

WORKSHOP

- WPIW Awareness

WORKSHOP

SPLIT INTO 2 GROUPS



WORKSHOP OVERVIEW: 3 TOPICS

15 MINS TO DISCUSS / 15 MINS TO PRESENT

1. PUBLIC AWARENESS

- GROUP 1 - Plan a social media campaign for your NMO for World PI Week
- GROUP 2: What other strategies/platforms are there to get public attention to your cause with low cost?

2. MEDICAL AWARENESS

- GROUP 1 - Come up with ideas to raise awareness in the university/public hospitals
- GROUP 2 - What other low-cost ways and platforms/fora are there to raise awareness among medical professionals? Who should be targeted?

3. POLITICAL AWARENESS

- GROUP 1 - Try to find strategies to draw policy makers' attention to PIDs. How can you give more weight to your message?
- GROUP 2 - Choose an objective for your political awareness campaign and think of ways to encourage others to take part. What kind of materials can be used?

CONSIDER:



- What tools exist?



CONSIDER:

How do you use the materials?

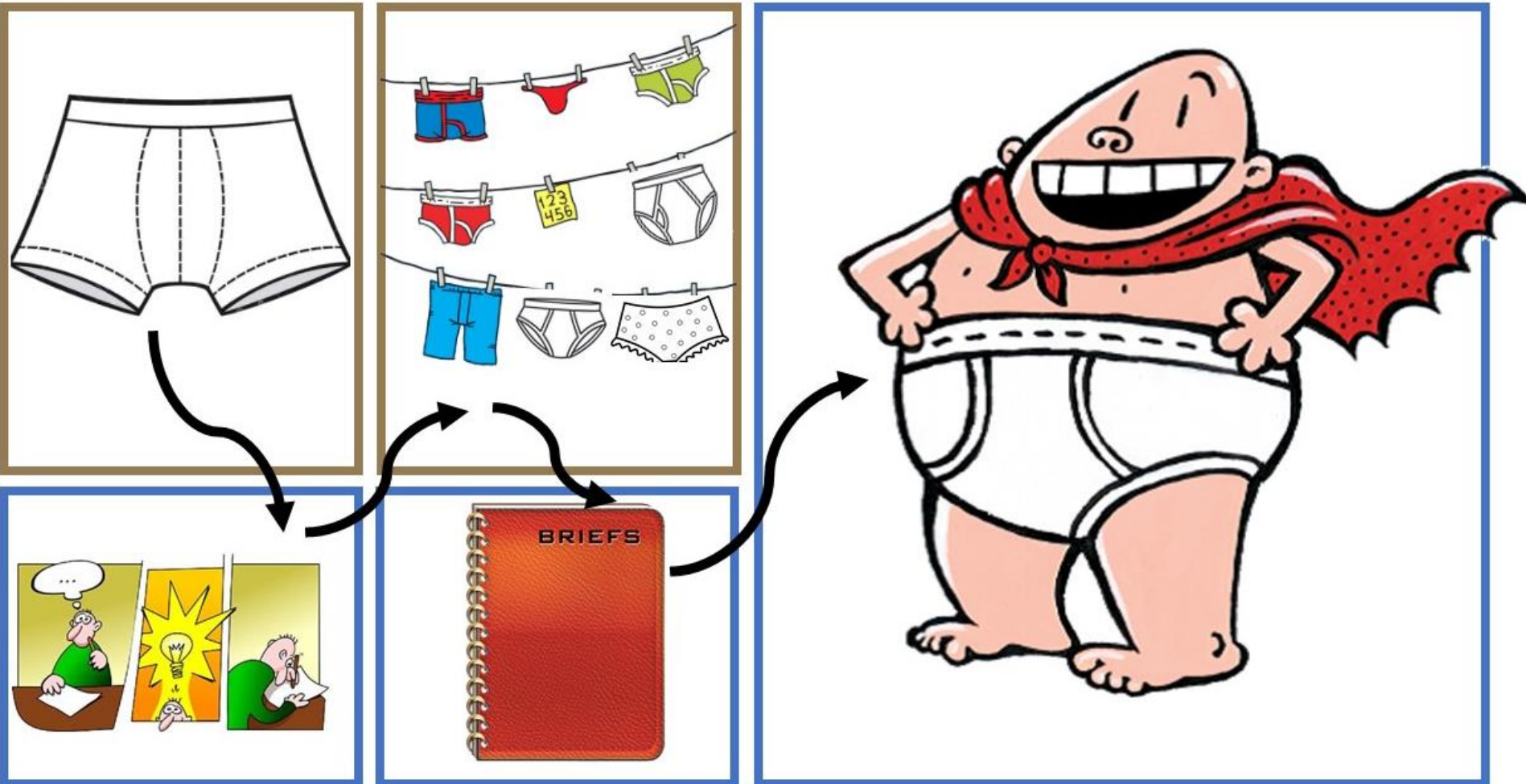


Info-briefs



CONSIDER:

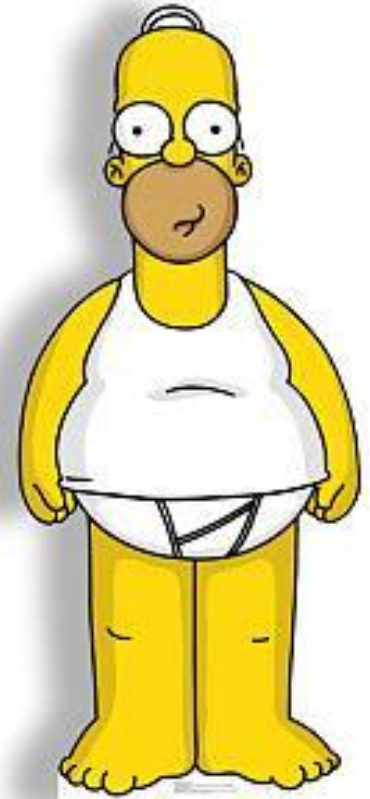
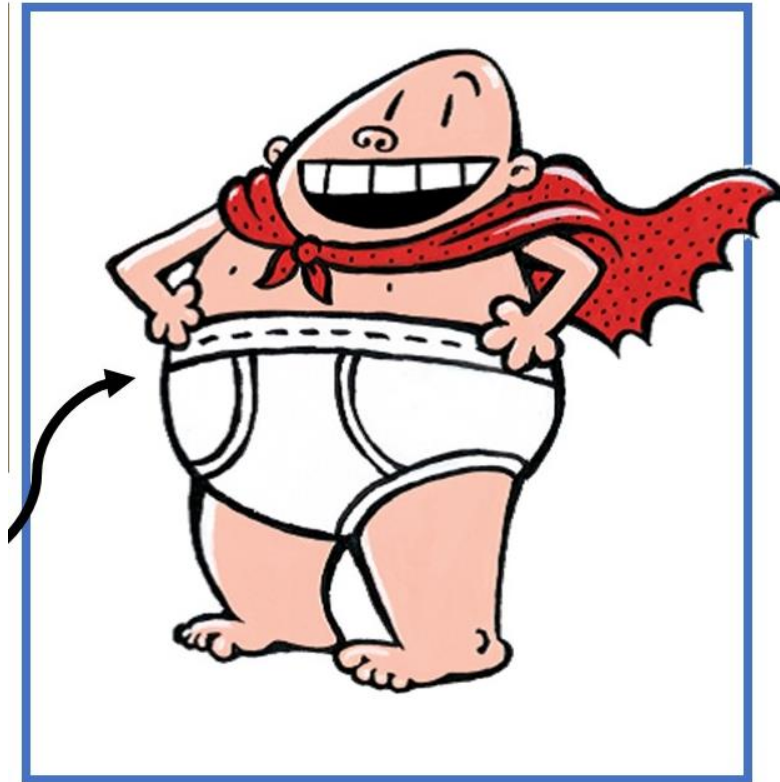
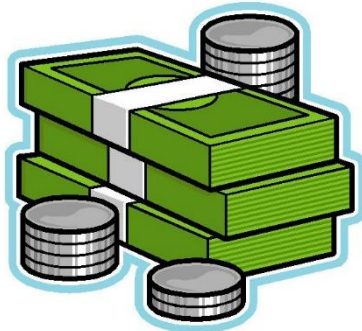
- Can you adjust the materials to match your purpose?



CONSIDER:

Can you plan a successful campaign with low resources?

Can you team up with a similar group?



CONSIDER:

- **K**ee**P** **I**t **S**hort & **S**imple!
(**KISS**)



Raise political awareness



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1. PUBLIC AWARENESS — 15 MINS TO DISCUSS

Group 1: Plan a social media campaign for your NMO for World PI Week

Group 2: What other strategies/platforms are there to get public attention to your cause with low cost?

Concept: Get an understanding which tools and settings to use to reach a large audience to raise maximum awareness with minimal cost.

2. MEDICAL AWARENESS – 15 MINS TO DISCUSS

GROUP 1 - Come up with ideas to raise awareness in the university/public hospitals

GROUP 2 -What other low-cost ways and platforms are there to raise awareness among medical professionals? Who should be targeted?

Concept: Come up with ideas on how to raise awareness with physicians, to encourage referrals to immunologists & to raise diagnostic rates of PIDs.

3. POLITICAL AWARENESS – 15 MINS TO DISCUSS

GROUP 1: Try to find strategies to draw policy makers' attention to PIDs. How can you give more weight to your message?

GROUP 2: Choose an objective for your political awareness campaign and think of ways to encourage others to take part. What kind of materials can be used?

Concept: Use World PI Week tools & momentum to raise awareness on policy level. This is a huge priority in this region, with limited access to diagnostics and treatment, and financial burden of treatment falling on families.

1. PUBLIC AWARENESS — 15 MINS TO REPORT

Group 1: Plan a social media campaign for your NMO for World PI Week

Group 2: What other strategies/platforms are there to get public attention to your cause with low cost?

Lessons learnt:

- What different ways/platforms/strategies are there to reach out to the public with low cost
- what to consider in order to plan a successful awareness and social media campaigns

PUBLIC AWARENESS: Group 1: Plan a social media campaign for your NMO for World PI Week

- Theme: follow WPIW theme
- Use patient organisation's social media page
- Testimonials, posters, video
- Endorsements,
- Infographics – visual materials
- Press releases to online media
- Video similar to last year
- Email blast
- People affected with PID
- HEALTHCARE PROFESSIONALS
- Event promotion
- Have a committed team to promote the campaign
- TIPS:
 - PLAN WELL AHEAD
 - Create a schedule

PUBLIC AWARENESS GROUP 2 - What different ways/platforms/strategies are there to get public attention to your cause with low cost

- March with placards
- Pamphlets
- Roadshow with logo
- drive around in a hired bus with external posters and speak to people to explain PIDs and give out pamphlets
- Doctor patient meetings
- Balloon day
- Radio day, live broadcast
- Link your cause with something exciting!
 - Interesting costumes for the day (e.g. Astronaut for bubble boy)
 - Bubble soccer tournament – maybe with soccer stars – exercise is healthy!
 - Ice bucket challenge
 - Public, free events with sports/music/lottery/other entertainment
- Find sports companies, foundations, theatre groups, entertainment companies who are willing to co-organise your event.
- Promote well to get a lot of people there
- Use WPIW materials, they are free.

2. MEDICAL AWARENESS – 15 MINS TO REPORT

GROUP 1 - Come up with ideas to raise awareness in the university/public hospitals

GROUP 2 -What other low-cost ways and platforms are there to raise awareness among medical professionals? Who should be targeted?

Lessons learnt:

- different ways to reach the medical audience with low budgets
- identify platforms best suited for the region for reaching medical audience
- how teaming up with the doctors will help reach your common goal

MEDICAL AWARENESS GROUP 1 - Come up with ideas to raise awareness in the university/public hospitals

- Determine audience
- Medical students
- Know doctors who give lectures to medical students
 - GPs, Paediatricians, Immunologists, Alumni
 - MED STUDENTS
- Lunch talk/event (a booth at a hospital)
- Quiz with free cinema tickets and donut
- DOCTORS
 - testimonials
- Send a PID patient to talk in an event
- Give out study credits
- HOSPITALS/UNIVERSITIES
- Pamphlets (tone down for universities)
- Short educational movie/video
- send printed info materials/warning signs to doctors, maternity clinics, nurses
- hang posters in hospitals

MEDICAL AWARENESS GROUP 2 - What other low-cost ways and platforms are there to raise awareness among medical professionals? Who should be targeted?

- Educational workshops for students (e.g. Difficult case conference)
- Med students – simple leaflets about PID
- Design a giant tree postcard, have it in a booth at conference/hospital/uni
 - apple sticker paper for passers by to send wishes to patients
- Attractive people to hand out educational material (celebrity to support your cause)
- raise awareness for pharmacy students
- Target people who are front line – GPs
- Pamphlet delivery, mass emails, look up specialty conferences and workshops and ask for a session to discuss PIDs
- Cover as many hospitals as possible
- Awareness booth rotation in different hospitals
- WPIW video played
- Write a letter about PID to specialist/Societies newsletters
- Keep a mailing list
- Build a list of useful people/contacts
 - medical writers, journalists, etc
- contact local medical journals,
- reach out to nurses

3. POLITICAL AWARENESS 15 MINS TO REPORT

GROUP 1: Try to find strategies to draw policy makers' attention to PIDs. How can you give more weight to your message?

GROUP 2: Choose an objective for your political awareness campaign and think of ways to encourage others to take part. What kind of materials can be used?

Lessons learnt:

- Choosing one main objective is the most effective way to advocate
- which tools can be used for which objective?
- What are different ways of engaging with policy makers
- Who to reach out to make allies
- Empowerment to take on advocacy measures to improve PID care & access to treatment

POLITICAL AWARENESS GROUP 1: Try to find strategies to draw policy makers' attention to PIDs. How can you give more weight to your message?

- Now how your political system works
- Meet govt and get them to give opening speech at family day (so they have to research PID)
- Identify 3 key messages for govt, e.g.
 1. Diagnosis
 2. Lack of treatment options
 3. effect of PI on families and patients: cause and cost (requires research)
- Target audience: Ministry of health, congress, local govt
- From local perspective: invite MOH rep for involvement and connection
- join a high exposure event
- Join up with haemaophilia, thalassaemia: Get patient voices together with a single theme, create a single event at the same time
- Leverage IPOPI: localised version on advocacy tools for PID
- Presentation and infographics localised for govt and the message
- Some politicians want to be helpful
- Sometimes you will present everything and the politician will ask: how can I do that? Be prepared for this question. Know what s happening at political level. Election coming up? Policy reviews? Have an answer!
- Find out drug licence Committee, write to them, offer your help as an expert
- Always follow up, thank stakeholders annually, invite them to a dinner, have a patient thank them, include media
- Focus on long term goals, create win-win situations, have concrete figures

POLITICAL AWARENESS GROUP 2: Choose an objective for your political awareness campaign and think of ways to encourage others to take part. What kind of materials can be used?

- SCIG availability/reimbursement of Ig therapies for adults, reimbursement of BMT, plasma donations.
- Involve stakeholders, patients, families, doctors, pharmaceutical companies
- create long term relationships with stakeholders
- Produce information to give better understanding to stakeholders
- Include cost effectiveness
- Use WHO statements, list of essential medicines, APEC guidelines
- Use infographics
- Make stakeholders remember you: follow up and keep communicating
- Include media
 - use patient stories, use success and sad stories so politicians can hear stories and understand: empathy/connection – to help achieve objectives
- WPIW is a momentum but only 1 part of the advocacy timeline
- Even when you feel comfortable, never let advocacy disappear
- Come with what you want to ask, but also what you can offer (win-win)
- Present challenges, solution and outcome (patient stories - good and bad) so politician cannot deny the issue
- Simple messages e.g. I want to live, you are my medicine
- Be a partner on advisory committees that have a say (Rare diseases etc)

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