

# HEALTH IN THE DIGITAL SOCIETY DIGITAL SOCIETY FOR HEALTH

16-18 OCTOBER 2017  
TALLINN, ESTONIA

## Power of Member Awareness & Involvement – Case Study Patient Voice™ in Sweden

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[www.ehealthtallinn2017.ee](http://www.ehealthtallinn2017.ee)



## Power of Member Awareness & Involvement - Case Study Patient Voice™ in Sweden

The Swedish Stomach and Bowel Association have a vision:

“To be a partner and make a difference for its members” (5,600)

Improve Digital Presence

We wanted to evaluate Patient Voice™ in reality

Sweden, Canada, Italy, Spain

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March 2017: Patient Voice™ prototype was presented.

May 2017: The pilot was accepted by the Swedish Patient Association Board

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### Challenges

The Swedish Data Protection Agency.

The Swedish Patient Law

Political Goals. Best WW eHealth Country 2020

Regional Goals. Best SWE eHealth Region 2020

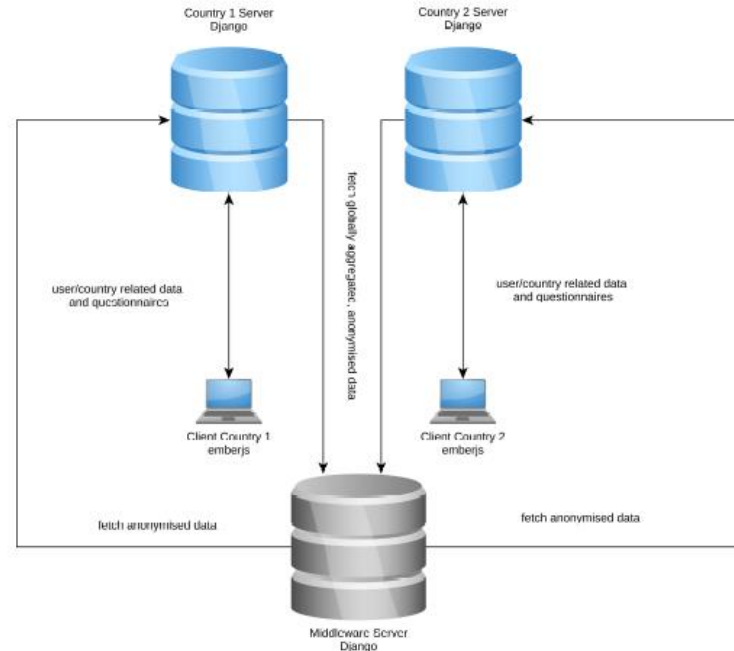
The eHealth Authority.

The Swedish Ministry of Transportation.

Foreign IT solution.

Local Adaptations

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More challenges

Technical Specification.

Tender for Swedish Territory Located Server Solution.

Security Certificates in place.

Questionnaire in place.

Initiation of the Swedish Legal Process:

**Data Processing Agreement** – Data Controller and Data Processor and more (GDPR)  
**Agreement** including All Info and the Reason for collecting data

No need to report to the Swedish Data Processing Agency if all the above is **Checked**

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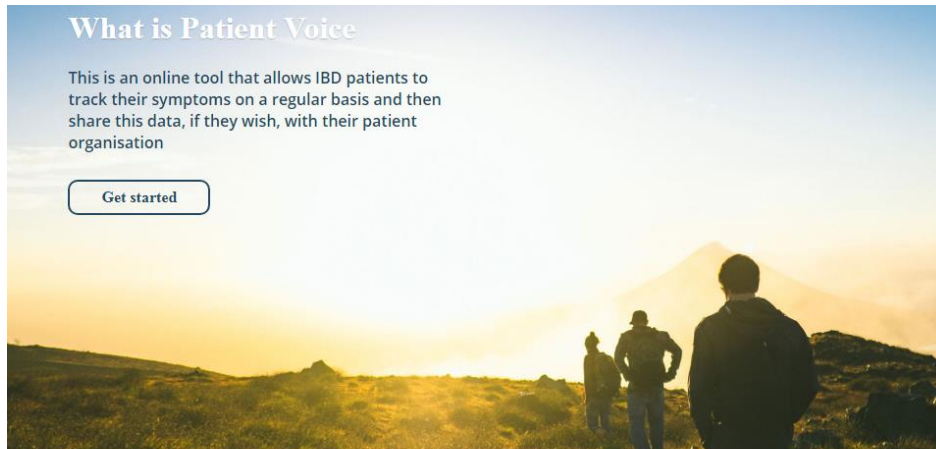
Ongoing Pilot study.

The Swedish Stomach and Bowel Association	5,600
Regional & National Board	70-80
Pilot group	(n = 71).

14 days followed by phone and mail to evaluate

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### Illustrations. Figure 1. A) Patient side I



**What is Patient Voice**

This is an online tool that allows IBD patients to track their symptoms on a regular basis and then share this data, if they wish, with their patient organisation

[Get started](#)

Patient data on the progression of their disease and their outcomes can give patient organisations the evidence they need to show how to improve care of the patients. Furthermore, the same data can help science understand the disease better in order to find a cure or at least ways to alleviate the burden.

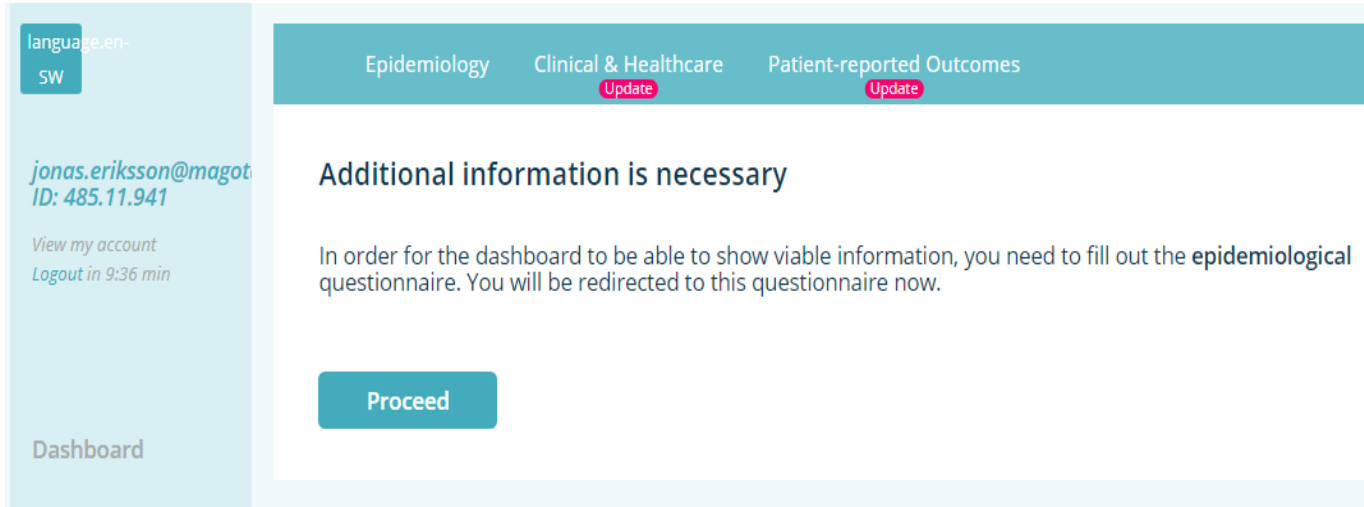
### The Aim with the Registry

The Tool should give the participating individual the chance to monitor disease and get an overview safe knowing that there is no profit interest involved. The Association in Sweden can use the information given to study the effect of given treatments and give support to influence politicians, healthcare providers, professions and scientists.



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### Illustrations. Figure 2. A) Patient side II



The screenshot shows a patient dashboard with a light blue sidebar on the left and a main content area on the right. The sidebar contains a language selector set to 'en-SW', the user's email 'jonas.eriksson@magot', ID '485.11.941', and a 'View my account' link. The main content area has a teal navigation bar with 'Epidemiology', 'Clinical & Healthcare', and 'Patient-reported Outcomes' (with 'Update' buttons). Below the navigation bar, a message states 'Additional information is necessary' and explains that an epidemiological questionnaire must be completed. A 'Proceed' button is located at the bottom of the message.

language.en-SW

jonas.eriksson@magot  
ID: 485.11.941

[View my account](#)  
Logout in 9:36 min

Dashboard

Epidemiology   Clinical & Healthcare   Patient-reported Outcomes

[Update](#)   [Update](#)

**Additional information is necessary**

In order for the dashboard to be able to show viable information, you need to fill out the **epidemiological** questionnaire. You will be redirected to this questionnaire now.

[Proceed](#)

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### Illustrations. Figure 3. A) Patient side III

Epidemiology   Clinical & Healthcare Update   Patient-reported Outcomes Update

- 1 In what year were you born?

Select year of birth ▼
- 2 Please indicate your sex at birth

Male


Female
- 3 Please indicate your weight in kilograms or pounds and your height in cm

Enter your weight   Select Unit ▼   Enter your height in cm
- 4 Please indicate the highest level of schooling you've completed

None

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### Illustrations. Figure 4. A) Patient side IV

not important at all  extremely important

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5 What are the two most important functions that IBD Specialists fulfill or should fulfill for you in the context of your IBD?

- They decide which treatment I should receive
- They educate me about the different treatment options
- They coordinate my interaction with the different healthcare professionals
- They provide me with emotional support
- Connection with the patient organization
- I was referred to this healthcare professional but I would not have gone on my own
- Other

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6 Do you, as a patient, currently have any possibility to take part in choosing your treatment?

- Yes
- No
- Not sure

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[www.ichom.org](http://www.ichom.org)

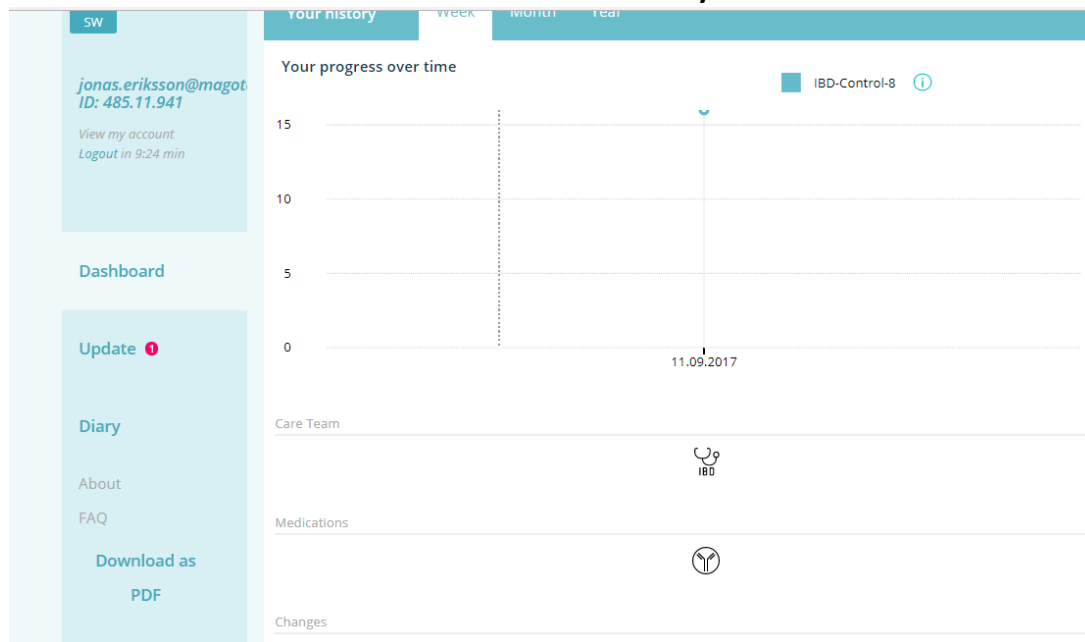
” Measuring the ICHOM Standard Sets means measuring the results of treatment that patients experience. We believe that this is not only a moral imperative. It also unites clinicians around what matters most: the outcomes of the care we deliver. For providers, measuring our Standard Sets serves four overlapping purposes: learning, improving performance, demonstrating superior performance, and enabling value-based payment.”

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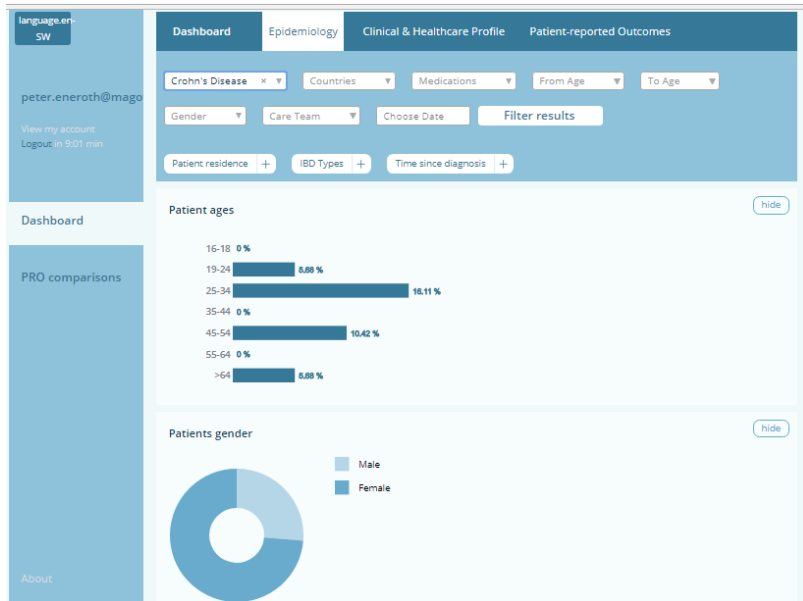
### Illustrations.

Figure 5.

A) Patient side V

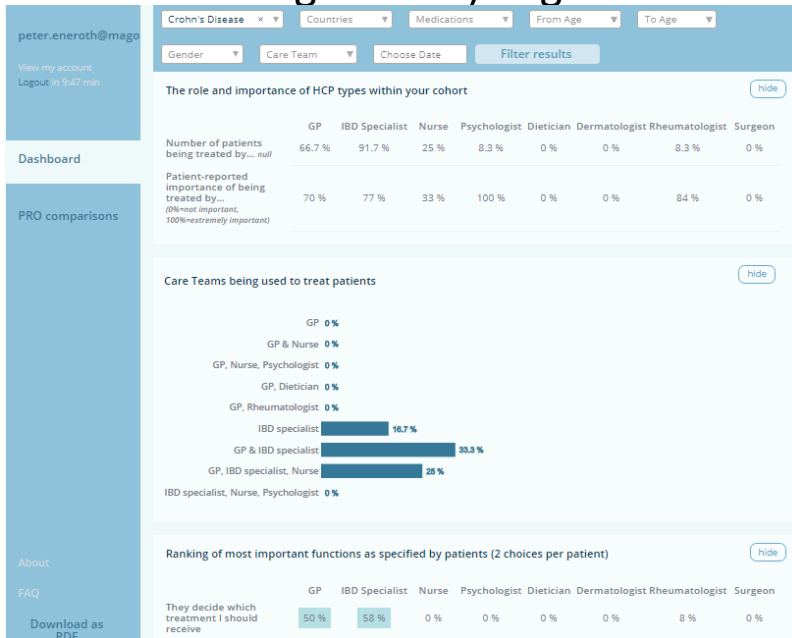


## Power of Member Awareness & Involvement - Case Study Patient Voice™ in Sweden. Illustrations. Figure 6. B) Organization side I




## Power of Member Awareness & Involvement - Case Study Patient Voice™ in Sweden.

### Illustrations. Figure 7. B) Organization side II



## Power of Member Awareness & Involvement - Case Study Patient Voice™ in Sweden.

### Illustrations. Figure 8. C) Admin side



The screenshot shows the admin interface for 'Voice to Patients Administration'. The page title is 'Voice to Patients Administration' and the date is 'Wednesday, 13th September 2017 13:53'. The user is logged in as 'Admin'. The breadcrumb trail is 'Home > Backend > Translations'. The interface includes a search bar, a 'Language' dropdown menu, a 'Frontend' dropdown menu, and a 'Search' button. There are also buttons for 'Recover deleted translations' and 'Add translation'. A table displays the following data:

<input type="checkbox"/>	Language	Frontend	Is active	Created at
<input type="checkbox"/>	en-SW	Organization	<input checked="" type="checkbox"/>	July 20, 2017, 8:45 a.m.
<input type="checkbox"/>	en-SW	Patient	<input checked="" type="checkbox"/>	July 20, 2017, 8:44 a.m.

At the bottom of the table, there is a 'Go' button and the text '0 of 2 selected'. The page footer indicates '1 - 2 / 2 translations'.

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### Summary

Pilot study (n = 71) in progress as we speak.

Congress of the Swedish Association on the 20th October

Goal to have 1,400 members and 9,000 Health Entries in January 2018!

Join? Ideas?

Talk to us!



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### Acknowledgement.

Takeda EUCAN.

Takeda Pharma AB

FYLGIA HB Law

The Swedish Stomach and Bowel Association

ANFEMA GmbH

The other Pilot countries Canada, Spain and Italy

EFCCA

Umeå Biotech Incubator AB and Uminova Innovation AB

Säljlabbet™

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## THANK YOU

Jonas Eriksson, Ph. D. and CEO, Biosolens AB, Umeå Sweden



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