APPG on Osteoporosis and Bone Health

13 July 2022

16.15-17.45

MICROSOFT TEAMS

Attendees: Judith Cummins MP (Chair), Lord Black of Brentwood (Co-Chair)

Apologies: Baroness Masham of Ilton, Peter Dowd MP

Minute Taker: Nikos Methenitis (ROS)

MINUTES

No.	Item	Action
1.0	**Welcome from Chair**	
	The chair, Judith Cummins MP, welcomed participants asked Parliamentarians to introduce themselves.	
2.0	**Lois Ainger,** Patient Advocate	
	LA is Lead Volunteer Advocate for the ROS. LA described her own experiences of the diagnosis and management osteoporosis in primary care. LA told of a frustrating experience for those diagnosed with osteoporosis at a younger age. LA was diagnosed with osteoporosis in her early 30s after a being referred for a DXA scan due to being underweight. LA received little support or information from HCPs regarding the condition she was forced to look online for information but much of this was aimed at older patients. After self-advocating for a referral to a consultant, LA was told that told that there was no treatment for pre-menopausal women and felt discriminated against because of her age. Subsequently LA fell and broke her hand but was given little support or advice of how to manage. Her ability to work was affected. LA has since been prescribed risedronate but was told there was no evidence that it would work for an individual of her age. LA concluded that she would like to raise awareness of the risk of osteoporosis for younger people, especially those who are underweight. She has fears over breaking her hip given the lack of information, care and support when she broke her hand. LA is concerned about the lack of	

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	information and inconsistent treatment for osteoporosis patients under 50. Judith Cummins MP asked what one change LA would have made in her treatment. LA responded that this would be the gap between diagnosis and receiving any information. LA felt she should have received thorough information and a treatment plan with continuity of care.	
3.0	**Dr Sunil Nedungayil,** Associate Medical Director at NHSA	
	Dr Sunil Nedungayil (SN) is an Associate Medical Director at the Northern Health Science Alliance. SN gave an overview of the barriers to identification and management of osteoporosis in primary care and how these may be addressed. SN highlighted the current issues in the management of osteoporosis in primary care. SN believes the condition is in a state of neglect. It is underdiagnosed, there are poor coding practices and poor record keeping and there is poor communication between primary and secondary care. This leads to undertreatment, poor medication optimisation and lack of follow up. A third barrier is the conflicting priorities for healthcare professionals (HCPs). Osteoporosis is not a long-term condition and therefore commissioning is poorer, it receives reduced QOF points compared to other conditions and so the financial benefits to practices are not tangible. This disparity can lead to QOF chasing in practices. SN discussed how to address these issues. Recommendations included a move away from practice-based initiatives to CCG commissioned locally enhanced services based on incentivisation. SN used the example of East Lancashire CCG of the benefits of this approach. Similarly, the Northern Bone Health Programme used centralised IT approach covering 59 practices to improve identification and prevention of high-risk patients. SN also highlighted the need for a public health campaign to improve the awareness of bone health for the population and for HCPs.	
4.0	**John Edwards,** General Practitioner, Wolstanton Medical Centre	
	John Edwards (JE) is a GP based in Wolstanton Medical Centre in Staffordshire. JE talked to the group about his experience as a GP and how osteoporosis is managed in primary care JE explained that some of the key issues impacting the care of osteoporosis are GP staffing and inadequate IT. JE felt that IT systems such as the QOF register is not fit for purpose, poor coding means that primary prevention is missed and many patients are wrongly coded. Coding is inconsistent depending on the system used. **ACTION: JE to meet with ROS policy team to give detailed demonstration of IT systems used**	**ROS**

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	Osteoporosis is not a priority and not a key part of the GP curriculum so awareness of fragility fractures is low among HCPs and patients. HCPs have low confidence in interpreting scan results or explaining these to patients.	
5.0	**Zoe Paskins,** Reader in Rheumatology, NIHR Clinician Scientist	
	Zoe Paskins (ZP) is a Reader in Rheaumatology and a Clinician Scientist at the National Institute for Health and Care Research. ZP discussed structural and workforce issues affecting osteoporosis in primary care. ZP explained the barriers to quality primary care for osteoporosis including poor identification of those at risk, lack of integrated IT, incentivisation of QOF. ZP highlighted issues of HCP attitudes, knowledge and skills in regard to osteoporosis and uncertainty over roles between and within primary and secondary care. This results in a lack of structured follow up, the need for patients to self-advocate, delayed diagnosis of spinal fractures and inadequate care and support of symptoms. ZP also described the negative impact of an increased reliance on remote consulting for osteoporosis patients. A recent patient experience survey showed 1.7million people in the UK feel unable to explain symptoms and concerns properly over the phone. Particularly for osteoporosis patients, diagnosis over the phone is a difficult experience and little information or support is given. ZP suggested possible solutions including a move towards a stratified approach and a changing primary workforce meaning that role such as community pharmacists can play a role in new clinical pathways. Professional education and support is also key to address HCP lack of confidence and awareness. Lord Black of Brentwood invited questions from the attendees for all speakers. Questions included how attitudes towards osteoporosis may be shifted to become an important issue and whether there were risks if it were labelled a long-term condition. JE argued that a solution would be a public information campaign which would drive better understanding and awareness. ZP felt that there would not be a risk in classifying osteoporosis as a long-term condition. Investment would result in fewer bed days taken up and the prevention of fractures.	
6.0	Close	

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	Lord Black of Brentwood thanked all of those who gave evidence and attendees. The next meeting in will be held on Wednesday 14 September 2022.	
	MEETING CONCLUDED AT 17.45	

The Royal Osteoporosis Society (ROS) aims to increase awareness and discussion of osteoporosis in the four Parliaments and Assemblies of the UK. This aim is shared by UCB, Amgen, Stryker and the Medical Research Council Lifecourse Epidemiology Unit, University of Southampton, who have each given the charity an arms-length grant to help achieve that outcome. Find out more about how we work with our corporate partners ***here****. The ROS is an independent charity, with the interests of patients, their families and the wider public at its heart. Our policy and research is editorially independent, with a view to influencing a wide range of audiences, including corporate partners. All agendas, reports, briefings and papers for meetings are prepared without external input.*