The Patient Voice Database

Empowering Patients to Shape the Future of Healthcare

Who We Are

PATIENT EXPERT CENTER

Non-profit organization founded by Belgian patient organisations to train patients to become Patient Experts, to co-design formal collaboration processes and to set up projects with healthcare partners that deliver value for all.

- Stefan Gijssels, Chairman

Curewiki

Belgian healthtech startup empowering patients to participate in research.

- Jean-Sébastien Gosuin, Founder

Here's Why This Matters

Every treatment exists because someone joined a study — but most people never get the chance.

1 in 4

Belgians live with a chronic condition or disease

80%

Of clinical trials are systematically delayed

64%

Of Belgians willing to participate in clinical research

But...

They don't know how to get involved

WHO Call to Action

> ***"Patients must no longer just participate, but also lead and help shape care and science."***
>
> World Health Organization

Growing Trends in Patient Data

Clinical Trial Participation

Higher need for clinical participation

Real World Evidence

Demand to pharma companies to show Real World Evidence

Hospital Services

Patient experience data to improve hospital services

Health Policy

Patient experience data to improve health policy

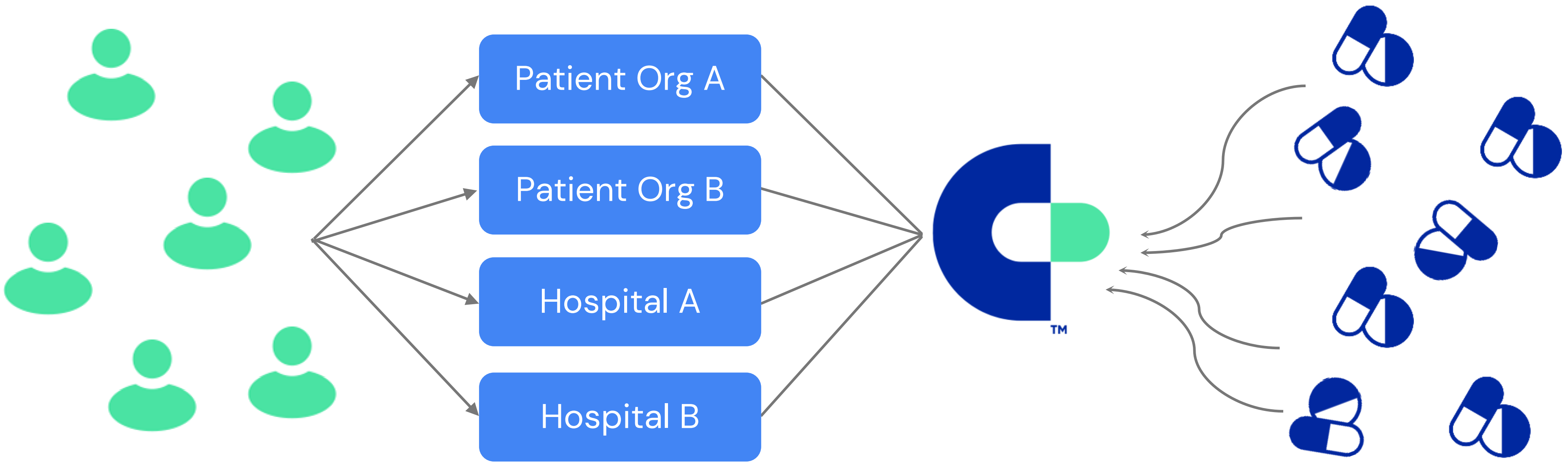
Innovation

Identification of problems and solutions

Patient orgs and hospitals are key, but need support.

Without the right tech, funding, and legal framework, patient organisations and hospitals struggle to support patients and to remain independent from the industry

We build a bottom-up flow from Patients to Research



Patient Org A

Patient Org B

Hospital A

Hospital B

Patient Universe

Patient Access Points

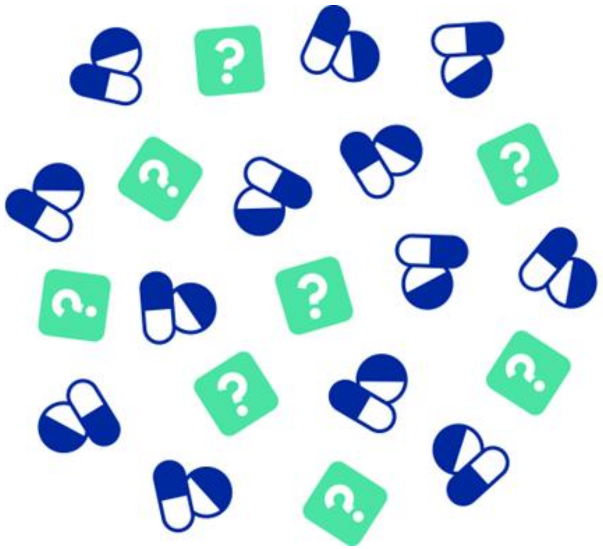
Curewiki Technology

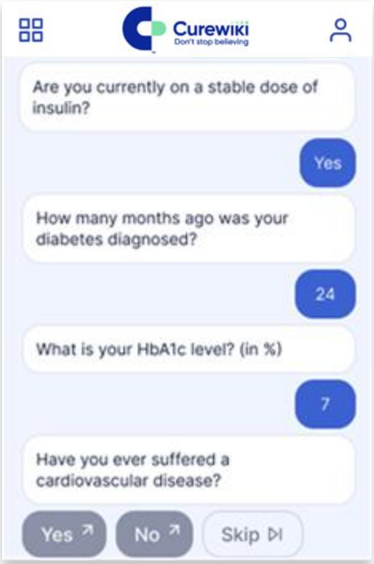
Clinical Research Projects

THE PATIENT VOICE DATABASE

MAKE YOUR VOICE HEARD

Using AI, we turn complex clinical trial criteria into a simple patient journey





Are you currently on a stable dose of insulin?

Yes

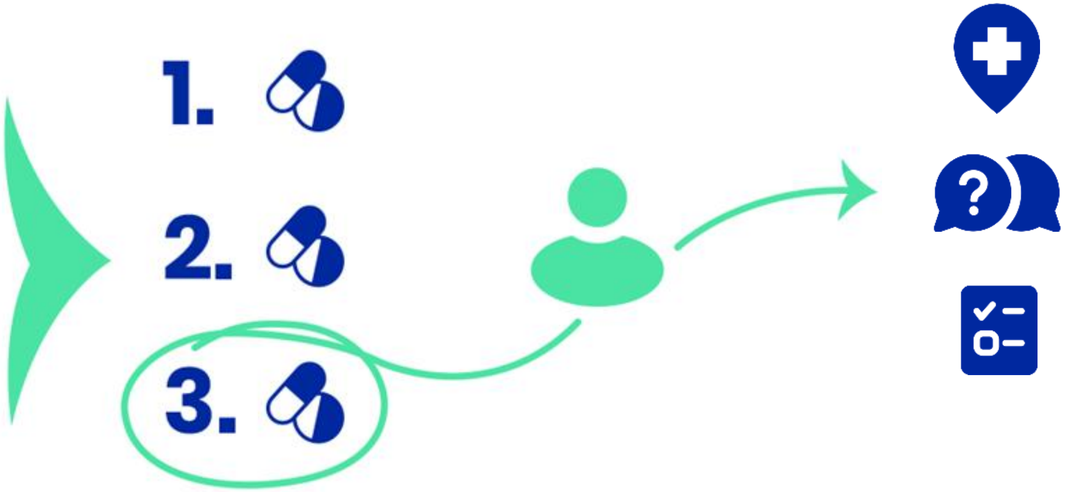
How many months ago was your diabetes diagnosed?

24

What is your HbA1c level? (in %)

7

Have you ever suffered a cardiovascular disease?



Patients get direct access to a wide range of research opportunities.

- Surveys
- Panels
- Clinical Trial Pre-Screening
- Insights

READI Project: Advance inclusion in EU clinical research

READI

1. **Partner in the EU-funded READi Project**: advancing equity and inclusion in clinical research across 73 organizations from 18 countries
2. **Curewiki's role:** providing AI-powered, patient-centric technology to ensure broader access to relevant clinical trials
3. **Impact:** enabling underserved communities to participate in research, fostering a more inclusive and accessible healthcare ecosystem
4. **CTDN as the new standard**: Establishing the Clinical Trial Data Network as the benchmark for patient access and participation across Europe

Yellow button for a better pre-screening

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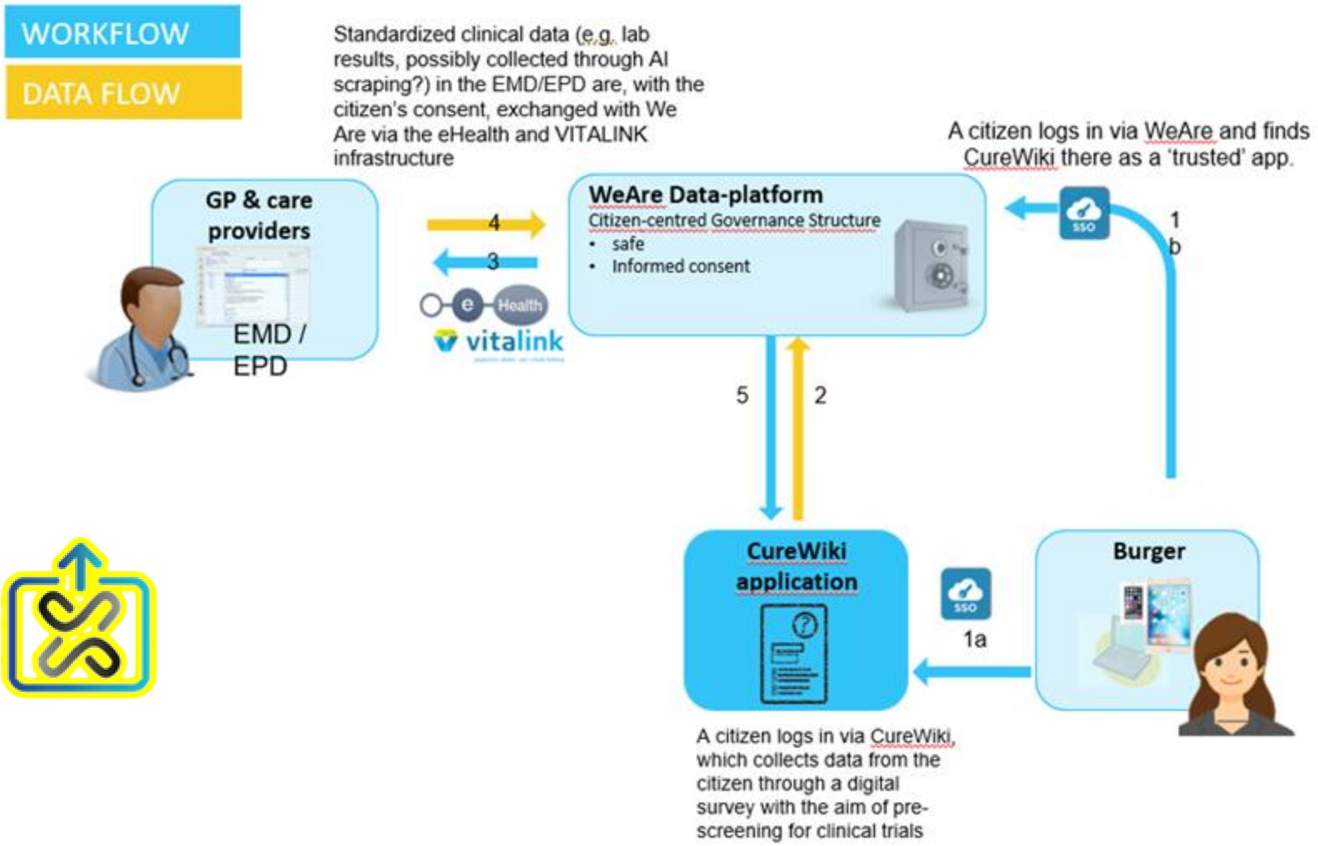
Our xShare pilot

Business Use Case 2 (BUC2): Patient self-nomination as possibly eligible for a trial via the xShare Yellow Button



Standardized clinical data (e.g. lab results, possibly collected through AI scraping?) in the EMD/EPD are, with the citizen's consent, exchanged with We Are via the eHealth and VITALINK infrastructure

A citizen logs in via WeAre and finds CureWiki there as a 'trusted' app.

A citizen logs in via CureWiki, which collects data from the citizen through a digital survey with the aim of pre-screening for clinical trials

1a-b: A citizen logs in via the IAM (Identity & Access Management) and then completes the CureWiki survey, either by directly using the CureWiki app (a) or by selecting it in the WeAre app store (b)

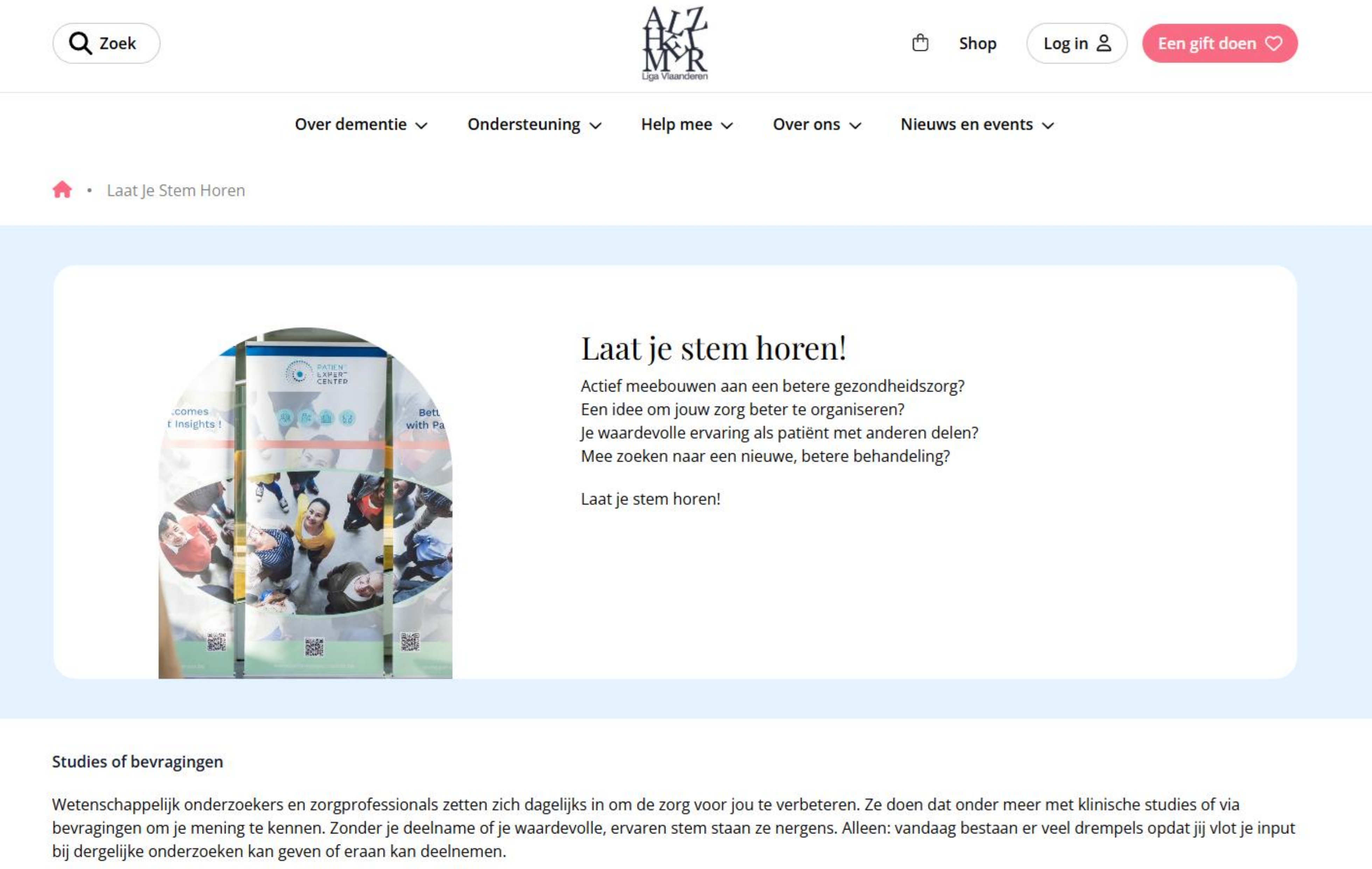
2: Data from the CureWiki survey are pushed to the WeAre pod

3: A query for missing clinical data is carried out via VITALINK

4: The required clinical data are, with the citizen's consent, read out by the WeAre data platform

5: CureWiki, with the citizen's consent, accesses the clinical data in order to deliver a screening recommendation to the patient

Co-funded by the European Union



Laat je stem horen!

Actief meebouwen aan een betere gezondheidszorg?
Een idee om jouw zorg beter te organiseren?
Je waardevolle ervaring als patiënt met anderen delen?
Mee zoeken naar een nieuwe, betere behandeling?

Laat je stem horen!

Studies of bevragingen

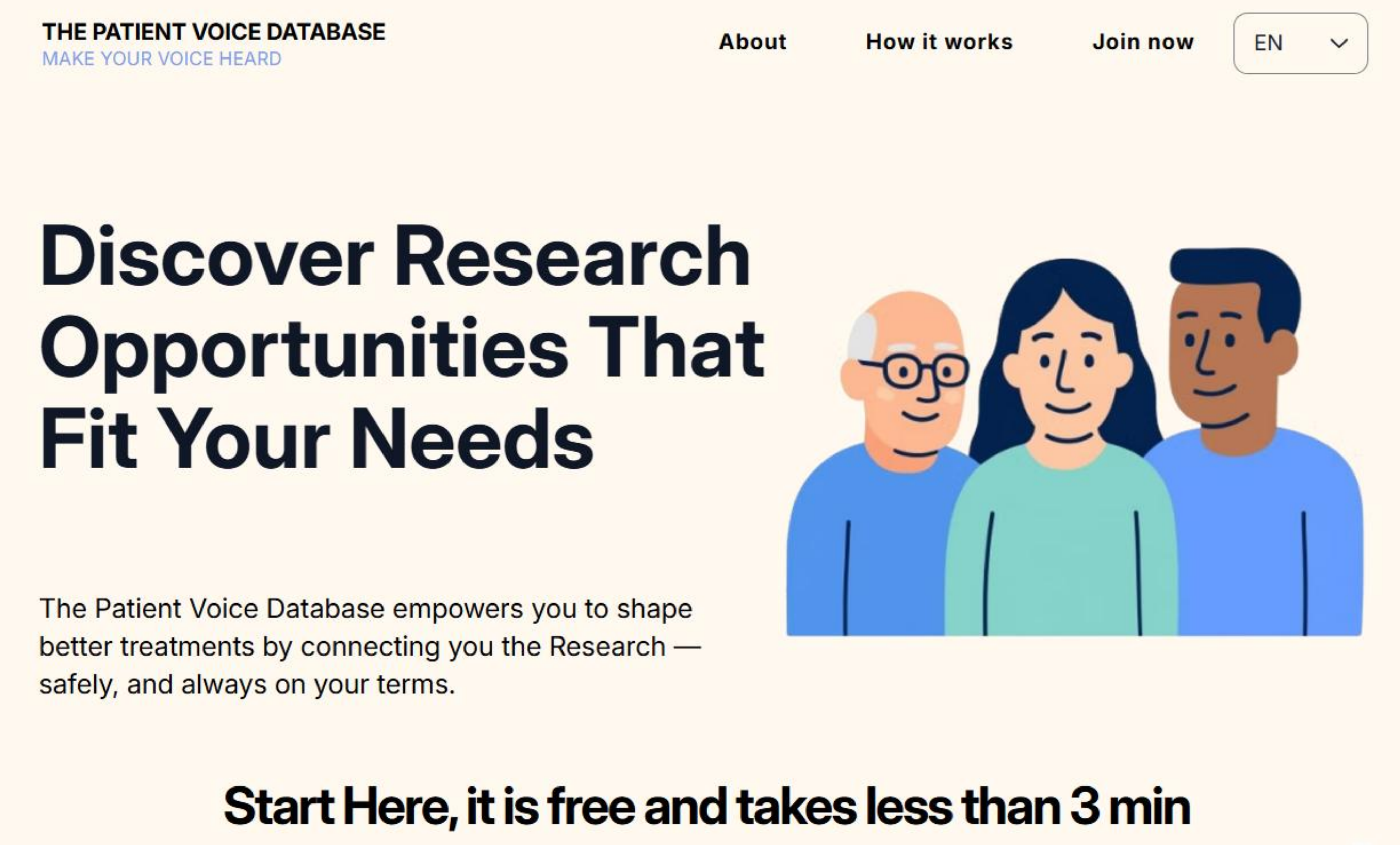
Wetenschappelijk onderzoekers en zorgprofessionals zetten zich dagelijks in om de zorg voor jou te verbeteren. Ze doen dat onder meer met klinische studies of via bevragingen om je mening te kennen. Zonder je deelname of je waardevolle, ervaren stem staan ze nergens. Alleen: vandaag bestaan er veel drempels opdat jij vlot je input bij dergelijke onderzoeken kan geven of eraan kan deelnemen.

Ontdek klinisch onderzoek dat bij jou past

Omdat zorg beter wordt als vrouwen hun stem laten horen

Beantwoord een paar korte vragen over je gezondheid en ontdek of er onderzoek is dat bij je past.

Welkom!



Discover Research Opportunities That Fit Your Needs

The Patient Voice Database empowers you to shape better treatments by connecting you the Research — safely, and always on your terms.

Start Here, it is free and takes less than 3 min

Already Making an Impact

18,000+

Belgian patients already registered (40,000+ in EU)

100%

Free, safe and GDPR-compliant

Belgium

Pilot country & restoring clinical research leadership

Our ambition: Engage 1,000,000 patients in Belgium via patient associations and hospitals

The Patient Voice in action: Flu Vaccination Survey

The challenge:

Flu vaccination risk perception and intentions

2 cohorts:
- +65 people with comorbidities
- Their beloved ones

Minimum 500 participants

Maximum 6 weeks

679

patients responded
In just 4 weeks

93%

of beloved ones know the risk

76%

of beloved ones plan to vaccinate!

The Patient Voice in action: Panel composition

The challenge:

Cardiovascular Patients Board

Minimum 9 participants

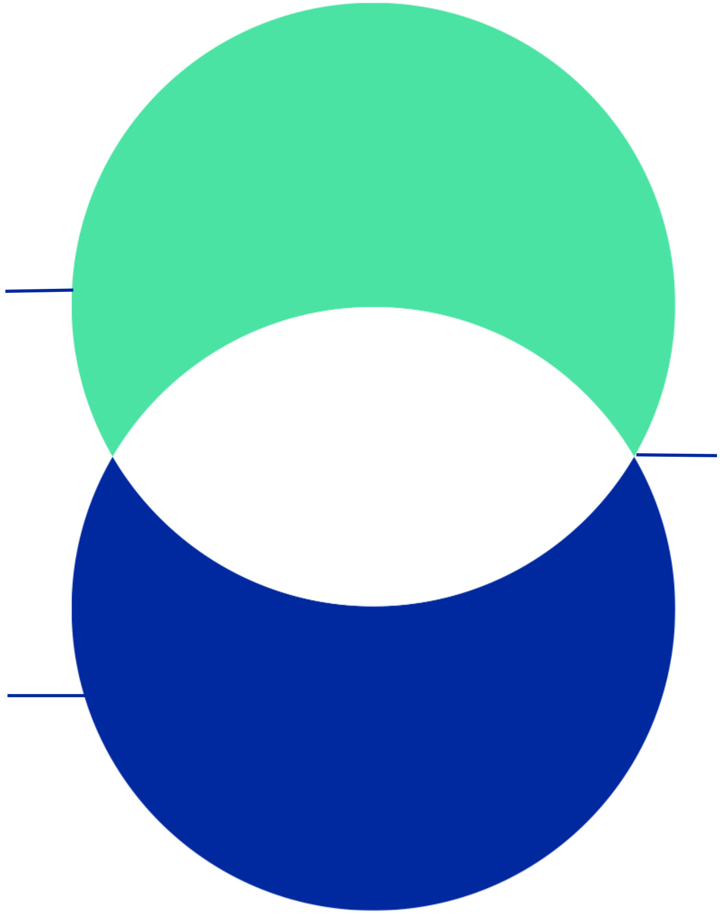
Criteria:
- Cardiac issues
- Age between 40 and 70

Recruitment from 15/9 for 3 months

8

validated candidates
In just 1 month

The Patient Voice in action: Study design Insights



Public data
from medical studies inventories (CTIS and CTgov); e.g.: compare your exclusion threshold of glycated hemoglobin rate with all other studies for diabetes

Patient real world data
anonymized from all pre-screening answers in Curewiki (already 2M+ data points); e.g: all the glycated hemoglobin rates of all diabetes patients per site / per country, ...

Curewiki magic
combines public data and patient real world data; e.g. when you change your threshold on glycated hemoglobin rate by z you will have x% more referals for your diabetes trial in this site

The Patient Voice in action: Prevention

Asthma: 504 registered users

Are you Currently a smoker? 452 answers

186 (41%!) say YES

“Pharma.be is delighted to support this initiative, which strengthens patient involvement in clinical research.”
Caroline Ven, CEO of pharma.be

“Your values that stand behind the service delivery, are very noticeable and we are happy to now be part of this movement.“
Procurement Europe, Bayer

“Thank you to the many patients for their input and enthousiasm to strive and help understanding and building flu vaccination together. A clear proof of the added value of the Patient Voice!”
Tineke Vanlerberghe, Viatris

Join the Movement

For the first time in history, patient voices can be systematically heard across all diseases

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