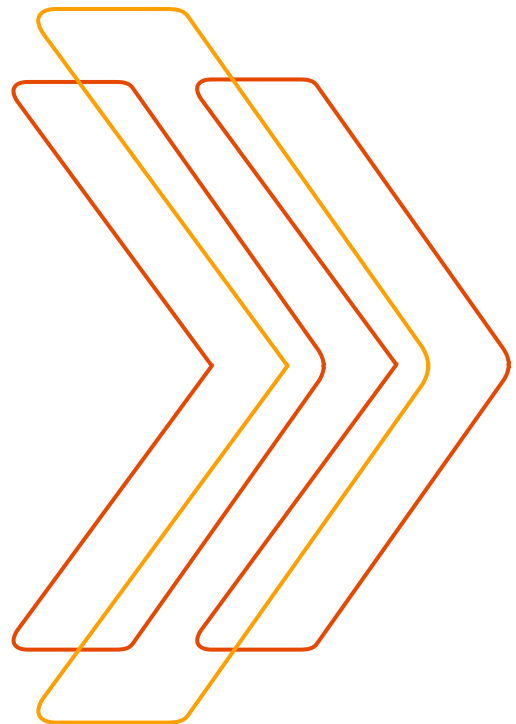


Innovation in treatment for people with rarer or less well-recognised long-term conditions

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Key messages

- Hundreds of thousands of people in the UK have severe psoriasis, inflammatory bowel disease (IBD), axial spondyloarthritis or osteoporosis – four rarer or less well-recognised long-term conditions.
- While these diseases are far from uncommon, they inevitably receive less attention from policy-makers and health services leaders than the most prevalent long-term conditions.
- There are huge costs for individuals and families when services fail to diagnose these diseases quickly and provide rapid access to appropriate treatment. While people wait for diagnosis and treatment, they often suffer irreversible damage to skin, joints or organs and lasting damage to their mental health.
- Alongside primary care, specialist teams in hospitals can play a major role in speeding up diagnosis by creating rapid-access clinics and proactive case-finding. Innovative services can also do a huge amount to speed up access to appropriate treatment in hospitals.
- In this report, we describe a traditional approach to treatment and support that gives people limited support at an early stage in their disease and drip feeds support over many years. There are strong arguments for inverting this 'pyramid' and providing intensive support at an earlier stage, when it is possible to slow the progression of the disease.
- We also describe a traditional phased model of treatment where GPs and hospital specialists start with the least aggressive therapies before incrementally trying more aggressive therapies. There are benefits in accelerating this process or moving directly to more aggressive therapies for some patients, getting people on to the most appropriate therapy as quickly as possible.
- While this is a complex subject, the paper describes concern among leading specialists about the impact some current guidelines and protocols have on their ability to deliver the most appropriate care. In some cases, these guidelines and protocols mean professionals focus on narrow biomedical aspects of a person's condition, rather than making a holistic assessment of the severity of the person's illness.
- Even specialist centres struggle to combine high-quality biomedical care with support for the psychosocial aspects of these conditions. There are also

untapped opportunities to support patients more effectively, for example, through peer-support networks and connecting people with social prescribing services.

- The centres in this paper are combining specialist expertise in related conditions, including through co-locating specialists, informal joint-working across related specialisms, running clinics in parallel and combining clinics.

1 Introduction

Anne Savile remembers her back pain starting in her teens. She struggled to sit as a 15 year old preparing for her O-levels. Over the next 20 years, Anne tried osteopathy, physiotherapy, back rehabilitation classes, podiatry, anti-inflammatory drugs, megapulse shortwave therapy and painkillers. But the back pain remained a constant. In her mid-40s, Anne had to give up her role as a deputy headteacher because of chronic pain and severe depression.

A decade later, in 2014, Anne stumbled on an article about fibromyalgia, a condition that causes widespread pain, muscle stiffness and fatigue, and asked her GP whether this might explain her symptoms. Anne's GP referred her to a rheumatologist who diagnosed axial spondyloarthritis, a type of inflammatory arthritis that affects the spine and other joints. There are effective treatments for axial spondyloarthritis but it is a progressive disease. Left unchecked, it can cause severe disability. It had taken 40 years to diagnose Anne's condition and prescribe appropriate treatment (National Axial Spondyloarthritis Society undated a).

Access and appropriate treatment

Anne's story is heartbreaking, but it is not an exception. In the UK, people with these rarer or less well-recognised long-term conditions generally wait for months to receive an accurate diagnosis and appropriate treatment. Many people with these conditions wait for years, and some, like Anne, wait for decades to access appropriate medical care. Recent research funded by Crohn's and Colitis UK found that one in ten people with inflammatory bowel disease (IBD) waits five years or more after first speaking to a doctor about their symptoms for a diagnosis (Blackwell *et al* 2020). On average, people with axial spondyloarthritis wait eight and a half years after the onset of symptoms for an accurate diagnosis (All Party Parliamentary Group for Axial Spondyloarthritis and National Axial Spondyloarthritis Society 2020).

Once they have been referred to hospital services, people can wait months to see a specialist, complete tests and be prescribed treatment. Even then, interviewees described substantial variations in the care people receive depending on where they live. In Greater Manchester, people with severe psoriasis can access world-leading specialist services, while people in some other parts of England visit hospitals where there are no specialists in their disease.

Patients with more severe forms of inflammatory conditions often need access to complex drugs, such as biologics. Many people spend years cycling through ineffective treatments for their conditions before being prescribed the most appropriate drug treatments. Consultants at Salford Royal NHS Foundation Trust explained that people with severe psoriasis generally wait a decade before they are prescribed a systemic drug and 12 to 14 years before they are prescribed a biologic drug.

Consequences for patients

For some people with rarer or less well-recognised long-term conditions, these delays in obtaining an accurate diagnosis and receiving appropriate treatment have profound consequences. People with IBD may experience lasting damage to the lining of the bowel and require life-changing surgery (Ricciuto *et al* 2020). People with axial spondyloarthritis may experience lasting disfigurement to the spine (National Axial Spondyloarthritis Society undated d). Older people with osteoporosis are at greater risk of serious, disabling fractures (Blume and Curtis 2011). As these diseases worsen, people are also at much greater risk of developing other diseases. For example, people with severe psoriasis, IBD or axial spondyloarthritis are at greater risk of developing other types of inflammatory diseases and cardiovascular disease (Argollo *et al* 2019; de Oliveira *et al* 2015)

Like Anne, many people who wait months or years for diagnosis or appropriate treatment experience severe pain and fatigue (Borren *et al* 2019; Skoie *et al* 2015). Without access to advice and support, people also live with profound uncertainty about their conditions and, often, lack of understanding or recognition of their conditions among friends, family and others. There is also some evidence that inflammatory conditions can trigger physiological changes in the brain that are associated with depression and fatigue (Lee and Giuliani 2019). Research suggests that people living with Crohn's disease or colitis may be twice as likely to experience mental health problems as the general population (Byrne *et al* 2017; Mikocka-Walus *et al* 2016). Up to 64 per cent of people with axial spondyloarthritis have symptoms of depression (Zhao *et al* 2018). People with psoriasis may experience cumulative damage to their quality of life (Kimball *et al* 2010). Many people with these diseases experience damage to relationships (Strand and Singh 2017), lose their jobs or have to give up work (Feagan *et al* 2004). Children and young people may struggle to complete their education successfully, enter the workplace or pursue a fulfilling career (Gay *et al* 2011).

While delays in diagnosis and treatment may sidestep a few costs in the short term, they create additional costs for health, care and other public services in

the long term (Wylezinski *et al* 2019). If these diseases remain untreated at earlier stages, people often require more aggressive, invasive and costly treatment later in their lives. People with psoriasis, IBD and axial spondyloarthritis may require the most expensive biologic therapies (Wylezinski *et al* 2019). People with IBD are more likely to require intestinal surgery (Lee *et al* 2017). People with osteoporosis who experience fragility fractures may require surgery and may need ongoing support for daily living, with fragility fractures a major reason for older people having to move into care homes (Smith *et al* 2015). In short, there are substantial problems in how health services currently treat these diseases, with profound consequences for people, their families, health care budgets and the economy.

Aims of this research

This paper, commissioned by UCB, investigates how five leading specialist hospital services in the UK are innovating in care for people with severe psoriasis, IBD, axial spondyloarthritis, osteoporosis and combinations of inflammatory conditions. While they are not 'rare', these diseases are rarer and arguably less well-recognised than the most prevalent long-term conditions. People's conditions fall on a spectrum, with some people experiencing more severe or life-limiting illness. We focus on five specialist services that deliver care for people with more severe conditions:

- the psoriasis clinic at Salford Royal NHS Foundation Trust, which delivers care for people with psoriasis across Greater Manchester and people with severe psoriasis across north-west England
- the IBD service at Western General Hospital in Edinburgh, which delivers care for people with IBD in Edinburgh and the Lothian and Borders regions of Scotland
- the axial spondyloarthritis service at the Royal National Hospital for Rheumatic Diseases, part of Royal United Hospitals Bath NHS Foundation Trust
- the osteoporosis service at Oxford University Hospitals NHS Foundation Trust, which runs fracture liaison services and delivers treatment for people with osteoporosis and rare bone diseases across Oxfordshire
- the specialist spondyloarthritis service at Leeds Teaching Hospitals NHS Trust, which delivers multidisciplinary care for people who have multiple related inflammatory conditions, in particular axial spondyloarthritis, IBD-associated arthritis, psoriasis and psoriatic arthritis.

Approach to this research

We started with initial desk research and interviews to identify rarer or less well-recognised long-term conditions where there appeared to be greatest potential for innovation. We focused on conditions that are prevalent in the UK population but that are rarer, and/or less well-recognised than the most common long-term conditions such as diabetes, coronary heart disease or hypertension. We identified conditions that appeared likely to be amenable to innovation in care delivery, for example, because the condition follows different patterns from one person to another or because there is uncertainty regarding underlying causes, diagnosis or treatment. We also identified conditions that require a combination of different forms of treatment, for example, medical care, psychological therapies and social support.

We conducted interviews with patient associations and carried out desk research to identify leading services in the UK with strong reputations for high performance that were distinctively different to other services. This allowed us to identify the five centres listed above. We spoke to around six members of staff at each of these services, including the lead consultants, the lead specialist nurses and other key health care staff, for example, pharmacists, physiotherapists and psychologists. In total, we conducted more than 50 interviews with hospital consultants, specialist nurses and other health care staff, representatives of patient associations and staff at the selected sites.

The paper describes a set of common themes in how these services are innovating to improve care for the people who access them. For example, each of the services has made changes to speed up diagnosis of these rarer or less well-recognised conditions, to speed up access to appropriate treatment in hospital services, to provide greater upfront support for newly diagnosed patients or to accelerate the process of stepping up to more aggressive treatments where needed.

The paper highlights how these services are innovating to deliver more holistic care that addresses patients' biomedical, psychological and social needs. For example, it describes how staff are incorporating better support for anxiety and depression into routine care and how they are connecting patients to social prescribing and other services.

The paper also describes strategies being deployed at some sites to provide more joined-up care for patients with more than one complex long-term condition. In some cases, these strategies have radically reduced the time patients must wait to receive an accurate diagnosis and start an appropriate treatment plan for multiple inter-related inflammatory conditions.

While the paper focuses on innovation within five services for people with rarer or less well-recognised conditions, the objective is to highlight learning that may provide inspiration for other services and conditions. For example, it is possible that these services' approach to improving diagnosis could be applied to other rarer or less well-recognised inflammatory conditions or that these services' strategies for accelerating access to the most appropriate treatment could be usefully applied to a wide range of other long-term conditions, where faster access to the right care can avoid lasting damage to people's lives.

The conditions covered in this paper

Psoriasis

Psoriasis is an immune-mediated inflammatory condition that speeds up the skin replacement process, leading to an accumulation of skin cells that cause raised 'plaques' on the skin. These 'plaques' can be flaky, scaly, discoloured or itchy and can affect any area of the body including the scalp, hands, feet and genitals (Psoriasis Association undated). It is possible to diagnose psoriasis based on the appearance of the skin or, in rare cases, a skin biopsy. However, it can be easily confused with other skin diseases.

Psoriasis affects around 2 per cent of the UK population (Springate *et al* 2017). Nearly a quarter of people with psoriasis have cases that are considered moderate to severe (National Psoriasis Foundation undated). While psoriasis cannot be cured, there is now a wide range of treatments. However, psoriasis is unique to each individual, and finding a treatment that works can be a process of trial and error (Psoriasis Association undated).

A significant proportion of people with psoriasis develop psoriatic arthritis, which causes affected joints to become swollen, stiff and painful. People with psoriasis are also more likely to suffer from other inflammatory diseases such as IBD and to have cardiovascular disease (Mease *et al* 2013).

Inflammatory bowel disease

Inflammatory bowel disease (IBD) is a term used to describe two immune-mediated inflammatory conditions affecting the gut, Crohn's disease and ulcerative colitis. Crohn's disease causes inflammation of the digestive system (gut). Ulcerative colitis causes inflammation and ulceration of the inner lining of the colon and rectum (Crohn's and Colitis UK undated a). Tests of blood and stool samples, endoscopic procedures and imaging such as x-rays or MRIs are used to diagnose the two conditions.

Around 0.4 per cent of the UK population have Crohn's disease, while around 0.6 per cent have ulcerative colitis (King *et al* 2020). Like psoriasis, symptoms – including pain, cramps or swelling in the stomach, recurring diarrhoea, weight loss and extreme tiredness – vary from person to person and range from mild to severe. People's symptoms may vary over time, with periods of flare up and remission. At present, there is no cure for either disease, but drugs and sometimes surgery can give long periods of relief (Crohn's and Colitis UK undated a).

A significant proportion of people with Crohn's disease and ulcerative colitis develop IBD-associated arthritis, psoriasis and uveitis, an inflammatory eye disease that can cause blindness (Argollo *et al* 2019).

Axial spondyloarthritis

Axial spondyloarthritis is a form of immune-mediated inflammatory arthritis affecting the spine. Like rheumatoid arthritis, the body's immune system causes inflammation to the joints and areas around them causing pain and damage. Unlike rheumatoid arthritis, people with axial spondyloarthritis experience inflammation and joint damage primarily in the spine and/or the sacroiliac joints, which connect the spine to the pelvis (National Axial Spondyloarthritis Society undated d). The patient's history, physical examination, blood tests to detect inflammation and genetic markers, and imaging tests including x-rays and MRIs are used to diagnose the condition. There are particular challenges in diagnosing axial spondyloarthritis, including the high prevalence of back pain in the population and the time it can take for damage from inflammation to become clear in imaging results (Lapane *et al* 2020).

Around 0.5 per cent of the UK population have axial spondyloarthritis (National Axial Spondyloarthritis Society undated b). Symptoms include inflammation causing pain and stiffness, most often of the spine. People may also experience bone destruction causing deformities of the spine and poor function of the shoulders and hips. A quarter of people will have irreversible spinal fusion which causes kyphosis and deformity and increases risk of spinal fracture. While there is no cure for axial spondyloarthritis, medication and exercise can help address pain, stiffness and inflammation (National Axial Spondyloarthritis Society undated c).

Many people with axial spondyloarthritis develop uveitis, psoriasis and IBD. Axial spondyloarthritis is also closely associated with osteoporosis (National Axial Spondyloarthritis Society undated b).

Osteoporosis

Osteoporosis is a skeletal disorder characterised by low bone density and deterioration in bone tissue, which leads to bone fragility. From their late thirties onwards, the volume of people's bone tissue naturally starts to decrease. However, this process can happen much faster for some people. Studies have shown the role of endocrine, metabolic and mechanical factors in reduction in bone density (Fitzpatrick 2002). Emerging evidence also suggests that inflammation also exerts significant influence on bone density (Ginaldi *et al* 2005). Smoking, alcohol consumption and malnutrition can also play an important role (Pouresmaeili *et al* 2018).

Around 2 per cent of the UK population have osteoporosis, with women more likely than men to have the condition (Age UK undated). Health services typically diagnose osteoporosis after people have had a fracture, using radiography to assess their bone mineral density. People with osteoporosis are at significantly greater risk of fractures, in particular of the wrist, spine, shoulder and hip. They are also more likely to suffer disability as a result of these fractures (Age UK undated). There are established medications to slow down the cells that break down bones or stimulate the cells that build new bone.

2 Diagnosis and initial access to care

The most pressing priority to improve care for people with these conditions is to speed up the process of reaching an accurate diagnosis and referring patients to specialist services where needed. This is essential to avoid people experiencing irreversible damage or an escalation of psychological and social problems while waiting for care. However, there are huge challenges in doing this for some of these conditions, which are often easily confused with other conditions or hard to identify using simple tests. It is unclear whether traditional strategies for improving detection in primary care, which have worked well for more common conditions, such as such as diabetes or hypertension, will be as effective for these rarer or less well-recognised conditions.

Osteoporosis services at Oxford University Hospitals NHS Foundation Trust

When Kassim Javid joined Oxford University Hospitals NHS Foundation Trust as a consultant in metabolic medicine in the mid-2000s, he identified substantial variation in the diagnosis and treatment of people with osteoporosis. At the time, hospital consultants relied on GPs to identify patients with the condition and manage most patients' treatment. The result was a lottery in which some GPs correctly identified osteoporosis through bone-density scans while others struggled to do so. Some GPs correctly administered low-cost medicines to strengthen people's bones while others did not. And there was typically little follow-up of patients to ensure that they adhered to the treatment plan.

Kassim secured funding to establish a more systematic, specialist-led approach to diagnosing and treating osteoporosis. The service is run by specialist nurses, with consultant oversight, who scan patients' primary care and hospital records to identify people who have suffered fractures and are at risk of osteoporosis. The team intervenes directly when patients attend services with a fracture or return for follow-up appointments after a fracture, wherever they are in the system. It has also developed new approaches to treatment, for example, more proactive use of intravenous drips for patients who struggle to take oral medication.

In the mid-2000s, the hospital treated a few hundred osteoporosis patients each year; now it treats more than 3,500. Every six months, the team analyses its

data and identifies quality-improvement objectives for the immediate future, for example, improving identification of individuals with osteoporosis who have been diagnosed with Parkinson's disease or had a stroke. One current initiative is to develop an algorithm to identify patients with vertical fractures using CT and MRI scans. The team is about to start testing the algorithm and expects that it will identify hundreds of new osteoporosis patients in Oxfordshire each year.

Challenges in diagnosis

There are a number of reasons why non-specialist health care staff may struggle to diagnose these conditions correctly. Most of these conditions affect only a relatively small proportion of the population. A GP might have only a handful of patients on their list with severe psoriasis, axial spondyloarthritis or IBD. There may be substantial variation between one patient and another, with patients with IBD ranging from those with very mild symptoms to those with severe illness. It is therefore extremely difficult for GPs, and other professionals, such as opticians or physiotherapists, to accumulate experience in spotting these conditions.

Other confounding factors are the overlap between the symptoms of these conditions with those of other conditions. While psoriasis is easy to diagnose in secondary care, non-specialists may confuse it with other skin diseases. As explained in Crohn's and Colitis UK and the Royal College of General Practitioners' IBD toolkit (undated), unless they conduct a faecal calprotectin test it is easy for a primary care doctor to confuse suspected IBD with irritable bowel syndrome. It is also easy for primary care staff to confuse axial spondyloarthritis with other forms of back pain. In comparison with people with rheumatoid arthritis, people with axial spondyloarthritis are less likely to have visible physiological signs of the disease such as swollen joints. It may take many years to gain definitive evidence of the condition through tests and scans.

GPs receive in-depth initial training in the treatment of many long-term conditions and build their knowledge through continuing professional training and practice. However, they receive limited training in some. For example, GPs might complete only two weeks of dedicated training in dermatology. A UK-wide survey of GPs in 2017 for the Royal College of General Practitioners and Crohn's and Colitis UK IBD Spotlight Project found that more than 70 per cent of GPs had no formal training in recognising and treating IBD (Crohn's & Colitis UK undated c).

Interviewees described a common scenario where a person might visit their GP multiple times without receiving an accurate diagnosis, treatment or referral to a specialist service. In these circumstances, people might stop trying to access a

diagnosis and appropriate treatment, assuming that nothing can be done for their condition. They might then wait many years, while the condition progressed, before receiving a diagnosis. One interviewee gave the example of a person who lived with axial spondyloarthritis for ten years before an optician saw him struggling to stand up in the waiting room and made the link between inflammatory eye conditions and inflammatory back pain.

Awareness raising and education

In response to these challenges, specialist services, professional bodies and patient associations have typically focused on raising awareness among the public, primary care staff and other key groups. For example, the National Axial Spondyloarthritis Society has worked with specialist services across the UK to raise awareness among GPs, opticians, physiotherapists, osteopaths and chiropractors of how to diagnose axial spondyloarthritis. Crohn's and Colitis UK works closely with professional bodies and patient bodies as part of IBD UK to improve understanding of IBD in primary care. It has partnered with the Royal College of General Practitioners to improve understanding of IBD in primary care through its IBD spotlight project (Crohn's and Colitis UK and Royal College of General Practitioners undated).

While these strategies can be effective, some experts we spoke to argued that there were limits to what can be achieved through raising awareness of these diseases. Raj Sengupta, the clinical lead for axial spondyloarthritis at the Royal National Hospital for Rheumatic Diseases in Bath, described 20 years' experience of leading education campaigns on axial spondyloarthritis. As he explained, GPs need to be experts in so many more common diseases that there are limits to their focus on and engagement with rarer conditions, such as IBD and axial spondyloarthritis. GPs who attend a back-pain seminar may remain engaged in the issues for a few months but might not see any patients with axial spondyloarthritis in that period, and over time, their attention shifts back to other, more common, conditions.

There are similar challenges in engaging staff in hospital services in supporting diagnosis of conditions outside their specialisms. Gastroenterologists will see significant numbers of patients with joint pain as well as gastroenterological symptoms but may struggle to distinguish between joint pain caused by inflammation or pain caused by wear and tear. Ophthalmologists who see patients with inflammatory eye diseases are well placed to spot other inflammatory conditions but may only see a few patients with these conditions throughout their careers. Junior doctors rotate quickly through specialist services, making it harder for them to maintain awareness of rarer conditions.

Technology to support diagnosis

Some of the services in this paper are developing technological solutions to support more systematic diagnosis of patients with rarer diseases in primary care, as a necessary supplement to raising awareness and education. For example, the Royal National Hospital for Rheumatic Diseases in Bath is currently testing with GP practices a new pop-up alert on the EMIS Web and SystemOne IT systems to prompt investigation for ankylosing spondylitis including axial spondyloarthritis.

When GPs note that a person is experiencing back pain on their patient record, the system checks whether the person has common co-morbidities of axial spondyloarthritis or ankylosing spondylitis such as IBD or psoriasis. For patients with relevant co-morbidities, the pop up then prompts the GP to ask a set of follow-on questions to reveal whether the patient might have axial spondyloarthritis or ankylosing spondylitis, for example, does the patient wake up with back pain in the night or experience stiffness in the morning?

The Bath team has also developed a more detailed decision-support tool, called 'Spadetool' to help health care staff calculate the probability that a patient has axial spondyloarthritis. This tool specifically aims to help GPs determine whether adults under the age of 45 may have axial spondyloarthritis before changes to the spine can be seen on an x-ray. The tool captures information on the type of pain suffered by the patient, their family history, their co-morbidities and existing test results. It determines whether axial spondyloarthritis is improbable, whether further tests are needed, or whether a probable or definitive diagnosis of axial spondyloarthritis can be given.

Greater reliance on specialist teams

Some of the specialist services covered in this paper have concluded that they needed to develop bespoke outreach services to improve the diagnosis and initial treatment of rarer diseases as an alternative or addition to primary care. As discussed above (see p 14), the osteoporosis service at Oxford University Hospitals NHS Foundation Trust has developed its own nursing team to find osteoporosis patients, using primary care and hospital records, rather than relying on primary care services.

The specialist psoriasis service at Salford Royal NHS Foundation Trust has established a community-based rapid access clinic for patients with psoriasis in Greater Manchester. While GPs refer patients in, the team ensures that people can gain a definitive diagnosis rapidly, and can access appropriate treatment straight away.

Similarly, the IBD service at Western General Hospital in Edinburgh has created a telephone hotline and email service for GPs and patients where nurses or consultants provide rapid advice on diagnosis and treatment of IBD. The GPs value being able to access specialist advice and some routinely refer patients to the hotline rather than attempting to distinguish between IBD and other gastroenterological conditions themselves. The King's Fund's paper on specialists working in out-of-hospital settings provides examples of other similar initiatives (Robertson *et al* 2014).

Proactive case finding

Some of these specialist services are also playing a more proactive role in finding patients at risk of rarer inflammatory conditions. At Oxford University Hospitals NHS Foundation Trust, the osteoporosis team's fracture liaison service aims to review every patient aged over 50 who experiences a fracture, to test for osteoporosis and start patients on appropriate treatment. The team trawls through patient records to identify fracture patients and intervenes when, or soon after, patients attend hospital fracture services.

In 2020, the team in Oxford worked with Zebra Medical Vision to develop an artificial intelligence algorithm that identifies patients with possible vertebral fractures by analysing their CT scans. In its first month of using the algorithm, the team identified 350 patients with possible vertebral fractures and, of these, an additional 200 patients with osteoporosis. This suggests that the team will be able to appropriately diagnose and treat around 2,500 patients per year.

Embedding effective systems

Overall, the focus of these specialist services has moved away from relying solely on raising awareness or education in primary care and other services to embedding effective systems for diagnosis of rarer or less well-recognised diseases. Where it is possible to establish a system to improve diagnosis, this seems likely to have a more lasting impact than awareness raising projects. As Raj Sengupta put it, 'It's much better to have protocols than to rely on champions or raising awareness.'

Another common theme was reluctance to rely on an overstretched primary care system to diagnose or manage some forms of these conditions. As Kassim Javid argued, 'You can upskill primary care as much as you want but they are just too busy to deliver.' This may explain the trend of specialist services developing 'outreach services' that provide an alternative to the traditional model of primary-to-secondary referral to improve access to diagnosis and treatment for at least some conditions or more severe forms of some conditions. Our examples suggest that these approaches can be extremely effective in achieving their

objectives, although there are inevitably additional costs, complexities and potential overlap with other services.

3 New approaches to delivering specialist services

Once people have been referred to hospital services, they need to be able to see a specialist consultant quickly, to complete diagnostic tests without long delays, and start on the most appropriate treatment plan as soon as possible. Patients also need to be able to access rapid specialist advice during a flare up. While this might appear obvious, there are substantial barriers to doing so. There are significant shortages in specialist staff and insufficient capacity for some diagnostic tests such as endoscopies, CT scans and MRIs (Derakhshan *et al* 2018; Hospital Times 2020).

Services are often poorly designed to make best use of scarce staff, minimise delays in diagnosis and starting treatment, and respond quickly when people's conditions worsen. Traditional approaches to delivering medical care may add to these problems, contributing to delays in getting people on the most appropriate treatment. The services in this paper have introduced wide-ranging changes to address these issues, from quality improvement projects to new treatment approaches.

IBD services at Western General Hospital, Edinburgh

Ian Arnott became a consultant gastroenterologist specialising in IBD at Western General Hospital in the early 2000s. At the start of the 2000s, Ian and his colleagues were among the first in the UK to develop a specialist gastroenterology clinic for IBD, an approach that allowed them to develop much greater specialist expertise in the condition and to start treating more complex patients as tertiary referrals from other hospitals.

Since the mid-2000s, Ian and his colleagues have started to test more innovative ways of delivering services that could help them provide services for a growing number of patients and deliver more patient-centred care. One pressing challenge was to provide much faster access to specialist advice and guidance when patients first have severe IBD symptoms and during flare ups. In the early 2010s, the team established a nurse-led IBD telephone hotline to help speed up diagnosis, provide rapid advice on self-care or bring people quickly into nurse or consultant-led clinics to review their medication.

After the success of the telephone service, the team began to develop ideas for restructuring its consultant and nurse-led outpatient services, so that patients can see the right person quickly while avoiding unnecessary travel. One major change has been to establish four nurse-led IBD clinics in community hospitals across Lothian, so that IBD patients can see a specialist nurse rapidly while avoiding long drives to Edinburgh. The team has also introduced video consultations using the NHS Near Me platform.

Another major change has been to establish a new flare clinic at Western General Hospital for patients experiencing a flare up. In the past, a patient experiencing a flare up might see their GP or specialist nurse in the short term, while waiting weeks to see a consultant and be put on the right medication. With the new clinic, the nurses staffing the hotline can refer patients can see an on-call consultant gastroenterologist the same day. The consultant can institute the right treatment regime immediately, helping to prevent avoidable hospital admissions.

Speeding up time to treatment

The services covered in this paper have pursued structured quality-improvement programmes to speed up the process of completing diagnosis and putting patients on an appropriate treatment plan. At Oxford University Hospitals NHS Foundation Trust, staff have developed a national audit process for diagnosis and treatment of osteoporosis, which benchmarks rates of identification and treatment of osteoporosis across regions. Every six months, the team looks at the data and identifies quality-improvement objectives for the immediate future, for example, improving identification of patients with osteoporosis who have been diagnosed with Parkinson's disease or had a stroke.

At Western General Hospital in Edinburgh, staff led dozens of quality-improvement projects to reduce time to referral and waiting times for investigations before treatment can start. The team has also developed a detailed process map with key performance indicators to speed up the process of prescribing and starting biologics. This led to changes such as creating group education sessions on the side effects of medications and a one-stop shop rather than multiple appointments to get patients ready for treatment. Once a consultant has prescribed a biologic, it now takes two to four weeks to get patients started on the treatment. When there are delays in starting treatment, it is possible to look quickly at the service's key performance indicators to identify what is causing the problem.

Inverting the pyramid

Interviewees described a traditional 'pyramid' model for caring for people with these rarer long-term conditions. Under this model, health services dedicate fewer resources to treating patients with less severe illness and concentrate their efforts on patients with the most severe forms of the condition. This means that a newly diagnosed patient with less severe disease might see doctors and nurses for a few brief appointments to establish a treatment plan, before being left to manage their largely condition on their own. Only when their condition worsens would these patients receive more intensive monitoring and support.

Interviewees highlighted significant problems with this model of care. Staff have little time to support patients at the early stages of their disease, when ensuring the most appropriate treatment, helping patients make lifestyle changes and educating patients in self-management could prevent deterioration in the disease. Meanwhile, they provide substantial resources at the point when people have already experienced lasting physical and psychological damage.

Helena Marzo Ortega, the clinical lead for spondyloarthritis at Leeds Teaching Hospitals NHS Trust and associate professor at the University of Leeds, explained that consultants might spend just 20 to 30 minutes with newly diagnosed patients at the critical early stages of their disease, 'In any follow-up appointment, we have no more than 10 to 15 minutes to assess patients, 40 per cent of whom will have anxiety and 30 per cent of whom will have depression. We base their treatment on an incredibly rapid assessment, even though their treatment will cost thousands of pounds over the course of their lifetime.' As Richard Warren, a consultant dermatologist at Salford Royal NHS Foundation Trust, put it, 'We don't give patients a lot of support at the start, when we could avoid them becoming seriously ill. Then we provide a lot of support at the end, when they have irreversible damage and might never return to work.'

The services in this paper are attempting to 'invert the pyramid' so that they give people intensive support at an earlier stage and prevent deterioration in their conditions. Claire Reid, a consultant dermatologist at Salford Royal NHS Foundation Trust, explained that psoriasis is now recognised as a complex and multi-system disease. However, traditional services often manage psoriasis as if it was a simple rash. One of the objectives of Salford Royal NHS Foundation Trust's rapid access psoriasis clinic is to provide treatment that reflects the complexities of the condition. The aim of the service is to 'give people a complete once over' irrespective of the apparent severity of their disease.

When GPs refer patients to the service, they see a multidisciplinary team including a consultant dermatologist, specialist nurse and health psychologist.

The team can refer patients directly into hospital services if they believe they need systemic or biologic drugs. The team also screens for physical co-morbidities such as psoriatic arthritis, assesses whether patients have anxiety or depression, and provides practical advice on lifestyle changes, self-management and what to do in the event of a flare up. Data so far shows that the majority of patients attending the clinic are young adults with moderate or severe psoriasis and high prevalence of anxiety or depression.

At the Royal National Hospital for Rheumatic Diseases in Bath, the axial spondyloarthritis team runs an intensive two-week residential course to help people learn how to live with axial spondyloarthritis and prevent deterioration. Participants learn about the pathology and progression of the disease, exercises to maintain mobility, and discuss strategies to protect their health and wellbeing, for example, stopping smoking, losing weight and using mindfulness techniques. Raj Sengupta, the clinical lead for axial spondyloarthritis, describes it as an 'acute' model of upfront support for a long-term condition. 'We invest in setting people on the right track, giving them key messages and helping to establish the right habits intensively and early. A lot of people say it is life-changing.'

From phased treatment to accelerated step up

Interviewees also described a traditional model of phased treatment for people with many of these conditions. When people first have symptoms, they visit their GP who might prescribe cheaper or less aggressive therapies such as topical therapies (ie, creams and medicated shampoos) for psoriasis or non-steroidal anti-inflammatories for axial spondyloarthritis and other forms of rheumatoid arthritis. Patients are not always followed up to assess their response to less aggressive therapies and escalate treatment if needed.

GPs are encouraged to manage patients in primary care if possible, rather than referring them to a specialist. This means they might try a number of therapies before eventually referring a patient to specialist services. These services may, in turn, continue to try incrementally more aggressive treatments and dosages. For example, dermatologists might move from topical therapies to phototherapy or a systemic drug before prescribing a biologic for psoriasis if these earlier options prove unsuccessful. Gastroenterologists might start with milder oral drugs for ulcerative colitis before moving on to an immunosuppressant or more powerful biologics.

This approach is appropriate for some patients with less severe forms of disease. The concern is that this incremental approach can lead to very long delays in getting patients with more severe conditions onto the most appropriate therapies, with the risk that delays lead to irreparable damage to skin, joints or

internal organs. Richard Warren, a consultant dermatologist at Salford Royal NHS Foundation Trust, argued for a reversal of the current system, 'We need to pluck relevant patients out of the primary care system as early as possible, get them to a specialist quickly and put in place a management plan.' The consultant dermatologists at Salford Royal's psoriasis clinic see people who have been referred from other hospitals, many of whom have spent years cycling between primary care and hospital services and from one therapy to the next.

The services in this paper are leapfrogging some of the steps followed at more traditional outpatient clinics or implementing an 'accelerated step-up' model to get patients on the appropriate therapies much faster. Specialist outreach services, such as Salford Royal's rapid access psoriasis clinic, aim to do this by giving patients faster access to consultants who can prescribe more aggressive therapies straight away. The dermatologists at Salford Royal also might also accelerate some steps before placing patients with severe psoriasis on a biologic.

At Western General Hospital in Edinburgh, the IBD team has improved monitoring of patients on biologics so that they can change treatment faster when needed. This has included a switch from reactive to more proactive monitoring of patients who complete symptom report cards when having blood and other tests in the community. As a result, the team makes faster changes to drug doses and switches patients to new drugs more quickly than under the previous system.

Interviewees highlighted the importance of treating significant numbers of patients with more severe forms of disease at a specialist centre. This allows consultants and other staff to develop greater experience in using more aggressive therapies. At the psoriasis clinic in Salford, consultants might see 60 people with severe psoriasis in a single day, while dermatologists in other hospitals might see only 60 patients with severe forms of the disease in a year.

For many services, one challenge is now to speed up identification of people who are at the greatest risk of severe forms of disease to enable an even faster transition to more aggressive therapies. At the axial spondyloarthritis service in Bath, staff look for indicators that patients are at severe risk: the severity of inflammation on an MRI; evidence of new bone formation or bone marrow oedema; genes that make people more susceptible to the disease; gender; and lifestyle. For those at highest risk, consultants might forego accelerated step up in favour of a top-down approach, starting immediately with more aggressive therapies.

Another challenge is to become more precise in pinpointing the specific biologic therapies that will be most effective for an individual patient. At the psoriasis

clinic at Salford Royal NHS Foundation Trust, staff and researchers are working on an artificial intelligence algorithm to identify which patients will respond best to which drugs, so they can start on the most appropriate biologic straight away.

Flexible services for cyclical diseases

Interviewees were critical of the ability of traditional outpatient services to respond to the needs of patients with severe cyclical, relapsing and remitting conditions, in particular their ability to communicate effectively with patients and respond appropriately when conditions worsened. The services covered here are developing more flexible ways to ensure that patients can quickly access the professionals they need when their conditions worsen.

Ian Arnott, the consultant gastroenterologist who leads Western General Hospital's IBD service, described the limitations of its traditional outpatient model as follows. Once patients started treatment, they would typically have a scheduled follow-up appointment with the hospital consultants every six months or every year. When people had a flare up, there was no easy route to see the right hospital staff quickly. They would often see the specialist IBD nurses in the first instance, as they had more spare capacity than the doctors. Meanwhile, the consultants would spend their time in routine appointments with people who had been in remission for a year. Patients' conditions would worsen while they were waiting for the right team member to review their treatment. In some cases, a patient could have avoided a hospital admission if the team had intervened faster.

As described briefly above, the IBD team at Western General Hospital has introduced a series of changes to make better use of staff time and ensure that people can see the right clinician when their conditions worsen. These have included their nurse-led IBD telephone hotline and new consultant-led flare up clinic. The on-call IBD consultant keeps flare up slots in their diary and sees people on the day to institute a proper treatment plan and prevent a hospital admission. Patients can also be screened and receive a start date for more complex treatments on the day.

Staff at Western General Hospital described the extent of changes needed to make the transition to this more responsive approach. Hospital consultants need to spend less time on routine follow up so that they are free to see patients who need them during a flare up. In order to achieve this, the specialist nurses are now seeing increasing numbers of patients for routine follow up in their community clinics. The team estimates that this change will free up between 2,000 to 3,000 consultant appointments per year. The specialist nurses are able to do this because they are, in turn, shifting to a model of 'patient-initiated

follow up' where an increasing number of patients with less severe illness or whose IBD is in remission will not have routine follow-ups at all, but contact services only if their conditions worsen.

At the Royal National Hospital for Rheumatic Diseases in Bath, the team is starting to put in place a similar set of changes to shift attention from routine follow up to seeing the patients when they need care. Under current arrangements, the service sees patients on biologics for follow up every six months and other patients for routine follow up once a year. Like Western General Hospital, this means that consultants spend time in appointments with people who are reasonably well. The team is trialling asking patients to complete three-monthly questionnaires and deciding, based on their responses, whether to offer a follow-up appointment, again freeing up consultant time to respond to flare ups. Each of these changes needs to be implemented carefully, for example, ensuring that staff have the training and support to carry out their new role and putting in place safeguards for vulnerable groups.

Services are also researching how they might better predict flare ups so that they can intervene earlier. At Bath, the axial spondyloarthritis team is running a pilot with 100 patients who use a wearable device and a mobile phone app to record daily symptoms such as heart rate, sleep patterns, work, exercise, and pain and fatigue. The ambition is to be able to predict when people are about to experience a flare up based on their sleep patterns, heart rate and other live-streamed data. Some IBD services in England are introducing the use of home faecal calprotectin testing to predict the risk of flare up in IBD patients.

The psoriasis clinic at Salford Royal NHS Foundation Trust

In the early 1990s, Chris Griffiths began work as a dermatology consultant at Salford Royal NHS Foundation Trust. In his first year, he remembers receiving referrals for patients with complex psoriasis that he struggled to deal with in a general dermatology clinic. In 1994, Chris and Dr Robert Chalmers established a dedicated clinic for patients with severe psoriasis at the hospital, the first such clinic in England and one of the first in the world. The aim was to offer patients with severe psoriasis, people who had tried common therapies without success, access to support from specialist consultants and nurses, as well as the possibility of joining clinical trials to access experimental medicines.

Chris and Robert began to receive referrals for patients with complex conditions from around Greater Manchester and across England. With increasing numbers of patients with complex conditions, the consultants and registrars quickly became much more expert in prescribing new systemic and biologic therapies. They also needed to work more closely with specialist nurses to support patients

on these new drugs. The clinic was one of the first in England to establish protocols for nurses to prescribe therapies and monitor patients on experimental drugs. The consultants and nurses sit in an open plan office, modelled on the 'residents' room' in US hospitals, rather than in separate offices, enabling a constant exchange of information and ideas, teaching and supervision, rather than this only happening in catch ups or monthly multidisciplinary team meetings.

With specialisation and scale, staff at the clinic have developed the expertise to deviate from standard clinical protocols for patients with complex conditions, for example, being more proactive and aggressive in treatment and using a wider range of therapies. Professor Richard Warren, a consultant dermatologist at the clinic, oversees a combined clinic with rheumatologists for patients with both psoriasis and psoriatic arthritis, with the rheumatologists able to prescribe a broader range of therapies that might be beneficial for both conditions. The clinic has played a central role in establishing and maintaining the British Association of Dermatologists' Biologic Interventions Register, a national register of all patients receiving biologic therapy for psoriasis, which helps to monitor the safety of these drugs.

In 2018, staff launched a new 'rapid-access clinic' that aims to see all people with suspected psoriasis or a new diagnosis of psoriasis, provide a complete specialist assessment, and immediately provide people with an appropriate treatment plan. GPs refer patients to the clinic, where they quickly see a specialist team including a dermatology consultant, specialist nurse and psychologist. On average, patients who attend the clinic have had psoriasis for two years. In comparison, research has found that people with psoriasis in the UK have the disease for an average of 15 years before they are referred to a specialist (Simpson *et al* 2017).

Guidelines and protocols on treatment

Interviewees highlighted the benefits of guidelines and protocols as a way of ensuring greater consistency across services and raising standards of care. However, many consultants were sceptical of the benefits of National Institute for Health and Care Excellence (NICE) guidelines for some drugs and other protocols that restrict their ability to move patients on to more aggressive drugs quickly under an 'accelerated step-up model'. For some conditions, clinicians must verify that patients meet specific diagnostic or disease severity thresholds, typically based on observable and measurable physiological symptoms, before they can prescribe some drugs. In doing so, these types of guidelines direct attention to a narrow set of typically biomedical factors while downgrading other factors such as the patient's experience of illness or the impact it has on their

lives, and preventing consultants making an overall, holistic assessment of the severity of people's illness.

For example, dermatologists can only prescribe particular medicines for psoriasis when patients have a high score of above 9 on the Psoriasis Area and Severity Index (PASI) which captures the area of the body covered by psoriasis and its intensity. This fails to account for material factors for patients such as whether psoriasis affects particularly sensitive parts of the body such as the face, hands or genitalia, the impact on their daily life and the impact of co-morbidities. Consultants find themselves unable to prescribe more aggressive therapies for people whose lives have been destroyed by the condition. Claire Reid, a consultant dermatologist at Salford Royal, explained, 'There is a clear discrepancy between what constitutes severe disease in prescribing guidelines and what patients and dermatologists consider to be severe disease.'

Consultant rheumatologists who treat people with axial spondyloarthritis expressed similar concerns. Current guidelines allow them to move patients from anti-inflammatory drugs to biologics only when patients continue to report severe illness and this is confirmed by MRI and other tests. However, patients report their symptoms in different ways. There is a subset of patients who appear to have severe inflammatory disease, but where this is not apparent in their scans. Consultants would like to move these patients on to more aggressive biologics to halt the disease earlier, rather than waiting for lasting damage to occur.

For some conditions, clinicians are also required to prescribe one or more drugs before they are permitted to prescribe others. For example, patients with psoriasis are expected first to take topical therapies, such as corticosteroids, and then to try phototherapy or a systemic drug that slows down the entire immune system, before finally being able to receive a biologic drug.

Richard Warren was sceptical of the benefits of requiring services to try these drugs before moving patients with severe psoriasis on to a biologic. Patients cannot safely take systemic drugs such as cyclosporine for long periods, meaning that they are unlikely to provide a lasting solution for people with severe psoriasis. 'What we don't find helpful is preventing somebody with a PASI of 9 being put on a biosimilar, it's an illogical cut off.' Gastroenterologists also indicated that guidelines sometimes make it harder to move people quickly on to the right medicines.

There are sometimes good reasons for these types of restrictions, for example, to check whether patients will respond to a less aggressive medicine before putting them on a drug with more significant potential side effects, or to check

whether a patient will respond to a cheaper medicine before using a more expensive one. However, interviewees questioned whether all the current restrictions are needed to address either of these concerns.

In the psoriasis example above, it is unlikely that requiring patients to take systemic drug is safer than moving them on to a biologic. There are well-recognised risks to taking systemic drugs for prolonged periods. Meanwhile, there is now a strong body of evidence on the safety of biologics (National Institute for Health Research 2019). Nor is it likely that requiring patients to take a systemic drug such as cyclosporine before moving onto a biologic reduces overall spending. There are high monitoring costs for systemic drugs. Meanwhile the costs of some biologics have fallen since they were launched.

Consultants also highlighted the challenges they faced treating patients with particularly complex conditions under existing guidelines and protocols. At tertiary centres, consultants see a relatively large proportion of patients with severe illness who have tried all the available therapies for their disease. This is a particularly significant problem where there are only a small number of approved classes of therapy for the disease or where patients have co-morbidities that limit the range of therapies they can take. As one gastroenterologist explained, 'If a patient has two conditions, this can narrow the classes of available drugs down to one. And then I need to be able to use every agent in that class.'

Where a patient has a number of different inflammatory conditions, consultants in one specialism regularly ask consultants in another specialism to use their prescribing rights to prescribe different drugs or dosages. In Greater Manchester, for example, rheumatologists can access a broader range of biologics than dermatologists. Gastroenterologists can also sometimes prescribe a wider range of therapies and in some cases higher doses. While consultants continued to respect existing guidelines, some recognised that, at least in some cases, they were finding creative ways through a restrictive system to get patients the drugs they need.

In other cases, consultants might need to seek specific authorisation to use a higher dosage of an approved drug or to use a drug 'off label', meaning a drug that wasn't specifically licensed for the patient's condition. In England, consultants need to make individual funding requests to clinical commissioning groups. In Scotland, consultants follow a much simpler process where they inform their hospital's medicines governance committee of their prescribing decisions.

4 Addressing the psychosocial aspects of illness

Interviewees highlighted the complex interplay between physical health, mental health, lifestyle, socio-economic and other factors for patients with these long-term conditions. The services covered in this paper are starting to put in place more structured support for the psychosocial aspects of these conditions in addition to specialist support for the biomedical aspects of the disease. However, services face huge difficulties in securing clinical psychologists and other resources. There is also more work to do to embed support for the psychosocial aspects of illness within medical services and connect patients to other forms of support.

The axial spondyloarthritis service at the Royal National Hospital for Rheumatic Diseases, Bath

The Royal National Hospital for Rheumatic Diseases has been a specialist centre for the treatment of axial spondyloarthritis since the 1960s and a pioneer in improving diagnosis and treatment of the disease. Over the past decade, it has led campaigns to raise awareness of axial spondyloarthritis among primary care staff, physiotherapists, chiropractors and other professional groups. In the past few years, staff have developed a new notification system for GPs on EMIS and SystemOne and a separate website to support more accurate initial diagnosis and referral to specialist services.

Raj Sengupta, a consultant rheumatologist and the clinical lead for axial spondyloarthritis at the hospital, described how the clinic had moved away from a rigid, protocolised approach to diagnosing axial spondyloarthritis. Unlike diseases where there are unambiguous diagnostic tests, staff need to look at a broader picture including the patient's description of the condition, and evidence from blood tests and MRI scans, to adapt their analysis to individual cases. This has meant that they sometimes consider a diagnosis of axial spondyloarthritis where a less specialist clinic would be unlikely to do so.

With specialisation and accumulated experience, the clinic has also diverged from some established treatment protocols. For example, staff try to make an early assessment to identify patients at risk of severe forms of the condition so

they can intervene earlier with more aggressive drugs. Current guidelines encourage staff to start patients with anti-inflammatory drugs in the first instance, track patient's progress using patient-reported outcomes, and move patients onto biologics, if needed, later. Staff at the clinic use their clinical judgement to determine whether to start patients on biologics much earlier.

The hospital is only of only a handful of centres in the world to run intensive programmes to help patients manage the condition (see p 22). Rather than drip feeding support over a patient's lifetime, the focus is on intensive support from consultants, nurses and therapists at an early stage to get the condition under control. The aim is to help patients gain confidence in managing their condition and establish the right behaviours as early as possible, to avoid a spiral into poor physical and mental health. Another key feature of the course is the focus on relationship building and peer support among participants. The eight participants on each course develop strong relationships and in some instances friendships that last long after the programme has finished.

Addressing mental health problems

Staff emphasised the importance of addressing the psychological as well as the medical aspects of these severe long-term conditions. Andrew Kirtley, a clinical psychologist at the Royal National Hospital for Rheumatic Diseases in Bath, described the complex ways in which physical health and mental health can interact for people with severe long-term conditions. Uncertainty regarding the diagnosis and the progression of the condition can be major causes of anxiety and depression. The physiological features of these diseases, for example, physical disfigurement or loss of control of bodily functions, can be sources of stigma and shame that can impose a high psychological burden. Increased levels of stress, anxiety and depression can be associated with increased disease activity and reduced functionality. Stress, anxiety and depression may be triggers for the onset of these diseases or exacerbate them. Symptoms such as pain and fatigue can contribute to people's mental health problems, lowering their motivation to maintain lifestyle changes, which in turn worsens their physical condition.

The specialist services in this paper were all actively working to improve the quality of mental health support for their patients. At Salford Royal NHS Foundation Trust's rapid-access psoriasis clinic, a clinical psychologist uses motivational interviewing to help patients make lifestyle changes and screen for anxiety and depression. At Salford's specialist psoriasis clinic, consultants and nurses complete training in motivational interviewing so that they can carry out a similar role. At the Royal National Hospital for Rheumatic Diseases in Bath, Andrew Kirtley runs sessions for patients to explore the biological, psychological

and social components of axial spondyloarthritis, help patients identify and manage factors that could exacerbate their condition, discuss how to manage the impact of the disease on work and relationships, and introduce patients to mindfulness techniques.

Across services, staff highlighted huge challenges in securing resources to build support for mental health into the care they offered. At Western General Hospital in Edinburgh, the IBD team had access to a dedicated clinical psychologist a decade ago, but lost the role due to cost cutting. After years of trying, it has now just secured funding for a part-time clinical psychologist. Other services have made multiple business cases for mental health support for patients unsuccessfully. This suggests a lack of understanding of the importance of incorporating support for mental health into these services. Some interviewees also suggested that they needed to present a stronger evidence base on the benefits of doing so. The King's Fund's report on bringing together physical and mental health highlighted similar challenges in improving support for the mental health of people with long-term conditions (Naylor *et al* 2017).

Where services do manage to secure additional resources, these are typically small and staff need to think carefully about how to use them. For example, should services use part-time clinical psychologists primarily to deliver face-to-face support to patients or primarily to upskill consultants and nurses in motivational interviewing and identifying anxiety and depression? Ian Arnott, the gastroenterologist who leads the IBD team at Western General Hospital in Edinburgh, wants to use its new part-time clinical psychologist to upskill the whole clinical team, ensuring that psychological issues are high on everyone's agenda, and give staff tools so that they can all make interventions in the clinic, rather than just delivering support for a small group of patients.

There was recognition that specialist nurses are often particularly well placed to develop strong relationships and with some training and support, deliver ongoing psychological support for patients. However, there are severe limitations to what staff can achieve in 10-minute clinic appointments. One specialist IBD nurse at Western General Hospital, Janice Fennell, is hoping that a shift to patient initiated follow up will allow her to book double appointment slots for some patients, so that she can spend 20 minutes with them in future. Services were also using online cognitive behavioural therapy and online mindfulness courses as an alternative to costly, one-to-one and face-to-face therapy sessions.

Helping patients manage their conditions

For the conditions covered in this paper, making lifestyle changes can sometimes be as important as ensuring rapid diagnosis and appropriate medical treatment.

For patients with axial spondyloarthritis, Raj Sengupta explained that stretches and exercises can be as important as medicines, with drugs helping patients to control their pain as they become more active and improve their lifestyles. There is strong evidence that obesity, smoking and alcohol consumption are contributory factors in axial-spondyloarthritis and psoriasis (Adışen *et al* 2018; Zhang *et al* 2015). There is also evidence that smoking exacerbates Crohn's disease, one form of IBD (Thomas *et al* 2000).

At the Royal National Hospital for Rheumatic Diseases in Bath, the two-week residential course for people with axial spondyloarthritis focuses intensively on helping patients make lifestyle changes to control their disease. Patients are often worried about destroying joints with stretches and exercises and structure their lives to avoid pain. A key component is education on the role of lifestyle in progression of the disease. The staff also provide advice on how to stop smoking and group physiotherapy classes to learn appropriate stretches and exercises.

At Salford Royal NHS Foundation Trust's rapid access psoriasis clinic and specialist psoriasis clinic, staff provide information and use motivational interviewing to help people to lose weight and stop smoking. Most of the services covered in this paper also refer people into external weight loss and smoking cessation services. However, none of the services had the resources or structures to provide intensive ongoing support for patients making lifestyle changes. It is possible that changes in staffing and service delivery at services such as Western General Hospital's IBD service will allow the nursing staff to build better relationships with some patients and provide ongoing support for lifestyle change in future.

Patient education and empowerment

Staff at specialist services highlighted the importance of education as a foundation for supporting people to live with cyclical, progressive disease and for sharing information about self-care, how and when to engage effectively with services and the importance of lifestyle and other factors in managing their disease. There is also some evidence that education can address feelings of loss of control and hopelessness that come with some of these conditions and exacerbate anxiety and depression (Zangi *et al* 2015).

Speeding up patients' access to appropriate advice on self-care is one of the objectives of Salford Royal NHS Foundation Trust's rapid-access psoriasis clinic. At Western General Hospital in Edinburgh, staff have focused on providing earlier advice and education for patients with IBD, including while they are waiting for tests and appointments with hospital consultants. One key aim of patient education is to support patients to understand the triggers and early signs of

flare ups and how they can access and engage with services during a flare up. Another key component is helping patients to understand the reasons for making lifestyle changes.

One of the challenges, however, is to build substantial patient education into very short and spaced-out appointments with consultants and specialist nurses. The IBD team in Western General Hospital has moved to group sessions with patients preparing to start new therapies so it can deliver more intensive education faster. At Bath, staff running the intensive residential course for patients with axial spondyloarthritis have gone furthest in supporting patients' to understand their condition. Here, the objective is to share information about the biomedical and psychosocial aspects of the condition and how it progresses, as a basis for motivating patients to pursue significant lifestyle changes. At Leeds Teaching Hospitals NHS Trust staff are signposting patients to a dedicated portal for advice on how to manage spondyloarthritis.

Connecting patients and peer support

Staff at some of these services emphasised the importance of connecting patients with peers and enabling peer support. For Andrew Kirtley, this was one of the main benefits of the two-week intensive residential course for people with axial spondyloarthritis at the Royal National Hospital for Rheumatic Diseases in Bath. Participants are able to meet other people with axial spondyloarthritis and share experiences, sometimes for the first time. Participants can also meet people with different stages of the disease, something which can give them confidence that it is possible to manage the disease. Participants on the course spend time socialising with each other during the day and in the evening, and often establish lasting friendships and support networks.

There is evidence that peer support can play an important role in helping people to manage many long-term conditions (Fisher *et al* 2015). There is also a broader evidence of the potential benefits of peer support for people with long-term pain and fatigue, mental health problems and other long-term conditions. At present, though, relatively few specialist NHS services for these types of conditions appear to be harnessing peer support or using their resources to help establish peer-support networks. It isn't clear why specialist services have not invested in peer support, whether because they don't consider it their role, are unsure of the benefits, don't see it as a priority, or have simply overlooked it. Associations such as the National Axial Spondyloarthritis Society and Crohn's and Colitis UK play an important role in bringing patients together, although not specifically in peer-support groups.

Linking with social prescribing services

Claire Reid, the consultant dermatologist who leads Salford Royal NHS Foundation Trust's rapid access psoriasis clinic, highlighted the importance of connecting patients with social prescribing services to support lifestyle changes. In her words, 'Patients come to our clinic and we see them a few times. If a patient wants to develop a healthier lifestyle, we need to offer them more than a brief 10-minute clinic consultation.' The rapid-access clinic has started to refer patients to social prescribing services in Greater Manchester and has now secured funding from the Psoriasis Association to develop a bespoke social prescribing service for people with psoriasis. In general, however, these specialist services seem to be disconnected from social prescribing services, which are better linked to primary care. As Claire Reid put it, 'The interesting thing was to realise was these services are under our noses but not integrated into secondary care.'

5 Care for people with multiple inflammatory diseases

Patients with severe immune-mediated inflammatory conditions often develop other inflammatory conditions, experiencing common clusters of conditions affecting the skin, joints or internal organs. This creates challenges in co-ordinating care for patients and ensuring appropriate treatment for their combination of diseases. In some cases, there is a single appropriate drug to treat both conditions. In other cases, the preferred drug for one condition will worsen the other. For example, some treatments for rheumatoid arthritis are likely to worsen the patient's IBD. This section looks at how services bring together generalist and specialist expertise for these patients to ensure appropriate treatment without long delays.

Multi-disciplinary services for inflammatory diseases, Leeds Teaching Hospitals NHS Trust

When Helena Marzo-Ortega was appointed clinical lead for spondyloarthritis at Leeds Teaching Hospitals NHS Trust in 2007, she joined a team where there was already close joint-working between rheumatologists, dermatologists, gastroenterologists and other specialisms such as radiologists and ophthalmologists. Some of these specialists worked on the same floor at Chapel Allerton Hospital and consulted each other informally on patients with multiple rheumatological, dermatological and gastroenterological conditions.

In the late 2000s, Helena and her colleagues established a combined psoriatic service for people with skin psoriasis and psoriatic arthritis. The clinics see, on average, 180 patients with psoriatic arthritis and 120 patients with skin psoriasis each week. People affected by psoriasis and psoriatic arthritis from the dermatology and rheumatology departments are reviewed 'on request' by both teams. This means that the rheumatologist can take a patient for a consultation with a dermatology consultant and team specialising in severe psoriasis immediately, without the need for an additional referral.

In addition, the team set up a bi-monthly combined clinic with rheumatologists, dermatologists and gastroenterologists where a subset of patients with psoriasis, psoriatic arthritis and inflammatory bowel disorders can be seen by three

specialists at the same time. The impact of organising services in this way is dramatic. Patients with a constellation of different inflammatory conditions can receive an accurate diagnosis and appropriate treatment plan straight away rather than, potentially, waiting for months to see specialists separately.

As part of a service improvement project the team assessed the number and outcomes of patients requiring combined review over a 22-month period from May 2018 to February 2020. During this period, an estimated 6,600 patients attended the parallel rheumatology and dermatology clinics. Of these, 166 patients required a combined review from rheumatologists and dermatologists. As a result of these reviews, new diagnoses were given for 73 patients (44 per cent).

Pharmacists in hospitals

In some hospitals, pharmacists may play a key role in ensuring the safe and effective use of medicines including biologics and other complex drugs. Lynne Merchant, a pharmacist at Western General Hospital in Edinburgh, described how she liaises with colleagues across specialities to ensure joined-up decision-making for patients with more than one inflammatory condition. She explained that this could be useful when services are not co-located and where there aren't formal joint-working arrangements such as combined clinics. In Lynne's words, 'A good pharmacist who focuses on the biologics across a hospital can ensure co-ordination of treatment a lot of the time without the need for specialist consultants to meet together in MDTs [multidisciplinary teams].'

Co-location and joint-working

Consultants in one specialism need to develop a degree of knowledge in other inflammatory conditions, so that they can spot co-morbidities and know when to seek advice from other specialists. They also need to be able to access advice from other specialisms quickly to avoid delays in starting appropriate treatment. Helena Marzo-Ortega, the clinical lead for spondyloarthritis at Leeds Teaching Hospitals NHS Trust, highlighted the length of time it could take for consultants across specialisms to co-ordinate care through traditional channels. This included the delays associated with, for example, writing letters to other specialists and referring patients to other clinics. Without co-ordination mechanisms, a patient might need three separate appointments with different specialists. In these cases, developing a co-ordinated care plan might take years, as patients wait months to see specialists in different services.

At Leeds Teaching Hospitals NHS Trust, the main rheumatology and dermatology services are co-located on the same floor of Chapel Allerton Hospital. There is

also a rheumatology day-case unit that provides treatment care for patients of other specialties including gastroenterology and ophthalmology. This has helped consultants in different specialisms to develop close working relationships, speeding up discussion about patients with complex conditions. Christian Selinger, a gastroenterologist at the Trust, emphasised the importance of interacting with other specialists outside formal clinics, 'If somebody has rheumatoid arthritis and colitis, I will email the rheumatologists to say that I have diagnosed them. It might only take a day or two get a complete diagnosis. It relies on people knowing each other, being responsive, and not writing letters to whom it may concern in the rheumatology department.'

Co-location and closer joint-working allows specialists to gain expertise in other related disciplines. For example, the dermatologists and gastroenterologists become more skilled in assessing when to engage rheumatologists to determine whether somebody's joint pain is due to wear and tear or inflammation. At Leeds, the dermatologists have developed materials for the rheumatologists on diagnosis and treatment of common skin diseases in their patients. Both teams have worked together on teaching materials to be used interchangeably by staff in the different specialties.

Under these arrangements, consultants still need to be able to access rapid advice from other specialists. Interviewees were, overall, sceptical of the benefits of a generalist model for treating inflammatory diseases, given the complexities of individual inflammatory diseases. However, through close joint-working and learning about other diseases, consultants could speed up diagnosis of co-morbidities, avoid duplication in the process, and make better decisions on when to refer patients to other specialists. Joint-working also creates opportunities to share learning and innovation across specialisms. For example, rheumatologists, dermatologists and gastroenterologists use similar drugs, and are able to share new ways of administering and monitoring them.

Combined and parallel specialist clinics

Many of the services described in this paper run combined specialist clinics for patients with complex co-morbidities. For example, the consultant dermatologists at Salford Royal's specialist psoriasis clinic run a combined clinic with consultant rheumatologists for patients with severe forms of psoriasis and psoriatic arthritis. Other dermatology and rheumatology services refer patients into the service and the consultants at Salford Royal decide who needs to be seen in a combined clinic. At Leeds, the specialist spondyloarthritis service runs combined clinics including a weekly combined psoriasis and psoriatic arthritis clinic and a bi-monthly combined rheumatology and gastroenterology clinic.

These clinics appear to be hugely beneficial for patients with the most complex co-morbidities. However, only a relatively small proportion of patients really need to be seen by two specialists at the same time. There are substantial additional costs to having two consultants in the same room, rather than delivering separate consultations, with slower decision-making processes. Patients may also have to wait longer for appointments at these clinics, as there are fewer of them each year. This means it is important to use the clinics for patients who most need them, and to ensure there are also other co-ordination mechanisms.

Consultants at Leeds Teaching Hospitals NHS Trust run parallel rheumatology and dermatology clinics as part of the Trust's combined psoriatic service. The consultants see patients separately, avoiding the costs of having two consultants in the room. However, they run their clinics in parallel, meaning that the rheumatologists can take a patient to the dermatologists for an immediate opinion on a skin condition when needed. With these arrangements, Helena Marzo-Ortega explained that consultants could resolve problems that might otherwise take months if they relied on correspondence or sending people to combined clinics.

6 Insights for treatment of other long-term conditions

This paper has considered innovation at leading centres in the diagnosis and treatment of four rarer or less well-recognised long-term conditions. While there are some similarities between these conditions, they also raise very different challenges. Some are easier to diagnose using simple tests, while others require greater skill and experience and more complex diagnostics. For some of these conditions, there is a broad range of effective treatments. For others, there are narrow groups of available drugs that a proportion of patients do not respond to. Nevertheless, it was notable that there are many commonalities in how leading centres are innovating to improve care.

Speeding up diagnosis

Regarding diagnosis, these examples highlight some of the challenges and limitations of traditional approaches to improving diagnosis and speeding up referral to specialists in a system where GPs act as the gatekeepers to specialist services. The hospital specialists we interviewed for this project were sceptical of approaches to improving diagnosis that rely on raising awareness in primary care, particularly where diagnosis is challenging and patient numbers within individual primary care practices are small. Instead, these examples highlight the benefits of more proactive approaches to embed better diagnosis within primary care IT systems or proactive outreach by hospital services to find patients with these conditions. The benefits are clear, with many of these services substantially speeding up diagnosis and revealing unmet need. But of course, these services are also proliferating new clinics in an already fragmented system, with new small teams having occasional contact with patients and duplicating some activities.

Faster access to the right treatment

Some of these services highlight the benefits of persisting in cumulating small quality-improvement projects to strip out delays in testing, diagnosis and starting patients on treatment in hospital services. These services consistently highlight the need to provide intensive support for patients at earlier stages to avoid diseases worsening, rather than only providing intensive support at a point where irrevocable damage has occurred. They also highlight the need to move away from incremental approaches where services try therapies in rigid

sequences to approaches that aim to get patients on the most appropriate therapy as quickly as possible.

Flexible services for cyclical conditions

These services also describe some of the strategies that other services might follow to offer more flexible services. There has been agreement for many years that hospital services need to develop more responsive services for people with cyclical, relapsing and remitting long-term conditions. However, progress in making these changes is slow. Some of these examples highlight the combinations of changes needed to make the shift to responsive care, for example, hospital consultants keeping spare slots for flare clinics and seeing smaller numbers of patients with more complex conditions for routine follow up, while nurses see more patients for routine appointments while supporting others in self-management.

Guidelines and protocols

These examples raise questions about the role of guidelines, protocols and restrictions on decision-making and other tools of evidence-based medicine, at least in relation to some patients with these conditions. Most of our interviewees were enthusiastic about the benefits of high-quality management guidelines, providing they remain guidelines rather than protocols. However, it was less clear whether some restrictions on specialists' ability to exercise judgement in diagnosis and treatment reflected the latest scientific knowledge or delivered any other benefits, such as patient safety or reducing costs. These examples show consultants in England, in particular, navigating a complex bureaucracy to provide the best care for their patients. It is surely worth asking whether similar criticisms apply to guidelines and protocols for other diseases.

Psychosocial support

Our examples highlight the importance of bringing together biomedical care, support for mental health problems and social support for people with complex long-term conditions, where addressing psychosocial issues can be as important as prescribing the right medicines. Our examples describe some paths that other services might follow, for example, using scarce clinical psychologists to upskill consultants and specialist nurses in motivational interviewing, and identifying anxiety and depression. They also highlight the need for other changes to medical services so that consultants and nurses can give patients the time they need. Our examples also make clear just how difficult it is to shift from primarily biomedical services to services that provide holistic care, with a lack of recognition among commissioners and hospital managers of the case for broadening care.

Connections to other services

Our case studies also provide occasional examples of how hospital services can connect effectively with other forms of social support for patients, including social prescribing teams based in primary care. A few also show how services can harness the resources of patients themselves in peer support groups. In general, though, even the most advanced and innovative specialist hospital services seem disconnected from the services designed to support health and wellbeing. There has only been very limited adoption of peer support models that have proved successful for people with mental health challenges and for some long-term conditions in primary and community care. These are surely potential areas for future innovation.

Multidisciplinary care

Finally, these examples highlight some of the challenges of combining generalist, whole-person care with specialist support for complex conditions and supporting the increasing number of patients with complex co-morbidities, including multiple severe inflammatory conditions. The paper points to some of the strategies that might be adopted to address these complexities by minimising delays for patients and controlling costs, including the relatively simple reorganisation of hospital services to enable relationship-building, an easier flow of information, and informal joint-working between specialists for related conditions.

End note

Our case studies point to an alternative to traditional approaches to delivering specialist care for people with severe forms of some rarer or less well-recognised long-term conditions. Under this alternative approach, hospital specialists work more directly with communities, and in closer partnership with primary care, to speed up diagnosis, deliver more intensive upfront support for patients to help them manage their conditions, accelerate the process of putting patients with more severe conditions on more powerful therapies, and combine high-quality medical care with effective support for the psychosocial aspects of long-term conditions.

While there is broad agreement on the importance of many of these changes, our interviewees highlighted the challenges of making the transition from traditional models of care to these new approaches, for example, securing time and resources to deliver improvement projects and persuading wider systems to provide the resources to deliver more holistic care. The development of integrated care systems in the NHS, and other arrangements to enable more effective planning and co-ordination across services, may create opportunities to

accelerate this transition, for example, by enabling the redeployment of resources for the development of more effective joint-working across services.

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