

ARDEnt publishes its findings on how the fragile rare disease ecosystem was disproportionately impacted by the COVID-19 pandemic

The UK, 6th May 2021.

Today Action for Rare Disease Empowerment (ARDEnt) has published its findings and recommendations in the report 'Making The Unseen Seen: Rare disease and lessons learned from the COVID-19 pandemic'.

This time last year it became clear to the rare disease community that the pandemic was having a disproportionate and sometimes devastating effect on all aspects of the lives of those living with rare conditions. 3.5 million people in the UK live with a rare condition however each individual disease only affects fewer than 1 in 2000 people in a population. This can make it hard for people with a rare condition to have their experiences heard and understood. This was further exacerbated when those affected were cut off from society through shielding, had their fragile support networks shut down and were living in fear of an unknown illness (in addition to the rare condition they already had to manage on a daily basis).

To remedy this, a large group of UK-based and cross-sector rare disease advocates were assembled to ensure the capture and analysis of what was truly happening to the fragile rare disease infra-structure - in order to protect what has been so desperately fought for over decades and to find opportunities where they arose. 'Making The Unseen Seen: Rare disease and the lessons learned from the COVID-19 pandemic' has been written based on collated evidence along three different themes:

1. Diagnostic delay
2. Health and social care coordination
3. Research, drug development and access to treatment

These themes were decided prior to the publishing of [The UK Rare Diseases Framework](#) by The Department of Health and Social Care in January 2021 however correspond to the priorities outlined in this piece of policy. The 'Making The Unseen Seen' report outlines learnings from the pandemic and gives recommendations for service-providers and policy makers to ensure the lived experience is embedded in future projects, not only protecting the rare disease community, but enabling it to thrive in the aftermath of this pandemic.

ACCESS THE REPORT HERE: <https://www.camraredisease.org/ardent/>

"The aim of the ARDEnt report is to shed light on the unseen impact of the pandemic on people living with rare conditions in order to protect the existing services for people living with rare conditions and lessons can be learned."

"In 2020 everybody had a taste of what it's like to live with a poorly understood health condition with limited treatment options and a desperate need for expedited research. People living with

rare conditions are all too familiar with this reality. We can learn a lot from this resilient and problem-solving community, in return they must be supported to keep leading the way.”

“Despite the challenges during 2020, the rare community’s spirit of ingenuity and resilience of all involved in this fight is beyond parallel. So too and in equal measure to the adversity faced, has opportunity emerged.”

- Nicola Miller Editor of Rare Revolution Magazine and mother of a child with a rare condition

“It is time to use this lived experience borne by our rare disease community to build a legacy for future generations as we seek to protect this community through progressive regulatory, strategic and practical action. And now is the time for that action – from grass roots to legislators we can all play our part – and play our part we must because if we do not, we effectively ignore a disease that affects over 3 million people in the UK and that cannot be acceptable.”

- Nicola Miller Editor of Rare Revolution Magazine and mother of a child with a rare condition

Contact:

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About ARDEnt:

Action for Rare Disease Empowerment is an open group of stakeholders from across different sectors who all have a passion for bettering the lives of those living with rare conditions. Over 30 individuals and groups were involved in the creation of the ‘Making The Unseen Seen’ report and the group welcomes new participants and contributors at any time. Although currently the focus of ARDEnt has been around the pandemic the group hope that this open collaboration sets the template for future activities. Rare is stronger together. If you would like to be involved please do not hesitate to contact any of the Theme Leads. For a full list of contributors please read the report.

Link to report: <https://www.camraredisease.org/ardent/>

Social Posts:

	Twitter	Facebook/LinkedIn/Instagram
General	1. ‘Making The Unseen Seen: Rare disease and lessons learned from the COVID-19	Today Action for Rare Disease Empowerment (ARDEnt) has published its findings and recommendations in the report ‘Making The Unseen Seen: Rare disease and lessons learned from the COVID-19 pandemic’.

	<p>pandemic' - ARDEnt has published its findings and recommendations in this report <u>https://www.camraredisease.org/arden/</u> #UnseenSeen #RareDisease</p> <p>2. ARDEnt was formed because last year it became clear that the pandemic was having a disproportionate and sometimes devastating effect on all aspects of the lives of those living with rare conditions. Findings & recommendations here <u>https://www.camraredisease.org/arden/</u> #UnseenSeen</p> <p>3. The aim of the ARDEnt report is to shed light on the unseen impact of the pandemic on people living with rare conditions in order to protect the existing services for people living with rare conditions and lessons can be learned. <u>https://www.camraredisease.org/arden/</u></p>	<p>This time last year it became clear to the rare disease community that the pandemic was having a disproportionate and sometimes devastating effect on all aspects of the lives of those living with rare conditions.</p> <p>To remediate this, a large group of UK-based and cross-sector stakeholders were assembled to ensure the capture and analysis of what was truly happening to the fragile rare disease infra-structure - in order to protect what has been so desperately fought for over decades and to find opportunities where they arose.</p> <p><u>https://www.camraredisease.org/arden/</u></p> <p>#UnseenSeen #ARDEnt #RareDisease #pandemic #advocacy #livedexperience #patientvoice</p>
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	https://www.camrar.edisease.org/arden/t/ #UnseenSeen	
Theme 1	<p>1. The pandemic has exacerbated diagnostic delay in rare disease. Read ARDEnt's recommendations https://www.camrar.edisease.org/arden/t/ #UnseenSeen #RareDisease #ARDEnt</p>	<p>(Add to the above)</p> <p>Theme 1 examined how the diagnostic process in rare disease was affected by the response to the pandemic. The journey to a rare diagnosis is already recognised as a long and arduous process and has been coined the 'Diagnostic Odyssey'. The ARDEnt Theme 1 team found that diagnostic delay has been further exacerbated during the pandemic and the consequences of this will be felt for years to come as the population of people living with an undiagnosed rare disease will have grown even bigger in 2020. Read Making The Unseen Seen: Rare disease and lessons learned from the pandemic' to find out their recommendations.</p>
Theme 2	<p>2. The pandemic has compounded existing inadequacies in health and social care provision and coordination for the vast majority of rare conditions https://www.camrar.edisease.org/arden/t/ #UnseenSeen #RareDisease #ARDEnt</p>	<p>(add to the above)</p> <p>During times of global disruption it is often those who are already disadvantaged that are disproportionately affected. Theme 2 of the ARDEnt report highlights just this impact on those with rare conditions. The reduction to healthcare, social services and SEND education has had a devastating impact that will be felt long after restrictions are lifted. As the world begins to find its new normal we must ensure we are "making the unseen seen". Read Making The Unseen Seen: Rare disease and lessons learned from the pandemic' to find out their recommendations.</p>
Theme 3	<p>3. The pandemic has exposed the fragility of rare disease drug development. Read ARDEnt's recommendations https://www.camrar.edisease.org/arden/t/ #UnseenSeen #RareDisease #ARDEnt</p>	<p>(Add to the above)</p> <p>Theme 3 explored the impact of the pandemic response on UK clinical trials and drug development for rare diseases. Safety considerations, travel restrictions, shielding, trial-sites being repurposed to COVID-19 wards and research staff either being called to the front-line, or called to replace others who were, have compounded the already fragile world of clinical development for Rare Diseases. Read Making The Unseen Seen: Rare disease and lessons learned from the pandemic' to find out their recommendations.</p>

