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Cross-speciality collaborative care in complex immune-mediated inflammatory diseases: treating the person living with the condition

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Abstract

Background Immune-mediated inflammatory diseases (IMIDs) are a wide group of autoimmune conditions that share common inflammatory pathways, meaning that people with one IMID are at elevated risk of developing another. People living with IMIDs are at increased risk of co-morbidities and quality of life (QOL) is negatively impacted. The economic cost of IMIDs is high both in terms of healthcare resource and lost productivity. In particular, there is significant unmet need in terms of clinical outcomes and patient satisfaction for people living with complex IMID (multiple IMIDs, co-morbidities and people for whom IMID(s) have a significant impact on QOL).

Main body Existing clinical service models focused on single specialty management provide fragmented care caught between individual specialities with delays to decisions and treatment plans, with individual IMID specialities competing for the same scarce National Health Service (NHS) resources. This siloed approach often focuses on suppressing inflammatory activity which may not adequately address the range of impacts on the person living with IMID. These issues have prompted a movement towards collaborative cross-specialty care. A collaborative cross-specialty approach has the potential for sharing knowledge and resources, to ensure timely referral and diagnosis, more effective use of available time for clinical consultation and early recognition and treatment of concomitant IMIDs. Compared with a traditional siloed model, a cross-specialty approach was associated with QOL theme benefits including positive patient experience and perceived disease control. Involvement of a cross-specialty team and well-defined referral criteria are key to optimal collaborative cross-specialty working. Existing initiatives have shown that relatively small changes to existing practice and cross-speciality collaborative working can result in bespoke solutions, such as parallel clinics, combined clinics and multidisciplinary team (MDT) sessions, face-to-face or virtually depending on the individual needs. A patient-centric framework, with individualised care, helps to address multimorbidity whilst improving physical and mental well-being.

Conclusions The development of a cross-specialty service for complex IMID cases has the potential to reduce the number and length of consultations, and available data indicate that such innovations may improve clinical outcomes, patient experience and quality of care in a cost-effective manner and suggest wider societal benefits.

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Keywords Immune-mediated inflammatory diseases, Quality of life, Patient experience, Quality of care, Cross-specialty care, Service redesign

Background

Immune-mediated inflammatory diseases (IMIDs) are a wide group of autoimmune conditions that share common inflammatory pathways, resulting in systemic chronic inflammation and with potential for eventual tissue damage [1].

Overall there are more than 80 different IMIDs [2], which involve multiple disciplines including the following examples in distinct specialties such as Rheumatology (rheumatoid arthritis [RA], axial spondyloarthritis [AxSpA], psoriatic arthritis [PsA], systemic lupus erythematosus [SLE]), Gastroenterology (inflammatory bowel disease [IBD]: Crohn's disease [CD] and ulcerative colitis [UC]), Dermatology (psoriasis [PsO], atopic dermatitis [AD], hidradenitis suppurativa [HS]) and Ophthalmology (uveitis, scleritis).

Main text

IMIDs share common or overlapping genetic factors, environmental triggers, and pathophysiological mechanisms, a phenomenon known as autoimmune tautology [3]. In all IMIDs, the immune system is dysregulated resulting in an imbalance in inflammatory cytokines [4]. Many IMIDs cluster around signature inflammatory cytokines, for example interleukin (IL)−6 in RA, IL-23 in IBD, PsO and PsA, IL-17 in AxSpA, with tumour necrosis factor-α (TNF-α) as the common downstream effector in inflammatory arthritis and IBD [4, 5].

Around 5–7% of the population have IMID [6]; the shared pathobiological mechanisms of autoimmune-triggered inflammation means that IMIDs tend to cluster and people with one IMID are at elevated risk of developing another or others [2]. In one study of 1620 people with IBD, 39% had more than one IMID, with 11% reporting two or more additional IMIDs [7].

The risk of developing a secondary IMID depends on the primary IMID; a recent large retrospective matched cohort study found that the hazard ratio (HR) of developing a second IMID is as high as 62.2 for people with PsA and 31.4 for those with AxSpA ranging to 5.4 for people with HS [2]. There are also established links between IMID—for example between PsA and PsO, RA and IBD [2] and uveitis and AxSpA [8]. More than one-third of cases of uveitis are in people with an existing IMID [9].

Each IMID has a distinct risk profile for co-morbidities [10, 11], due in part to the inflammation associated with IMIDs. Co-morbidities include cardiovascular disease [10], obesity, metabolic syndrome, type 2 diabetes, non-alcoholic fatty liver disease, kidney disease and depression [12, 13]. The co-morbidities associated with IMIDs [13] have a considerable impact on people with IMID.

IMIDs have a deleterious impact on quality of life (QOL) [14], with far-reaching effects on presenteeism, absenteeism, social functioning and relationships. Concomitant IMIDs can result in a more aggressive disease course [15] and lead to additional co-morbidities [16], both of which impact still further on people's QOL, ability to work and live an active life [11, 17, 18].

Therapeutic aims for the management of IMIDs should be patient-centred, focusing on the needs and preferences of the patient [19]. Rapid control of inflammation ameliorates symptoms and prevents tissue damage, with an ideal aim of achieving long-term disease remission with an overarching goal of optimising QOL [6]. These goals have been facilitated in recent years by the availability of an expanded armamentarium of biologic or small-molecule immune-targeted therapies with proven efficacy to improve disease activity, and at the very least, to reduce the frequency and severity of flare-ups. Targeted therapies are routinely recommended in national and international consensus management guidelines [20–26]. However, the high cost of originator biologics and patented small molecules has resulted in restricted access in some health care economies [27, 28].

Despite these aspirational treatment goals, only a minority of patients achieve and sustain remission, organ integrity is not always preserved and QOL remains suboptimal in these patients [29]. This is particularly the case in people with complex disease, which includes those with multiple IMIDs, co-morbidities and people for whom IMID(s) have a significant impact on their QOL. Optimal management can be challenging for people with complex disease and the coordinated involvement of several different health specialities is frequently required [30]. Indeed, we suggest that the definition of complex disease should include those people whose disease expression encompasses more than one traditional specialty domain and where cross-specialty expertise offers the best opportunity to ameliorate the range of disease impacts on such an individual's QOL and thus optimises achievable outcomes. Identification of complex disease should be made as early as possible by an expert clinician taking into account the range and severity of IMID features, co-morbidities and their impact on QOL and daily life.

However, typically, each IMID condition is primarily managed within a single speciality service, requiring multiple consultations, and collaboration between specialties can be challenging [30]. This siloed approach often focuses on suppressing inflammatory disease activity which, whilst beneficial symptomatically, may not adequately address the range of disease impacts on the person living with IMID [31]. For example, people with IMID may reach their treatment targets suggesting disease control, yet continue to experience debilitating symptoms such as pain and fatigue—which impact on QOL [32]. Furthermore, patients may reach their treatment target for the IMID within the specialty they are being treated, but co-existing IMID(s) may be unrecognised and untreated. Treatments used successfully within one specialty may be suboptimal in another, for example paradoxical provocation of uveitis by the anti-TNF, etanercept, despite its efficacy in rheumatology and dermatology [33].

Indeed, with a siloed approach, people with multiple IMID report poor continuity of care and the paucity of inter-specialty communication means that patients themselves may need to convey information between specialties potentially resulting in misunderstanding, contradictory information, unnecessary additional consultation time and delayed diagnosis [34].

Recognition of the need to address these challenges in managing complex IMID has prompted a movement towards collaborative cross-specialty care [30, 35–40]. Such an approach has the potential not only for sharing knowledge, but also resources, to ensure timely referral and diagnosis, more effective use of available time for clinical consultation and early recognition and treatment of concomitant IMIDs. Therefore, optimising management approaches to achieve the best possible QOL and high patient satisfaction [30, 41].

Comparison of the patient experience with the traditional 'specialist' approach, where services are organised within a single speciality, and a cross-specialty approach demonstrates advantages with the cross-specialty approach in terms of QOL theme benefits. A qualitative study comparing the traditional and cross-specialty approach revealed benefits including perceived disease control and positive experience of shared decision-making, understanding of disease and patients' role in disease management, together with feelings of security and being met by health care professionals (HCPs) with respect and understanding [42]. A recent single-centre observational study carried out in Italy found that a dedicated IMID clinic significantly reduced diagnostic delay of an additional IMID in people with IBD by almost 3 months compared with conventional single specialist referral, resulting in significantly earlier treatment interventions [40].

Empowering and educating patients is an important element of patient-centred care and is crucial to ensure the best outcomes, as increased understanding is necessary to improve self-management [43]. Involving patients in the decision-making process ensures that their voices are heard and validated, resulting in a deeper understanding of their condition(s), empowerment in self-management strategies and ensuring the acceptability to the individual of the anticipated benefit/risk ratio of pharmacotherapeutic intervention [42]. Work with patients with IMID or metabolic disease at Barts Health NHS Trust gives a clear insight into what patients want and need from such a service.

Overall, 41 patients (63% women, 76% with > 2 years of care at Barts) were recruited via clinical teams or at their clinic visits and interviewed via telephone/video call or during clinic visits. Of the participants, 22 (54%) had IMID, ranging from the more common (IBD, psoriasis, RA) to rarer conditions (chronic inflammatory demyelinating polyneuropathy, lupus, myasthenia gravis, sarcoidosis).

Following these patient interviews, two workshops were held with 14 patients and ten HCPs, facilitated by the Patients Association (https://www.patients-association.org.uk/). Participants discussed and reflected on patient stories captured during the earlier interviews and pulled out key themes. Three key themes emerged: need for holistic care, support and self-management (emotional, nutrition, lifestyle, physical support and tools for self-management), cross-specialty and cross-organisation working (pharmacy support, cross-specialty and General Practice-Specialist links, access to urgent care) and improved appointments, communication and information (timing of appointments, records and information sharing, clear contact points, language support). Participants were then asked to imagine what it would be like if they could design the ideal centre for people with inflammatory and metabolic conditions (see Fig. 1).

The aim at Barts Health NHS Trust is to implement these patient insights in a new collaborative care model, which will include a team of patient navigators and support workers to streamline and help patients with appointments, dedicated time for joined up cross-specialty working, a holistic care team (physiotherapy, dieticians, clinical psychologist), access to apps to view appointments and test results, tailored training programmes to support all stakeholders, research/data collection and information technology support to link patient data across the Trust.

Engaging with the appropriate range of clinical expertise is crucial to develop individualised treatment and

Fig. 1 Patients' views on the ideal inflammatory service, reproduced with permission from the Patients Association. Patient views on the ideal inflammatory service, with cartoons and quotes denoting patient views on specific questions, including if you could have one thing, what would it be? How will the centre make you feel? What will be there? What will it look like? What opportunities will staff be given? How will you communicate with the centre?

care ensuring that risk/benefit ratios are optimised. Involvement of a cross-specialty team and well-defined referral criteria have been identified as key to optimal collaborative cross-specialty working [30, 44]. An IMID coordinator scheduling patients for review in IMID clinic can be helpful; alternatively one specialty, potentially the one with the greatest disease burden, can take ownership of the patient's treatment pathway and responsibility for cross-specialty liaison.

Small changes to existing practice and cross-speciality collaborative working allow for bespoke treatment solutions, which might include parallel clinics, combined clinics and multidisciplinary team (MDT) sessions, face-to-face or virtually depending on the needs of the person with complex IMID [41]. Individualising care is key to allow a patient-centric framework, addressing multimorbidity and also improving mood and well-being, pain and fatigue [45]. Once a service is in place, it is important to ensure it is sustainable and can withstand staff turnover to ensure equitable care and continued staff development.

Expanding knowledge and understanding beyond specialties will also create opportunities for clinicians to develop true patient-centred care [46]. This requires training to enable identification of complex disease and to better research and understand the link between pathobiology and symptomology in such a way as to inform optimum targeted therapy strategies for individual needs. This might include fostering cross-specialty clinical reviews, in-house upskilling across specialities and highlighting the importance of early disease identification by linking to Primary Care.

Some units across the UK have recognised the challenge of treating people with complex IMID and developed new ways of working. Three examples are discussed briefly below, two are established services (Leeds and Newcastle), with the other in development.

The Leeds Combined Psoriatic Service is a model of care which runs three weekly parallel Rheumatology and Dermatology clinics (two for PsO/PsA and one for connective tissue disease), with close links to Gastroenterology, Obstetrics and Ophthalmology. A monthly clinic with Gastroenterology allows patients with PsO, PsA and IBD to be seen by three specialists in the same outpatient clinic and bi-monthly clinic with Obstetrics provides support for pregnant and post-partum women. The service has access to specialist ultrasound, physiotherapy, podiatry and occupational health input on demand and a part-time youth worker provides support to newly diagnosed young adults or patients transitioning from Paediatrics [47]. The service demonstrated considerable savings, avoiding 96 separate outpatient appointments, with an estimated saving of £24,600 over a 22-month period between May 2018 and February 2020. Over the same period, new diagnoses were given in 44% (73/144) of patients and almost one-third (30%, 49/166) of patients had a change in treatment plan as a result of the attending the combined service [47]. The Leeds Combined Psoriatic Service found that the number of people with IMID requiring cross-speciality care was less than 3%, suggesting a manageable increase in workload [47].

The Newcastle Gastroenterology and Dermatology clinic is held every 3 months and allows patients to be reviewed jointly by a gastroenterologist and a dermatologist [48]. Data from 10 clinics ($n=44$) revealed all patients had a dermatology diagnosis (PsO, AD, HS, cutaneous CD, pyoderma gangrenosum) with 89% also having IBD. Patient survey responses were positive with a median satisfaction score of 50/50; proactive decision-making across both IMIDs at one appointment was particularly valued [48].

Barts Health NHS Trust is currently developing a new care model for people with IMID, comprising a patient-oriented functional structure which integrates HCP around IMID diseases in a coordinated way, with the common goal of making effective use of available resources and improving both the patient experience and health outcomes.

Cross-specialty care may require that additional expertise is co-opted on an 'as required' basis, rather than on a more formal combined service. For example, ophthalmology expertise may be needed for IMID-related ocular complications which can be serious (due to the unforgiving nature of delicate ocular tissue with regard to ocular inflammation) with considerable impact on QOL. Similarly psychological support can improve patient-centred care and increase adherence [30].

In the UK, the National Institute for Health and Care Excellence (NICE) recommendations for spondyloarthritis [49] endorse the need for a cross-specialty approach, as do recent Consensus Guidelines for the management of PsA and its co-morbidities [50]. The Consensus Guidelines also note that there is room for improvement in collaborative working, and that in PsA there is a pressing need to find a balance between treatment of the joints and the skin to maximise patient QOL [50]. A UK survey of Dermatology and Rheumatology HCPs involved in the management of PsO and PsA carried out between 2020 and 2021 found that most respondents (75%) worked collaboratively with at least one other speciality, including joint clinics (25%), email (25%) and other approaches including parallel clinics, MDT meetings (with and without patients) and virtual combined clinics. Although this is encouraging, one-quarter of HCPs did not collaborate across specialties at all [41]. Furthermore, many people with multiple IMID are not aware that they have multiple IMID [7], meaning that patient-led management is suboptimal in many cases.

Drivers to collaborative cross-specialty working include HCP's desire to share knowledge, improve patient outcomes and patient satisfaction [41]. Recent government proposals, such as the Getting It Right First Time (GIRFT) programme, which focuses on sharing insights and best practice to improve efficiency and patient care, support the collaborative interdisciplinary approach.

Barriers to collaborative cross-specialty working include lack of time within current role, logistics and unsupportive senior management—rated in a recent UK survey as difficult/very difficult by 78.8%, 67.5% and 66.3% of respondents respectively [41]. Funding streams, which often determine the organisation of services, and finding willing collaborators across disciplines can also be challenging [41].

Overcoming barriers can be demanding; however, engagement with all stakeholders including Primary Care, together with a focus on additional benefits (staff satisfaction and development, economic benefits), can support change. It will be important to ensure continued education of HCPs, as well as changes in service delivery, to ensure that HCPs are confident in delivering cross-speciality care.

Meticulous planning, looking at the needs of the local community and gaps in provision and how they might be filled, is essential when considering the change to collaborative cross-specialty working [44]. Physical and organisational surroundings, psychologically supportive environment and appropriate education and training are all important in promoting collaborative practice [51]. A new integrated care model for people with IMID found that involving both hospital management at director level and the local health service was key to successful implementation. A School of Patients was also developed to improve self-care and QOL of people with IMIDs

through teaching and learning and the provision of an app with digital tools to facilitate self-care and communication between patients and their HCP [39]. There is a potential role for many of the excellent patient organisations to be proactively involved and contribute to such initiatives. Examples include the National Rheumatoid Arthritis Society (NRAS), the National Axial Spondyloarthritis Society (NASS), Crohn's & Colitis UK (CCUK), Psoriasis Association, Birdshot Uveitis Society and Olivia's Vision. The initiatives discussed herewith have tended to take place in large hospitals, with experience in implementing change [39, 40, 47, 48]. Clearly, change will be more challenging in less resource-rich settings or smaller hospitals. However, in the experience of the authors, relatively straightforward changes in clinic organisation can often be undertaken to ensure that the needs of people living with complex IMID can be optimally addressed with a multidisciplinary clinic frequency set according to the prevalence of these conditions within the population served by a given hospital.

There is a movement towards collaborative cross-speciality care and the evidence base is evolving as services develop and mature. Large-scale longitudinal data and randomised controlled trials, including patient-reported outcome measures including QOL, are awaited to validate the efficacy of this approach in practice. A pragmatic randomised trial (NCT04200690) looking at the effectiveness of interdisciplinary combined care (Dermatology–Gastroenterology–Rheumatology) vs a siloed approach in people with more than one IMID is currently underway. The primary outcome is the change from baseline to 24 weeks on the Short-Form Health Survey (SF-36) Physical Component Summary with other outcomes including patient-reported outcomes and clinical outcomes [34]. Further research is important to capture the benefits (and challenges) of collaborative multidisciplinary care to help guide and support appropriate HCP education and evolving practice. Continued collaboration between patients, HCP and the healthcare system is essential to ensure that practice continues to evolve and improve.

Conclusions

The issues raised in this debate article highlight the significant unmet need for people living with complex IMID in terms of clinical outcomes and patient satisfaction. Furthermore, the economic cost of IMIDs is high both in terms of healthcare resource and lost productivity. Existing clinical service models that are focused on single specialty care provide fragmented care caught between individual specialities with delays to decisions and treatment plans, with individual IMID specialities competing for the same scarce National Health Service (NHS) resources. The development of a cross-specialty service for complex IMID cases has the potential to reduce duplicate consultations and the number and length of consultations, and may shorten diagnostic delay, with possible improvements in patient self-management and work productivity, which could result in cost savings. Available data indicate that such innovations may improve clinical outcomes, patient experience and quality of care in a cost-effective manner and suggest wider societal benefits. There is a need for health policy support—for example funding models, service reorganisation incentives, training programmes, sharing of best practice to scale and sustain these approaches in routine practice.

Abbreviations

AD	Atopic dermatitis
AxSpA	Axial spondyloarthritis
CCUK	Crohn's & Colitis UK
CD	Crohn's disease
GIRFT	Getting It Right First Time
HCP	Health care professional
HR	Hazard ratio
HS	Hidradenitis suppurativa
IBD	Inflammatory bowel disease
IL	Interleukin
IMID	Immune-mediated inflammatory disease
MDT	Multidisciplinary team
NASS	National Axial Spondyloarthritis Society
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NRAS	National Rheumatoid Arthritis Society
PsA	Psoriatic arthritis
PsO	Psoriasis
QOL	Quality of life
RA	Rheumatoid arthritis
SF-36	Short-Form Health Survey
SLE	Systemic lupus erythematosus
TNF-α	Tumour necrosis factor-α
UC	Ulcerative colitis

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

We did not consider the patient feedback workshops to be research. These were designed to give patient and staff an opportunity to feedback about the current service. There were no fixed protocols or criteria. As such (and in line with the NHS research services guidance, which can be found at https://www.hra-decisiontools.org.uk/ethics/index.html), we did not need to seek ethics approval.

Consent for publication
Not applicable.

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