inflammation such as raised ESR, CRP, serum amyloid A and leucocytosis. With the notable exception of severe CAPS (see below) most are compatible with near normal life expectancy except for the risk of developing AA amyloidosis in later life. Despite similarities in symptoms, they have differing aetiologies, inheritance, duration and clinical features.

The hereditary autoinflammatory diseases are associated with mutations in genes involved in innate immunity and generally the onset is early in childhood affecting both sexes equally. Seven major syndromes (below) are currently recognized, although novel autoinflammatory diseases are rapidly being discovered as a direct result of advances in genetic technologies.

- Familial Mediterranean fever (FMF)
- TNF receptor associated periodic syndrome (TRAPS)
- Mevalonate kinase deficiency (MKD) (also known as Hyperimmunoglobulin D and periodic fever syndrome (HIDS))
- Cryopyrin associated periodic syndrome (CAPS) (subdivided into Familial cold autoinflammatory syndrome (FCAS), Muckle Wells Syndrome (MWS) and chronic infantile, neurological, cutaneous and articular syndrome/neonatal onset multisystem inflammatory disease (CINCA/NOMID))
- Pyogenic arthritis, pyoderma gangrenosum and acne (PAPA) syndrome
- Deficiency of IL-1 receptor antagonist (DIRA)
- Blau syndrome/early onset sarcoidosis (EOS)

There are now effective treatments for most patients with FMF, CAPS and DIRA and although not always quite as effective, good treatments are available for the remainder. Table 1 provides a summary of the genetics and treatments currently used for the hereditary autoinflammatory disorders.

This talk will provide a clinical overview of these major hereditary autoinflammatory diseases, current therapies, and will summarize an approach for the discovery of new genetic fever syndromes using emerging genetic technologies.

**Disclosures:** The author has declared no conflicts of interest.

### Table 1.

<table>
<thead>
<tr>
<th>Autoinflammatory disease</th>
<th>Gene</th>
<th>Mode of inheritance</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>FMF</td>
<td>MEFV</td>
<td>Autosomal recessive (dominant in rare families)</td>
<td>Colchicine</td>
</tr>
<tr>
<td>TRAPS</td>
<td>TNFRSF1A</td>
<td>Autosomal dominant, can be de novo</td>
<td>Etanercept? anti-IL1, high dose and corticosteroids</td>
</tr>
<tr>
<td>HIDS</td>
<td>MVK</td>
<td>Autosomal recessive</td>
<td>Anti-TNF and anti IL-1 therapies</td>
</tr>
<tr>
<td>CAPS</td>
<td>NLRP3</td>
<td>Autosomal dominant or sporadic</td>
<td>Anti IL-1 therapies</td>
</tr>
<tr>
<td>PAPA</td>
<td>PSTPIP1 (CD2BP1)</td>
<td>Chromosome 15</td>
<td>Anti IL-1 or Anti-TNF therapy</td>
</tr>
<tr>
<td>DIRA</td>
<td>IL1RN</td>
<td>Chromosome 2</td>
<td>IL-TrA</td>
</tr>
<tr>
<td>Blau Syndrome</td>
<td>NOQ2 (CARD15)</td>
<td>Chromosome 16</td>
<td>Autosomal dominant</td>
</tr>
</tbody>
</table>

**Clinical musculoskeletal research in the UK (Arthritis research UK and BSR joint session)**

**IP101. CURRENT AND FUTURE ACTIVITY IN RHEUMATOLOGY TRIALS**

Alan Silman
Rheumatology, Arthritis Research UK, Manchester, United Kingdom

Abstract not provided.

**Disclosures:** The author has declared no conflicts of interest.

**IP102. BUILDING A UK CLINICAL RESEARCH NETWORK IN RHEUMATOLOGY**

David Scott
Rheumatology, King’s College London, London, United Kingdom

**Background:** A “National Arthritis Research Network” is needed to encourage and enable most rheumatology and orthopaedic units to participate in clinical research studies. Increasing recruitment to clinical studies will be of crucial benefit to our specialty.

**Methods:** Rheumatologists and orthopaedic surgeons need to enrol patients under their care into clinical research studies. Both randomised controlled trials and observational studies are important in furthering our understanding of the effects of treatment and therefore providing optimal clinical care. This presentation will consider ways in which the enrolment of patients into clinical research studies could be enhanced.

**Results:** Clinical research is challenging to deliver. Much of the current administrative work involved in setting up individual studies is repetitive. There are currently substantial delays involved in the process. By establishing a national research network it will be possible to reduce these delays to a minimum. This is because the network could ensure all relevant data is held in a secure on-line database and would not need to be collected repeatedly. It will also be possible to identify any specific causes of delay and to ensure these are overcome by concerted action.

The Network will simplify the enrolment of patients into national clinical studies by:

a. Liaising with Chief Investigators and their research staff to both assist in overcoming the various regulatory issues involved in initiating research and providing information about individual units wishing to participate in research studies.

b. Interacting with Research and Development Departments and the local Clinical Research Networks to ensure research studies are started and completed in a timely manner.

c. Provide advice and training for clinicians involved in research.

**Conclusions:** The network should involve all the main constituents involved in promoting research in arthritis. This includes rheumatologists, orthopaedic surgeons, allied health professionals and funders. It should also take into account the needs of patient groups.

Although the concept of a network is under development, it has the potential to be a key method of helping specialists delivers their research goals. The views of BSR members are vital in defining how a register should be organised and function. There is a unique opportunity to streamline clinical research by acting in unison as a community and engagement of a range of BSR members, spanning senior consultants, trainees and allied health professionals, will prove invaluable.

**Disclosures:** The author has declared no conflicts of interest.

**IP103. WHAT ARE THE PRACTICAL ISSUES?**

Deborah Symmons
Rheumatology, University of Manchester, Manchester, United Kingdom

Abstract not provided

**Patient and public involvement in musculoskeletal research**

**IP104. PATIENT AND PUBLIC INVOLVEMENT IN MUSCULOSKELETAL RESEARCH: THE NATIONAL AGENDA**

Sarah Buckland
INVOLVE Coordinating Centre, University of Leeds, Eastleigh, United Kingdom

INVOLVE is a national advisory group which supports active public involvement in NHS, public health and social care research (www.involve.org.uk). INVOLVE was established in 1996 and is funded by the National Institute for Health Research (NIHR). We use the term ‘public’ to include: consumers, patients and potential patients, service users, carers and parents, long term users of health and social services, disabled people and organisations representing the public. Active involvement is an active partnership between the public and researchers, where research is carried out ‘with’ the public rather than ‘to’, ‘for’, or ‘about’ the public. For example, advising on a research project, assisting in the design of a project, or involvement in undertaking the research.

Members of the public bring perspectives and skills that are not always the same as those of researchers and health and social care professionals. Their involvement helps to ensure that the research process is focused on what is important to people and is therefore more relevant and acceptable to the users of services. We believe that