

DIGITAL COMMUNICATIONS FOR RARE DISEASE DAY

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WHY DIGITAL COMMUNICATION?

Digital communication is:

- Fast,
- Efficient
- Convenient
- And it's Measurable

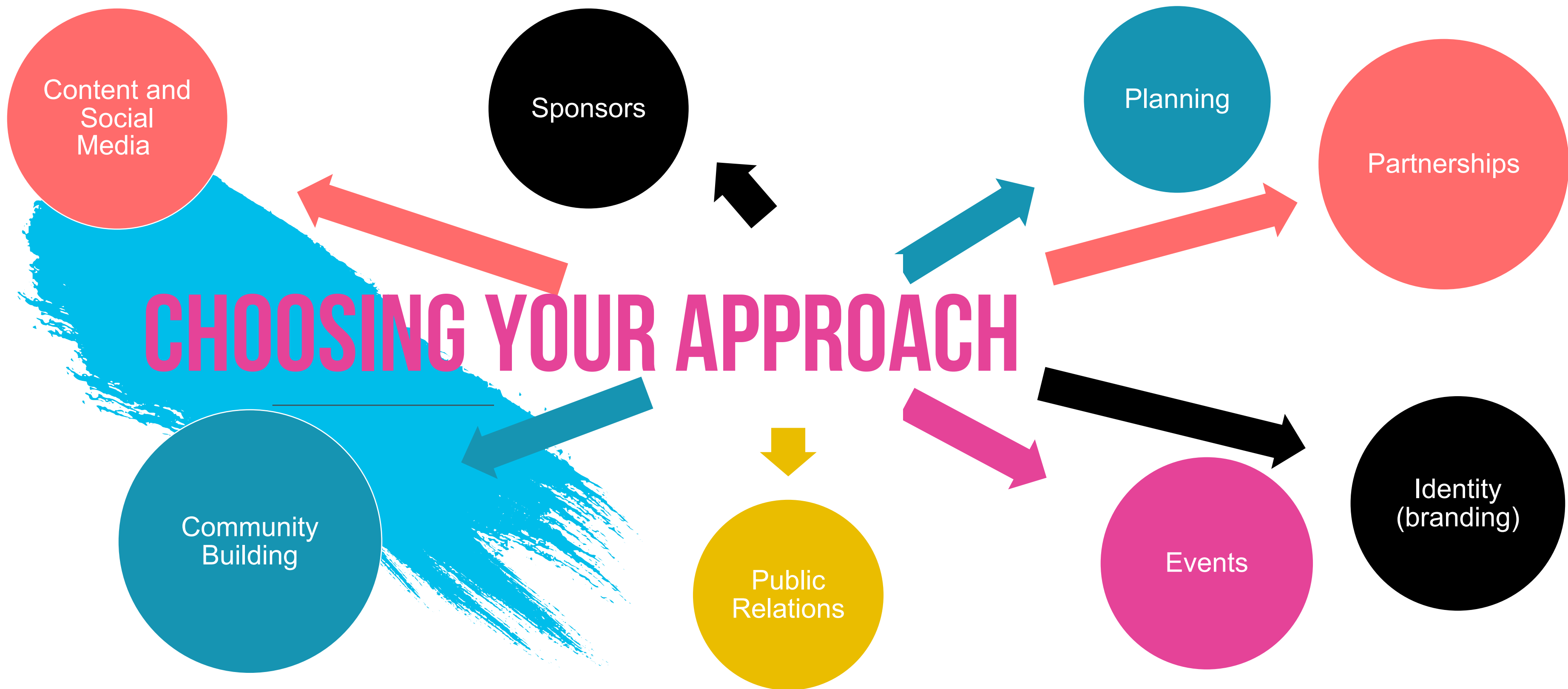
**“PLEASE, DON’T BELIEVE WHO TOLD YOU: “YOU’RE NOT A
SUPERHERO”. “YOU CAN’T DO IT”. “IT’S TOO LATE”. DON’T
FORGET TO PLAY SPORT, AS **YOU CAN DO IT**. DO ACTIVITIES FOR
YOUR HEALTH. SURROUND YOURSELF WITH PEOPLE WHO VALUE
YOU AND HELP YOU TO BE REBORN. **OVER AND OVER AGAIN.**”**



RARE DISEASE DAY: OUR APPROACH

- Focus on the existing Rare Disease Community
- Targeted, passionate and creative communication
- Bring the community together as one
- Celebrate and connect our worldwide Rare Disease community
- Using digital tools that can be enhanced by adapted/ localised materials to engage with our audiences and key stakeholders/ partners throughout the campaign period and beyond
- Monitor, evaluate and improve





Digital isn't the only way to communicate- choose the **most effective tool** to do the job efficiently

DIGITAL COMMUNICATIONS TOOLS

VS

DIGITAL COMMUNICATIONS CHANNELS

Website
Video
Social Media
Webinars
Conference Calls
Project Management
tools
Instant Messaging
Newsletters
Polls
Online forms
Education
Toolkits
Blogs
Wikipedia
Search Engines
Mobile Phone
Tablet
Laptop
Computer
CMS
CRM

YouTube
Linked
Canva
Slack
Monday
Twitter
Whatsapp
Facebook
Instagram
Flickr
Reddit
Medium
Slido
Monday
HouseParty
Mailchimp
Typeform
SurveyMonkey
Facebook Messenger

And many more!



PLANNING DIGITAL COMMUNICATIONS

WHY WE PLAN

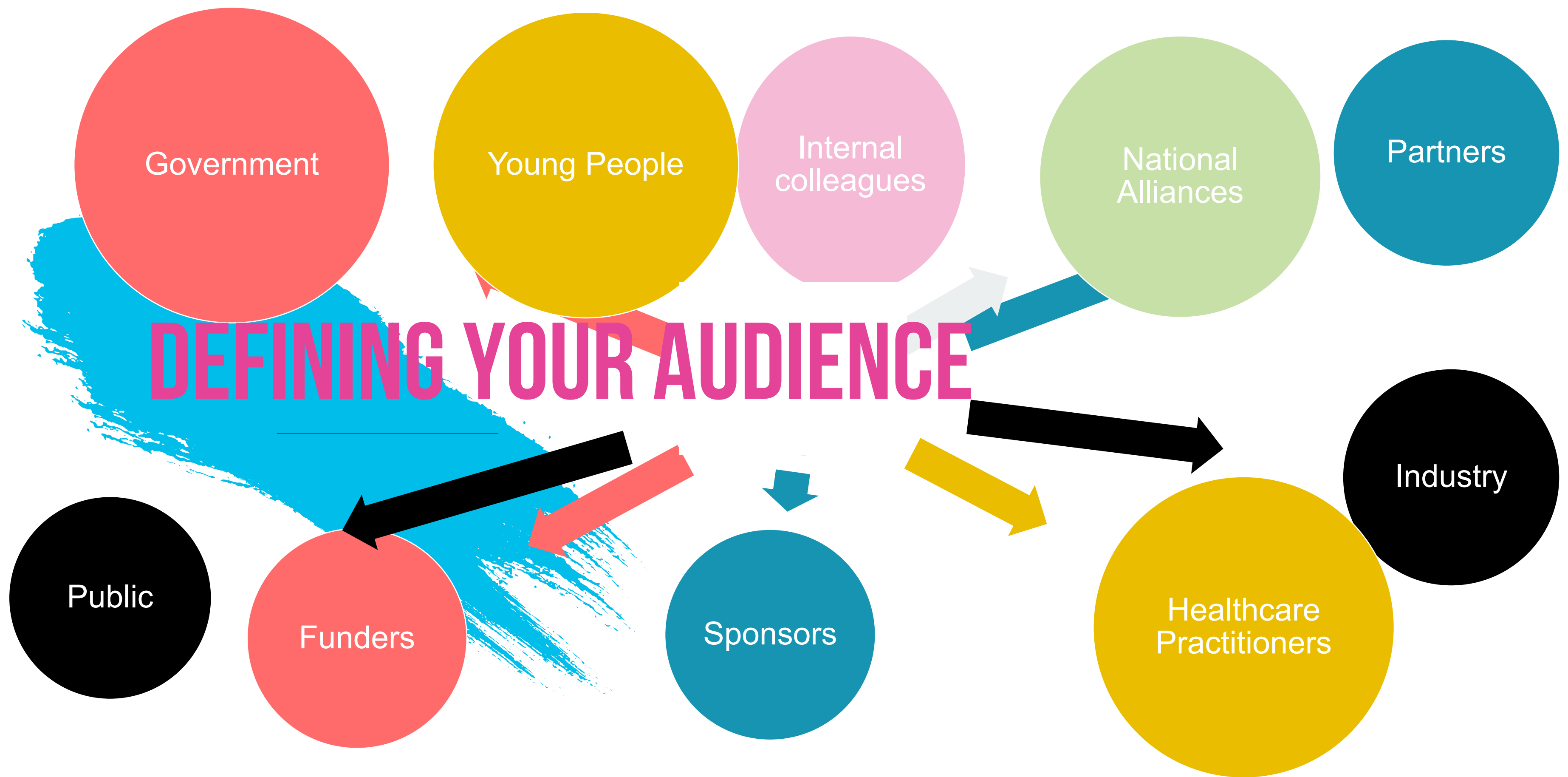
We have a digital communications plan to help identify who we need to reach, tell them what we want them to know, and how we will reach them.

This includes the identification of our audiences and key messages, and tools we will use to communicate with each audience.

“WE WOULD LIKE TO GET IN TOUCH WITH THE OTHER THREE FAMILIES THAT ARE DEALING WITH VARS SYNDROME, SO WE CAN LEARN TOGETHER MORE ABOUT THIS DISEASE, TO SHARE OUR EXPERIENCES, AND EVENTUALLY TO FIND A CURE FOR THIS DISEASE WITH THE HELP OF SCIENTISTS! WE DON'T KNOW WHAT THE FUTURE LOOKS LIKE LIVING WITH A RARE DISEASE AND THIS IS SO SCARY!”



DEFINING YOUR AUDIENCE



Being clear on what you are trying to achieve and who with- The global Campaign focus is the Rare Disease Community.

**WHO IS YOUR
AUDIENCE?**



BE TARGETED AND SPECIFIC

The Global Campaign is Promoting the Rare Disease Community. (not Rare Disease Day)

Remember your audience. Be clear on:

- What you are trying to say to them?
- What you are asking them to do
- When you are saying it (timing)
- What outcome you are looking for (measure it)
- How will you say it (tone)

#RareDiseaseDay

DEVELOPING CONTENT AND SOCIAL MEDIA ACTIVITY



Keeping Rare Disease Day at the front of mind

- Your stories- Ready made 'Assets' and blogs
- Social Media Graphics
- Videos and images
- Toolkits

Harnessing Social Media

- Working with your partners
- Planning Activity
- Identifying influencers
- Use tagging and hashtags



2021 RDD KEY MESSAGES

These will be used throughout all communications materials. The key messages are:

- Rare is **many**
- Rare is **strong**
- Rare is **proud**

These are supported by the term '**Show your colors**' and the hashtag **#RareDiseaseDay**.

**WHAT ARE YOUR
KEY MESSAGES?**



WHAT WE COVERED

- Digital Communications are part of your communications toolkit
- Be clear on your timeline, AND your goals,
- Understand who you want to communicate to (your audience and your messages)
- Know your audience and tailor your messaging to them
- Keep messaging simple (KISS)
- Use the most efficient communications tools to do the job
- With limited funds, digital tools including social media, webinars and working with your partnership and community can be key.
- Ensure stakeholders are involved to help you promote
- Keep measuring for success.

IMPACT OF DIGITAL COMMUNICATIONS

CASE STUDIES FROM AROUND THE WORLD



THANK YOU!

ANY QUESTIONS?

SUMMING UP

- ADDD IN INFO FROM CASES STUDIES
- You are not alone
- Lots of resources available via EURODIS and online to help you.
- We'll share useful links after this session.