

CROSS-PARTY GROUP ON ARTHRITIS AND MUSCULOSKELETAL CONDITIONS

MINUTES OF MEETING ON WEDNESDAY 26 NOVEMBER 2014

1. Margaret McCulloch warmly welcomed the six speakers, members and a number of guests with particular interest in the topics of the evening.

Meeting on 8 October: Minutes and Matters Arising

2. The minutes were approved. Following the presentation given by Dr Stefan Siebert, Margaret McCulloch had offered to write to NICE on the true cost of Ankylosing Spondylitis; **the letter had been sent, would be circulated to members and the response reported back.**

'Treating Arthritis to 2020: the Right Patient, the Right Treatment, the Right Time.'

Stratified Medicine Scotland - Innovation Centre (SMS-IC)

3. Professor McInnes gave a picture of Rheumatoid Arthritis (RA), a disease in transition, summarising its scale and scope, its effects on the individual, both directly on the joints and systemically, and its burden on society as a whole. Huge progress in treatment and potential outcome over the last thirty years had brought us to the point, with key strategic developments of early diagnosis and effective treating to target (remission or low disease activity), of contemplating, for the future, cure and even prevention. Against this background Dr Beggs outlined stratified medicine - personalised prescribing based on patient genetic sequence and phenotype data rather than an empirical process, in effect trial and error. He explained its potential in terms of human and economic benefit and its incentive to further research and development. SMS-IC aimed to be a world-class centre of research, innovation & commercialisation, bringing together excellence in the academic, industrial and NHS communities; Scotland was an ideal base and the permanent location would be the new South Glasgow Hospital Campus along with a grouping of other high-level capabilities. Professor McInnes completed the presentation with an account of PROMISERA, an exemplar project in stratified medicine looking to identify a biomarker profile to predict the outcome of Methotrexate (MTX) therapy in RA. Utilising the Scottish Early Rheumatoid

Arthritis (SERA) cohort, this study brought RA into the lead in the drive for a stratified approach and might prove to be the first step towards a complete drug response profile for the RA portfolio.

4. Members applauded this impressive and exciting initiative; **being kept in touch with progress would be welcome.** In answer to questions, the following points were made –

- The reason for RA lagging behind cancer, where, in the case of single gene abnormalities, likely response to treatment could be predicted now, lay in the relatively much more complex genetic nature of RA.
- Resourcing was progressing well; much was owed to Arthritis Research UK.
- The PROMISERA research aimed to identify a really good response to MTX, but could be adjusted to allow judgement on a lesser level result.
- Translating findings into practice would be critical; a whole re-education programme would be called for with support tools and diagnostic services. Evidence on successful rolling out, in practice, of benefits from previous key discoveries should incline us to optimism.
- The evidence that the UK, far from being slower in implementation than elsewhere, is at the world forefront should allay any concerns about reticence in NHS and Government.
- The regulatory environment in Scotland might point to its being ideal for early rather than phase 3 stage development.
- Patient groups welcomed the clear commitment of professionals to improve services and patient outcomes.

Osteoporosis in Scotland

SIGNing Up: National Guideline on Management of Osteoporosis and the Prevention of Fragility Fractures

5. Dr Black outlined the nature of Osteoporosis as a condition, explained the need to update the 2003 SIGN Guideline, described the process and outcome. The new Guideline changed the emphasis from managing the condition to fracture prevention,

encouraged the use of fracture risk assessment tools, gave evidence for lifestyle and treatment factors, discussed risks and benefits of treatments and recommended the most appropriate model for integrated care.

Osteoporosis in Men

6. Professor Ralston described as a political issue what he termed 'the male paradox' – the fact that men suffer Osteoporosis (though the incidence is lower than in women), bioequivalence is accepted, safety and efficacy similar for both genders, but treatments licensed for both are approved by the Scottish Medicines Consortium (SMC) only for women. Full fracture studies are called for to redress this but would be too costly to undertake. Dr Alan McDonald, Vice Chair of SMC, indicated a willingness on the part of SMC to find a solution to this anomaly. **The CPG would wish to know when and how this matter was resolved.**

Osteoporosis Services in Scotland

7. Dr Gibson reviewed services at all levels and assessed the effectiveness of interventions; studies showed a significant trend towards better outcomes as well as cost-effectiveness with more intensive regimes. Staffing allocation funded by the NHS, however, was low, (68 consultant hours per week, Scotland-wide, and one nurse per 68,000 people over 65 years of age), comparing very unfavourably with Diabetes services. To achieve excellence NHS Scotland should ensure that every Board recognise Osteoporosis as a major health issue, establish Bone Health and Falls Managed Care Networks, fully fund consultant hours with sufficient administrative support and establish the post of Fracture Liaison Co-ordinator to track fractures.

Moving Patient-Centred Care Closer to Home: GO-MOBILE, a Mobile DXA-Scanning Service for Island Communities

8. Dr Hollick's study had examined referral patterns for DXA scanning from island communities and rural Aberdeenshire, possible barriers to referral, the impact of the Go-Mobile initiative

and the way forward. Clearly frailty, age and travel distance were critical factors reducing referral for and uptake of scans. The mobile unit, charity funded with NHS Grampian providing the driver, offered a real solution in rural Grampian and Shetland with Orkney about to come on board. Long-term sustainability would require NHS buy-in and it was to be hoped that the study findings would strengthen the case for this.

9. Discussion on the whole subject of Osteoporosis in Scotland produced the following points –

- Prevention as a policy was so important and, with adequate resources, we had the means to carry it through; benefits that would follow might include reduction in delayed discharge from hospital.
- Low consultant numbers were challenging; there was a real lack of appreciation of the importance of Osteoporosis as a condition. Bone health could still be seen as the ‘Cinderella’. This stemmed partly from the situation where it was the responsibility of everyone – and therefore no one in particular in terms of focused response.

10. In response to the concerns raised, Margaret McCulloch offered to sponsor a Parliamentary exhibition to raise awareness among Members or to put forward a Motion which, with the appropriate cross-party support, could lead to a Members’ debate. The National Osteoporosis Society and clinicians involved should e-mail her indicating how they would like to proceed.

11. The next meeting, to include the AGM, would be on Wednesday 4 March 2015.

12. Margaret McCulloch warmly thanked all concerned.

CPG Secretariat
December 2014