

Additional file 8: Summary table of topics raised in the discussion

<p><b>Communication is an important factor to consider when developing rare disease support</b></p> <p><i>Communication within the health service</i></p> <p><i>Communication within rare disease collaborative groups</i></p> <p><i>Online communication</i></p> <p><i>Collaboration</i></p>	<p>Improved communication between General Practitioners (GP) and other healthcare professionals is required, especially at diagnosis.</p> <p>A move is happening away from face to face support to more support <i>via</i> online platforms, but with this change effectiveness of support provided needs to be evaluated.</p> <p>Use of online platforms is dependent on the habits and preferences of individuals. More investment in the online presence of groups may allow for more people to be supported.</p> <p>Collaboration between groups is valued, but also collaboration between healthcare professionals, and then between the groups and healthcare professionals.</p>
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<p><b>Rare disease registries</b></p>	<p>There is a desire from the majority of groups in the study for a rare disease registry in Northern Ireland which would help them to be more responsive in their support and advocating for service planning for rare disease patients.</p>
<p><b>Training</b></p>	<p>Some training is currently provided for healthcare professionals by the groups but evidence shows that more is required to improve the support provided to those with a rare disease, and understanding within the healthcare system.</p>
<p><b>Carers</b></p>	<p>The groups were very aware that better support is needed for carers of those with a rare disease, with these carers often being overlooked. Further research on how best to provide this support is needed.</p>
<p><b>Current care/support for those with a rare disease is not adequate.</b></p>	<p>Finding and securing funding to improve and develop the services available in Northern Ireland was perceived as important. The collaborative groups had many suggestions on how to improve these</p>

	services and should be consulted.
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