

# Supporting Dermatology Patients in the Digital Age

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*Cover photo: Participants of the Patient Perspectives Symposium at the GlobalSkin 2017 Conference in September 2017.*



## Introduction

We live in an era with unprecedented access to information and online tools relating to our health. This brings unprecedented opportunities to develop new ways to support patients and to expand the reach of patient organizations' support. And yet, dermatology patients report feeling isolated and alone.

Opportunities include e-health solutions that can support diagnosis, personalised care and adherence to treatment; more easily accessible information on how to approach and live with a condition; the ability to connect patients with each other to share experiences and overcome isolation; to better engage with young people and to run innovative fundraising campaigns.

Leaders of patient support and advocacy organizations need to be proactive in harnessing the power of digital technology to help improve quality of life for patients as well as the effectiveness and reach of their operations. This white paper explores the issues associated with greater use of digital technology, and is based on round table discussions at the Patients' Perspectives Symposium at the *GlobalSkin 2017* Conference in September 2017. Representatives from over 40 dermatological patient organizations from around the world participated in the Symposium.

## What are the challenges we need to resolve?

Leaders of patient organizations identified multiple challenges facing them and confronting the patients they serve. The digital world is vast and complex; resources are tight amongst virtually all patient organizations operating in the dermatology space.

### *Patients cannot always find trusted information online*

- In dermatology, the gap left by inadequate access to health services or specialist physicians means there is usually a void to fill, and a greater need for alternative sources of information.
- It is widely known that not all online information is reliable, and this has many negative consequences, from inaccurate self-diagnosis, to creating unreasonable fears or false hope.
- Pharmaceutical companies, in conjunction with third party developers, often create a new unbranded website for each disease covered by their medications.
- The challenge is how to ensure the good information is not being confused with the bad. There is a need to find ways to manage misinformation and enable patients to distinguish between the two.

### *Reinventing the wheel*

- There is a great deal of overlap in the digital offerings that are being developed in the health sector as well as a potential for 'app overload'.
- Where resources are limited, it makes sense for patient organizations to share best practices to avoid reinventing the wheel.

### *Keeping content fresh*

- Establishing a website is only half the battle. There is an ongoing need to keep content fresh to encourage repeat visits to a site. This requires a lot of work, including continued access to medical expertise for verification of content. For this reason, it is essential to have excellent relationships with local dermatologists and other healthcare specialists who can verify that updated information is correct.

### *Remaining relevance for young people*

- Children and young people are at the cutting edge of social media. They see Facebook as a platform for their parents and as a result have moved on to other platforms. This doesn't mean that patient organizations should not use these tools, but in order to also appeal to young people, they should explore other social media platforms as well.
- Facebook and YouTube are now so frequently used that increasingly novel ways are needed to stand out.

### *Safeguarding*

- Patient-to-patient advice in chat room forums are an invaluable support tool, but when connecting patients, patient organizations should take precautions to ensure that no personal information can be accessed. Also, where possible, having the space monitored is helpful to ensure that chat rooms don't become venues for advertising or misinformation.

### *Legal requirements*

- Patient organizations should ensure they are familiar with local legislation governing data protection and information that can be shared.
- Disclaimers are usually recommended to make it clear that information given cannot be taken as medical advice nor replace the need for an individual consultation with a doctor.

In a fast-moving environment, it can be difficult to keep up with technological advances, and most dermatology patient organizations do not have the resources to finance the necessary expertise and training that can help them do so. Yet social media and digital technology have so much potential to connect people, and are now intrinsic to most of society. In addition, with respect to rare dermatological diseases, the relative lack of knowledge among primary care physicians means that the use of the internet tends to be more acute among these patients to fill the gap.

Access to the internet is not universal around the world. There is disparity between and within countries, be it for reasons of affordability and/or practical access. While this problem is beyond the scope of this paper, it serves as a useful reminder that patient organizations cannot focus on digital tools at the expense of other ways of supporting patients. Maintaining traditional print and face-to-face forms of communication will continue to be important.

## What are the solutions?

### *Patient organizations as the first port of call*

- Due to the abundance of unreliable information on the internet, patient organizations could work to help their communities distinguish the reliable and trusted sources, either on a country-wide basis or perhaps even as part of an international movement.
- When newly-diagnosed patients are first exploring the internet for information about their skin disease, ideally the first sources they will find will be the websites of, or material developed by, patient organizations. Search engine optimisation (SEO) is essential to ensuring an organization's website appears at top of the results list when a search is performed.
- It is well established that users of the internet rarely view the second-page results on search engines. And if the link does not 'work' for any reason they will move on.
- As more and more people access the internet through smartphones, it is also critically important that groups do not overlook the need to ensure their websites are configured for viewing on mobile devices.
- Physicians should also be mobilised to share patient organizations' information during an appointment with patients. Simple cards with an organization's details could be supplied for passing on to patients. In several countries, pharmaceutical representatives have been willing to assist in distributing these and other print materials to physicians.
- Pharma and third-party developers of informational websites are encouraged to work directly with patient organizations and rather than re-inventing the wheel with another new website. They should also consider providing funding support to help patient organizations improve the quality and reach of their websites.

### *Trusted and credible information*

- To ensure that information for patients on patient websites is up-to-date, and medically correct, patient organizations should partner with respected physicians to review medical information before it is released online. It is important to develop and maintain excellent relationships with local specialists who share the patient organization's vision; this helps meet the goals of both the organization and the physicians themselves.

### *Building capacity and expertise*

- Google runs a 'non-profit' arm that provides various support products for charities that register with them. While organizations in many countries have access, Google is still in expansion mode and organizations in currently ineligible countries are encouraged to check back frequently.<sup>1</sup>

- **Google Ad Grants:** Free AdWords advertising to promote non-profit websites on Google through keyword targeting.
- **YouTube Non-profit Programme:** Access to exclusive resources, features and programs designed to maximise the organization's impact on YouTube.
- **Google Apps for Non-profit:** Free version of the Google Apps business productivity suite, including Gmail, Docs, Calendar and more.

<sup>1</sup> <https://www.google.ca/intl/en/nonprofits/products/>

- Groups can also seek grants from commercial entities or government (which may be available for charities in some countries). Forward-thinking pharmaceutical companies are increasingly supporting patient organizations in their digital outreach. If financial support is not available, companies may be willing to provide in-kind support.

### *Collaboration*

- A cost-effective way for patient organizations to upskill is to learn from other groups – in both dermatology and in other disease areas. As part of the development of its global community, IADPO is ideally placed to enable the sharing of best practices, and in the facilitation of resource-sharing networks.

### *Patient support tools*

The global community that gathered at *Globalskin2017* shared their experiences in implementing digital support:

- Tools can be developed to support enhanced communication between physician and patient, such as digital diaries, symptom trackers and discussion aids.
- Patient stories, testimonials and inspirational quotes on websites are important. Providing these in a 'digital' format means that they are more engaging and can also be used on social media, such as YouTube.
- 'Webinars' are a great way to reach many people with training and up-to-date information, and can be saved as a link for patients to access in their own time. Physicians can be invited to participate in these from time-to-time on medically-based topics. These are very popular with patients, and help fill the gap where access to expert care is limited.
- Fact sheets for patients can be made available online to download.
- Disease management apps have been created by industry and by patient organizations. While some patients really like them, these apps also have a reputation for high development costs and high drop off rates.

### *Teenagers spearheading their own efforts*

- It is also reported that teenagers have moved on from Facebook as a social media tool, meaning that to effectively communicate with them, platforms such as Instagram, Twitter and Snapchat are better options for this group.
- It seems unlikely that an adult can replicate the language or have true insight into the needs of young people and that is why involving them in the development and dissemination of age-appropriate material is ideal. Chat-rooms are a good vehicle that can be considered.
- Innovative new ways of providing information for schools could be led by students themselves to raise awareness of dermatological diseases.

### *Safe conversations*

- It is possible to set up anonymous WhatsApp groups, co-ordinated through a moderator so contact details are not shared.
- Experts can also be instructed to build safeguards into any new tools being developed.

### *Targeting physicians*

- As well as catering to the patient community, many groups have found tools and approaches that have been effective in educating primary care physicians, and facilitating better dialogue between physicians and their patients. One group in the US has been exploring the possibility of collaborating with the providers of physician software. The aim is to introduce screen ‘pop-ups’ carrying information when certain key words are entered, for example certain medications or symptoms. Similarly, links could be provided that will enable physicians to print out patient group fact sheets to give to patients.
- Web-based educational tools are common in medical education and collaborating with the companies or professional organizations developing these could improve the quality and breadth of education on dermatology in primary care, by including the patient perspective and information on accessing peer support.

## **Conclusions**

Dermatology patients are unique in that they isolate themselves due to shame and embarrassment. They also often struggle to gain timely access to diagnosis and treatment and so there is a crucial need for reliable and trusted information as well as for peer-to-peer support. Patient organizations can play a key role but are generally hindered by a shortage of resources.

Digital media expands the reach of patient organizations, industry and physician organizations. Strategies to maximize effectiveness of digital outreach exist and can be implemented by patient organizations, often in collaboration with other stakeholders. While print and face-to-face communication outreach remains important in this audience, increasingly as all corners of the globe shift to digital communication as the primary means for information sharing, patient organizations must stay current and fresh in this domain.

### **If you have questions about this report, please contact:**

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