Patient Empowerment through Research

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Presentation outline

• Challenges
• GRIDD project/GRIP tool
• The big picture
• Next steps
Dermatology Patient challenges...

Dispel Myths
- Over 2 billion people living with over 3000 discrete conditions
- Derm. diseases are largely considered to be of low impact which is simply false.

Add information
- Skin diseases are more than skin-deep-psycho-social impact, and co-morbidities greatly add to BOD

Ho hum
- Our Patients need to be taken seriously and heard
- Need to get decision-makers to care
Core Advocacy Dilemmas

- Decision-makers/HTA want the patient voice
- They *do* and they *don’t* want patient stories
- **BUT...** their decision-making rubrics are based on DATA
The Challenge

- HTA bodies want unbiased input from patient organizations about the impact of disease.
- Patient organizations usually don't have the capacity to provide scientifically validated data.
- Patient stories aren't data.
- Currently, QOL/Burden of Disease/Impact studies are designed by doctors and researchers.

So...
How do we gather and provide patient-derived, patient-reported impact of disease?
What if…

• Quality of Life was measured using a measurement tool *developed* by patients
• A credible patient voice could be built upon *verifiable* data
• Policy-makers wouldn’t ever make a decision without including a *patient-led* measure
What is GRIDD? What is GRIP?

- First Global Patient-initiated Research Project in Dermatology
- First Global Project on Disease Burden in multiple skin diseases
- Ground-breaking patient-led methodology called GRIP
- Unique PRIM measure- Questions created by gathering patients’ views on the impact of their disease on themselves and family members

Who truly knows what it's like to live with skin disease?
GRIDD Overview:

- New unique QOL instrument

- Data to support global, regional or national Advocacy campaigns

- Global or regional Communications campaigns

- Validate patients’ experiences

- Stimulate funding for research and patient support
But isn’t that project about *skin*?

**Yes AND No. We can use this new methodology in all therapeutic areas.**

The Goal: To insert the patient perspective into the very core of patient-reported impact of disease measures:

- the questions in the instrument come from the patients themselves
- measure what patients deem important to them,
- help close the gap between knowledge about the impact of disease(s) on patients and their access to required care.
- Use data from the measures derived from the GRIP tool to **augment the Disability Adjusted Life Year (DALY)** which currently does not include patient-initiated and derived data.
Outcomes

1. **Measure** impact of disease in response to HTA needs
2. **Embrace** patient-centricity by asking patients to define their issues
3. **Build** credibility for patient advocates through verifiable quantitative data
4. **Influence** access to treatment and care (country, region, global DALY, WHO)
Together we can!

• Once beta-tested and fine-tuned in Dermatology, we plan to pass the GRIP tool to the Global Patient community

• YOU will then have access to a methodology that is scientifically validated and allows you to create a unique patient centric measure of disease impact for your population(s) for use in advocacy
GRI??? Approach:

1. Collect Issues

2. Analysis

3. Your New unique QOL instrument

4. Data

Your disease/your related disease?

- Disease X?
- Disease Y?
- Region or area?
- Disease subsets?
- Other?
Together, we **CAN** do it!

Step 1 - GRIP and GRIDD beta - IADPO
   - with 90 patient organizations in 35 countries/ 25 diseases

Step 2 - GRIP tool shared with global patient community – **HOW??**

Step 3 - decision-makers get patient input in their language... **DATA**... and the patient voice can be at the centre
The Big Picture

- Scientific team working with patient organization team
- 4 phases (1. Environmental scan, 2. GRIP, 3. MPRIDD, 4. Analysis and Communication)
- GRIP phase starts in 2018. We want to make sure it has wider applicability.
Next steps: What **YOU** can do to help...

*Get in touch with us.*

- Tell us if you know of similar patient-led research initiatives
- Connect us to dermatology patient organizations in your country
- Volunteer to get involved – join a committee
  - *Ensure GRIP is adaptable to all diseases/conditions*
  - *Determine how it gets passed on and coordinated*
Imagine if... we could create truly patient-centric PRIMs for all diseases!
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Thank you!