Implementation Plan for the UK Strategy for Rare Diseases – progress report

Implementation Plan for the UK Strategy for Rare Diseases – progress report

Version number:2

First published: November 2020

Prepared by: NHS England Specialised Services

INTRODUCTION

The UK Strategy for Rare Diseases was published by the Department of Health in November 2013. The Strategy contained a total of 51 commitments which all four countries have agreed to achieve by 2020. This is the first strategy of its kind, aiming to help build an understanding of rare diseases and boost research in this important area of healthcare. NHS England published the 'Implementation Plan for the UK Strategy for Rare Diseases' in January 2018. This Plan sets out NHS England's delivery contribution to the UK Strategy.

The Plan should be read in conjunction with the Department of Health and Social Care's overall plan, which sets out the broader set of actions being taken by other parts of the health and care system against the commitments in the Strategy.

This update reviews progress against the dashboard of performance measures set out in the Plan and is in the order set out in the Plan for ease of reference. This is the second update; the first version can be found here.

Measure (corresponding commitments from Strategy)	Progress Report
• Number of individuals involved in the Genomic Medicine Centres patient and public involvement (PPI) groups (1) • Examples of good practice in patient and public involvement in the Genomic Medicine Centres (1)	• As part of the NHS Genomic Medicine Centres (GMCs) contracts, there was a requirement to establish patient participation groups. Each NHS GMC has taken a slightly different approach to best suit the needs of their local patients and participants. • It is estimated that across all 13 NHS GMCs, around 350 patients have been involved in these activities at any one time, for example, young people were involved in developing a process for reconsenting 16-year-olds. • Two successful events were held with families affected by rare disease in collaboration with SWAN ('syndromes without a name') UK. The event provided an opportunity for families, who can feel isolated, to come together to discuss how genomics may: help them either understand what is happening to their child; help them make decisions about the future; and look for treatments.
• Published service specification development process available on the NHS England website (1, 4, 5, 12, 23, 32)	• A published process for service specification development is available on the NHS England website here.

Measure (corresponding commitments from Strategy)	Progress Report
• Number of service specifications that have been out for stakeholder engagement (1, 4) • Number of service specifications that have been out for public consultation (1, 4) • Number of service specifications published (5, 12, 23, 32) [Note – there is an ongoing programme of service specification development/refinement and the numbers of documents at each stage of the process varies from year to year] • Examples of good practice in the development of service specifications (5,12,23,32)	• In 2019, seven service specifications for specialised services went out for stakeholder engagement. • In 2019, six service specifications for specialised services went out to public consultation. • In 2019, 12 service specifications for specialised services were published. All service specifications can be found in the NHS England website service specification library here. Example of good practice: • In the NHS England service specification for an 'Inherited White Matter Disorders Diagnostic and Management Service (IWMD) (All Ages)' – and following feedback from the Rare Diseases Advisory Group – the specification sets out three Levels of care: o Remote MDT assessment for patients already diagnosed o Remote MDT review for patients who have had tests o Multi-professional face-to-face clinical review for complex cases • This minimises travel for patients but allows rapid access to high levels of expertise when this is required. • Further examples of good practice in highly specialised services can be found in 'Highly Specialised Services 2018', which is available on the NHS England website here.
• Published clinical policy development process available on the NHS England website (1, 5, 12) • Number of clinical policies that have been out for stakeholder testing (1) • Number of clinical policies that have been out for public consultation (1) • Number of clinical policies published (5, 12)	• A published process for policy development is available on the NHS England website here. • In 2019, 30 policies for specialised services went out for stakeholder testing. • In 2019, 28 policies for specialised services went out for public consultation. • In 2019, 37 policies for specialised services were published. All policies can be found in the NHS England website policy library here.

Measure (corresponding commitments from Strategy)	Progress Report
[Note – there is an ongoing programme of policy development and the numbers of documents at each stage of the process varies from year to year] • Examples of good practice in the development and implementation of clinical policies (5, 12)	Example of good practice: • The Clinical Commissioning Policy: Cholic acid and chenodeoxycholic acid for treating inborn errors of bile acid synthesis (all ages) was prioritised for funding in the May 2019 commissioning round. • This policy sets out the criteria for when the two therapeutic products should be used (either on their own or together) for a number of inborn errors of bile acid synthesis. These are very rare conditions that cause liver disease and can also lead to progressive diseases of the central nervous system.
• Number of patient and public voice individuals involved in NHS England specialised commissioning governance processes (1) • Examples of good practice in patient and public participation (1)	• There are 142 patient and public voice individuals involved in NHS England specialised commissioning governance processes. • Patient and public voice members of the Rare Diseases Advisory Group and patient groups have taken part in selection processes to identify providers of new highly specialised services. • There are four long-standing PPV members who are actively involved in the Rare Diseases Advisory Group meetings, providing challenge and advice as required. • Ongoing engagement with PPV groups and charities is regularly undertaken to design rare disease services for patients. For example, NHS England worked with NICE and three Patient Advocacy Groups to develop the managed access agreement for the use of the drug, nusinersen, in treating patients with spinal muscular atrophy.
• % of providers compliant with rare disease insert elements (2, 3, 24) • Examples of good practice in use of the rare disease insert and how non-compliance is being addressed (2, 3, 24)	• In its annual contracting letter to providers for 2019/20, NHS England signalled its intention to implement a rare disease ‘insert’ from April 2019, which is a set of criteria that will sit alongside NHS England service specifications for services that treat patients with rare diseases. Providers will be assessed for their level of compliance during the coming year. These criteria will allow NHS England to hold providers to account for the way in which they treat patients with rare diseases. There will be up

Measure (corresponding commitments from Strategy)	Progress Report
	to three criteria in the insert (depending on the nature of the service): o That the provider must ensure that there is a person responsible for coordinating the care of any patient with a rare disease; o That the provider must give every patient with a rare disease an 'alert card' (including information about: the patient's rare disease; any particular aspects of the treatment of that rare disease that need to be taken into account in providing care to that patient; and details of how to contact an individual expert in that patient's care); and, o That the provider must ensure that every paediatric patient with a rare disease has an active transition to an appropriate adult service, even if that adult service is not the commissioning responsibility of NHS England Further information about the implementation of the rare disease insert is given in **Appendix A**.
• Progress report on the development of a privacy impact assessment to examine suitable arrangements for the sharing of data within the NHS where genomic testing could be used as part of routine clinical care (6)	• The Privacy Impact Assessment for the NHS Genomic Medicine Service (GMS) is being developed as part of the Data Protection Impact Assessment (DPIA) in line with NHS England's policy and the requirements of GDPR. These cover the complex privacy issues that arise from genomic testing, such as the potential impacts on the patients and family members. The approach notes the current practice and the evolution being delivered through the NHS GMS. The DPIA will be submitted to NHS England's Senior Information Risk Owner and Data Protection Officer, with the Corporate Information Governance team engaged and providing input as the documentation is developed. • The programme has engaged with the National Data Guardian, key professional and patient representative groups on privacy issues and concerns. Further consultation and discussions will

Measure (corresponding commitments from Strategy)	Progress Report
	continue as the service develops and will form part of the assessment of changes.
• Number of rare disease collaborative networks endorsed (8, 27, 33, 47, 51) • Number of rare disease collaborative centres endorsed (8, 27, 33, 47, 51)	• NHS England has developed a process and is piloting two rare disease collaborative networks: CDKL5 and refractory coeliac disease. • CDKL5 has one centre (and will collaborate with other centres internationally) and refractory coeliac disease has two centres. • NHS England has agreed two further RDCNs: rare cystic lung disease (two centres) and hereditary haemorrhagic telangiectasia (HHT) (five centres, including one in Wales and one in Scotland. Further information about the progress being made by the two RDCNs is given in **Appendix B**.
• Published Genomic Testing Strategy available on the NHS England website (10, 43, 44)	• The National Genomic Test Directory is published on NHS England's website. • The Test Directory specifies which genomic tests are commissioned by the NHS in England, the technology by which they are available, and the patients who will be eligible to access to a test. The Test Directory will be delivered by the seven Genomic Laboratory Hubs. • The Test Directory will be updated annually supported by robust and scientific evidence.
• Number of specific early diagnostic interventions implemented (11)	• NHS England has established a Rare Diseases Data Innovations Subcommittee (under the auspices of the Rare Diseases Advisory Group) with the primary aim of exploring how Specialised Commissioning can support the use of data innovations to facilitate the early identification and diagnosis of rare disease and support improvements in intervention development. The first meeting was held in December 2019.
• Progress report on the Genomics Clinical Leads Group(11)	• In January 2018, NHS England partnered with the Academy of Medical Royal Colleges to set up the Genomic Clinical Leads Group, bringing together members from all Medical Royal Colleges.

Measure (corresponding commitments from Strategy)	Progress Report
	• The remit of the Genomic Clinical Leads Group is to oversee the work related to championing and supporting the NHS to embed the use of genomic medicine into clinical practice in the NHS. This will help to ensure that the NHS is prepared to harness the full potential of genomics across all clinical specialities. • The Group continues to meet on a quarterly basis and has two main workstreams: education and training; and clinical pathways. The education and training workstream has been working to identify what is required to ensure relevant healthcare professionals are provided with tools and support to deliver genomic testing. The clinical pathways workstream is developing care pathways for genomic testing that achieve maximum benefit for patients while minimising potential risks.
• Published processes for the evaluation of the costs and benefits of treatments available on the NHS England and NICE websites (13)	• Published processes for the evaluation of the costs and benefits of treatments are available on the NHS England website here. Products that are prioritised for funding are subsequently commissioned by NHS England. This may require new providers to be selected in line with their expertise. • In 2019, four products were agreed through the NICE Highly Specialised Technology Programme: o Inotersen for treating hereditary transthyretin amyloidosis; this is subject to a patient access scheme o Patisiran for treating hereditary transthyretin amyloidosis; this is subject to a simple discount patient access scheme o Voretigene neparvovec for treating inherited retinal dystrophies caused by RPE65 gene mutations; this is subject to a simple discount patient access scheme o Cerliponase alfa for treating neuronal ceroid lipofuscinosis type 2; this is subject to a manged access agreement
• Progress report on the adoption of SNOMED (16, 17, 21)	• SNOMED CT is a clinical terming language that enables the consistent identification and transmission of clinical information across many clinical settings. The NHS has set a target that SNOMED CT will be utilised by all secondary care settings by

Measure (corresponding commitments from Strategy)	Progress Report
	April 2020. Whilst good progress in this target has been demonstrated in the acute emergency care, maternity and mental health settings, little progress has been made elsewhere within acute secondary care. It is probable therefore that the deadline for adoption may be extended by a further year. • SNOMED CT is expected to be advantageous to both Specialised Services Commissioning and the identification / reporting of rare diseases as it has the capability to be of greater clinical granularity than is possible using the OPCS / ICD clinical codes. • Specialised Services have supported the adoption of SNOMED CT within secondary care pharmacies by requiring that the drug SNOMED CT term is captured in the patient level high cost (tariff excluded) drug patient level monitoring. • Specialised Services are also working with NHS Supply Chain to imbed the relevant high code device SNOMED term into the supply chain catalogue, thereby making the SNOMED CT term more accessible to healthcare providers.
• Progress report on standardisation of data collection areas (18)	• NHS England has achieved standardisation of the four core data flows used to support the commissioning process. • NHS England continues to pursue the creation of Information standards to enable four core data flows to be used to support the commissioning process and therefore to be applicable to all acute Trusts and all commissioners: NHS England and CCGs. The proposed reporting formats can be found at the bottom of this webpage. The aspiration is to have standards for these flows in place for 2021/22 commissioning. • NHS England has an identification rule software tool and supporting guidance to enable the consistent identification of (more common) easy to report specialised services.
• Number of providers endorsed as members/leads of European Reference Networks (22, 27, 28)	• While the UK continues to have access to the European Reference Networks (ERNs), there are currently 114 providers in the UK endorsed as members, more information can be found here. In the context of the exit of the UK from the EU, only

Measure (corresponding commitments from Strategy)	Progress Report
	providers in mainland Europe are able to lead ERNs and the previous leads in the UK have relinquished these roles. • In November 2019, NHS England endorsed a further 15 providers to apply to be members of ERNs.
• Number of providers engaging with NHS England through aspirant market entrant process (24) • Number of service reviews initiated through the aspirant market engagement process (24)	• NHS England has developed a process and has piloted the aspirant market entrant process with two providers. Following a comprehensive review of a number of factors a decision has been taken that a service review should not be initiated as a result of the process for these first two proposals. The process has been refined following learning from the process.
• Reprocurement/mobilisation of the genomic infrastructure complete (26)	• Following the conclusion of the Genomic Laboratory Services procurement in October 2018, detailed planning and consolidation activities have been underway across the NHS to build the national genomic testing network. • The national genomic testing service has been established to consolidate and enhance existing genetic laboratory provision and create a world class resource for the NHS. • The national genomic testing service is delivered through a network of seven NHS Genomic Laboratory Hubs, each responsible for the provision and coordination of genomic testing for a defined area of the country.
• Published process for excess treatment costs available on the NHS England website (33)	• Information about excess treatment costs can be found here.
• Number of Whole Genome Sequencing samples collected (43, 44)	• On 5th December 2018, the 100,000 Genomes Project completed the sequencing of 100,000 genomes. • The NHS commitment was to provide 90,000 samples. As of 18th January 2019, the NHS has collected: o 69,379 samples for rare and inherited disease o 32,404 samples for cancer

Appendix A – implementation of the rare disease insert

Each provider that delivers specialised services self-assesses the quality of all the services they deliver on an annual basis. NHS England commissions specialised services through about 200 service specifications and from about 280 providers so this is a systematic way of collating information about each service at each provider that delivers it. If a provider is unable to give a positive response, they have to provide an explanation and an improvement plan may need to be agreed. NHS England has used this Quality Surveillance System to collate information about the rare disease insert. Some service specifications will have one rare disease criteria, some two and some all three.

Results

1. NHS England identified 100 service specifications that included at least one element of the rare disease insert and requested 150 providers to self-assess against these criteria. In total, 1,000 teams undertook the assessment. The completion rate was 85%. Of those providers that self assessed: 91% confirmed that there is a person responsible for coordinating the care of any patient with a rare disease; 56% confirmed that they gave each person an alert card; and 91% confirmed that they had active transition in place.

Feedback

2. There was other helpful feedback from the exercise. For example, some services felt that the one or more of the criteria were not applicable to their services (for example, HIV and specialist rehabilitation) and therefore did not feel that it was appropriate to respond to the self-assessment; conversely some services have requested to be included in future compliance exercises. There was feedback that some NHS England specifications covered both patients with rare diseases and other facets of treatment and care and therefore it was not feasible to self-assess for the rare disease elements only. There was a view that alert cards should be available but that some patients would not wish to use them and there was also feedback that the criteria for care coordination could be more flexible to allow for other models. This feedback will be incorporated into future exercises. NHS England will dovetail the transition criteria into its broader workstream on this important area.

Next steps

3. Once relevant feedback has been taken into account, any low completion and compliance rates will be followed up by the relevant Programme of Care Team, by the Highly Specialised Commissioning Team (for highly specialised services) or by the relevant Regional Team where there are patterns of poor completion or compliance across whole providers.

Examples of best practice in rare diseases

Bardet Biedl service

In the Bardet Biedl syndrome service, a telemedicine clinic was piloted in the four units for those patients who are stable. Feedback has been obtained systematically from families following these appointments and has been consistently positive. Key benefits are time and travel cost savings for families and a much less stressful way of accessing review for patients, some of whom have multiple disabilities. Clinicians have conducted care reviews successfully, have given management advice and, where appropriate, directed patients to other clinicians in primary or secondary care for urgent review. Given the success and benefits of these clinics, the service plans to implement them on an ongoing basis.

Beckwith Wiedemann syndrome service

In the Beckwith Wiedemann syndrome service, a telemedicine clinic was piloted for post-operative reviews of patients once they had been discharged back home. Feedback has been obtained systematically from families following these appointments ad has been consistently positive.

Cockayne Syndrome/Trichothiodystrophy (CS/TTD)

The national CS/TTD highly specialist service started formally in February 2019 as an overarching provision of DNA repair disorders which includes the well-established and highly regarded Xeroderma pigmentosum (XP) service. There are many symptoms that overlap between XP/CS and TTD. Patients are seen in an all-day multidisciplinary clinic by six specialities with input from allied specialities as needed. The aim of the service is to share knowledge and experience of CS/TTD to help optimise management in liaison with local paediatric community teams and the patient's GP.

The service has built on many aspects of the service to enhance the complex co-ordination needed and taken on board the very helpful feedback and suggestions received from the families using the service. These include:

- MDT clinics
- Triage and discharge pathways, pathways for symptom management or end of life care
- Transition for young adult patients
- Bespoke management plans for liaison with the local team (hospital or community paediatrician, paediatric specialities, GP); all reports are copied to the parents

- A website (under construction) that includes information about the team, wat to expect in clinic, information leaflets
- Language support where needed
- Availability of phone advice, pastoral care and support
- Central e-mail address to ensure continuity of cover for triaging referrals and responding to queries
- Highlighting the service in relevant publications including patient support groups, for example, Rare Revolution Magazine: https://t.co/wOjZYhYf5F
- Home visits by a dedicated CNS to allow professionals to be aware of each child's 'normal'
- An acute care plan, especially for use during the winter period
- A bespoke patient passport
- Provision of information to inform the patient's Education, Health & Care Plan
- Collaborative work with other countries, for example, the development of standardised specific growth charts with colleagues in France
- Post-graduate educational sessions planned for local teams at Evelina and South East in 2020

Congenital hyperinsulinism (CHI) service

In the congenital hyperinsulinism service, the two centres work together as a single team and have introduced joint MDT videoconference meetings to review the care of patients and ensure systematic reviews of patients. The service is also developing a prototype App for CHI patients and is using continuous glucose monitoring for patients with hypoglycaemia. The service's Clinical Nurse Specialists supports school staff to ensure children are safe in the school setting.

Craniofacial service

Children who are diagnosed with one of the craniofacial conditions have a care plan set out for them and the service's Clinical Nurse Specialists liaise with local schools to make sure that children are assessed for and receive additional support depending on their changing needs.

Complex congenital osteogenesis imperfecta (CCOI) service

In the CCOI service, the four centres work collaboratively to streamline current medical treatments as well as offering patients opportunities to access innovative medical treatments through enrolment in research studies. Through care planning, there is support for patients to be cared for in the local setting and Clinical Nurse Specialists support and provide education materials for school staff to enable children to access education.

Neurofibromatosis type 1 (NF1) service

In the two national centres, clinical psychologist offers weekly clinics and telephone support to help illness adjustment and anxiety in adults with NF1. There are also neuro-disability paediatricians who focus on children with chronic neurological problems.

There are weekly phone clinics held by Clinical Nurse Specialists to support complex NF1 patients in between clinic visits, lessening the need for people to travel to face to face clinics, helping people who live a long distance from the centres to access care and review locally and triaging sick patients for urgent assessment to the centres.

Multiple sclerosis management service for children

This service was established in April 2018. As well as involvement of the MS Trust and the MS Society in the development of the specification, the provider selection process and the mobilisation of the new MS for children service from April 2018, the clinician, charity and commissioner group still meet every three months to progress the implementation of the service, including developing patient information. A third MS charity has now joined the group – Shift.ms – and is working with the service lead unit provider group to refresh and adapt further its patient information.

The MS Trust recently reviewed the content of its 'Young People and MS' section of its website, on its YouTube channel, which features a new film for September 2019 featuring Sharon Whyte and Mary Fraser from Addenbrooke's Hospital and which features both the children's and adult MS Service. It discusses transition to adult services, see here:

https://youtu.be/5Omwlk7RtDA and there is an interview with GOSH's Cheryl Hemingway's with her patient Eden here: https://www.youtube.com/watch?v=503qFPmolOM

The MS Trust recently won several awards at the BMA patient information awards – the website was awarded Runner Up in the Long-Term Conditions Category, and the YouTube Channel for young people affected by MS, was Highly Commended, and shortlisted in the Young Adult Category.

The reviewer for MSTV commented: 'This is a great resource for children with MS in an appropriate format. A well-thought through project with sound evidence and health care professional and user involvement. A good range of health care professionals are involved in the process, either in writing MS resources or through being interviewed giving their professional opinion. Young people affected by MS, both with a diagnosis themselves or with a family member with MS, have been extensively involved in content

creation for this project. It's great to see an organisation responding to the needs of users and this is a well-designed resource for children with MS. Well done to all involved.'

Primary ciliary dyskinesia management service for children

Patients' GPs are sent comprehensive outcome letters following clinic review – the delivery of any requests for local clinical actions such as further local testing and review is followed up by the service's nursing staff to make sure that patients receive the management of care that is required. Patient's families have a direct phone number to the service's nursing staff to discuss any issues or concerns.

Xeroderma pigmentosum (XP) service

The care is coordinated for these patients, who live all over the country and have a life limiting rare complex multiorgan disease, as follows:

- The national MDT clinic provides a multidisciplinary (six-clinical specialty) one stop clinic at which clinical problems too complex for local care to meet all the needs are managed
- Patients are jointly cared for by the central national MDT and their local hospital consultants and GP. This is achieved by two specialist XP nurses who liaise with local clinicians, and also local schools, workplaces and Social Services as required. The specialist nurses travel to the patients' homes/local hospitals/schools as and when required. The specialist nurses act as the 'glue' that binds together local primary and secondary care, and the national XP Service. This is important because patients live so far from London that using the expertise of the national centre to improve local care, as well as providing direct clinical care when necessary, is necessary to avoid patients having to travel long distances unnecessarily. Not only does this avoid inconvenience and expense for patients but, with a disease where exposure to ultraviolet from daylight is a significant clinical issue, minimising unnecessary long journeys is important.
- Patients are given a folder to keep all the multidisciplinary XP clinic reports and other relevant clinical paperwork in. They are encouraged and helped to keep this up to date and to bring it to all appointments to avoid difficulties caused by letters, reports from the national service, etc not being available in the patient's notes at the local hospital or GP practice.
- The national service uses a secure version of Skype for communicating with patients, including nurse-led consultations as necessary.

Appendix B – progress of the Rare Disease Collaborative Networks

CDKL5

The three priorities for the RDCN in its first year of operation (2018) were:

1. To improve patient outcomes by consolidating and expanding our knowledge about the natural history of this rare multiorgan disease and finding suitable treatments for its related morbidities.
2. To operate as a portal to create a platform for innovative research ideas by collaborating with funding providers, charities, patient groups, regulatory authorities, scientists and pharmaceutical companies.
3. To support a higher quality of care to be delivered throughout the UK by implementing the outcome of these innovative research projects, producing guidelines and closely collaborating with colleagues who encounter patients with CDKL5.

Since its inception, the RDCN has been collaborating with the British Paediatric Neurology Association (BPNA) and the European Paediatric Neurology Society. Paediatric neurologists in the UK will be aware of the service via communications from the BPNA.

In 2018/19, the RDCN saw five patients and the clinical lead provided advice to other clinicians regarding approximately 30 patients in the UK. An international registry is being established which will help to identify how many patients in the UK with this disease.

The RDCN is looking to increase its expertise and understanding of the disease via collaboration with a well-established centre of excellence for CDKL5 in Colorado.

The RDCN clinical lead will be a co-author on the planned international clinical guidelines with the Colorado team.

The CDKL5 RDCN has set up a website http://bristolcns.org/posts/news/cdkl5-rdcn/

The family organisations are CDKL5 UK and the Lou Lou Foundation, which are very supportive of the RDCN and a recent international meeting for families included a CDKL5 annual meeting. The Lou Lou Foundation has funded a part-time co-ordinator for the RDCN for 2-3 years.

Rare & refractory Coeliac Disease

The three priorities for the RDCN in its first year of operation were:

1. To establish a national registry for patients with Refractory Coeliac Disease

2. To centralise diagnostic pathways
3. To develop collaborative research between centres

Since the creation of the RDCN :

1. The two centres have coordinated efforts to provide a unified service. Current data shared shows 121 cases seen in Sheffield (from 1998-2019) and 23 cases from Cambridge since 2015. The diagnostic pathology service is being standardised in order to ensure that both centres use the same methodology for reporting flow cytometry.

2. The RDCN has successfully applied for and been granted ethics approval for a National Database for Refractory Coeliac Disease (REC Reference 19/YH/0095 and IRAS 260844).

3. Publicity and awareness: There have been a number of publications across both the gastroenterology community and patient groups:
   - *EM Baggus et al*: How to manage adult coeliac disease: perspective from the NHS England Rare Diseases Collaborative Network for Non-Responsive and Refractory Coeliac Disease. Frontline Gastroenterology 2019
   - British Society of Gastroenterology Newsletter
   - Coeliac UK Autumn Newsletter
   - Gastroenterology Today (non-medline journal with wide UK distribution)
   - Currently the RDCN are also developing their profile on the Coeliac UK National Patient Charity Website.

4. The inaugural meeting of the RDCN took place in London in July 2019, with the next meeting Sheffield in January 2020. The meeting will take place semi-annually thereafter.