

# Survey on experiences with vitiligo treatment

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<b>Registration date</b> 10/02/2025	<b>Overall study status</b> Completed	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
<b>Last Edited</b> 04/02/2025	<b>Condition category</b> Skin and Connective Tissue Diseases	<input type="checkbox"/> Individual participant data <input checked="" type="checkbox"/> Record updated in last year

## Plain English summary of protocol

### Background and study aims

Vitiligo is a common autoimmune skin condition that causes white patches and can significantly affect a person's quality of life. Treatment decisions for vitiligo vary depending on individual goals and circumstances, making it important for doctors and patients to work together to decide on the best approach. This study explores how patients feel about shared decision-making (SDM) when choosing their treatment and identifies any unmet needs they face during treatment. The study aims to understand how much patients feel involved in decision-making about their treatment. It will explore how factors like age, education, and ethnicity affect SDM and unmet needs, assess patients' uncertainty or conflict about decisions, and identify gaps in current vitiligo treatment.

### Who can participate?

The study will include 100–150 patients per country who have a doctor-confirmed diagnosis of vitiligo, are 18 or older, and visited a dermatology department in the past two years.

### What does the study involve?

A survey study will be conducted across three countries (Netherlands, Singapore, and Egypt) in collaboration with hospitals in these regions. The 10-minute survey asks about demographics, and unmet needs, and uses validated tools to measure SDM and decision-making challenges. The survey was developed and tested with input from vitiligo patients and translated into English and Arabic for use in all three countries.

### What are the possible benefits and risks of participating?

This study aims to better understand how patients experience SDM and identify areas where vitiligo treatment can be improved. Insights will help improve patient-centred care for vitiligo globally. The study has a minimal burden for participants and has been cleared by the ethical committee.

### Where is the study run from?

Amsterdam University Medical Centers, Netherlands

### When is the study starting and how long is it expected to run for?

May 2024 to May 2025

Who is funding the study?  
Amsterdam University Medical Centers, Netherlands

Who is the main contact?  
Dr Marlide Jukema, m.jukema@amsterdamumc.nl

## Contact information

### Type(s)

Public, Scientific, Principal Investigator

### Contact name

Dr Albert Wolkerstorfer

### Contact details

Meibergdreef 9  
Amsterdam  
Netherlands  
1105 AZ  
+31 020 566 9111  
a.wolkerstorfer@amsterdamumc.nl

## Additional identifiers

### EudraCT/CTIS number

Nil known

### IRAS number

### ClinicalTrials.gov number

Nil known

### Secondary identifying numbers

Nil known

## Study information

### Scientific Title

Survey on experiences with vitiligo treatment

### Study objectives

Vitiligo is a common autoimmune disorder characterised by depigmented macules which has a significant impact on patients' quality of life. Treatment options vary based on individual factors and goals, making shared decision-making (SDM) crucial for aligning treatment with patient preferences. This study aims to investigate how patients experience shared decision-making in choosing their vitiligo treatment and which unmet needs they encounter in the treatment of vitiligo.

### Ethics approval required

Ethics approval required

### **Ethics approval(s)**

Approved 13/08/2024, The Medical Ethics Committee of the Amsterdam University Medical Centers (Meibergdreef 9, Amsterdam, 1105 AZ, Netherlands; +31 020 566 9111; metc@amsterdamumc.nl), ref: 2024.0692

### **Study design**

Multinational cross-sectional exploratory survey study

### **Primary study design**

Observational

### **Secondary study design**

Cross sectional study

### **Study setting(s)**

Internet/virtual

### **Study type(s)**

Other

### **Participant information sheet**

### **Health condition(s) or problem(s) studied**

Vitiligo

### **Interventions**

This multinational, cross-sectional exploratory survey study will be conducted across three countries at the Amsterdam UMC, National University Singapore, Cairo University and Ain Shams University. The survey will be carried out using the free online survey tool 'LimeSurvey'.

The patients will be asked to fill out a questionnaire that will take about 10 minutes to complete. The questionnaire was developed with the input of three patients of the Dutch National Vitiligo Patient Association. It was also tested by three vitiligo patients who visited the dermatology department in Amsterdam UMC and was adjusted based on their feedback. The survey contains questions about demographic variables (such as educational level, ethnicity, etc.) and unmet needs during the treatment of vitiligo. Besides this, three validated questionnaires will be used: the 9-item Shared Decision-Making Questionnaire (SDM-Q-9) (Each item will be scored on a 6-point Likert scale ranging from 0 (no SDM) to 5 (optimal SDM). This results in a score ranging from 0 to 45, which will be converted to a scale of 0–100), the Control Preference Scale (CPS) and the Decisional Conflict Scale (DCS) for assessing the need for and extent of shared decision-making. The survey was translated into English and Arabic for the participating hospitals in Singapore and Egypt by a certified translation agency. The English survey and the Arabic survey will be reviewed in LimeSurvey by two doctors who are (near)-native speakers of these languages before sending the survey out to the patients.

**Data Collection and Analysis:** Patients will receive an email with a secure link to the survey. Data will be anonymized and hosted securely by the Amsterdam University Medical Centre. Statistical analysis will summarize patient experiences and examine differences across countries and between demographic groups.

## **Intervention Type**

Other

## **Primary outcome measure**

The following primary outcome measures are assessed at one time point after treatment:

1. The extent to which shared decision-making (SDM) is experienced will be measured using the validated nine-item Shared Decision-Making Questionnaire (SDM-Q)
2. The extent to which patients want to be involved in the SDM process will be measured using the validated Control Preference Scale
3. The uncertainty patients experience when making healthcare decisions will be measured using the Decisional Conflict Scale
4. Potential shortcomings patients may encounter during their treatment for vitiligo measured using a 5-point Likert scale (ranging from strongly disagree to strongly agree)

## **Secondary outcome measures**

There are no secondary outcome measures

## **Overall study start date**

01/05/2024

## **Completion date**

31/05/2025

# **Eligibility**

## **Key inclusion criteria**

1. Physician-based diagnosis of non-segmental vitiligo
2. Aged 18 years or above
3. Had a treatment visit at the dermatology department in the past 2 years

## **Participant type(s)**

Patient

## **Age group**

Mixed

## **Lower age limit**

18 Years

## **Upper age limit**

100 Years

## **Sex**

Both

## **Target number of participants**

The desired sample size is between 100-150 patients per country

## **Key exclusion criteria**

Non segmental vitiligo

**Date of first enrolment**

26/11/2024

**Date of final enrolment**

31/05/2025

**Locations****Countries of recruitment**

Egypt

Netherlands

Singapore

**Study participating centre****Amsterdam UMC**

Meibergdreef 9

Amsterdam

Netherlands

1105 AZ

**Study participating centre****National University Singapore**

Lower Kent Ridge RD 21

Singapore

Singapore

119077

**Study participating centre****Cairo University**

Gamaa Street 1

Giza

Egypt

12613

**Study participating centre****Ain Shams University**

El-Khalyfa El-Mamoun Street Abbasya

Cairo

Egypt

11566

# Sponsor information

## Organisation

Amsterdam University Medical Centers

## Sponsor details

Meibergdreef 9

Amsterdam

Netherlands

1105 AZ

+31 020 566 9111

[vitaligo-onderzoek@amsterdamumc.nl](mailto:vitaligo-onderzoek@amsterdamumc.nl)

## Sponsor type

Hospital/treatment centre

## Website

<https://www.amsterdamumc.org>

## ROR

<https://ror.org/05grdyy37>

# Funder(s)

## Funder type

Hospital/treatment centre

## Funder Name

Amsterdam University Medical Centers

## Alternative Name(s)

Amsterdam UMC, Amsterdam University Medical Centres, AUMC

## Funding Body Type

Government organisation

## Funding Body Subtype

Universities (academic only)

## Location

Netherlands

# Results and Publications

## Publication and dissemination plan

Planned publication in peer-reviewed journal

## Intention to publish date

04/05/2026

## Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study will be available upon request from Dr Marlide Jukema, m.jukema@amsterdamumc.nl

## IPD sharing plan summary

Available on request

## Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">Participant information sheet</a>	version 124	24/07/2024	24/01/2025	No	Yes
<a href="#">Protocol file</a>			24/01/2025	No	No