# RAIRDA Summer Update

From getting to the final stages of the Quality Standard for Rare Disease project, to parliamentary meetings, and the release of the 10-Year health plan, it has been a busy and productive past few months for RAIRDA.

## Quality Standard Work

Our key activity has centred around the Quality Standard work.  We held a Steering Group meeting in June to refine the draft statements based on feedback received from the second round of the community survey. Following that meeting, the number of statements was reduced to 13. These statements were taken forward for discussion at a **Consensus Workshop** on 15th July, where individuals from across the rare disease community met and ranked the statements.

We will now focus on finalising the statements ahead of our meeting with the NICE Quality Standards Committee in November.

## Parliamentary engagement:

- We met with **Genetic Alliance UK** to discuss potential collaboration through the **APPG on Rare, Genetic and Undiagnosed Conditions**. A follow-up meeting is scheduled for **September** to explore a joint session in **December**.
- RAIRDA attended the APPG on Rare, Genetic and Undiagnosed Conditions session in June which explored the **Rare Disease Framework** learnings and need for its continuation beyond 2026.
- We held productive meetings with **Jim Shannon MP**, sponsor of the Westminster Hall debate in December, and **James Evans MS**, Conservative Health Spokesperson in Wales. We are also in the process of scheduling a meeting with **Lord Kamall** for after summer recess.
- We met with **DHSC** to discuss the recommendations of the Rare Care Matters report, our progress with the quality standard project, and the steps needed to achieve the **best possible outcomes for people with RAIRDS**.
- Following the launch of the **Rare Care Matters** report, we've developed a list of **Parliamentary Questions for Wales** and are working on a similar list for the other nations, aiming to have these tabled after the summer recess.

## Other key activity includes:

- We submitted RAIRDA's response to the **DWP Pathways to Work consultation**, following a dedicated workshop where we gathered input to shape our submission. The draft response was shared for review ahead of submission.

- Discussion with **Shouvik Dass -** National Specialty Advisor for Specialised Rheumatology, and **Frances Hall -** Consultant Rheumatologist and Clinical Lead for Connective Tissue Disease, to continue work around high-cost drugs and specialised networks.
- Regarding the **RAIRDA Schools Prize,** Dorian and the team at Imperial College are reviewing the submissions and will send RAIRDA member organisations shortlisted posters to select the final 10, which will go through to the online judging round in **October**. Find out more here.

## 10-Year Health Plan for England:

- RAIRDA issued a statement which we published on the RAIRDA website and posted across social media channels.
- In the table below we've outlined relevant points from the plan and how they compare to our recommendations in the Rare Care Matters report.

| 10-year health plan | Rare Care Matters recommendation |
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| **Focus on earlier diagnosis**<br>Commitment to earlier identification, investment in genomics (including newborn testing and risk scoring), and greater use of emerging diagnostic tools. | Our report shows that while a third of respondents (34%) were diagnosed within a year of symptom onset, 30% waited over five years for a diagnosis, with an average wait of 2.5 years.<br>The Plan's considerations on early diagnosis must also consider conditions that are non-genetic. Early diagnosis goes beyond genomics for many conditions, including RAIRDs. It is vital that there is a balanced investment in methods including blood tests, imaging and clinicians experienced in looking after these conditions. |
| **Care plans and personalised care**<br>By 2027, people with complex needs will have an agreed care plan. | This is a welcome commitment and a key recommendation in our Rare Care Matters report. In the report, 34% of respondents said they were not involved in developing their care plan. It is key that people living with RAIRDs feel that they can be involved in their care and treatment planning, as much as they want to be. |

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| **Digitisation and remote access**<br>Expansion of NHS App functionality, greater use of e-referrals, and virtual consultations. | Some aspects of the updated NHS App functionality may be beneficial for patients with RAIRDs, this includes the ability of having all their data in one place, which becomes particularly helpful when dealing with multiple specialists, and online appointments can remove the need  to travel long distances for specialist care. However, other aspects can create additional hurdles. For people with RAIRDs, knowing who to refer to is not always clear and without appropriate guidance and support, these measures could risk adding confusion rather than clarity. From our 2024 survey we know one in ten (8%) respondents reported that they feel they have been left to cope alone and need more support in managing their condition(s). |
| **Neighbourhood health service**<br>Bringing care into communities through the Neighbourhood Health Service. This will free hospitals to focus on specialist treatment. | While the aim is to free hospitals to focus on specialist treatment there is limited information on how that will happen. People living with RAIRDs rely on expert, coordinated support that GPs alone often cannot provide. There needs to be good shared care between the community, secondary and tertiary care so that as much care and treatment as possible can be delivered close to home. Shifting some care into the community may ease pressure on hospitals and reduce waiting times which would be positive for people needing specialist care. However, this must be carefully designed to ensure that patients with rare and complex conditions can still access the specialised care they need, without delay or disruption. |
| **Mental Health and RAIRDs** | An important development. Our report called for patients with RAIRDs to have access to holistic support, which must include effective psychological support. 73% of respondents said their condition |

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| £120 million investment into dedicated mental health emergency departments. | negatively affects their mental wellbeing. We will continue to advocate for emotional and psychological care to be integrated into care pathways for RAIRDs. |

- **Key concerns** include:
    - Rare disease is only mentioned in relation to genomic testing, not generally as an area for improvement. This does not cover RAIRDs which are mainly non-genetic.
    - Risk of exclusion in community-led models: While there is a mention that access to specialist care will be focused on those who need it, there is limited detail on how that will happen. There is no mention of specialised networks which are an established way of ensuring access to specialist care for people with RAIRDs. patients may fall through the cracks in a movement away from hospital care.
    - Self-referral and self-mange models may not suit RAIRDs: Without clear guidance, patients may be uncertain where to turn, adding delays and confusion.
    - There is a need for a lot more clarity on implementation of the Plan.

- **Our two key recommendations** include:
    1. **Renewal of the Rare Disease Framework:** The 10-Year Plan does not include a commitment to renew the UK Rare Disease Framework. Considering the Framework comes to an end in January 2026, a commitment to renew is essential. For RAIRDs specifically, the framework has been a vehicle to drive increased focus on predominantly non-genetic conditions and to drive the development of a Quality Standard for Rare Disease. However, there is still much more to be done beyond January 2026. Improvements remain inconsistent across regions and nations, and many people with RAIRDs continue to face poor experiences in accessing care.
    2. **Specialised networks:** A recommendation made in the Rare Care Matters Report is the allocation of resources for the development and ongoing management of specialised networks, including specialised rheumatology networks, to increase healthcare practitioner knowledge and expertise in supporting people with complex conditions such as RAIRDs. Such an investment could offer long term savings. Specialised networks allow health

professionals to access the knowledge and expertise of tertiary and specialist whilst also developing capability and capacity for more care and treatment to be carried out locally than would otherwise be the case. The upcoming plan needs to allocate resources to support clinicians to develop these networks.

- **Next steps**:
    - Following our meeting with Jim Shannon MP, he agreed to send a letter after summer recess to Ashley Dalton and Wes Streeting on behalf of RAIRDA. We are in the process of finalising the letters, which will also include RAIRDA's reaction to the 10-Year Health Plan.
    - Later in the year, we will look to feed into James Evans MS' Welsh Health Manifesto.