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# Hand Issues on Scleroderma Patients

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# Hand issues on scleroderma patients

— Ana Font Hernandez —  
ICUR 2018

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# Background: a Rare Disease

Scleroderma means hard skin:

- *Sklēros*: hard in Greek
- *Dermis*: skin in Modern Latin

1873: Dr. Van Harlingen defines it as an "affection of the skin, characterized by diffuse symmetrical hardening, and generally accompanied by more or less pigmentation".<sup>1</sup>

2018: autoimmune disease, not contagious, that can cause disability<sup>2</sup>

<sup>1</sup> "Dermatology.—Scleroderma." *Edinburgh Medical Journal* 19.6 (1873): 557. Print.

<sup>2</sup> Winter, Fabiola. "Dureza En Piel y Dificultad Para Mover Manos Son Síntomas De Esclerodermia." *Primer Minuto*, 8 July 2018, [primerminuto.com.mx/dureza-en-piel-y-dificultad-para-mover-manos-son-sintomas-de-esclerodermia/](http://primerminuto.com.mx/dureza-en-piel-y-dificultad-para-mover-manos-son-sintomas-de-esclerodermia/).

# Background: a Rare Disease

- The specific cause is unknown
- This condition can't be cured
- It is a chronic condition
- Affects women more than men
- Occurs between the ages of 30 and 50
- Symptoms:
  - Tightening of the skin
  - Joint pain
  - Exaggerated response to cold (Raynaud's disease)
  - Heartburn
- Treatments include medication, physical therapy, and surgery

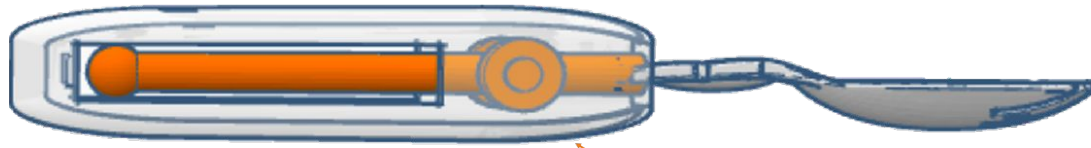
# (one) Scleroderma Symptom



Romero, Mónica. Rehabilitación en la esclerodermia. Revista Paraguaya de Reumatología, [S.l.], v. 2, n. 2, p. 81-86, mar. 2017. ISSN ISSN 2413-4341. Disponible en: <<http://www.revista.spr.org.py/index.php/spr/article/view/44/87>>.

Winter, Fabiola. "Dureza En Piel y Dificultad Para Mover Manos Son Síntomas De Esclerodermia." Primer Minuto, 8 July 2018, [primerminuto.com.mx/dureza-en-piel-y-dificultad-para-mover-manos-son-sintomas-de-esclerodermia/](http://primerminuto.com.mx/dureza-en-piel-y-dificultad-para-mover-manos-son-sintomas-de-esclerodermia/).

# An Assistive Utensil: a Spork



Interior bar weight supported by roll joints

Roll joints allow weight bar to pitch during shaking

# Testing on Scleroderma Patients

## Methods:

1. Testing on real patients at Scleroderma Foundation group support meeting
2. Surveying patients at Scleroderma Foundation group support meeting
3. Surveying patients from around the globe
  - a. Social Media: 17 groups or pages in Facebook
  - b. Google Forms: 10 questions
    - i. 2 questions were no useful because the wording was confusing and the answers didn't make sense

# Testing on Scleroderma Patients

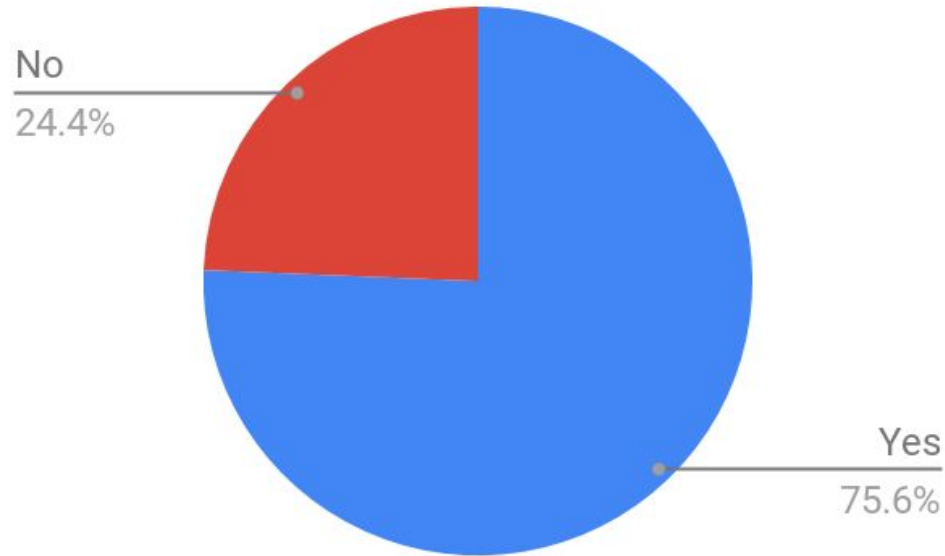
Collected responses from:

- United States
- Spain
- Puerto Rico
- Colombia
- Chile
- Mexico
- Peru

- Total responses: 78  
(as of September 25<sup>th</sup>, 2018)
- Preliminary results: the spork is useless

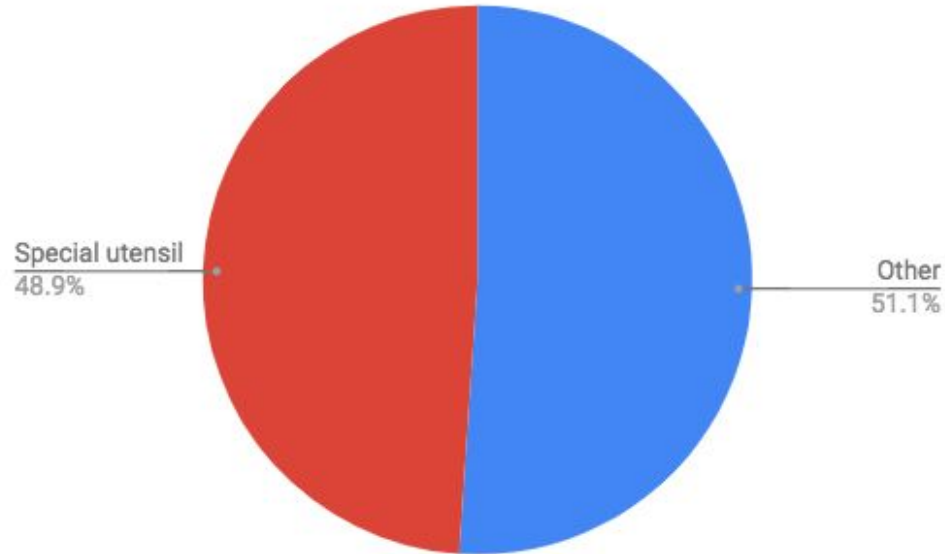


# Do you have trouble eating or using your hands in any way due to scleroderma?



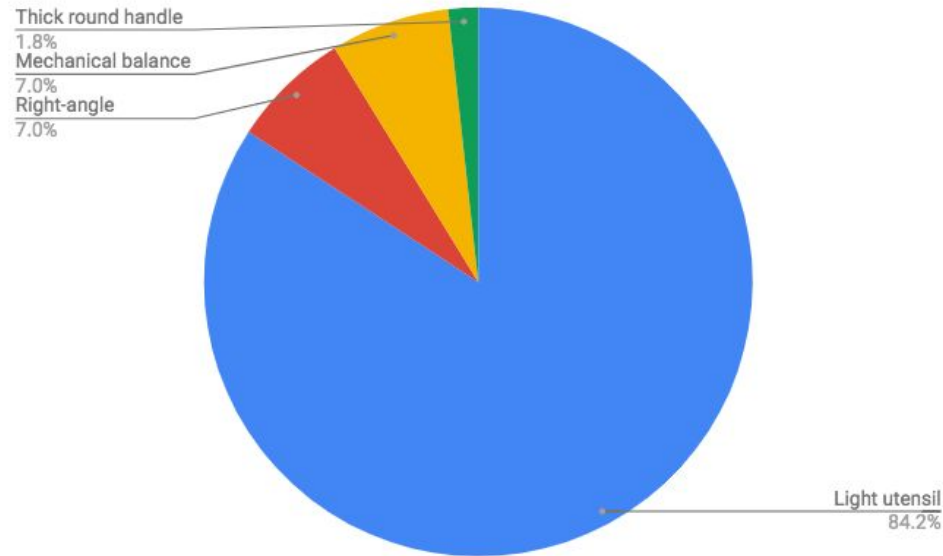
Total answers to question: 78

# If you need special help to eat, what is most helpful to you?



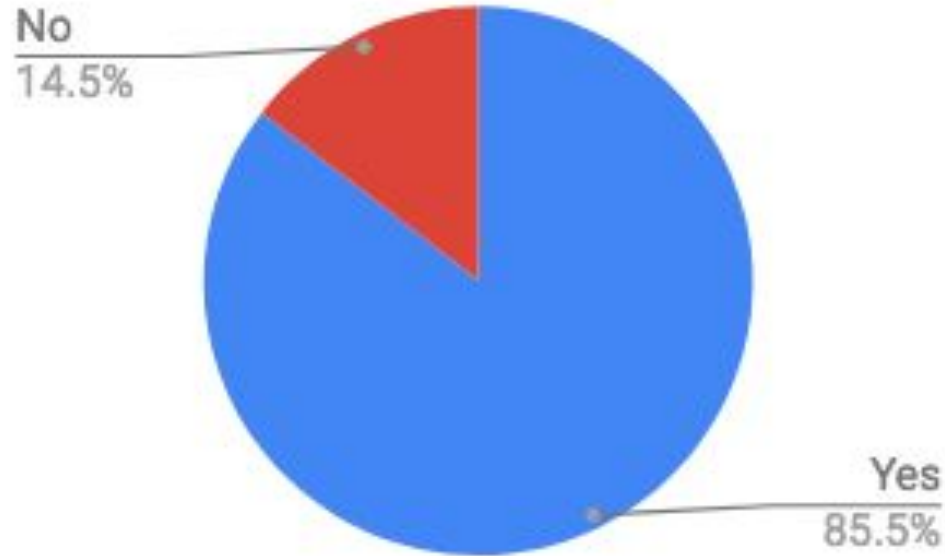
Total answers to question: 47

# What feature of the device you use to eat do you value the most?



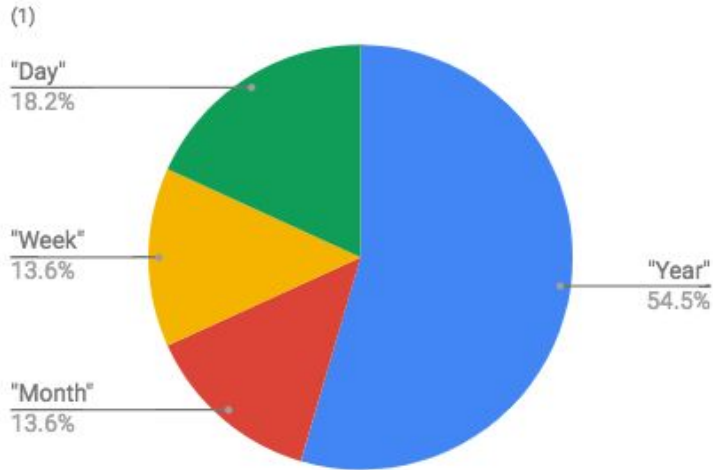
Total answers to question: 57

# Has your grip changed since you started developing issues with your hands?

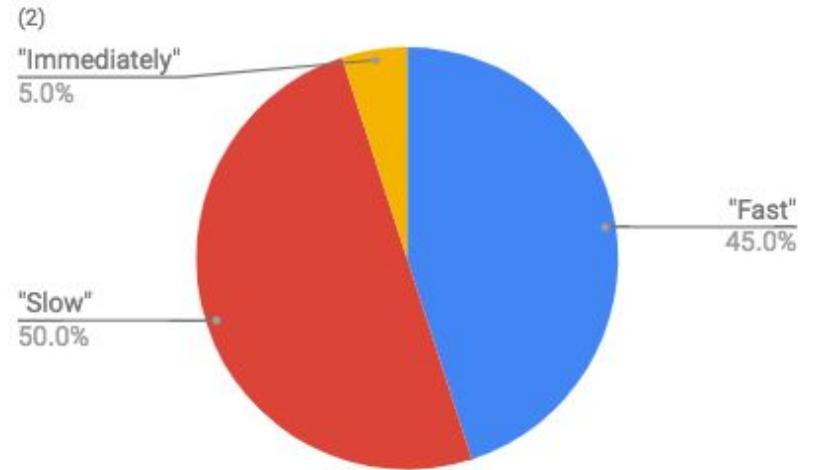


Total answers to question: 76

# How often have your hands changed their form?

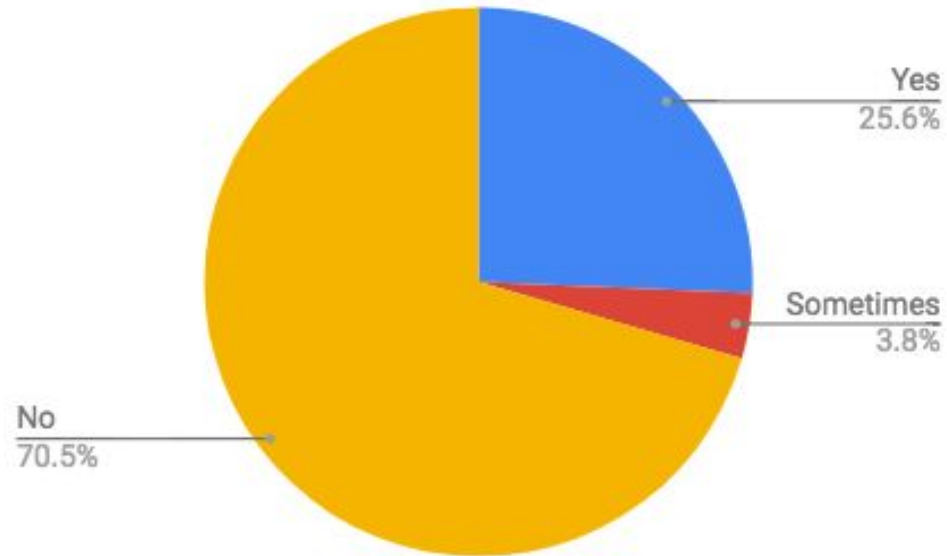


Total answers to question: 22



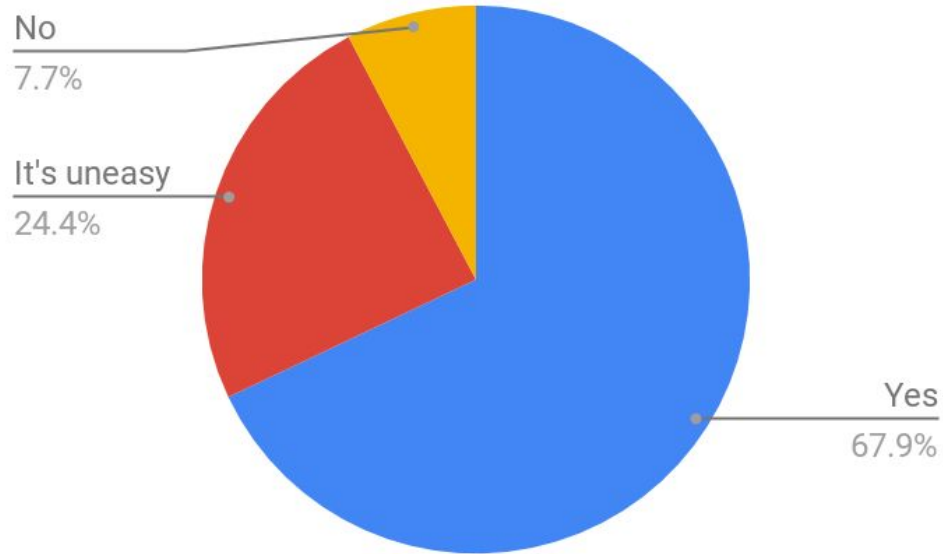
Total answers to question: 20

# Do you suffer from hand tremors?



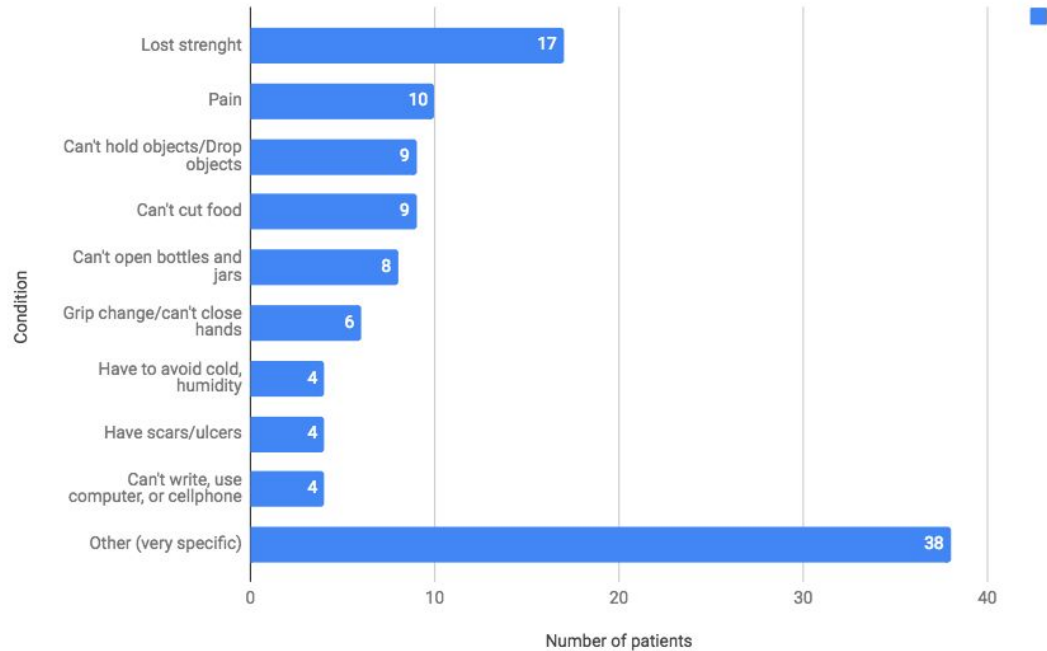
Total answers to question: 78

# Are you able to use a cellphone without help?



Total answers to question: 78

# What else should we know about your situation?



Total answers to question: 78. Multiple entries per answer.



# Have your doctor asked for your DNA test?

Tú médico te ha hecho una prueba de ADN? / Have your doctor asked for a DNA test? / O seu médico pediu um teste de DNA? / Il tuo medico ha chiesto un test del DNA?



8% Sí / Yes / Sim / Sí



92% No / No / Não / Non ☑

Undo Vote

26 Votes

# Other findings

- 58 Facebook groups with at least 6000 people
  - Not including Asia or Africa
- 2 million people suffer from scleroderma around the world
  - 300,000 recorded by this project, not including Asia or Africa
- Other diseases associated with scleroderma are
  - Lupus
  - Interstitial lung disease
  - Renal failure

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# A possible solution for scleroderma patients?

— Further research is needed —

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- Google Forms
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