Mapping for Better Care

RHEUMAPS

Supporting service planning for people with rheumatic and musculoskeletal conditions

Executive summary

February 2025

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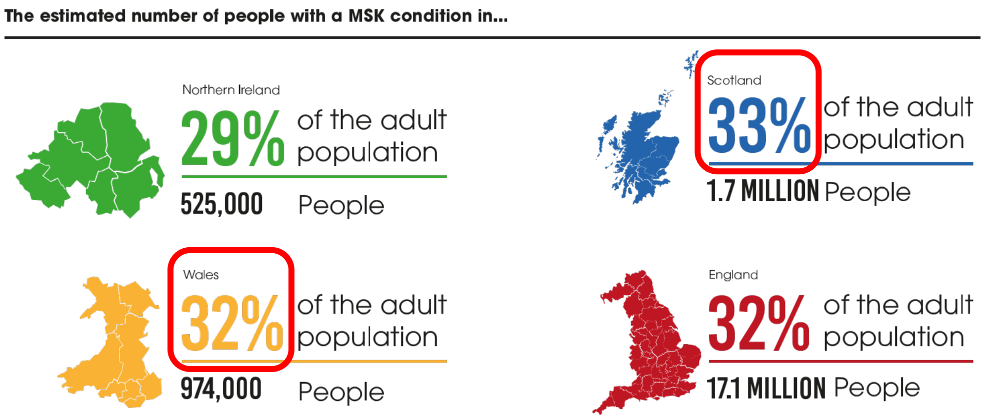
Rationale for study

Around one third of the UK population live with a rheumatic and musculoskeletal disorder (RMD). Diagnostic and treatment delays are associated with poorer outcomes; however, national audits have highlighted significant unwanted variations in access to care and outcomes for people with RMDs across the UK. This is shaped by many factors including individual characteristics (e.g., socio-demographic), and place-based attributes.



From Versus Arthritis '[The State of Musculoskeletal Health 2023](#)'

For example, around **one-fifth of the UK population lives in rural areas**, where the combination of geography, the centralisation of services in large urban centres and a population that is ageing more rapidly than the national average can create challenges for delivering timely and equitable healthcare services. This is compounded by local variations in workforce and the accessibility of health and care-related resources.

MSK services are delivered differently in different places...

Recognising the unwanted variation in care and health inequalities in RMDs, there is a **drive to better support local services to meet the needs of their local population**. To do so we first need to understand individual priorities for care, the existence and extent of any geographical differences in prevalence and health outcomes. For example, in each area, **how many people are there with RMDs, what is the current service provision and to what extent do these services enable people living with RMDs to meet their care priorities**?

However, **this is challenging on several levels**:

Firstly, most of the evidence on patient priorities for care is focused on **specific conditions and symptoms** as opposed to components of services needed to meet these priorities.

Secondly, existing planning tools commonly **estimate geographical prevalence** by extrapolating data from other populations. To date, the prevalence and health outcomes for those living with RMDs in different geographical areas is largely unquantified.

Routinely collected healthcare data offers an opportunity to measure actual burden of disease within a given population. However, **much of the data we have is patchy** and **collected by different systems** that **do not talk to each other**. Some RMDs (e.g., osteoarthritis) are looked after mainly in primary and community care, whereas others such as inflammatory arthritis and rarer rheumatic conditions are looked after in specialist services. Together, this makes it hard to plan and target local, regional and national healthcare services to improve patient outcomes.

Aims

The RHEUMAPS study aimed to address these key evidence gaps by:

Exploring the priorities for care across different groups of patients with a broad range of RMDs living in different places across the UK, and the resources and components of service that are important to meet these needs.

Measuring the prevalence of RMDs and health outcomes across different geographical areas in Scotland and Wales using national administrative healthcare data, specifically:

- whether there are **differences in health outcomes** between those living in **rural** and **urban** areas, and
- the extent to which they can be explained by **socio-economic factors**

Developing interactive maps to provide timely and accessible data to inform local, regional, and national service planning and evaluation of RMD services, sensitive to the needs of local populations.

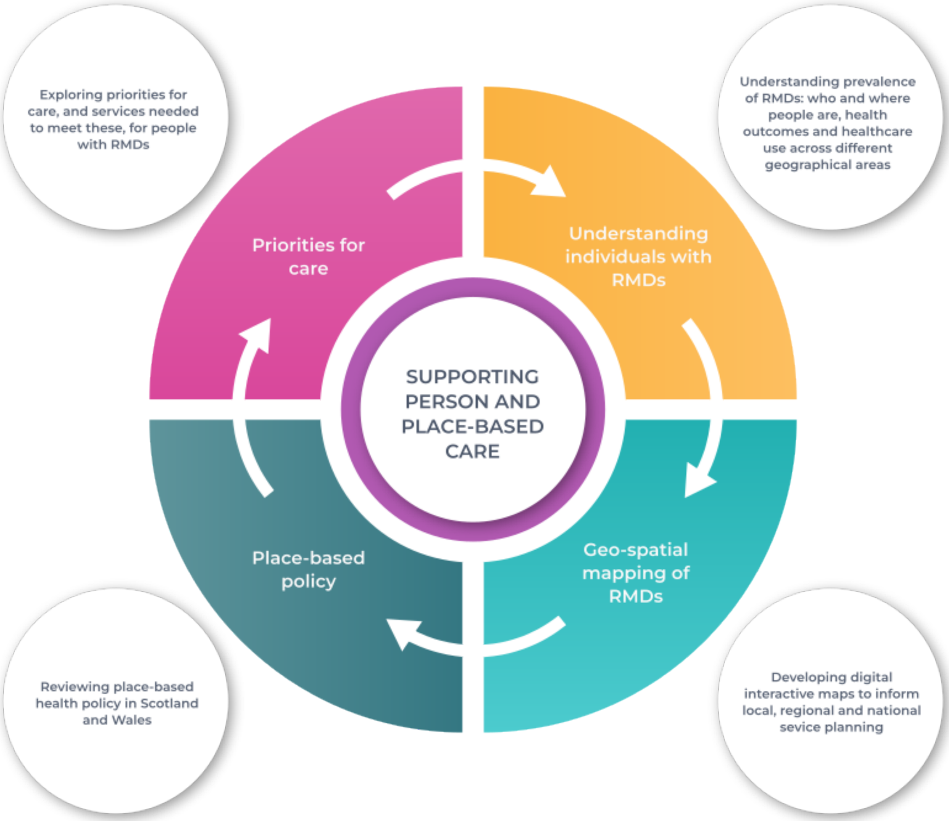
Reviewing the approach to rural healthcare policy in Scotland and Wales over the past 20 years, identify gaps, and consider ongoing and future policy directions.

Scotland and Wales, with large rural populations and unique national healthcare record linkage capabilities, provided an ideal opportunity to do this. Together, the study aims to provide evidence and strategic context to create a sustainable, data informed approach to support the development of person and place-based policies and services to better meet the needs of local populations with RMDs.

Methods

To achieve this, we conducted **four interlinked work streams**: priorities for care, understanding individuals with RMDs, geo-spatial mapping of RMDs and place-based policy.

Overview of RHEUMAPS study work streams



Priorities for care

Firstly, we gathered **insights into the care priorities** of people living with a broad range of rheumatic conditions, what services were needed to meet these needs and identified any gaps and challenges in accessing services those living with RMDs experienced through a UK wide survey, co-designed with our patient partners. Alongside this we conducted in-depth interviews with people with RMDs living in rural communities across the UK to further explore issues identified in the survey.

Our priorities for care survey was co-designed with our RHEUMAPS patient partners

Understanding individuals with RMDs

Secondly, we used **routinely collected healthcare data** in Scotland and Wales to **understand individuals with RMDs**. We identified people with relevant codes (using validated code lists) for **inflammatory arthritis** (including rheumatoid arthritis, psoriatic arthritis and axial spondyloarthritis), **rare autoimmune rheumatic conditions** (including systemic vasculitis, SLE, myositis, scleroderma and Sjogren's syndrome) and **osteoarthritis** from primary care datasets (and linked these to secondary care health datasets).

We chose to identify people from primary care records. This approach provided a more holistic assessment of health and healthcare use as it captured co-existing conditions such as diabetes and high blood pressure that are mainly looked after in primary care. Only identifying individuals from secondary care records would miss a significant proportion of people , such as those with osteoarthritis, and those not attending hospital clinics.

The date the code first appears in the primary care electronic health record (index date) was taken as a surrogate for date of diagnosis.

In **Wales**, we accessed the SAIL databank (85% population coverage). This included primary care records, from the Welsh Longitudinal General Practice (WLGP), linked to secondary care datasets.

In **Scotland**, primary care data was accessed through a trusted third-party provider (TTP), Albasoft, with individual practice consent required. Data was collected across five health boards in Scotland (two mainland and the three island-only boards included a mix of urban, accessible and remote rural mainland communities and island communities) and linked to national healthcare datasets covering secondary care, community prescribing, cancer and deaths.

Across rural and urban areas in Wales we explored **how many people in each region had a given condition**(s), their **socio-demographic characteristics** (e.g., age, sex, deprivation (income-based domain of the Welsh Index of Multiple Deprivation), the presence of **other health conditions**, and their **healthcare use**.

We also explored how **time to access specialist rheumatology and orthopaedic services** by car and bus (at individual household level and aggregated to small geographical areas) **varied by region in Wales**, and its **relationship to healthcare use**.

A **more limited analysis was undertaken in Scotland** due to issues with access and quality of primary care data, particularly from island-only health boards, and subsequent time constraints. However, we were able to characterise the prevalence and sociodemographic features of RMDs across two mainland health boards; NHS Grampian and NHS Highland.

Geo-spatial mapping of RMDs

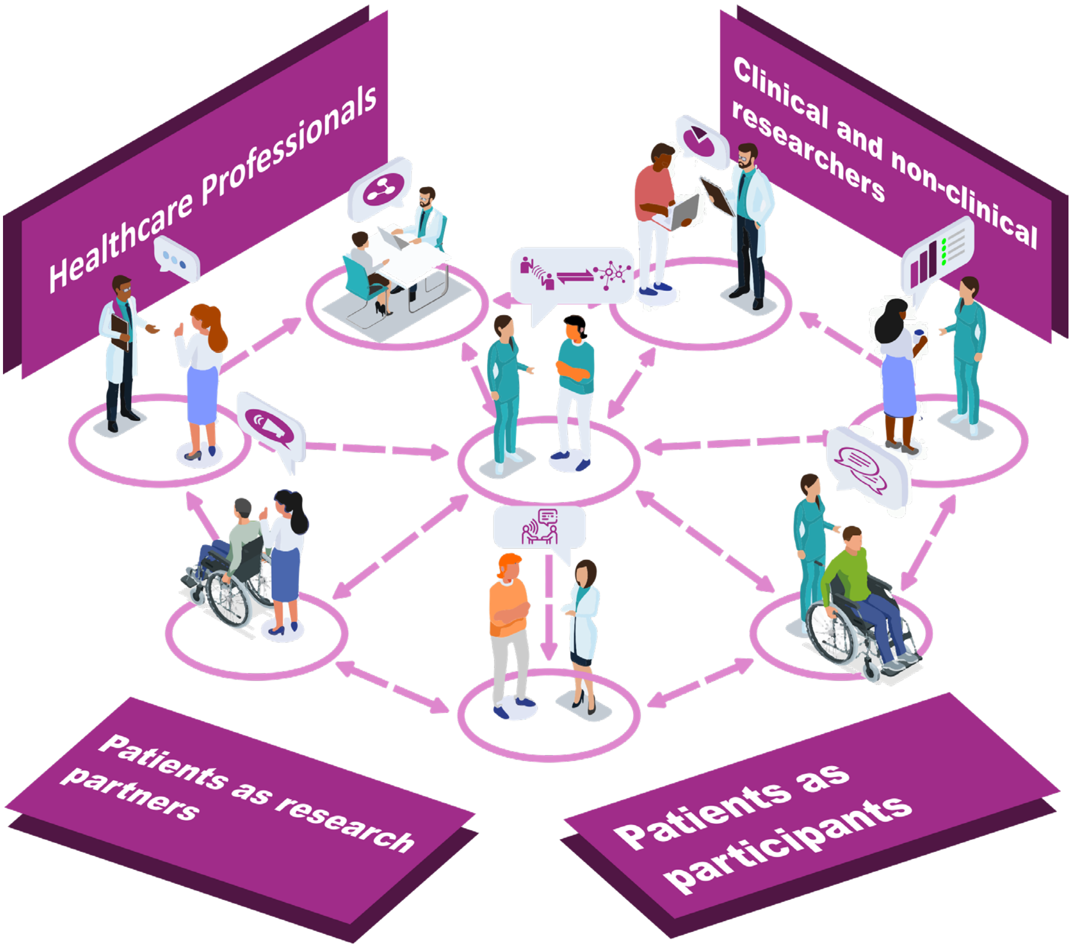
We then used these data to create a series of **interactive geospatial maps** using ARC GIS software (StoreyMaps). These maps illustrate the **prevalence of RMDs** in relation to **key socio-demographic features** at both **health board and regional level** (primary care cluster in Wales/integrated joint board level in Scotland).

In Wales prevalence of RMDs was also mapped in relation to **access to specialist services** (rheumatology and elective orthopaedic services) and key outcomes (e.g., joint replacement).

Place-based policy

Finally, we conducted a **rapid review of place-based policy in Scotland and Wales**. This included **academic publications**, publicly available **policy documents** and other grey literature that either included or was exclusively concerned with urban-rural health inequalities in Scotland and Wales and published within the last 20 years. The search strategy included: databases such as Google Scholar and PubMed; government websites; news websites and search engines. Identified documents were also searched for additional relevant publications. **A total of 126 documents** were identified and reviewed, comprising 62 policy documents, 40 academic publications and 24 items of grey literature. This was narratively synthesised and key themes identified.

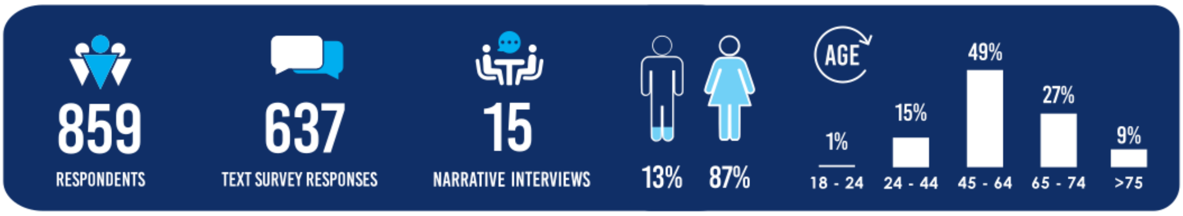
Embedded across the study were **engagement activities with a broad range of stakeholders** to understand, co-create, synthesise, generate and use research knowledge and support translation of this into action in policy and practice. We engaged with **people living with RMDs**, **healthcare professionals**, **health care decision makers**, and **third sector organisations**.



Findings

Priorities for care

Responses from **859 survey participants**, including **637 free-text responses**, and the transcripts of **15 semi-structured interviews** with individuals with RMDs from across the UK were analysed. Compared to urban dwellers, rural dwellers (256 (29.8%)) were **older** (% 65 years or older 39.5% v. 34.8%) and **less likely to be from the two highest multiple deprivation quintiles** (15.7% v. 26.9%).



People with different RMDs shared a **common set of care priorities**, **key service needs** (other than from their rheumatology team) and **valued aspects of care**, irrespective of where they lived (see Box 1). **Complementary medicine services** were perceived by many to offer more time, continuity and a holistic approach to care than was available from existing clinical healthcare services.

Box 1. Common health, service needs and care delivery priorities of people with RMDs

Individual health priorities

- **Remain physically active**
- **Better management of pain and fatigue**
- **Participate in work**
- **Engage in social activities with their family and friends**

Service priorities

- **Chronic pain services**
- **Complementary medicine services**
- **Sports and exercise medicine**
- **Mental health services**

Care delivery priorities

- **Access to multidisciplinary RMD care services at one location**
- **See the same members of the care team to ensure consistency of care**

Overall, 373 (43%) of survey respondents said that the services they currently accessed **did not enable them to meet their care priorities**. Approximately 1 in 3 respondents reported that they had **difficulty accessing information about their condition**, including work-related support for those who wished to work. More than half of respondents reported that they had **difficulty attending services**, specifically they mentioned **travel difficulties**, while 44% reported that **caring responsibilities** meant that it was difficult to attend health services.

Rural dwellers were **not more likely to express dissatisfaction with services** than their urban counterparts. However, there were some **aspects of services** which impacted a greater proportion of rural patients, namely two interlinked factors (i) **travel issues** creating difficulties in attending services and (ii) services **not being available locally**.

Factors significantly associated with service dissatisfaction included:

Socio-demographic factors (being female, younger age, living in areas with higher levels of deprivation, and not being in paid employment due to illness)

Musculoskeletal health-related factors (having a non-inflammatory musculoskeletal condition, and a longer time between symptom onset and seeking care)

Factors linked to accessing care (not knowing how to access locally available services; relevant services not being available in their local health board or trust; problems accessing information; and caring responsibilities)

People told us that it was important to know **where to go for help** – a '*map and compass*' to signpost relevant self-management resources – and to have **timely access** to community-based and specialist services. A complex interaction between factors affected people's ability to access services.

These findings highlighted the importance of better understanding the characteristics of both the **local population** and the **places where they live** when designing or delivering services.

> Lack of certain services means that I feel unsupported at times and feel that there are moments when I feel that I'm floundering. Not knowing which way to turn for the help I need.

Understanding individuals with RMDs in Wales

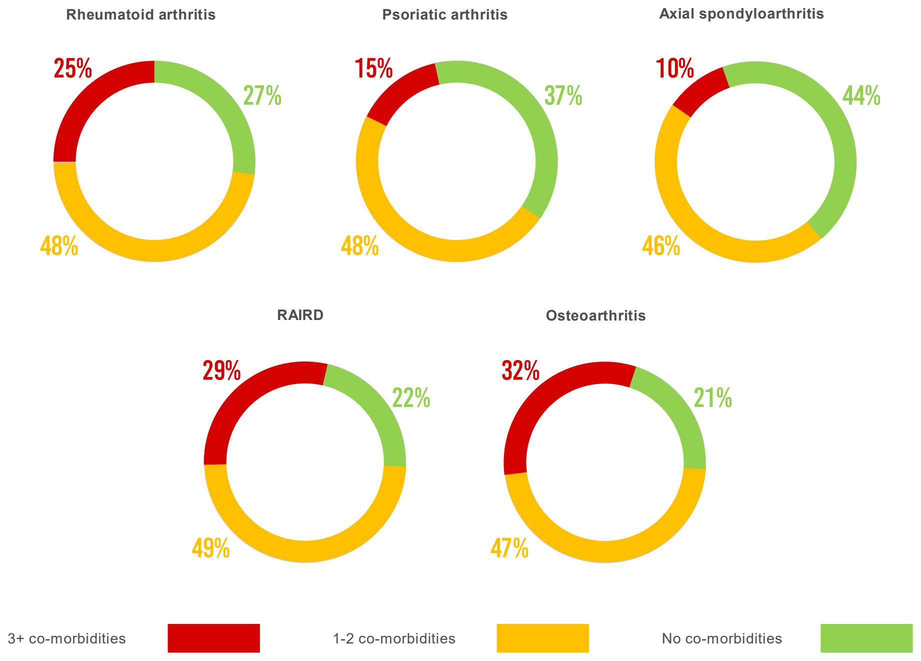
Prevalence of RMDs

Our analysis identified that around **10%** of the Welsh population had **osteoarthritis**, **0.9%** had **inflammatory arthritis**, and **0.7%** had a **rare autoimmune rheumatic disorder (RAIRD)**, based on the presence of at least one relevant code in primary care records. In those with inflammatory arthritis and RAIRDs who also had two prescriptions or more for at least one relevant disease modifying drug, the prevalence was 0.7% and 0.1%, respectively. Overall, the prevalence of RMDs was in keeping with the published literature.

Compared to living in an urban area, the **risk amongst those living in a rural area of having osteoarthritis** (RR 1.10, 95% CI 1.09 – 1.11), **inflammatory arthritis** (RR 1.1, 95% CI 1.07, 1.14) and **RAIRD** (RR 1.16, 95% CI: 1.07 to 1.26) **was higher**. However, this excess risk is most likely a result of the **rural population being older**.

Clinical characteristics

In people with osteoarthritis, inflammatory arthritis and RAIRDs, around a half had at least one comorbidity and **over a quarter had three or more comorbidities**. **Rural dwellers with osteoarthritis and inflammatory arthritis** were **more likely than urban dwellers** to have had a **hip replacement in the 5 years following diagnosis**, even after accounting for age, sex and income based measure of deprivation.



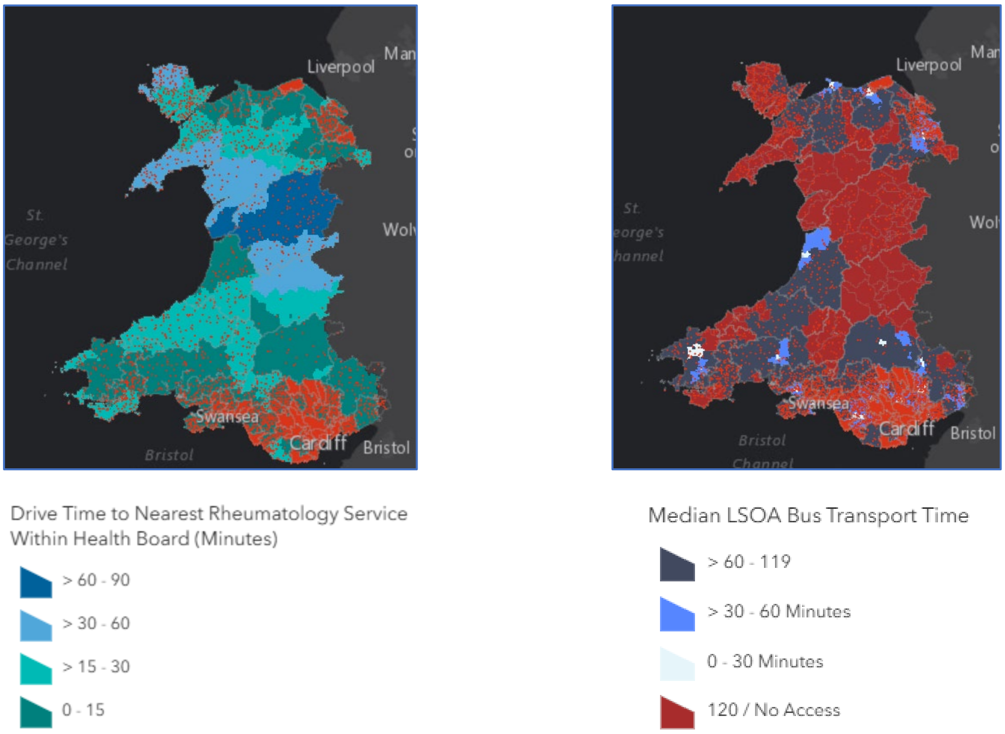
Healthcare use

Individuals with inflammatory arthritis and RAIRDs require long term care from rheumatology services. Whilst most people had at least one outpatient appointment at 0-1 and 4-5 years post index date, **12% of those with inflammatory arthritis and 28% of those with RAIRDs had no recorded rheumatology outpatient appointments in the year after the index date,** rising to 22% of those with inflammatory arthritis and 33% of those with RAIRDs at 4-5 years.

Proportionally fewer people with RAIRD appear to have rheumatology outpatient appointments compared to those with inflammatory arthritis, with a greater proportion having outpatient appointments in other specialties. This may reflect the multi-system nature of their condition and care provided across multiple specialities. **Individuals with RAIRDs (in comparison to those with inflammatory arthritis) had proportionally more emergency and elective hospital admissions**, as well as days with a GP "event".

Travel time to access specialist services

Across Wales, **car-based travel times to rheumatology services** were generally **within 30 minutes** (although it should be noted that around 22% of the population in Wales do not have access to a car). For those **without access to a car**, **bus journeys to specialist care facilities could be long** which presents significant challenges for people with limited mobility and multiple health issues. Approximately **1 in 10** people with inflammatory arthritis and RAIRDs in Wales **do not have access to rheumatology services within a 2-hour bus journey time**. Approximately **2000** people with these conditions live **more than 60 minutes away by car** from their nearest rheumatology service.



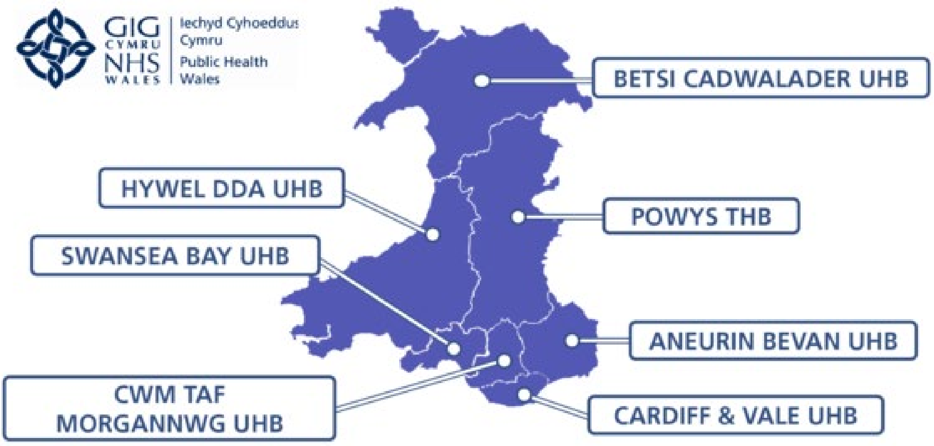
Travel time by car and bus to nearest specialist rheumatology services.
Click here to access live versions of these maps.

Relationship between travel time to access specialist services and healthcare use

Individuals with inflammatory arthritis in Wales who lived **more than 60 minutes' drive away from a rheumatology service** were **half as likely as those who lived closer to have at least one rheumatology outpatient appointment within the first-year post index date** (OR 0.48, CI 0.43 – 0.54). They remained less likely to have had a rheumatology outpatient appointment at 4-5 years post index date (OR 0.63, CI 0.55 – 0.73). They also had a **greater likelihood of having any hospital admission within the first year** (OR 1.28, CI 1.03 – 1.58) **and at 4-5 years** (OR 1.67, CI 1.35 – 2.04) post index date, driven by an increased likelihood of elective hospital admissions.

Similarly, **individuals with RAIRDs in Wales who lived more than 60 minutes' drive away from a rheumatology service** were **half as likely to have at least one rheumatology outpatient appointment within the first-year post index date** (OR 0.46, CI 0.34 – 0.64). There was a greater likelihood of having at least one hospital admission but there was uncertainty around this estimate (OR 1.27, CI 0.92 – 1.72).

Most people with RMDs who lived more than 60 minutes' drive away from a rheumatology service lived in either Hywel Dda University Health Board (81%) or Powys Teaching Health Board



Understanding individuals with RMDs in Scotland

Challenges encountered

In Scotland we encountered **significant challenges in accessing and analysing primary care data** due to the **absence of a national dataset**, **reliance on third-party providers**, and **data quality issues**, particularly in relation to data covering the three island-only health boards. This meant that we conducted a **more limited analysis** than that undertaken with Welsh data.

The Scottish analysis therefore focused on two health boards: **Grampian** (comprising **Aberdeen City**, **Aberdeenshire** and **Moray** integrated joint boards responsible for health and social care delivery) and **Highland** (which serves mainland and island communities within the jurisdiction of **Highland and Argyll and Bute Councils**) where we had primary care coverage of around 50% of the population.

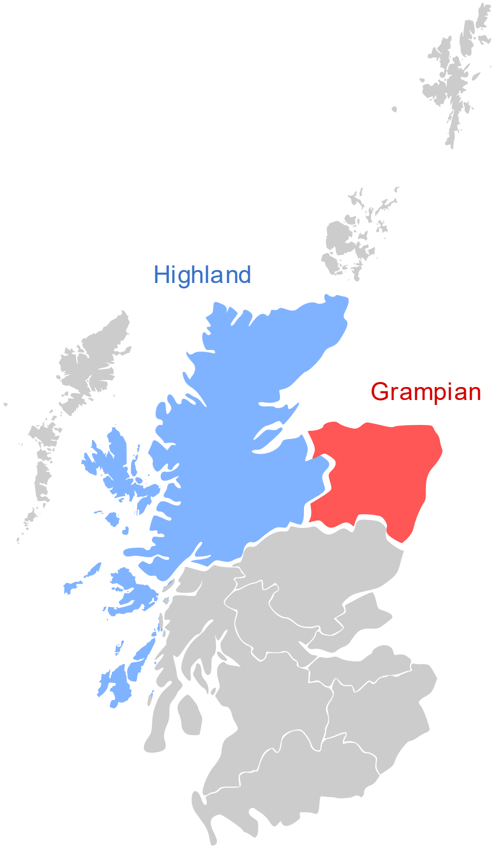
Despite the limitations of the Scottish data our research represents **the first effort in Scotland** to establish geospatial prevalence data for RMDs using routinely collected primary care data to inform service planning.

Prevalence of RMDs

Prevalence of RMDs was based on the **presence of at least one relevant code in the primary care record**. Issues with the community prescribing dataset precluded further analysis that also included the presence of a relevant disease modifying drug. There was a **higher prevalence of osteoarthritis amongst those living in predominantly rural areas**, those which also have demographically older populations, such as Aberdeenshire, Moray, and Highland, compared to those living in large urban areas, such as Aberdeen City. For example, within NHS Grampian, the prevalence of osteoarthritis was 10% in Aberdeenshire and Moray compared to 7% in Aberdeen City. In NHS Highland, the prevalence of osteoarthritis was 11%.

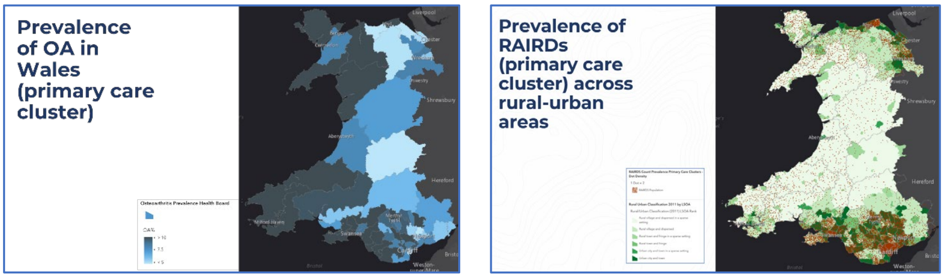
Inflammatory arthritis and **RAIRDs** were also **more prevalent in rural regions** and **among older females**. The prevalence of inflammatory arthritis was almost double in Aberdeenshire and Moray (2.5%) compared to Aberdeen City (1.3%). A similar pattern was seen with RAIRDs with a prevalence of 2.4% in Aberdeenshire and 2.9% in Moray, compared to 1.4% in Aberdeen City.

In NHS Highland, the prevalence of inflammatory arthritis and RAIRDs was 2.2% and 2.4%, respectively. In females over the age of 65 years, the prevalence of inflammatory arthritis and RAIRDs was considerably higher at 5-7% and 6-8%, respectively. In females aged 24-64 years it was around 1-3%.



Geospatial mapping of RMDs

Unlike existing planning tools that estimate disease prevalence by extrapolating data from other populations or assessing the prevalence of risk factors, the **interactive maps** created in this study **provide a detailed view of the actual burden of disease within a given population**, derived from routinely collected healthcare data.



Examples of our digital interactive maps. Click here to access live versions of these maps.

Using the data gathered for individuals with RMDs, **we created interactive tools to support service planning**. In **Wales**, these incorporated **geo-spatial mapping** to show **where individuals with RMDs reside**, the **number of cases** at primary care cluster and health board levels, and **travel times by car and bus** to access specialist services. Additionally, the maps highlight the prevalence of RMDs in relation to **key socio-demographic factors**, such as **area-based deprivation** and **rural versus urban residency**. They also examine **prevalence among working-age individuals** (18–65 years) and **those over 65**, aiding **targeted support for those who wish to remain in work**—an important priority for people living with RMDs. Key outcomes, such as **joint replacement rates** were also mapped at health board and primary care cluster levels.

A **more limited set of maps** were created using the available data in **Scotland**, which **serve as a prototype for what could be achieved** with improved access to data, and the findings have **already been used to inform discussions about regional service planning**.

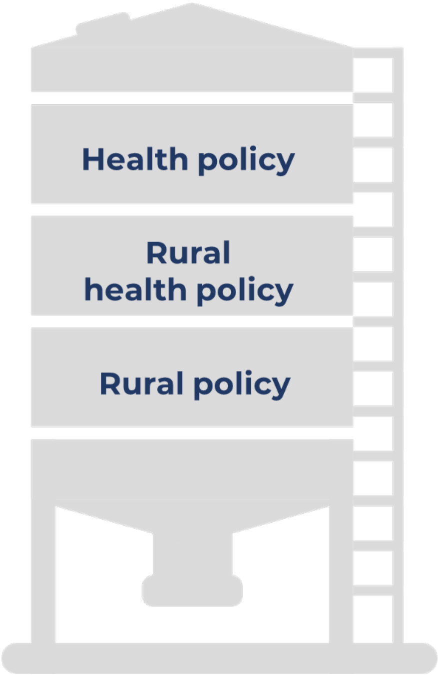
What the data can and cannot tell us

We faced **considerable challenges in conducting the geo-spatial analysis**, specifically in terms of **access to, and quality of, primary care data in Scotland**, and in the **extraction of geo-spatial healthcare data in Wales** to create the interactive maps, due to **concerns about use in performance management of health boards** and the **potential for identification of individuals with RMDs**. However, the insights gained in the process have been **invaluable in informing future work** to **create sustainable data platforms that can usefully inform service planning**.

Discussions with stakeholders at national workshops emphasised the **importance of interpreting and using the maps alongside both local insights into service structure and delivery** and an **understanding of the lived experiences of people with RMDs**. This includes understanding **which groups of people are potentially under-represented** in the data and an **awareness of how local parts of the health care system work**. It is also important to acknowledge that **reliance on area-based measure of health determinants** such as deprivation to measure geographical inequalities in health outcomes **can underestimate levels of deprivation in rural communities**. As such, these maps serve as a **starting point for informed discussions** to understand local needs and engage stakeholders in planning RMD services at local, regional, and national levels

Place-based policy

The review of rural healthcare policy in Scotland and Wales over the past 20 years **highlighted persistent challenges** such as **workforce shortages**, **health inequalities**, and **accessibility to services challenges**, particularly for the **most geographically remote rural populations**. Efforts to address these challenges have often been **siloed**, with **limited coordination** across health, transport, housing, and digital infrastructure policies.



A significant issue identified is that if policy decisions are informed by the assumption that health inequalities are positively correlated with high levels of socio-economic deprivation, the **extent of health inequalities between rural and urban populations can be underestimated**. Spatial clusters of **deprivation** are **less likely to be identified in villages and small towns** than they are in larger towns and in cities, but **similar proportions of the urban and rural population are known to live in poverty**. Addressing these challenges requires a **more integrated and sophisticated person- and place-based approach to policymaking**.

One approach to address this and reflected within recent Scottish policy initiatives is **'rural proofing'**, a process by which policymakers evaluate how proposed policies might have unintended outcomes that negatively affect rural communities and identify potential mitigations. For example, 'rural proofing' can ensure that the unintended consequences of centralised healthcare services, inadequate public transport, or poor digital infrastructure are considered and addressed.

Furthermore, the development of **National Clinical Frameworks in Wales and Scotland** marks a **significant shift in the policy landscape**. These frameworks emphasise **person-centred care**, **data-driven decision-making**, and **cross-sector collaboration** to address geographical health disparities.

Key recommendations for policy and practice

Our findings were **shared at national workshops in Wales and Scotland**, offering opportunities for validation, collaboration, and sense-making with stakeholders. These discussions underscored the **importance of contextualising data within lived experiences and local healthcare delivery**. Our findings demonstrate that **a complex interplay of factors** influence whether services effectively support individuals living with RMDs in meeting their care priorities, including their access to and use of healthcare.

A deep **understanding of the local context** from patients, carers and professionals, alongside the **information gathered from routine health care data**, provides **important insights grounded in patient experience to better support local service planning**. Stakeholders also highlighted the need to understand both the **potential benefits and limitations of routine healthcare data** for service planning, including incomplete or missing data and underrepresentation of certain populations and health outcomes, and the importance of ensuring adequate resources and **robust information governance** to enable detailed geospatial analysis.

Building on these insights, **we developed recommendations to improve care delivery** and support policymakers and service providers in **creating effective, person- and place-based healthcare strategies** tailored to the **unique needs of populations and their locations**. We anticipate that the insights from the RHEUMAPS study will help **shape development of the National Clinical Frameworks** in Scotland and Wales.

As well as **clinical recommendations**, these include **broader data and policy considerations**, such as the **information governance and technical infrastructure**, which are essential to **support development and implementation of sustainable services for people with RMDs** within a learning healthcare system.

The key recommendations are summarised on the following page.

Key achievements and lessons from RHEUMAPS study

- **Support to better meet the care priorities of people living with rheumatic and musculoskeletal conditions**

  It is important to **ensure that the solutions developed are relevant to the care needs of local populations**, particularly those **we identified whose care priorities are not currently being met**, including **younger adults**, people who are **not working due to their RMD**, those who have **longer to travel to access specialist care**, and **those with non-inflammatory RMDs**.

- *Improved access to information and services*
  - Timely, relevant and accessible information and services, particularly to **manage pain and fatigue**.
  - **Development of a framework for understanding** and **sharing pathways and resources** across community, health and social care services to **improve signposting and access to support** for people living with RMDs.

- *Enhance access to multi-disciplinary care*
  - Ensure patients can access multi-disciplinary care in a single location and see the same care team members consistently to improve continuity and quality of care.

- *Support patients with caring responsibilities to access services*
  - Implement flexible service options, such as appointment scheduling support and remote consultations, to improve access for individuals with caregiving duties.

- *Support to meet key care priorities*
  - **Development of strategies to improve awareness and access** to **work-related support** for people with RMDs.
  - **Development of effective pathways to community-based resources** to support people living with RMDs who struggle to achieve their desired levels participate in social and community-based activities.

- *Support for self-management*
  - **Development of an overarching policy framework for sustainable self-management support** for long-term conditions to enable early access to visible support as part of their overall treatment plan and to ensure equitable and sustainable resourcing.

✓ **Support to enable better and sustainable use of national healthcare data to inform service planning and evaluation across a broad range of RMDs**

Moving data from research to real time to inform service planning presents several **challenges that need to be overcome**. The following recommendations consider the **infrastructure**, **resources**, **methods** and **information governance issues** that need to be addressed to support this.

- **Strategies to improve the quality of routinely collected healthcare data** – transparent and consistent coding, understanding the purpose of data collection, and support for creation of a data catalogue and metadata for new datasets.

- **Agreed information governance protocols to enable timely extraction of granular (e.g. data zone level) geo-spatial prevalence and outcome data** from national health databases to inform service planning, and review service delivery and clinical outcomes.

- Future work should include **methods that combine administrative health data with lived experience** and an **understanding of the context** in which health data is **collected** and **used**.

- Opportunities to **ensure research technical code is curated**, **shared** and **acknowledged** for future use, supporting **open and reproducible science**.

Conclusion

In summary, the RHEUMAPS study has provided important insights into the care priorities, geo-spatial prevalence and health outcomes, and access to services for individuals living with rheumatic and musculoskeletal disorders in Wales and Scotland.

The study identified **shared care priorities** across diverse populations, including managing pain and fatigue, staying physically active, maintaining social connections, and participating in work and hobbies. Access to multidisciplinary care in one location and consistent, holistic care were particularly valued, with many participants expressing dissatisfaction with current services due to travel challenges, limited local availability, and insufficient information. We have also identified structural barriers, such as limited local services and travel challenges, that disproportionately affect rural communities.

Our findings underscore the need for **place-sensitive policies** and **sustainable, data-informed strategies** to **improve healthcare delivery and support for people with RMDs**. The creation of **interactive geospatial maps** serves as an important starting point for informed discussions on how to **tailor healthcare planning and delivery to meet local needs**, cognisant of what the data can and cannot tell us. By visualising the prevalence of RMDs, socio-demographic characteristics, and travel times to services, these maps **provide actionable, data-driven insights** to **inform person- and place-based strategies**. There has been a **historically siloed approach to rural health policy,** where healthcare, transport, housing, and workforce challenges were often addressed in isolation. Encouragingly, **there is now momentum toward a more integrated framework**.

The findings from the RHEUMAPS study offer **important evidence and tools to support this shift**, helping policymakers and healthcare providers **develop sustainable, equitable, and person-centred solutions** to meet the diverse and evolving needs of people with RMDs as part of a **learning healthcare system**.