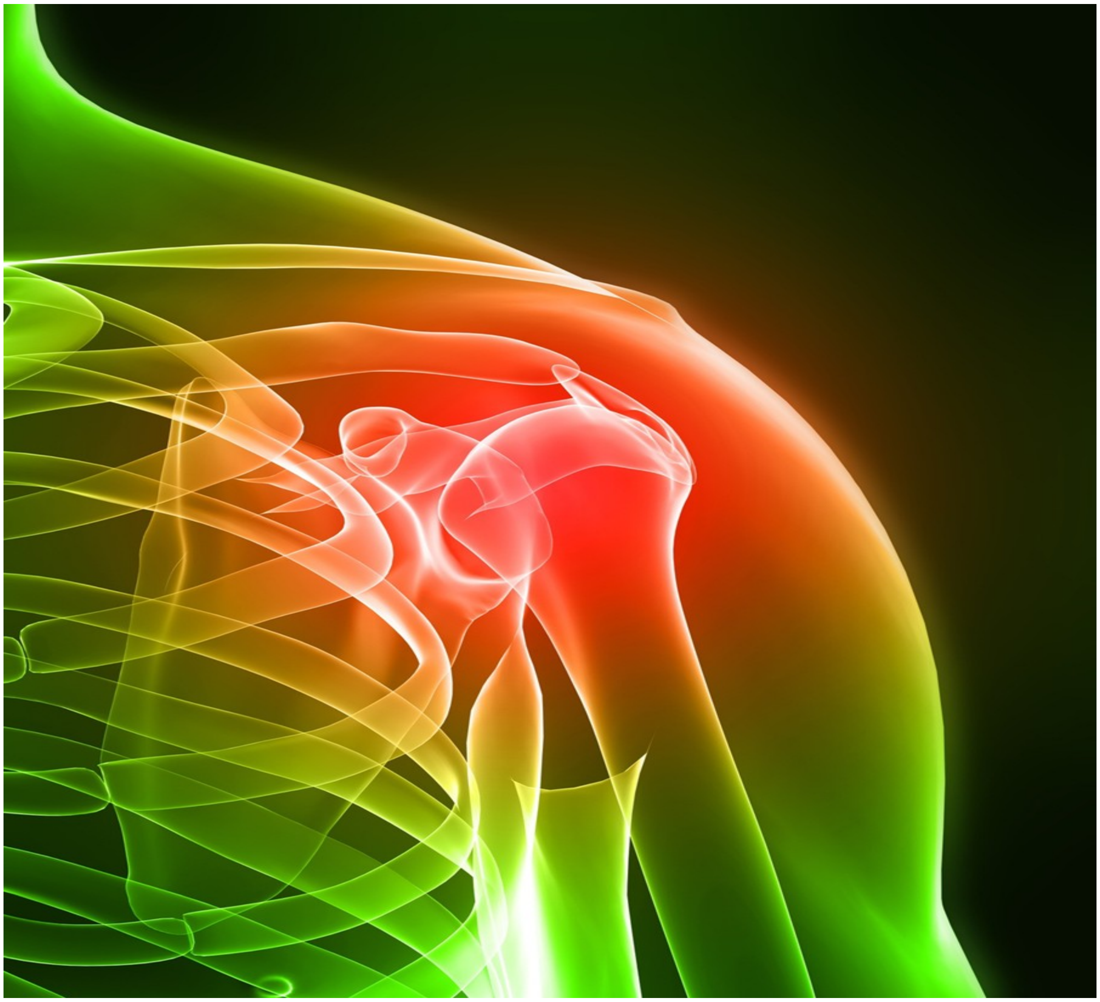
A report on the implementation of the Welsh Assembly Government's Service Development and Commissioning Directive for Arthritis and Musculoskeletal Conditions



Produced for the **ABPI Cymru WIG Arthritis & Musculoskeletal Group**

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GOFAL ARTHRITIS
ARTHRITIS CARE
Galluogi pobl gydag arthritis.
Empowering people with arthritis.

ARMA
Arthritis and Musculoskeletal Alliance

nras
National Rheumatoid Arthritis Society

Summary

This report is an evaluation of the implementation to date of the Welsh Assembly Government's Service Development and Commissioning Directive for Arthritis and Chronic Musculoskeletal Conditions.

Drawing on information gathered via an online survey of Consultant Rheumatologist and Clinical Nurse Specialists, we have been able to consider progress with the implementation of this Service Directive.

Key findings

- The report highlights that key actions from the Service Development and Commissioning Directive for Arthritis and Chronic Musculoskeletal Conditions have not been implemented
- Only 3 of the 22 LHBs had established a Joint Service Advisory Group as mandated by the directives. Some limited joint service planning seemed to be being carried on regionally rather than through LHB boundaries often without clinical staff being aware that this was happening.
- Only 6 LHBs were said to have developed care pathways for arthritis and chronic musculoskeletal conditions in partnership with health professionals and with support from users of services.
- 12 out of 22 LHBs had patient-centered, integrated, multi-disciplinary services in place for people with arthritis and chronic musculoskeletal conditions across primary, secondary and tertiary care that were considered of average or above quality. Many LHBs did not have patient-centered, integrated, multi-disciplinary services in place.
- Respondents were rather uninspired about the information and support services available.
- Most respondents were positive about the availability of technologies for diagnosis and treatment of arthritis and musculoskeletal conditions although access to MRI scanning was seen as an issue resulting in unnecessary waits for patients.
- Some respondents reported issues around patient access to NICE approved Biologic medicines. 15 respondents declared problems with infrastructure and availability of staff to administer medicines resulting in significant delay for patients in receiving treatment. 5 respondents said there was an issue of funding such medicines.

Background

This is the report of a survey of the implementation to date of the Welsh Assembly Government's Service Development and Commissioning Directive for Arthritis and Chronic Musculoskeletal Conditions. The survey was commissioned by the Arthritis and Musculoskeletal sub group of the ABPI Cymru Wales Industry Group and was completed using data gathered via an online survey of Consultants and Nurse Specialists delivering rheumatology services, for patients with arthritis & musculoskeletal conditions in Wales.

The Service Development and Commissioning Directives for Arthritis and Chronic Musculoskeletal conditions was released almost two years ago, on St David's Day 2007. It was a recognition of the need for NHS Wales to change and meet new challenges in order to raise standards in the management of chronic conditions across the nation. The policy document included a particular emphasis on improving local services. As then Health Minister Dr Brian Gibbons AM stated in the introduction to the Service Directives: "The current pattern of services has to change to tackle arthritis and chronic musculoskeletal conditions. These directives will support commissioners of services to make the changes necessary to provide access to high quality patient-centred services."

Although examining Service Directive implementation can appear a dry theoretical almost bureaucratic process we have not forgotten the rationale for why the implementation of the Directives is important to patients, clinicians, the NHS and the Welsh nation. This is set out clearly in the introduction to the Directives themselves:

> "Along with other non-communicable diseases, arthritis and chronic musculoskeletal conditions already account for the largest share of the burden of illness in the developed world. They are the most frequently reported chronic condition in Wales and the most common cause of severe long-term pain and physical disability amongst people of all ages, young and old. The cost of these conditions to the individual, the economy and the health service, is considerable.
>
> "Arthritis and musculoskeletal conditions are the most common type of self-reported illness and account for almost 20% of all GP consultations."

The directives can be found at
http://www.wales.nhs.uk/documents/Final-Arthritis_English.pdf

Arthritis and Musculoskeletal sub group

Working to raise standards of patient care in Wales

ABPI Cymru Wales Industry Group currently has over 15 disease specific sub groups.

The Arthritis and Musculoskeletal sub group was established to create a link between interested pharmaceutical companies and stakeholders in arthritis and musculoskeletal services in Wales. Stakeholders include: the Welsh Assembly Government, the NHS and patient organisations.

Our Vision

Is to promote and improve the health of people with arthritis and musculoskeletal disease through integrated joint working with key stakeholders in Wales.

The objectives of the Arthritis and Musculoskeletal sub group can be tied closely to the aims of the wider health economy in Wales, and to the vision outlined in the "Service Development and Commissioning Directives – Arthritis and Chronic Musculoskeletal Conditions" and as such have prompted the commissioning of this report.

We would like to take this opportunity to thank all those who took the time to respond to the survey. We believe the enthusiasm with which it was received is evidence of the importance of the effective implementation of the Service Directives.

Our hope is that this report and the data on which it is based will help to inform future delivery of these important Directives and so improve the outcomes for people with Arthritis and Musculoskeletal Conditions.

There is no doubt that many advances have been made in the treatment and service provision for people with these conditions, however it is clear from the results of our survey that there is still more to be done. We would therefore encourage all involved in delivering services in Wales to acknowledge the findings of this report and to make use of it in considering future service development.

Sub Group Member Companies

Wyeth Pharmaceuticals - Katie Panton (Chair)

Abbott Laboratories - Brendan Dobrowolny

Bristol-Myers Squibb Pharmaceuticals - Victoria Consterdine

Janssen Cilag Ltd - Sian James

Pfizer – Tina Denham-Parry

Schering Plough - Andy Dyson

Endorsements

This report has had the support of Arthritis Care Cymru, the National Rheumatoid Arthritis Society (NRAS) and the Arthritis and Musculoskeletal Alliance (ARMA).

"ARMA welcomes the work of the ABPI WIG Arthritis and Musculoskeletal Group, in identifying areas of work that have started as a result of the Arthritis and Chronic Musculoskeletal Commissioning Directive. It is however clear that there is a long way to go if we are to meet the needs of this large number of people living with these conditions in Wales. ARMA Cymru looks forward to working with LHBs to provide patient-centred, integrated multidisciplinary services along appropriately designed care pathways."

Ros Meek, Director of ARMA

"Arthritis Care Wales welcomes this ABPI Wales Industry Group's report which clearly identifies not only the progress, but many of the challenges we face in implementing the Arthritis and musculoskeletal commissioning directives. The report compliments our own research into the implementation of the directives. We look forward to working with all our partners in Wales in assisting WAG and local health services in implementing the directives."

Peter Johnson, Director, Arthritis Care Wales / Gofal Arthritis Cymru

"We receive many calls from people with RA in Wales and it is clear that access to best care is patchy, so we are very glad to see the launch of this important report and hope that the Welsh Assembly will take action to improve the implementation of the Service Development and Commissioning Directive for Arthritis and Chronic Musculoskeletal Conditions."

Ailsa Bosworth, Chief Executive, National Rheumatoid Arthritis Society

Reponses

In the report we have focused on the key actions required by this policy. There are 23 Action Points in the Service Directive and the report has been compiled by looking at a number of critical Action Points which underpin delivery of key aspects of the Service Directives. These were:

- The existence and operation of Joint Service Advisory Groups.
- The effectiveness of integrated multi-disciplinary services across primary, secondary and tertiary care.
- Information services to underpin service delivery.
- Access to technologies and medicines to support people with arthritis and musculoskeletal conditions.

Respondents answered 32 qualitative and quantitative questions which examined if and how LHBs and Trusts were adopting the Service Directive. The responses split approximately evenly between Consultant Rheumatologist and Clinical Nurse Specialists.

Consultant Rheumatologist and Clinical Nurse Specialists were contacted from all parts of Wales. Respondents were asked to identify the NHS Trust they worked in and the 43 respondents divided as follows between the existing Trusts in NHS Wales:

Abertawe Bro Morgannwg University NHS Trust	14
Cardiff and Vale NHS Trust	5
Cwm Taf NHS Trust	2
Gwent Healthcare NHS Trust	8
Hywel Dda NHS Trust	4
North Wales NHS Trust	7
North West Wales NHS Trust	3

Respondents were then asked which LHB they were mainly associated with and this data demonstrated that every LHB had at least one respondent who was mainly or occasionally involved in delivering rheumatology services in the locality. In all, 33 respondents indicated they were involved in delivering services to more than one LHB.

Joint Service Advisory Groups

Overview

Action 2 of the Service Directives states:

> "LHBs should establish a joint service advisory group involving all key stakeholders, providers and users of services to strengthen the planning and commissioning of integrated services for chronic musculoskeletal conditions."

Joint Service Advisory Groups are seen as the cornerstone of delivering modern cost efficient services for people with arthritis and chronic musculoskeletal conditions. This is because they bring together, at a local level, all the interested parties that have a vital role in ensuring patients get the most appropriate mix of medical, social and community services. The effective treatment and management of arthritis and chronic musculoskeletal conditions is dependent on fully functioning integrated services where consultants, nurse specialists, occupational therapists, physiotherapists, representatives from primary care and patient groups can work together to create locally relevant appropriate services.

Results

When we asked if respondents knew if the LHBs they were associated with had established such a Joint Service Advisory Group, 4 respondents said Yes, 10 said No, and 20 did not know the answer to this question.

When we asked whether they had been directly involved with a Joint Service Advisory Group, again only 4 responded positively. It should be noted that JSAGs in all health economies should have been implemented by May 2007 based on the Minister's original plans. When responses were examined, we found evidence that only 3 out of 22 LHBs have active Joint Service Advisory Groups

A number of LHBs pointed to a local network approach being prevalent in various parts of Wales. It is unclear from our research what role if any the LHB had in the formation of these networks or how clinicians were involved. It obviously seems curious that such groups could be effectively constituted without the knowledge of the consultants and nurse specialists.

When we asked respondents why they were not involved in JSAGs, the most common answer was that the body had not been initiated by the LHB. There was however clear support for the idea of JSAGs and that they should include the full multi disciplinary team.

> “A Joint Service Advisory group has not been seen as a priority as far as I'm aware in the LHB. This was raised with them by our consultant and local patient groups at the time.”

When asked to identify “additional stakeholders” who might be involved in local JSAGs, respondents stressed the importance of involving allied health professionals such as physiotherapists, occupational therapists, podiatrists, and GPs with Special Interest (GPSIs) alongside clinicians or nurses specialising on rheumatology or orthopaedic services.

Some respondents reflected also on the place of expert patients, general service users or those representing patient groups such as Arthritis Care and the National Rheumatoid Arthritis Society (NRAS) within the JSAG. One respondent stressed such representation reflected a variety of musculoskeletal problems (i.e. non-inflammatory and inflammatory arthritis).

Respondents were also invited to note any additional action points they thought important in driving forward local delivery. Observations were made which reflected an unhappiness with the priority given to implementing the proposals around a JSAG, a lack of resources for implementation and, where JSAG meetings have taken place, these have not resulted in profound service change.

One observation reflected the need for reassurance for the future of the implementation of the JSAG approach as local health service delivery is systematically changed. However, since most LHBs have not created JSAGs and instead are working on a regional basis, this approach seems to fit naturally with the anticipated outcomes of a regionally planned and delivered service.

Integrated services

Overview

Action 10 of the Directives states that by March 2008 there should be

> “patient-centered, integrated, multi-disciplinary services in place for people with arthritis and chronic musculoskeletal conditions across primary, secondary and tertiary care available in each locality.”

Integrated patient centered services across primary, secondary and tertiary care are vital for the early identification and diagnosis of arthritis and musculoskeletal conditions and their effective and efficient treatment. It is important that all stages of the care pathway and those responsible for identifying and treating the conditions can work together seamlessly for the benefit of the patient and to ensure valuable resources are not wasted.

Results

Respondents were asked if patient-centered, integrated, multi-disciplinary services existed in their locality and if they did how would they grade it. 14 respondents indicated that integrated services existed and where they did the vast majority indicated that they were excellent or very good.

When respondents were asked to suggest how patient-centred, integrated, multi-disciplinary services might be improved, some stressed an emphasis should be placed on a rehabilitation model rather than a biomedical one and, as ever, more had to be done to improve links between primary and secondary care. One respondent seemed to summarise things well by suggesting that multi-disciplinary teams were critical when nurses, GPs, occupational therapists and physiotherapists were all integrated and applied across non-rheumatological chronic musculoskeletal diseases as well as traditionally viewed "chronic conditions."

Another respondent stressed the need for patients to have access to all services in a multi-disciplinary team; while another stressed that to enable such an approach to happen, effective commissioning was key. However, one respondent was worried about how this was achievable on a bigger scale when they argued that: "Our Trust is making some headway here though as we work across 5 LHBs it can be difficult to achieve a wieldy consensus."

According to Action point 16, care pathways for arthritis and chronic musculoskeletal conditions were to be developed by commissioners in partnership with health professionals and with support from users of services by December 2007. However, the survey data was far from conclusive in supporting the view that this had happened. Based on data received, only 6 LHBs were said to have developed such pathways.

This was particularly disappointing since, as one respondent reflected: "The first and most important aspect of any pathway is the provision of a diagnosis for the patient's presenting problems. Only after this can the patient be sent down specific pathways for that diagnosis. Unfortunately it has proved to be very difficult for stakeholders to agree on this very basic point, and especially *who* is properly qualified to make the diagnoses. To draw up a universal & simple generic pathway is impossible. Specific pathways for specific conditions are far more useful & realistic."

There was also a general consensus that the role of General Practitioners was critical: they could be sometimes best utilised through shared care schemes or clear referral pathways. Respondents felt services would improve when a community based back care pathway was introduced. Conversely, a lack of a defined GP role was not seen as helpful. One respondent gave the example where they argued that: "The vast majority of prescribing and monitoring has to be done by secondary care as the GPs are not willing to undertake these tasks. Moving these tasks to primary care with supervision and advice from secondary care would ensure a more convenient service for the patients and better integration."

Indeed, other examples were provided from across Wales where best practice was not being fully achieved. The most detailed example of a failing service, where alleged under resourcing was a factor, came from a respondent who claimed that; “There have been many proposals for multi-disciplinary services in [our LHB] but none have been actioned. The secondary care setting for these patients is currently very inadequate with not even enough clinic rooms in OPD to accommodate the number of staff we have at present. Day case beds are also an issue... At present we have patients that have been waiting for more than a year to commence such treatments.”

Respondents were also asked to reflect how people with arthritis and chronic musculoskeletal conditions been involved in the design, development, monitoring and evaluation of services. Responses fell into clear categories. Some said things like "As far as I am aware people with chronic musculoskeletal conditions have not been involved with designing or developing the service" or had no evidence of any involvement at all. Others praised the local impetus of an ARMA group and in about a third of respondent examples patient involvement was strong even if, in some cases, rather unfocussed. One respondent maybe hit a key point when they said: "There have been meetings of expert patients at trust level but I am unaware of patients themselves designing or evaluating services specifically."

Information services to underpin service delivery

Overview

Chapter Five of the Service Directives, ***Facilitating and Managing Independence***, stresses the importance of information on support services or local support networks for people with arthritis and chronic musculoskeletal conditions. The Chapter also emphasizes the importance of Expert Patient and other self-management programmes for people living with arthritis and chronic musculoskeletal conditions.

Results

We tested the views of respondents on these issues and found that in general people were rather uninspired about the services available, though not especially critical either.

	Information and Support Services	Expert Patient and Self Management Programmes
Excellent	0	1
Very Good	5	4
Average	13	13
Below Average	3	3
Poor	2	2

Chapter Five also set out how signposting of information, training or community equipment services for people with arthritis and chronic musculoskeletal conditions were critical to service delivery. Respondents were asked to suggest ways that this might be improved. Comments included - improved primary care services, more emphasis on links between primary and secondary care services, accompanied once again by better health professionals training.

Critical to several respondents was harnessing expertise and ensuring dedicated rheumatology services were available, perhaps led through nurses or more formalised training. One respondent drew attention to the local directory established with ARMA support, while another stressed such information needed to be regularly updated and informed by Expert Patients; and there was general agreement information needed to be easily accessible, and available in a variety of settings as well as on the internet.

In general respondents did feel there was a real value in delivering specific signposting, perhaps based on established care pathways, but at the same time one respondent argued that: "If specific pathways for specific conditions are available, signposting would be much easier to develop. Generic signposting is often not relevant to people with different musculo-skeletal diseases."

Access to technologies and medicines

Overview

Early access to the right medicines and technologies is vital for timely diagnosis and effective treatment of arthritis and chronic musculoskeletal conditions. This is not just about the supply of medicines and the availability of technologies. Consideration also needs to be made of adequate staffing levels and expertise to use the technology or to administer the medicines.

Results

Respondents were asked to consider access to the following technologies for assessment, diagnosis and treatment of Arthritis and Musculoskeletal conditions. In general, most respondents were positive about the access to technologies available.

	excellent	good	average	limited	no access
Anti-CCP:	13	5	0	2	4
CRP:	22	1			
MRI:	10	8	3	3	
Ultrasound:	9	10	3	1	
X-Ray:	20	3			

The key was however not just the availability of the technologies but also the ability for patients to access them in a realistic time frame. In terms of how access might be improved, there was general agreement that more staff and resources should be deployed, with improved training for using new technologies. For example, where MRI was not available this was quite clearly a key concern amongst respondents too; and one said plainly that:

> “There is not enough MRI resource for musculoskeletal conditions. It is dominated by the demands of the cancer guidelines with long hours taken up by staging and any patient with the slightest whiff of cancer jumping the queue and squeezing out people with MSM conditions. For example someone with an internal derangement of the knee who is unable to work will wait 4 months on the sick just for this test.”

Excessive waiting times for MRI scanning was cited as an issue by a number of respondents.

15 respondents thought that sufficient staffing levels were not in place to deliver the best treatments to people with arthritis and chronic musculoskeletal conditions. Respondents stressed there were particular shortages of consultants, qualified nurses and therapists. The lack of specialist nursing staff can result in a barrier to patients receiving NICE approved biologic treatments.

> “Waiting times for infusions on day unit are increasing due to no funding for extra qualified nursing staff required to meet demand. Patients are accessing newer biologic agents but there is a waiting time due to staff shortages”

Most bluntly, one respondent said: “The number of clinicians of any discipline is totally inadequate for the population of patients. This is from initial primary care review through to assessment, diagnosis and management.”

Twenty-one responders answered a question on whether they had experienced any issues with gaining funding for NICE approved Biologics or any other medicines for Arthritis & Musculoskeletal Conditions. Their responses revealed there was no Wales-wide problem since only 5 said there was an issue with funding of such medicines. Where access to biologic treatments was a problem, the issues identified that prevented access related to the infrastructure to deliver the new biologic treatment, specifically a lack of specialist nursing to administer the treatments. This aspect was also clear where a person argued that there was a “paucity of uptake of shared-care monitoring for anti-rheumatic drugs by primary care” which “places a large burden on expensive and limited secondary care services.”

Another said that: “We currently have a waiting list for biologics, no person has ever been denied treatment but the process could be easier and more efficient especially at the end of the financial year”.

In only a small number of cases was a direct lack of funding cited as a significant issue in accessing biologic treatments.

Closing Remarks

Respondents were also offered an opportunity to make additional comments on the implementation of the Service Directives. Some of the key reflections were as follows:

- “There is not enough recognition of these chronic conditions and the impact on the individual and their significant others.”
- “They deserve better access to all members of the multidisciplinary team and also facilities to encourage self management."
- “We have the tools via the recent WAG task and finish groups but I guess it is only political will that will bring these ambitious proposals to fruition.”
- "Until they (Rheumatology) reach parity with other specialties e.g. Cardiology and diabetes and there is a financial incentive to deliver we will always be a poor relation when discussing targets and action points.”
- "There should be more engagement of all interested stakeholders at a local level to ensure best possible services for patients.”
- “Ensure that we don't over-medicalise some of the issues. Promote healthy workplaces, active lifestyles, support for those who want to be independent, promote strong social networks and community responsibility”
- “Strong emphasis on musculoskeletal clinical skills in undergraduate training and for doctors training to become GPs."

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