

**Resource Sheet for NIHR Think Research**

**Rare Diseases Patient Day Training Sessions**

**Sessions:** Data and Research, Genomics**,** Social Media and Working with Industry

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# Data and Research useful websites

[Understanding patient data](https://understandingpatientdata.org.uk/)

[Managing Ethico-social, technical and administrative issues in data access](https://www.metadac.ac.uk/)

[Wellcome Trust report on public attitudes to commercial access to health data](https://wellcome.ac.uk/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf)

[Medical Research Council and Data sharing](https://mrc.ukri.org/research/policies-and-guidance-for-researchers/data-sharing/)

[University of Cambridge PHG Foundation](http://www.phgfoundation.org/)

[UK Data Archive](UK%20Data%20Archive)

[European Genome-Phenome Archive](https://ega-archive.org/)

[Global Alliances responsible genomic data sharing](https://www.ga4gh.org/)

# [Repositive platform for researchers to search for genomic data](https://repositive.io/)

# GDPR

# [Summary of key changes on GDPR](https://www.eugdpr.org/key-changes.html)

# [MRC GDPR implementation guidance](https://mrc.ukri.org/documents/pdf/gdpr-preparations-for-implementation/)

# [Data protection changes in 2018: what does that mean for research? (HRA)](https://www.hra.nhs.uk/about-us/news-updates/data-protection-changes-2018-what-does-mean-research/)

# [Guide to the General Data Protection Regulation (ICO)](https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/)

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# Genomics useful websites

[Genomics England](https://www.genomicsengland.co.uk/)

[Genomics Education Programme](https://www.genomicseducation.hee.nhs.uk/)

[A Brief Guide to Genomics (NIH)](https://www.genome.gov/18016863/a-brief-guide-to-genomics/)

# Social Media useful websites

[Rare Disease UK animated GIFF for Rare Disease Day](Rare Disease UK animated GIFF for Rare Disease Day  https://www.youtube.com/watch?v=Z1p-A9dfgjs)

[Pompe Disease Christmas Jingle helping to raise awareness](https://www.youtube.com/watch?v=OfDXE7P1JKE)

# [Rare Disease and Social Media: Making Connections](https://corp.inspire.com/patient-stories/rare-disease-social-media/)

# [Social Media Image Size Cheat Sheet (USA company)](https://www.mainstreethost.com/blog/social-media-image-size-cheat-sheet/)

# [Blog showing 60+ Social Networking sites](https://makeawebsitehub.com/social-media-sites/)

# Working with Industry useful websites

# [James Lind Alliance and Priority Setting Partnerships](http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-psps.htm)

# [Findacure e-learning portal](https://portal.findacure.org.uk/)

# [UEA's Toolkit for producing patient information](https://www.uea.ac.uk/documents/246046/0/Toolkit+for+producing+patient+information.pdf)

# [McKinsey launching a rare disease drug in a patient centric world](https://www.mckinsey.com/industries/pharmaceuticals-and-medical-products/our-insights/how-to-successfully-launch-a-rare-disease-drug-in-a-patient-centric-world)

# [Life Sciences Sector Documents (UK Government)](https://www.gov.uk/government/publications/life-sciences-sector-deal)

# *Please note this is just an example of sites that we have selected*