The Polymyalgia Paradox: Addressing north-south inequities in polymyalgia rheumatica using grassroots community connectors in a deprived urban area.

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Plain English Summary

Background

Polymyalgia rheumatica (PMR) is a common cause of severe body pain in older people. PMR is treated with long-term glucocorticoids (“steroids”). Clinicians are concerned about the potential health impacts of PMR and its treatment. The charity PMRGCAuk (Polymyalgia Rheumatica and Giant Cell Arteritis UK) has fewer support groups in the North of England compared to the South.

Aims of the Project

We aimed to find out more about things that can make it difficult for people with PMR to get the diagnosis, care and support that they need.

Methods

A Northern Outreach Lead surveyed charity members. People with PMR made short videos about their experience https://pmrgca.org.uk/get-support/your-stories. These videos inspired further discussions between people living with PMR and professionals, held both in-person and online. We evaluated our project to help us reflect on what worked and what didn’t.

Key Findings

- What professionals say about PMR does not always make sense to patients.
- Having PMR can contribute to social isolation and a sense of feeling alone.
- Not all patients are getting the help and support they need.

Patient and public involvement (PPI)

Using local expertise, we sought to move from “consultative” PPI towards a partnership approach.

Future plans

We will build on this partnership to raise public awareness; to challenge PMR myths and misinformation; and to improve education and support for all clinicians who look after patients with PMR.

Description of Research

Note on terminology: this project involved multi-stakeholder engagement of two main groups: “patients” and “professionals”. By “patients” we mean people who have experienced polymyalgia rheumatica (PMR) in their personal lives. “Professionals” comprised those who have expertise in PMR as part of their clinical/research roles. Many of these and others, including charity employees and PPIE professionals, had links with other more diverse groups including well-established community groups. Many project team members had dual/boundary-spanning roles. The reason for highlighting the patient-professional distinction in this report is because this is historically where the power imbalance has been the strongest.

PMR is an inflammatory musculoskeletal disease, causing widespread pain and stiffness. PMR has an average age of onset about 75 years; two-thirds of patients are female (Mackie SL et al. 2013). The prevalence of PMR is up to 2% in people over-55 (Partington et al. 2018). It is treated in primary care with long-term oral glucocorticoids (corticosteroids, “steroids”) (Espígol-Frigolé G et al. 2023). Primary care database studies showed that age-standardised diagnosis rates are higher in the South and East of England compared to the North (Smeeth L et al. 2006; Partington RJ et al. 2018). At a global scale, however, PMR is commoner in countries lying at greater distances from the equator (Kermani TA, Warrington KJ, 2014, Lundberg IE et al. 2022). This apparently paradoxical observation served as the trigger to begin conversations about how much we really know about PMR.

Established in 2008, PMRGCAuk is the leading UK charity providing support to patients with PMR and GCA. Most of its local support groups are in the South and East of England (https://pmrgca.org.uk/get-support/groups/) with just one in Yorkshire. PMRGCAuk also moderates an online forum (https://healthunlocked.com). The informal community has accumulated collective knowledge of a different kind to clinical knowledge. For many, online resources are more accessible than advice from healthcare professionals. Given the disparities in access both to clinical diagnosis and to in-person voluntary support, we situated this project in the North of England, seeking to explore new ways of working in partnership to uncover the complex factors influencing patient experience, treatment and outcomes in a rarely-discussed disease.

Methods

Video Creation

Initially the Northern Outreach Lead (NOL) surveyed PMRGCAuk members about their route to PMR diagnosis. The NOL created a guide for members how to self-record video stories about their experience of PMR. These were used to create short videos themed around key topics in PMR, fact-checked by the project team. These videos were critiqued by a group of public contributors supported by Dr Hanif Ismail, and by the Yorkshire PMRGCAuk Support Group.

Building Connections

The NOL played the videos to community groups in urban under-served areas to discuss PMR. The NOL also connected with a local Men’s Health Network, and we also consulted a Men’s Health researcher for advice on inclusion of men.

Patient and Public Involvement
PPI activities were designed to create the space for people to surface their own research questions about PMR, arising from their own lived experience. An in-person PPI session was convened by the Leeds Biomedical Research Centre PPI team, using "data cartomancy" https://catswetel.com/blog/2023/7/30/data-cartomancy. PMRGCAuk put out a shout-out for a virtual PPI focus group via an article in its newsletter Newswire.

Multi-Stakeholder Meetings
Multi-stakeholder meetings were designed to allow personal connections across key stakeholder groups (patients, primary care, specialists). The methods were chosen to generate "aporia" (a recognition that we do not know enough about a situation to come to a decision) that might allow routes out of entrenched positions (Rancati and Snowden, 2021; Snowden, 2024).

An in-person all-day workshop "PMR, A Call to Action" was held on 11th February, 2025 in Leeds. The workshop used principles of experience-based co-design (Raynor et al., 2020) using our video to "trigger" or frame discussions around lived experience. We added in other activities with various degrees of structure, including shared food, small-group work, an invented game "Answer a Question with a Question", and in a final plenary we used a simplified version of Estuarine Mapping (https://cynefin.io/wiki/Estuarine_framework) to discuss and position everyone's ideas on a "map" according to resource/time required.

Meanwhile, we held two series of virtual meetings with two mixed groups each comprising 4-8 patients and professionals. One group met on Monday and one on a Friday. Each group had four 30-minute meetings. The groups worked on Wardley maps (Wardley, 2016) to explore what patients and clinicians need, how those needs are currently met, and finally discussing priorities for where limited resources should be invested.

Reflection
Throughout the project Sarah Mackie kept field notes (observations, reflections) in a notebook. Before and after the multi-stakeholder phase, the core project team met virtually to reflect on the project using "Generative Dialogue" workshops (Mistry et al, 2022) that were recorded to support the evaluation.

Dissemination Week
We showcased our creative outputs in an in-person meeting on 18.03.2025 from 12-3 at SJUH, two virtual meetings and a Padlet allowing asynchronous engagement on 19.03.2025 and 21.03.2025. This allowed all attendees to contribute and discuss ideas for impact. A new poem, *Things We Have Heard About PMR*, was performed.

Evaluation
A formal evaluation was done by a post-doctoral researcher not otherwise involved with the project. This was the only formal qualitative research of this project and involved 1:1 qualitative interviews with project team members, recorded, transcribed and thematically analysed (appendix 1).

Findings
The findings listed here are collated from field notes and conversations amongst the project team; they are examples of insights that emerged from the partnership as it developed. They should all be considered subjective, provisional, and hypothesis-generating rather than definitive.

1. *Why is there a paradoxical UK North-South divide in PMR?*

Although there is a UK North-South divide in both PMR diagnosis rates and support group numbers, they are not necessarily caused by the same factors (1a, 1b). We discussed potential explanations with clinicians, researchers and patients.

1a. Factors proposed to explain higher diagnosis rates in the South

- Longer life expectancy in the South: If there are more older people in the South, PMR will occur more frequently, so may be recognized faster.
- Longer healthspan in the South: Less diagnostic overshadowing makes it easier to recognise the symptoms of PMR.
- Social capital: More privileged people can better navigate the system and "push" for a diagnosis.
- Values of stoicism and self-reliance: Yorkshire public contributors liked the explanation "Northern people are tougher".
- Different expectations of what ageing entails: In the member survey, more PMRGCAuk members in the North had initially thought their PMR symptoms were due to "getting old".
- Biological causes: Some public contributors proposed "genetics" as a reason for the North-South disparity, signalling curiosity about PMR's unknown biological causes.

1b. Histories of the Northern PMRGCAuk support groups
Charity members told us "origin stories" about how their groups were found. The charity PMRGCAuk itself was registered in London in 2009 after a taxi journey from the Northeast to London (The Free Library, 2008); there was already a separate charity in the Northeast (2010-2019). The Yorkshire Support Group was founded in 2017 by two members who met at a Wellcome-funded PMRGCAuk "research roadshow" at Chapel Allerton Hospital, Leeds. The charity staff told us that email campaigns saying "there are people in your area who also have PMR" did not seem to trigger group formation: in-person encounters seemed necessary to "seed" a group. Once established, however, many local groups now offer options to meet on Zoom as well.

2. Wandering in the mist

The project started in autumn 2023 and was slow to find direction at first (a team member later called this "wandering in the mist"). This was compounded by an initial strategy of "hybrid" team meetings: both in the sense of mixing virtual and in-person, and in the sense of mixing people accustomed to Zoom "support group" social conventions with other people more accustomed to "committee meeting" social conventions. As the project unfolded, we began to uncover some assumptions we had made during the project planning phase.

2a. From "barriers" to dynamic complex systems

The word “barrier” implies a thing that should not exist and needs dismantling, like a roadblock. But not all barriers are the same. Some barriers are immovable features of the landscape, others are more dynamic and may be unstable or self-reinforcing. “Barriers” show up as a mismatch of service provision to user need but may have their roots in multiple interacting factors. As the situation had elements of complexity (Plsek and Greenhalgh, 2001) we tried several methods in parallel in order to capture multiple perspectives, recognising that no single method is guaranteed to find a solution (Greenhalgh and Papoutsi, 2018).

2b. Whose needs were we serving by wanting to engage with under-served groups?
We held meetings with under-served groups in the community, to explore their reactions to the video that had been made. Our project took place during a cost-of-living crisis, in which immediate needs were foremost in people’s minds. Given the history of exploitation of minoritized groups by extractive industries, we would have needed far more time and resource to engage meaningfully with these groups and so we focused on patients instead.

2c. Isolation and miscommunication
Our original conception of “societal inattention” to PMR gained added depth. One patient said that PMR is an “isolating disease”: its invisible symptoms (pain, stiffness, fatigue) make it hard to participate in work or family life. The extent of social isolation produced challenges for a project seeking to create a partnership. Only a minority of people diagnosed with PMR join the charity. Inevitably by engaging with charity members we were not engaging with a representative sample of PMR patients. On the positive side, the local Support Group as a self-organising network supports its members, which may have made it easier for them to engage with us than if they did this alone. “Being seen” in person by one’s own doctor was generally seen as a positive thing on both sides; if these interactions did not go well, this could exacerbate the feeling of separation and isolation.

We discovered that healthcare professionals play their own role in dismissing or minimizing patient symptoms. “Invisible” diseases without clear physical signs or reliable blood tests tend to have lower “disease prestige” (Dhairyawan, 2025). Many patients with chronic, relapsing PMR experienced distress perceiving that their clinicians wanted them to be off steroids within two years when this was not possible for them. The videos highlighted the diversity of experiences while framing them positively https://pmrgca.org.uk/people-with-pmr-share-their-video-stories/.

It is now normal for individuals with a new diagnosis to “go online” to educate themselves and this is encouraged due to demand management by health services (e.g. appointment shortages). However social media algorithms (e.g. Facebook, YouTube) and AI can amplify negative sentiments and spread misinformation, including promotions from “wellness” influencers where words like “steroids”, “adrenal” and “inflammation” are used differently from their clinical meanings. The PMRGCAuk forum on HealthUnlocked is moderated and benefits from “expert patients” who attempt to counter misinformation when they see it.

Since the clinical and patient communities are isolated from each other, mutual misunderstandings can occur. The NICE Clinical Knowledge Summaries (CKS) webpages on PMR were accessed by many GPs and some patients but were interpreted in many

ways, and patients tended to learn from their own experiences of healthcare consultations; in which clinicians would try to deprescribe steroids. This could lead to conflict.

Lack of a good alternative to steroid treatment compounded non-communication: patients may not feel their GP can offer them anything more than steroids, so may learn not to consult; and GPs may not feel rheumatologists will offer anything more than steroids (and may even attempt to withdraw steroids in “atypical” cases), so may learn not to refer. GPs particularly highlighted challenges managing ongoing pain in younger patients or those with normal blood tests.

As the project unfolded, conversations became richer and more nuanced, and diverse views appeared. Some workshop discussions revealed a tension between “doing better with what we have” (in the now) and “research/innovation” (hope for the future); different individuals prioritized one or the other.

3. Strategies to incorporate diverse perspectives

3a. Including men
Having discovered the under-representation of men in the charity and in PPI work, we explicitly invited men to take part in the multi-stakeholder workshops. Men tend to approach problems in different ways to women (Flury C, 2024).

3b. Talking with each other, not about each other
Isolation and miscommunication has led to siloed communities (patient, primary care, secondary care) each with their own expertise rooted in experience or practice. Digital technologies have helped others find people like them, while potentially loosening ties to geographical places and increasing reliance on text-based communication. Transport and work/life constraints made meetings difficult to arrange. In the end, a partial solution involved offering several options and taking a flexible approach to attendance, with video meeting summaries created between meetings. While providing a safe space to discuss problems, the multi-stakeholder meetings helped identify good practices, enabling discussions about what actions could be taken to help the existing good practices spread more widely.

4. Evaluation

The evaluation explored team members’ perceptions about the project. Within the project team, negotiating (co-)leadership and achieving common understanding of individual priorities took time to stabilise. In using digital “fixes” to challenges with transport and scheduling of project team meetings, in-person relationship-building took longer than we had envisaged. As the project developed, goals of each stakeholder group were clarified, and this enabled future work to be planned.

Conclusions

PMR is a common disease of older people, treated mostly in the community, with rheumatology input reserved for more complex cases. The “topic” published by NICE Clinical Knowledge Summaries (Clarity Informatics Limited, 2024), publicly accessible online, states that this is “largely based on [the 2009 British Society for Rheumatology guideline]”; this appears to give an impression of a straightforward, self-limiting disease with a standardised treatment regimen.

However, the pace of recent changes to UK healthcare, including access challenges and remote and digital care, may have destabilised pathways whose inbuilt safety-nets relied on assumptions of continuity of care, an abundance of appointments, good informal links between primary and secondary care, and a historic “doctor knows best” culture amongst older generations. Outdated or unclear clinical pathways, combined with low public awareness, the paucity of accessible information and lack of research done into PMR, has caused some patients to feel isolated and unsupported. It is now commonplace for all age groups to “go online”; we heard many instances of online peer support via forums having positive or even transformational effects for patients who had been struggling through dark times with PMR. However, information found online is not always reliable, and there appeared to be a need for clinicians to be more pro-active about supporting patients with PMR, and indeed for rheumatologists to be more pro-active about supporting GPs when needed. Fear that glucocorticoids will be tapered/stopped is an incentive for non-consultation/non-referral that exacerbates the situation.

Shared decision making is a core principle of good care. However, shared decisions about glucocorticoid dosing rely on having sufficient shared understanding. Lack of clarity about what causes PMR and overly hopeful messaging about how long it may take to “go away” can widen the communication gap. Patients may fear PMR relapses or evolution to giant cell arteritis; this may push them towards over-medication. Conversely, clinicians may fear that glucocorticoids will do serious harm or that the treatment may be masking other conditions; this may push them towards trying to minimize medication. Each perspective appears reasonable; both are driven by the lack of a perceived alternative to glucocorticoids in PMR, whereas most other overlapping conditions have effective non-glucocorticoid treatments.

Credit for the project’s successes goes to everyone who took part, juggling multiple responsibilities to contribute their time and energy to the project. Some of the patients came from in-person or online groups/communities and some were not affiliated with any group; members of the public provided novel perspectives; and clinicians generously contributed their time and expertise in a difficult area. It takes time to rebuild bridges. We tried to choose facilitation methods that could deal with power/status differentials, hold space for differing perspectives and opinions, and give individuals the chance to express empathy for the difficult situations faced by others. Some personal stories were very hard to hear, and the semi-abstraction of maps and poems helped us in our collective task of establishing common language, challenging assumptions and working together towards shared goals of making things better for patients with PMR.

Patient and Public Involvement

Aim

This project was centred around patient and public involvement (PPI), and in order to do this well, we sought to engage with patients and the public throughout the project.

Methods

During the first months of the project, our lay co-applicants attended hybrid/virtual project team meetings and talked about their lived experience, providing context and direction for the project team as it moved forward. Informal links with the local Yorkshire Support Group were created from the start of the project and the Northern Outreach Lead (NOL) continued to engage with the group throughout. The development of the videos for public engagement benefited from feedback received from a PPI group of lay volunteers from diverse backgrounds. People with lived experience of PMR were also involved in the multi-stakeholder workshops that are described in other sections of this report. PPI events were supported by PPI professionals including co-applicant Hanif Ismail at Leeds Teaching Hospitals NHS Trust and the PPI team at the Leeds Biomedical Research Centre, who ensured that PPI was conducted according to the relevant policies including appropriate recognition payments. We sought to respect individual stories and yet avoid assuming that all experiences are shared. Difficult encounters with healthcare services can create trauma for patients, and the “shadow side” of PMR can be difficult to speak of. Peer and professional support are necessary both for speakers and listeners in these situations.

Results

The pace of the project began very slowly and accelerated towards the end. Gradually we moved from large formal meetings to smaller task-focused groups and used emails to share updates and plans. Engaging with the general public proved an extremely steep learning curve for us as a project team, even with the assistance of community connectors. We adapted strategies based on feedback; for example, not all attendees could read the text in the videos. Research ideas generated in Data Cartomancy were shared back with all participants and shared further at the Dissemination events, without ranking or selection. The “PMR Village Hall” participants demonstrated high literacy in using Zoom, and what was intended as a focus group resembled a panel discussion of experts, discussing controversial and complex topics in a nuanced and insightful way. Because of the depth and scope of discussions, we asked their permission to share the recording with other PMR researchers outside the project team, to which they kindly agreed.

Discussion and Conclusions

The project moved from PPI to multi-stakeholder work, and there was some confusion at times whether the professionals attending the multi-stakeholder meetings were “part of the research team” or “invited participants”; most held a status somewhere in between these two. The PPI specialists used their skills to manage power differentials within and between stakeholder groups. Patients too had diverse backgrounds and motivations for getting involved in the project; some had themselves worked in research or healthcare. Although “patient” and “professional” groups each had their own conventions and customs of thinking and talking, the conversations between patients and professionals helped to build bridges and appreciate the other’s perspectives. We would also like to acknowledge the time and

effort it took towards building confidence and trust, as well as capabilities within patient and all the other stakeholder groups to support each other.

Critical Reflexivity
Divergent opinions and dissent can signal important gaps but need skilled facilitation and it is never possible to entirely eliminate power differentials. It must be acknowledged that what was generated could only be a partial, provisional perspective and that the biases of the project team inevitably influenced what was produced.

Data Sharing

Data from the interviews conducted as part of the evaluation, in line with best practice for publicly funded research, will be uploaded, anonymised, to Research Data Leeds for transparency and to support further related research. Only researchers who agree to preserve the anonymity of the data will be granted access. We will not share data that may identify individuals or organizations.

The recording from the PMR Village Hall Zoom is stored on a University of Leeds OneDrive account. It can currently be accessed only by members of the research team. Participants agreed for it to be made available to *bona fide* researchers in PMR. Researchers who wish to access it may contact s.l.mackie@leeds.ac.uk.

The onlinewardleymaps code used to generate the Wardley maps is freely available to any person on request to s.l.mackie@leeds.ac.uk and will also be uploaded to Research Data Leeds.

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