HB to further enhance / develop a ‘ Waiting List Dashboard ‘ initially for Rheumatology will progress further when the BCU HB Information Services systems are fully overhauled and it will be extended to include waiting list data for other specialisms.

The positive pilot developments by BCU HB of Extended Scope Physiotherapists working within a number of GP surgeries is greatly welcomed and applauded. An indication from initial evaluations is that the pilots are proving successful.

9) Were there any areas where you unable to make as much progress as you would have liked? If so, why not?

9.1. Increasing and sustaining service user membership remains a serious challenge and concern, but as mentioned earlier, there is more optimism now for the long term future than recorded in previous reports. However, the fact remains that currently there is extreme difficulty in achieving physical attendance / representation from ARMA umbrella organisations at the quarterly meetings and, to some extent, their general involvement. See also Section 7.2

9.2. The lack of funds to provide Minutes in the Welsh language remains a problem.

10) Is there additional assistance you would like from ARMA UK? (Contact with ARMA member organisations, links with other Local Networks, etc.) If so, what type of assistance would be most useful?

**10.1. Sharing of Network Groups’ Minutes / Reports / Good practice through the new ARMA UK Members Web facility.**

* Ability to share a compilation of good practice; initiatives and key issues highlighted within the English network reports.
* It has been suggested that it would be good to get a mentoring / support scheme set up between ARMA groups / networks, or arranging representatives from one ARMA group that is doing well to visit and present at other groups and share their experiences.
* It would be advantageous if ARMA could develop some kind of template of activities based on what has worked in some groups that other groups could use.

10.2. The resurrection of ARMA Cymru and the development of Network Groups across Wales is again being discussed at a national level and the group would offer full support to the debate.

10.3.As highlighted previously in reports the servicing of the group has proven difficult at times with reluctance of members, through a variety of reasons, to provide voluntary secretarial support for minute taking. For the past three years, when possible, a member kindly offered her services for note taking which has been greatly appreciated although this has now come to an end.

10.4. As the group has unbelievably completed its 10h year progress has been shaky at times and greater overall participation remains a vital a long term goal. The importance of acquiring long term adequate funding and support to sustain the group and its future projects is vital, as is the commitment to ensure overall equality of participation between service users, their support groups/ organisations and the professionals who provide their health care and support.

The MSK JSAG will inevitably influence the composition and format of the NW ARMA in the future and it remains to be seen how NW ARMA will adapt to accommodate this very positive development.

10.5 The pending retirement of the long term Chairperson and co-convenor will initially create change.

10.6 The Betsi Cadwaladr University Health Board must be warmly thanked for its hospitality in the form of venue for meetings and for the provision of video conferencing facilities.

**The above Report was initially compiled by Christopher Sweetnam retiring Chairperson and convenor, viewed, edited and agreed by members ( April 2017).**

**References:**

1. BCUHB / NWARMA ‘Memorandum of Understanding’
2. Musculoskeletal Joint Service Advisory Group ( MSK JSAG ),
3. WG MSK Commissioning Directives 2007 Key Targets

3. Signposting Initiative

4. NWARMA Objectives 2014 - 2016

5.N Wales ARMA Service User Perspectives on participation within groups.

6. Terms of Reference( NW ARMA November 2015)

7. Get Active for Arthritis

NB. Reference documents have all been previously circulated and are available from nwarma2007@gmail.com on request.