

Social Media Messages

Ring20UK @Ring20UK · Mar 21
Looking forward to this schedule this afternoon. Data and Research- why data is central to research

KirstenK_MND @KirstenK_MND · Mar 21
Does anonymity matter? - the data spectrum #RareDPD

Beat SCAD UK Retweeted
Rebecca Breslin @BecksBreslin · Mar 21
Great examples of how to use social media to raise #awareness of a rare disease by patient Gemma Seyfang #ThinkResearch #RareDPD @NIHRBioResource @CambridgeBRC

Alison Cooper @AliCooper1970 · Mar 21
Always great to hear from BCH! Hope you are doing well @bchrare #RareDPD

Judith Gower @judith_gower · Mar 21
About to start NIHR rare disease patient day #RareDPD

Kelly Bear Retweeted
CRDN Retweeted
Cam Rare Disease @camrareddisease · Mar 21
#RareDPD Prof Patrick Chinnery explains what the NIHR BioResource is, working across 60 @NHS trusts

Genetic Alliance UK @GeneticAll_UK · Mar 21
Now hearing from @EEGMC on genomics, the 100,000 Genomes Project and how it can shorten the #raredisease diagnostic odyssey. #RareDPD

But...

diagnostic odyssey
/dajəgnastɪk ədəsi/
noun

1. The time taken between a patient first developing symptoms of their condition and receiving a correct medical diagnosis.
"A rare disease patient's diagnostic odyssey lasts on average four years."

Mattia Retweeted
Ella A @aella_ella · Mar 21
Useful insight into children moving from paediatric care to adult services #RareDPD

The Research Programme had three objectives

1. Work with young people with long term conditions to determine what successful transition means to them and what is important in their transitional care
2. Identify the features of transitional care that are effective and efficient
3. Determine how transitional care should be organised, provided and commissioned

Social Media Messages

Genomics England Retweeted

Gemma Chandratillake @GemmaChand · Mar 21
About to kick-off at the NIHR Rare Disease Patient Day, talking about genomics for rare disease later on #RareDPD @_EEGMC @camraredisease @GenomicsEngland @genomicsedu



NIHR Cambridge BRC @CambridgeBRC
@vickyford Chair of All Party Parliamentary Group on #rare, #genetic and #undiagnosed conditions opening our Rare Disease Patient Day #RareDPD @CambridgeBRC @NIHRBioResource



5 replies 16 likes



Emma Damian-Grint @EmmaDamianGrint · Mar 21
Excited to be hosting a workshop on maximising your social media for @OfficialNIHR 'Think Research' conference today. Looking forward to meeting patients and patient organisations & hearing what's worked for them. #RareDiseases


1 reply 4 likes

Alison Cooper @AllCooper1970 · Mar 21
Exciting developments. Would be great to see such advancements in #TSC @uktsa #RareDPD

1 reply 4 likes

Larissa Kerecuk Retweeted

Sharon Buckley @SharonBuckley · Mar 21
As a parent of children with #pku I'm fortunate not to have traveled along a diagnostic odyssey! Hopefully the 100'000 Genome project will help contribute to more people knowing the diagnosis for their #raredisease #RareDPD



GoPI3Ks charity (1176289) @GoPI3Ks
4 years is such a long time of rare condition terms, so much can happen in a day when you're rare. #RareDPD



3 replies 6 likes

Success stories

NIHR Inflammatory Bowel Disease (IBD) BioResource

NIHR IBD was founded via the NIHR BioResource in 2016

Collaboration between NIHR BioResource, MRC, Crohn's disease and ulcerative colitis

Aim to collect data from 25,000 patients, currently at 10,000 in first 2 years

58 sites are now open to patient recruitment

6 further research studies based on the IBD cohort

NIHR BioResource for Translational Research

1 reply 4 likes

Beat SCAD UK Retweeted

Leicester's Research @LeicResearch · Mar 21
An excellent example of what can be achieved when researchers and patients work together - great to see @BecksBreslin and Dr Adlam from @LeicesterBRC spreading the word on collaboration #whywedoresearch #puttingpatientsfirst



Beat SCAD UK @beatscaduk
@beatscaduk @BecksBreslin & Dr David Adlam, who is leading the @LeicesterBRC SCAD research, are talking at the @OfficialNIHR 'Think Research' Rare Diseases Patient Day today about how patients and researchers are collaborating to solve SCAD. bit.ly/2DBBDkE #scadheart

4 replies 5 likes

GoPI3Ks charity (1176289) Retweeted

JAMES @thisisjmx · Mar 21
Here for @GoPI3Ks at #RareDPD with @CambridgeBRC SO MUCH TO TALK ABOUT! #RareDisease



1 reply 1 like

Ella A @aella_ella · Mar 21
Scale of patients with severe sight conditions is more than 1 in 2000, research is needed to help with this#RareDPD

Genetic Eye Diseases

Reaching a genetic diagnosis is not always straightforward

Judith Gower @judith_gower · Mar 21
Social media workshop at #RareDPD great ideas @ukpips

Extending your reach

User-generated content

Conversational content

Join the conversation

Shareable content

Identify key influencers

NIHR Think Research Rare Diseases Patient Day

2 likes

PWSA UK @PWSAUK · Mar 21
Great to be attending the rare disease research patient day #RareDPD. Looking forward to hearing about latest developments and future plans



1 reply 1 like 4 likes

Social Media Messages

Lisa Middleton Retweeted

Rare Revolution Mag @RareRevolutionM · Mar 21

Great to hear a dedicated research area will be included in the new @BCH_Rare #RareDisease centre! #pioneering #passion #outstanding #RareDPD @CambridgeBRC

Child Growth @CGFCharity · Mar 21

#RareDPD

KirstenK_MND @KirstenK_MND · Mar 21

Very interesting morning at #RareDPD. The afternoon is about to begin

Sharon Buckley Retweeted

NIHR Cambridge BRC @CambridgeBRC · Mar 21

How does the health service help young people with complex health needs transition to adult services? Prof Allan Colver has done some research bit.ly/2ph6deg on this & he's talking about it at our #RareDPD @CambridgeBRC @NIHRBioResource

Natasha Kriznik @NMKriznik · Mar 21

Here today as part of the Consent Panel Session. Looking forward to hearing your questions! #RareDPD

NIHR Cambridge BRC @CambridgeBRC

#RareDPD in London is happening now - lots of talks, training & networking. Thank u to all the patients with rare diseases who are here today with @CambridgeBRC & @NIHRBioResource

galk Retweeted

Will Evans @willrheavans · Mar 21

#RareDPD Med technology initiative to help rare disease children. Ideas?

CYP MedTech National Institute for Health Research

Rare Disease Theme priorities:

- Identify unmet needs
- Catalyst to pull together diverse stakeholders
- Support and help develop new medical technologies for children with rare disease
- Identify funding opportunities

What's Next?

On 7th June we will be holding an event in Leeds with the Translate group (www.translate-medtech.ac.uk). Focus on identifying problems with rare diseases & working on solutions to these problems with academics and industry. Follow us on Twitter @cypmedtech

Do you have an unmet need in rare diseases you would like to talk to us about? Contact us at nhr-cyp-mir@nhr.ac.uk

NIHR Children and Young People MIC Retweeted

Larissa Kerecuk @BCH_Rare · Mar 21

Replying to @AllCooper1970

@TITCHinnovate @cypmedtech being discussed today #RDD @CambridgeBRC - we want to work with patient groups to develop new technology for #RareDiseases

Rare Revolution Mag Retweeted

NIHR Cambridge BRC @CambridgeBRC · Mar 21

Getting busy at #RareDPD we'll be starting this exciting day soon!!

East of England GMC @EEGMC · Mar 20

.@EEGMC staff Gemma Chandratillake & Karola Rehnström are running genomics training sessions at this event #RareDPD

NIHR Cambridge BRC @CambridgeBRC

Just 1 day left to #RareDPD in London from @CambridgeBRC & @NIHRBioResource - looking forward 2 lots of talks, training & networking. In the meantime click bit.ly/2IBjAhL 2 read this great magazine from ...

Social Media Messages

Ring20UK Retweeted



NIHR Cambridge BRC @CambridgeBRC · Mar 21
The start of personalised medicine #RareDPD

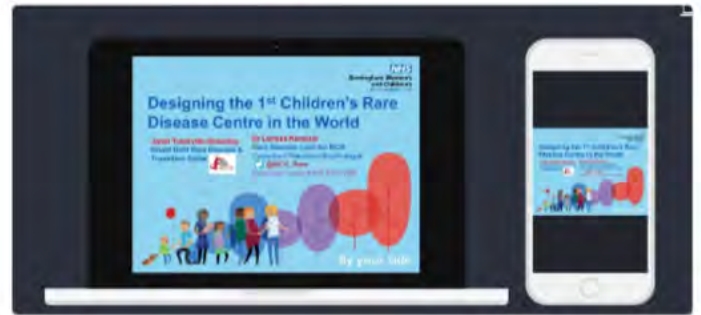


3 7

Roald Dahl Charity Retweeted



NIHR Cambridge BRC @CambridgeBRC · Mar 21
Amazing work at the world's 1st Children's Rare Disease Centre in Birmingham - thnk u Maria & Janet 4 explaining it 2 us #RareDPD @CambridgeBRC @NIHRBioResource @RoaldDahlFund



6 14



Sharon Buckley @SharonBuckley · Mar 21
Listening to a question and answer session involving consent; of particular interest is the idea of dynamic consent - it involves a two-way dialogue; important to remember that consent is a process and not an event. #RareDPD #ResearchChallenge



Sharon Buckley Retweeted



NIHR Cambridge BRC @CambridgeBRC · Mar 21
Since her diagnosis with Pompe disease Gemma has written poetry, sung for social media and all 2 raise awareness / funds 4 Pompe - thx Gemma 4 sharing yr ideas with us #RareDPD @CambridgeBRC @NIHRBioResource



1 2 4

Larissa Kerecuk Retweeted



SamebutDifferent @SBDRareProject · Mar 21
We hope you're enjoying the exhibition at #RareDPD. If you would like to take part or know someone who would like to take part in one of our projects, please get in touch samebutdifferentcic.org.uk



RaDaR @RenalRadar · Mar 21
Looking forward to some interesting talks and networking opportunities at the NIHR Think Research event #RareDPD

Katy Styles Retweeted



Katy Styles @WillowKaty · Mar 21
Here at the Think Research Rare Disease Patient Day #RareDPD #KennedysDisease #MND @mndresearch with @MarkStyles @mndassoc



Robert MitchellThain @PBCRobert · Mar 21
Learning more about research in rare disease with NIHR at #RareDPD and patient involvement @PBCFoundation

2 2

Social Media Messages

pelton boy Retweeted



The Lily Foundation @4Lilyfoundation · Mar 21

Team Lily representatives attending the 'Think Research' Rare Disease Patient Day #RareDPD #nhs #research #hope
Read about our research projects here: bit.ly/2Dml1fW

Julie Vallortigara Retweeted



Rebecca Breslin @BecksBreslin · Mar 21

At least 50% of #raredisease affect children

Same But Different #photography exhibition to raise #awareness

samebutdifferentcic.org.uk/rare-project/

#RareDPD



2 11 25

Julie Vallortigara Retweeted



Rare Revolution Mag @RareRevolutionM · Mar 22

@CambridgeBRC #RareDPD after great discussion in the @findacure_fdn #WorkingwithIndustry workshop we promised we would share @lifearc1 read here to find out more for advice on contracts etc



PLRH @plr_cambridge · Mar 26

Well done @CambridgeBRC @NIHRBioResource! #RareDPD was an excellent, informative event with a great turnout! We enjoyed Lunch Time Discussions with patient organisations interested in priority setting & funding for #PatientLed #ClinicalTrials. Thank you!



Natasha Kriznik @NMKriznik · Mar 21

What a fantastic day! Thank you for inviting me to take part on the consent panel @CambridgeBRC @NIHRBioResource #RareDPD



Will Evans @willrhevens · Mar 21

Thanks for organising @CambridgeBRC useful day and info to share with @NiemannPickUK #RareDPD



Ella A @aella_ella · Mar 21

#RareDPD

European Rare Diseases Network

EUNOS



European Reference Network
for rare or low prevalence complex diseases
© National Eye Diseases (neds.org.uk)

Ambition is for ERN-EYE to play a major role for rare diseases

Beat SCAD UK Retweeted

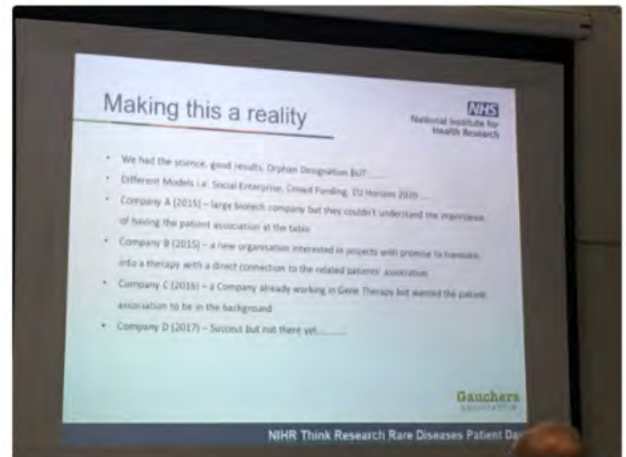


Rebecca Breslin @BecksBreslin · Mar 21

Patient organisations working with industry may require risks to be taken such as walking away from an offer that does not work well with the patient organisation expectations

#RareDPD

#PatientAdvocacy



4 2



KirstenK_MND @KirstenK_MND · Mar 21

A very interesting and thought provoking day at #RarePDP

Ataxia and Me Retweeted

Findacure @findacure_fdn · Mar 21

Retweeted by

And that's a wrap! We hope everybody who joined Libbie and Katie's #RareDPD Working With Industry workshop found it useful. Huge thanks to Tanya from @GauchersA for her sharing her excellent insight and experiences



4 6 20