Disseminating surveys & results on social media

EURORDIS Membership Meeting 2017

Eva Bearryman, Communications Manager

EURORDIS.ORG

Disseminating surveys

RD-Action Policy liked

Rare Diseases Europe @eurordis · 4 Oct 2016

Register for #RareBarometer Voices to share your experiences of what it means to live with a #raredisease eurordis.org/voices

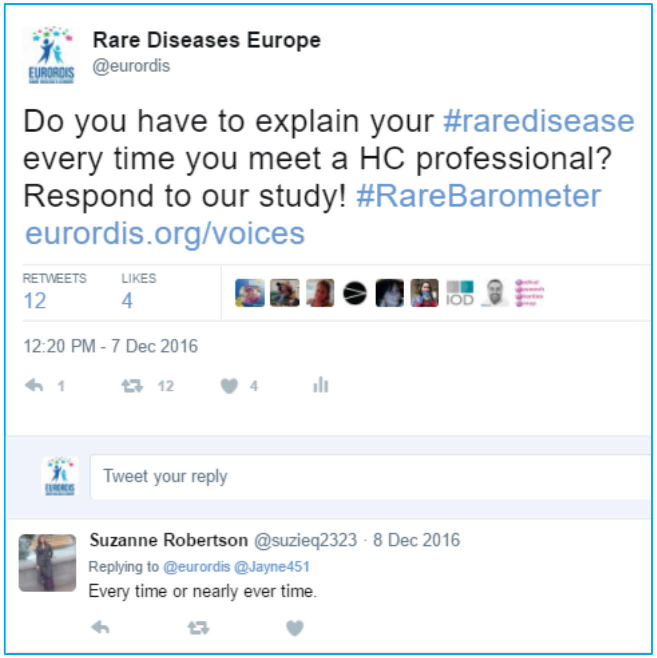
13 12

Rare Diseases Europe @eurordis · May 13

How do you use complementary & alternative therapies to manage your #raredisease? Respond this #RareBarometer survey ow.ly/jvpz30byAzv

1 3

- Images
- Specific questions that engage & incite people to tell their story



Rare Diseases Europe
@eurordis

Do you have to explain your #raredisease every time you meet a HC professional? Respond to our study! #RareBarometer eurordis.org/voices

RETWEETS	LIKES
12	4

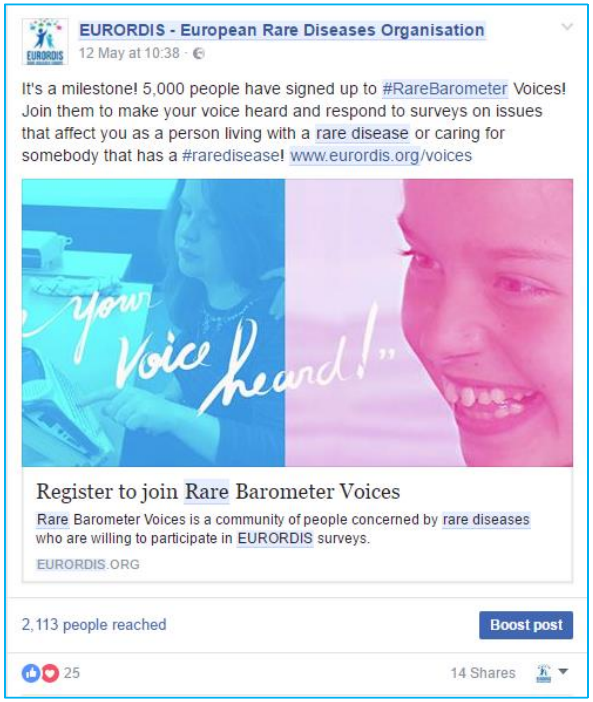
12:20 PM - 7 Dec 2016

1 12 4

Suzanne Robertson @suzieq2323 · 8 Dec 2016

Replying to @eurordis @Jayne451

Every time or nearly ever time.



EURORDIS - European Rare Diseases Organisation

12 May at 10:38 ·

It's a milestone! 5,000 people have signed up to #RareBarometer Voices! Join them to make your voice heard and respond to surveys on issues that affect you as a person living with a rare disease or caring for somebody that has a #raredisease! www.eurordis.org/voices

Register to join Rare Barometer Voices

Rare Barometer Voices is a community of people concerned by rare diseases who are willing to participate in EURORDIS surveys.

EURORDIS.ORG

2,113 people reached

25

14 Shares

In practice

IF SBH @ifsbh · 15 Jun 2016

Survey on discrimination in access to #healthcare. Available in DE, EN, ES, FR, IT, NL &PL! bit.ly/1YrgY9p

TAKE PART IN OUR SURVEY

HAVE YOU EVER BEEN TREATED INJUSTLY IN HEALTHCARE BECAUSE OF #SPINABIFIDA / #HYDROCEPHALUS ?

REACT Community

27 April at 09:53

The rare diseses' world need your help. Join the roar, sign the #RAREvolution petition to promote universal health coverage >> http://bit.ly/REACTCongressPetition

"We may be rare but we got roar"

Julia Flygare

RE(ACT) Community

#RAREvolution
www.react-community.org

Spina Bifida of CA @SBAofCA · 5 Oct 2016

Have you taken the Adults with #SpinaBifida **Survey** yet?
research.net/r/sba_adult_su...

Survey for Adults with Spina Bifida

https://www.research.net/r/sba_adult_survey

Answers Today for a Better Tomorrow

There are not enough physicians trained to treat adults with Spina Bifida. We don't know how many adults live with Spina Bifida. We don't know enough about Spina Bifida in adulthood.

Help us understand more about your life as an adult with Spina Bifida by taking a few moments to complete this survey. Your responses can help us build a better tomorrow.

Rare Disease UK @rarediseaseuk · Mar 4

What is the best way to communicate w/ patients about genome editing? Help @GeneticAll_UK by filling in this **survey**: ow.ly/NgLc309tZrl

TALKING ABOUT GENOME EDITING

Interested in how genome editing could shape research and clinic in the future?

Help us communicate in a way that is clear to everyone!

Take part here: http://bit.ly/TalkingGenomeEditing

Survey closes on March 19

GENETIC ALLIANCE UK

Presenting survey results

Infographics

ECDC HIV/AIDS
@ECDC_HIVAIDS

New campaign in 🇩🇪:"No AIDS for everyone" Let's tackle the persistent problem of late #HIV diagnoses
#keinAIDS2020
kein-aids-fuer-alle.de

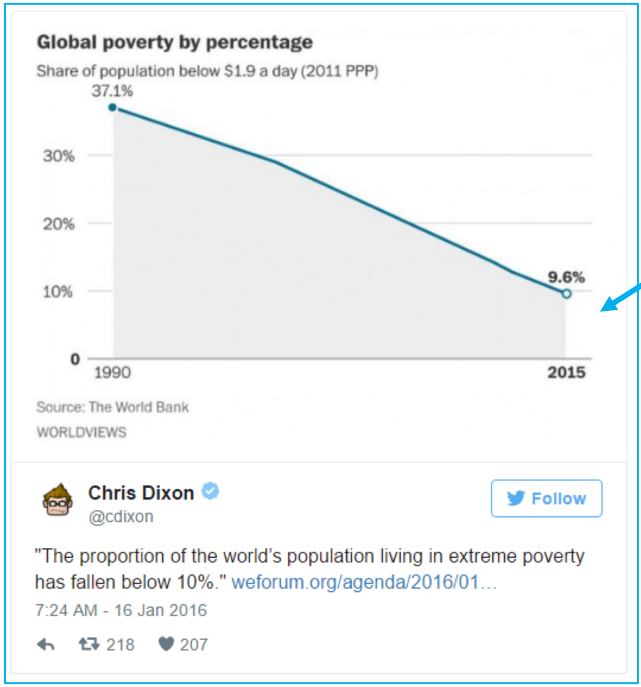
In the EU/EEA **47%** of those with a CD4 count reported are diagnosed late

RETWEETS 9 LIKES 10

2:54 PM - 12 May 2017

EATG, EU_Health, Vytenis Andriukaitis and EuroHIVHEPtestweek

Graphs



Global poverty by percentage

Share of population below $1.9 a day (2011 PPP)

Source: The World Bank

WORLDVIEWS

Chris Dixon
@cdixon

"The proportion of the world's population living in extreme poverty has fallen below 10%." weforum.org/agenda/2016/01…

7:24 AM - 16 Jan 2016

Images with anonymous quotes

Sean Gardner @2morrowknight · 20h

Some great #MondayMotivation from businesswoman, philanthropist, and music legend @MaryJBlige.

{#MusicMonday #quotes}

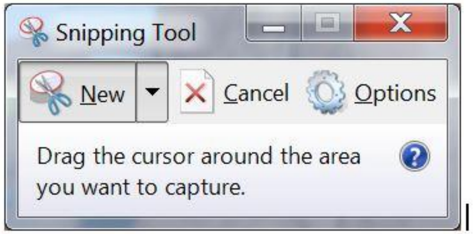
"Don't believe the negative labels people place on you because you are more than what they think."

Mary J Blige

Tips

- Good tool for infographics Canva

- Useful tool in Windows to take screenshot of a graph in survey report



Drag the cursor around the area you want to capture.

- Find out about other awareness days/ relevant conferences and use hashtag to spread relevant survey results to participants
  - World Mental Health Day on 10 October **#WMHDay #WMHD16**

- Create buzz around the announcement of the results #New
  - Target posts at relevant organisations to spread the word

New!

- First Rare Barometer Voices survey results out
- Social media posts about results coming over the next few weeks!
- #INNOVCare #RareBarometer

EURORDIS
RARE DISEASES EUROPE

3,000 rare disease patients & carers voice difficulties in balancing care & life

First Europe-wide survey on social impact of rare diseases publishes results

19 May 2017, Paris - The first Europe-wide survey on the social impact of rare diseases has revealed that rare diseases have a serious[1] impact on everyday life for **over 80% of patients and families**.

Over 3,000 rare disease voices across Europe responded to the survey '*Juggling care and daily life: The balancing act of the rare disease community*', which was conducted via Rare Barometer Voices and in the scope of the EU-funded INNOVCare project, focused on promoting person-centred care for rare diseases.

Rare diseases are complex - they are characterised by a wide range of symptoms that vary from disease to disease and also between patients living with the same disease. The care needs of patients are therefore also complex. Patients need to simultaneously access different health and social services, and coordination of care is a challenge.

> *"The different professionals that I need to see are usually not coordinated and do not see the person as a whole, but just as parts of a body."*
> *Female survey respondent, Spain*

Dorica Dan, Member of the EURORDIS-Rare Diseases Europe Board and Chair of the Romanian Prader Willi Association, commented, "As a mother of a daughter living with a rare disease, I know only too well the burden that a rare disease can bring to everyday life. This survey confirms what we already knew to be true, that the time burden of care is enormous, as is the effect of a rare disease on social, work and school life. Rare diseases pose real challenges for the person affected as well as their family or those who assume caregiving responsibilities. Patients and families need person-centred care to connect the dots across the various health and social services."

The current context: European Pillar of Social Rights

The timely publication of these survey results comes after the European Commission's release of its first proposals for a European Pillar of Social Rights. EURORDIS responded to the European Commission's public consultation on the Pillar to highlight for the first time the specific issues surrounding rare diseases.

Raquel Castro, Social Policy Senior Manager at EURORDIS, commented, "The results of this survey clearly show the severe care and time burden on people living with a rare disease and their carers. These challenges are not always accounted for within the social care system. We need a European Pillar of Social Rights that promotes integrated health and social care as well as adapted employment to respond to the needs of people living with a rare disease and other complex chronic diseases."

Time burden & consequences on work life

The survey results show that the **time burden** of daily care management and care coordination for rare disease patients and families is substantial.

- 42% spend **more than 2 hours** a day on care for their disease.
- 62% **of carers** reported they spend more than 2 hours per day on tasks related to the disease while **nearly a third spend more than 6 hours a day on care for a patient** (in comparison,

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[1] very severe, severe or medium

Suggestions and questions!