Proposed framework on a networked service model for care of adults with rare bone conditions in England

(Syowa KIRIN

Kyowa Kirin, a Japan-based global specialty pharmaceutical company, brought together a steering committee of clinicians and patient representatives to make recommendations on how to improve care for people with rare bone conditions. This led to the development of the *Proposed framework on a networked service model for care of adults living with rare bone conditions in England*.

Some of the challenges highlighted and recommendations made in the *Proposed framework* can be found below. If you would like to find out more on the other recommendations made, for example around the transition from paediatric to adult services, please refer to the *Proposed framework*.

Person experiences symptoms but has not received a correct diagnosis*
*Please note most people will be diagnosed as children

GP

*Please note some people are diagnosed or referred through other routes

Due to lack of awareness from clinicians of the symptoms experienced, people with rare (bone) diseases can face delays in receiving an accurate diagnosis

Educate clinicians on signs and symptoms of rare (bone) diseases



Diagnosis



Specialist centres should house multidisciplinary teams that include experts from different specialties



Referral to specialist centre

Referrals to incorrect specialists can delay access to care

Create an online portal of specialists and centres to speed up referrals and access to care

Specialist centres are not always close to one's home, with people having to travel long distances for appointments. This can be extremely burdensome

Ensure local care teams are set up to manage care on a regular basis, with support from the specialist centre, and that appointments with specialists can be held less frequently or, when possible, virtually



Multidisciplinary team develops treatment plan

Managing multiple appointments with specialists can be a full-time job for people with rare (bone) diseases

Assign each individual a care coordinator to manage care, monitor their treatment plan, and provide personalised care information



Access to additional resources and clinical trials

Due to the rarity of rare (bone) diseases, it can be difficult to access innovative clinical trials

Set up rare (bone) disease registries and develop a patient research database to enable greater research collaboration and assist researchers in finding trial participants



Due to the severity of rare (bone)
diseases, it is crucial that people feel
supported. However, due to their rarity,
it can be difficult to be signposted to
the correct information and support

Provide key information, including on patient organisations

Provide additional resources such as pain management services, genetic counselling and occupational therapy

Call to action

The authors of the *Proposed framework* urge the wider rare bone community, to join them in advocating for these recommendations to be adopted, so that care for adults with rare bone conditions is improved.

They hope these recommendations can also help the wider rare disease community access better quality care.