

Patient Health Survey Results ... What Next?

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So We've Done the Survey ... Now What?

Survey data are only valuable if people:

- Know about them
- Understand them
- Use them

- **So, we've done the survey, so now what!**
- **Surveys in and of themselves have no real value.**
- **It is the analysis and communication of this data that is valuable.**
- **To effectively communicate we need to know the data well enough to identify areas where the data can be most useful in driving change.**

Value of Patient Survey Results

- Provides accurate and up-to-date information based on scientific data, not personal opinions.
- Leads to transparency in decision-making, which is important for buy-in from policy makers and funding agencies.
- Helps shape or improve policies, programs, and research priorities which ultimately leads to improved patient health outcomes.

- **For scientists to have success in their applications for funding for research programs they need scientific evidence to support their claims. Personal opinions and observations are insufficient as justification for funding requests or healthcare policy changes.**
- **The survey provides this scientific evidence-based data.**

Create an Action Plan

Create an action plan to communicate results to:

- Patients
- Policy makers
- Media
- Medical publications
- Special Interest Groups
- Service Clubs
- Women's Groups

- **Simply getting information to potential users can be challenging.**
- **First we need to identify potential users and target a method of communicating with them that is most likely to be effective.**
- **Creating an action plan allows us to customize our approach to each of these audiences.**
- **How information is presented to special interest groups and policy makers may be entirely different.**

Put Findings into Context

- Keep your audience in mind...what do they need to know and want to know?
- Communicate results by keeping intended audience in mind so that the messages and images are clear, comprehensible, relevant, and appealing to that audience.
- Add policy recommendations and conclusions.

- **If the target audience is a special interest group like “Changing Faces”, we might want to highlight information that addresses body image concerns in the survey data.**
- **Alternatively when addressing government bodies concerned with disability and employment issues we are more likely to highlight the high rate of disability related to scleroderma in attempt to influence policy makers to acknowledge and classify scleroderma related disabilities.**

Communicating Results

- Ensure that the patients who participated in the survey receive the results.
- Prepare a presentation
 - Touch on the highlights
 - Descriptive analysis not detailed statistics
- Write articles for magazines, newspapers, including local papers
 - Women's health
 - Skin Alliance
 - Changing Faces

- **Communicating the results should take many different forms from e-mails to written letters, web-sites, PowerPoint presentations, to radio-talk show interviews.**
- **When making a presentation it is important not to get bogged down in the details.**
- **You don't want to present all 69 symptoms and the statistics that go along with them. It is far more effective to highlight the top 3 or 5 than to overwhelm your audience with all the details. Have the rest of the details as back-up, but focus your communication on the highlights of each area.**

Outcomes of the Canadian Survey



- One of the major outcomes of the Canadian Survey was the creation of SPIN, the Scleroderma Patient-centered Intervention Network. It was developed to address under researched areas identified through the survey.
- The Canadian data has been used to successfully secure funding for this international research group develop and evaluate non-pharmacological interventions for patients with systemic sclerosis. The target area for these interventions are the issues that patients indented as important in the survey. These include:
 - Hand function
 - Psychological Distress
 - Body Image Concerns
 - Development of a General Program of Self-Management

Compare Data

- Look for comparable data
- What are the similarities
 - The similarities re-enforce the credibility of the data
- What are the differences
 - Explanations?
 - Are they the result of healthcare policies, differences in government funding of treatments?
- Can the differences be explained?

•Now that there is European data available I would really like to compare your findings with ours in order to identify the similarities and differences.

•I would like to explore the differences and see if we can identify the factors that result in those differences. This will be particularly relevant if there are certain healthcare policies in place that have resulted in improved healthcare outcomes.



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