APPG on Osteoporosis and Bone Health

26 April 2022

10.00-11.30am

MICROSOFT TEAMS

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

Apologies: Baroness Masham of Ilton

Minute Taker: Nikos Methenitis (ROS)

MINUTES

No.	Item	Action	Timing
1.0	**Welcome from Chair**		
	Lord Black of Brentwood co-chair of the APPG, welcomed all attending, and asked Parliamentarians to introduce themselves. Craig Jones (CJ), CEO Royal Osteoporosis Society gave an update the campaign work following the last inquiry's findings. APPG members continue to engage with the Minister for Social Care and the Prime Minister's advisors. ROS policy and public affairs team will continue outreach to brief parliamentarians and to leverage local MPs in areas with no FLS or underperforming service. NICE reversed its decision to not recommend romosozumab for the treatment of osteoporosis following pressure from the ROS and clinicians. The drug will be made available to women in appropriate cases. The ROS is lobbying across the devolved nations. The establishment of an FLS-Database has been approved in Scotland following an application led by the ROS and CJ will be meeting with members of the Welsh Senedd today to discuss the approach for extending FLS coverage in Wales.		
2.0	**Dr Adrian Hayter**, National Clinical director for older people and integrated person-centred care, NHS England		

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	Dr Adrian Hayter (AH) presented to the APPG on the use of data in primary care to improve the diagnosis of osteoporosis and outcomes for patients. AH used the example of the local GP practices, primary care networks (PCNs) and integrated care systems (ICSs) in the Frimley area of Surrey. Data is collected from across hospitals, practices and other services in the area to improve care records. This data is then analysed to provide insights on the local populations. AH explained how this data is used to address underdiagnosis of osteoporosis patients. This information can help prioritise testing capacity for DXA scanning and with long term management of co-morbidities in collaboration with other parts of primary care to ensure care plans are established. AH believes there is a national opportunity to use population health insights such as these in integrated care systems to address under diagnosis and improve outcomes. Lord Black of Brentwood asked what the state of knowledge of osteoporosis is among health care professionals (HCPs) in primary care. AH responded that in his ICS there is much guidance and training provided for HCPs. Training needs are a strategic priority for the local ICS and so osteoporosis training receives prioritisation. Lord Black of Brentwood asked how optimistic AH is that a similar training system is replicated nationally. AH responded that this can be more difficult on a national level. A clinical champion, lobbying and support is needed. The ROS can be a driver of this. ICSs can also work to support each other.		
3.0	**Janice McKinley,** Patient Advocate		
	Janice McKinley (JM) is a member of the Leeds ROS Support Group and a Lead Volunteer Advocate. JM described her negative experiences of diagnosis with osteoporosis and the management of her condition in primary care. JM told the APPG of a long struggle to be taken seriously by her local GP and a reluctance to refer her for DXA scan. JM continued to advocate for her own care and after several attempts she was referred for a DXA scan which showed that she had osteoporosis. JM received very little information about her diagnosis or prescriptions and felt dismissed by her GP. She received no follow up and was scared to contact her GP due to her previous negative		

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	experiences and was made to feel like she was wasting her GP's time. JM explained that she has been reliant on information and support from the ROS and its community without which she would not have had the understanding of her condition, scan results or treatments. JM concluded that there needs to be a screening pathway based on NICE guidelines for those that are at risk but have not yet broken a bone. Preventative screening is needed. Upon diagnosis patients should also receive thorough guidance, information and an offer of support. Patients also need follow up consultations to explain results, prescriptions and lifestyle recommendations. Patients need to be at the centre of measures to improve the handling of osteoporosis in primary care. Judith Cummins MP asked what support JM thought should be in place to help her in the future. JM responded that similar to those diagnosed with diabetes, she should have a specialist or 'navigator' to provide a care plan and ongoing specialist advice. Judith Cummins MP asked whether JM was made to feel that osteoporosis was a normal part of ageing. JM responded that this may well have been the opinions of her GPs as she was made to feel of no importance and that she was wasting their time.		
4.0	**Mary Elliott**, FLS nurse based in primary care		
	Mary Elliot (ME) is an FLS nurse based in primary care. ME described her experiences of working within an effective FLS in Sussex supporting osteoporosis patients in primary care. ME felt that in her role she was given professional support. There was an osteoporosis specialist in her practice and ROS volunteers were active in looking to support patients diagnosed with osteoporosis. The FLS aimed to improve outcomes for patients with fractures and improve care after hip fractures. The FLS worked to NICE guidelines and had an early interventions falls care pathway in place. ME used the example of Crawley FLS which was set up in 2009 to demonstrate a similar effective model in the Sussex area. The FLS has a focus on recruiting the right GPs with relevant knowledge. The focus was on the prevention of primary and secondary fractures. The FLS provided patient follow up at 4 months and 12 months whilst identifying high		

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	risk patients across the ICS based on several factors. The FLS facilitated monthly clinics that rotated around the GP practices in the area. Lord Black of Brentwood asked what one lever ME would pull as a result of this inquiry. ME responded that leadership is needed. Osteoporosis needs to be a specific person's job.		
5.0	**Dr Lucy Douglas,** President of the Primary Care Rheumatology and Musculoskeletal Medicine Society		
	Dr Douglas (LD) is the President of the Primary Care Rheumatology and Musculoskeletal Medicine Society and GP. LD gave evidence to the APPG on her experiences of managing osteoporosis in primary care based on a case study of a former patient. LD has permission from the patient's family to share this story. LD told the group of a former patient who died following a hip fracture. Osteoporosis listed as a condition that contributed to death. When the patient came into LD's care, osteoporosis was not mentioned in her care notes though the patient informed LD that she had had a diagnosis. The patient had a history of fractures but none of these triggered any consideration or treatment by primary or secondary care. There was an FLS in the area but it was poorly functioning. The patient did not have awareness of bone health or osteoporosis and so could not advocate for herself as she did not know she was at risk. LD discussed recommendations and lessons following this case study. The public need to be better educated on bone health as patients need to be their own advocates in under prioritised areas. No speciality owns osteoporosis, if it is everyone's problem then it becomes nobody's problem. In this case there many opportunities for intervention missed by specialist across primary and secondary care. LD suggested several possible reforms to address these issues should including a greater priority in medical training for osteoporosis and an expansion of the over 40s health MOT to include bone health. Automatic detection through IT systems and better integration of FRAX into existing IT systems would improve identification of those at risk of fracture and reduce the administrative burden on HCPs. Lord Black of Brentwood asked what one lever LD would pull as a result of this inquiry. LD responded that this would be the improvement of IT systems as discussed above.		

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6.0	Close Lord Black of Brentwood thanked all of those who gave evidence and attendees. The next meeting in will be held in June with the date confirmed in the coming weeks.		
	MEETING CONCLUDED AT		

*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.*