

À la recherche du santé perdue

exploring tech-based
solutions through co-creation
to support quality of life with
an invisible disability

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Who:

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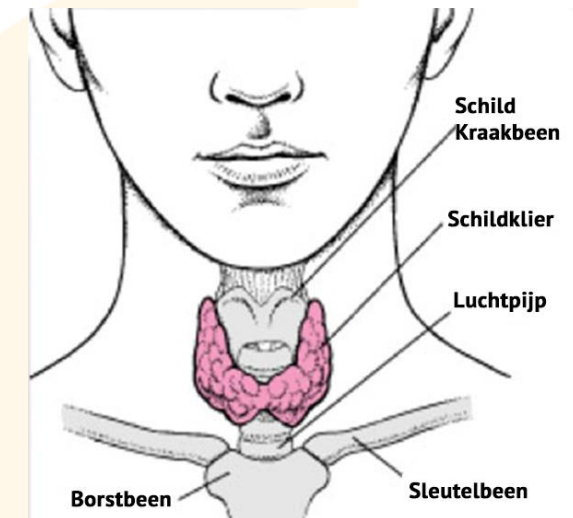
Introduction of SON

The Thyroid / Thyroid disorders

The thyroid: role in heat production, metabolism, energy supply, memory, skeletal and cardiac muscle contraction and sleep.

Thyroid disorders (Schildklieraandoeningen):

- Underactive thyroid gland (Te trage schildklier)
- Too active thyroid gland (Te snelle schildklier)
- Graves' eye disease (Oogziekte van Graves)
- Goiter and lumps (Struma en knobbels)
- Thyroid inflammation (Schildklierontsteking)
- Thyroid cancer (Schildklierkanker)



Essential

Schildklier, de grote onbekende

www.schildklier.nl



Schildklierhormonen zorgen voor de balans in het lichaam. Als deze is verstoord, kunnen verschillende lichamelijke en psychische problemen ontstaan.

Per jaar krijgen ongeveer
900 mensen
schildklierkanker.

Hoe langer een
schildklier-aandoening **niet**
wordt behandeld, hoe
lastiger klachtenvrij te
worden.

Vermoedelijk lopen
nog 300.000 mensen rond
met vage klachten die nog niet
(h)erkend worden als schildklierpatiënt.
Misschien bent u, zonder dat u het weet,
ook een schildklierpatiënt.

Wist u dat bijna
700.000
mensen
gediagnosticeerd
schildklierpatiënt
zijn?

Ieder jaar krijgen 8500
vrouwen **na de bevalling** een
schildklierontsteking.

De **hielprik** spoort jaarlijks
circa 80 kinderen met een
schildklierafwijking op.

In Nederland wordt bij 10%
van de jong volwassenen
(geringe) **struma** gevonden.
Ongeveer 8% van de
volwassenen heeft een
voelbare schildklierknobbel.

Who are we?

- The national patient organization
9500 donateurs
- Target group: all thyroid patients
and their relatives
In NL: more than 700.000 thyroid patients
- Volunteers
ca. 120



Who are we? - Mission

SON is:

- a partnership supported by patients and stakeholders
- that strives for recognition and visibility of thyroid disorders

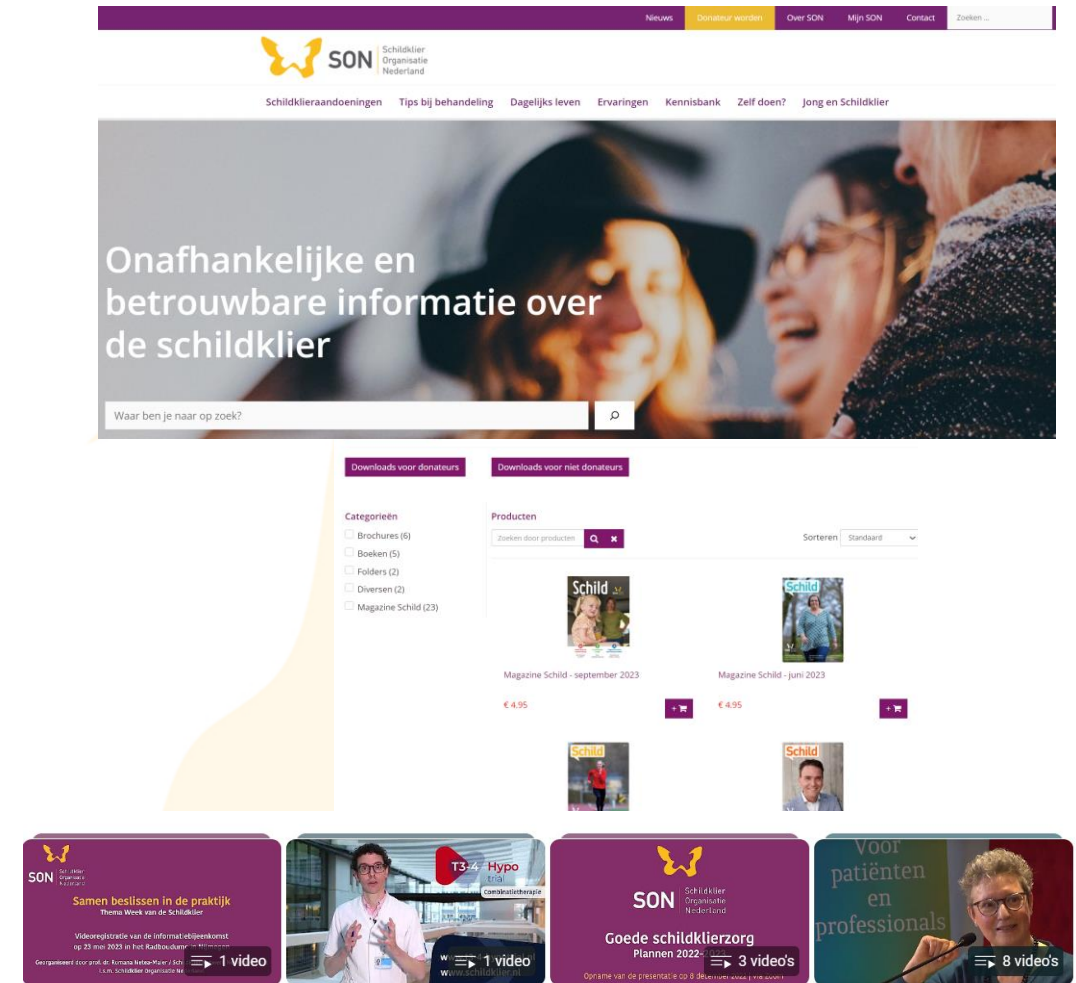
SON wants:

- from treating symptoms to solutions
- encouraging patients, stakeholders and institutions to take action themselves

What we are doing

Education

- Website: www.schildklier.nl
1,3 million visitors, > 8 milj. pageviews
- Webinars, podcasts
- Magazine, brochures, infographics
- Youtube, Facebook and Instagram
- Newsletter (13.000 readers)



What we are doing

Contact with fellows

- Meetings
- Facebook group (ca. 17.000 members)
- Schildkliertelefoon (1240 calls per year)



Schildkliertelefoon



What we are doing

Advocacy

SON is a discussion partner for the government, healthcare providers, health insurers and other social organizations.

Ongewenst wisselen van
medicatie

#stopdeswitch



SON | Schildklier
Organisatie
Nederland

What we are doing

Research

- **Initiate research** – based upon needs of our target group
- **Support research**
- **Contribute to patient recruitment**



SON | Schildklier
Organisatie
Nederland

www.schildklier.nl

About today:

10 min

[Who]

15 min

Activity 1

get to know each other's

20 min

Activity 2

identify personal values before/after

=5 min=

==Break==

20 min

Activity 3

co-creation phase

15 min

Sum-up

theoretical framework and next steps

Activity 1

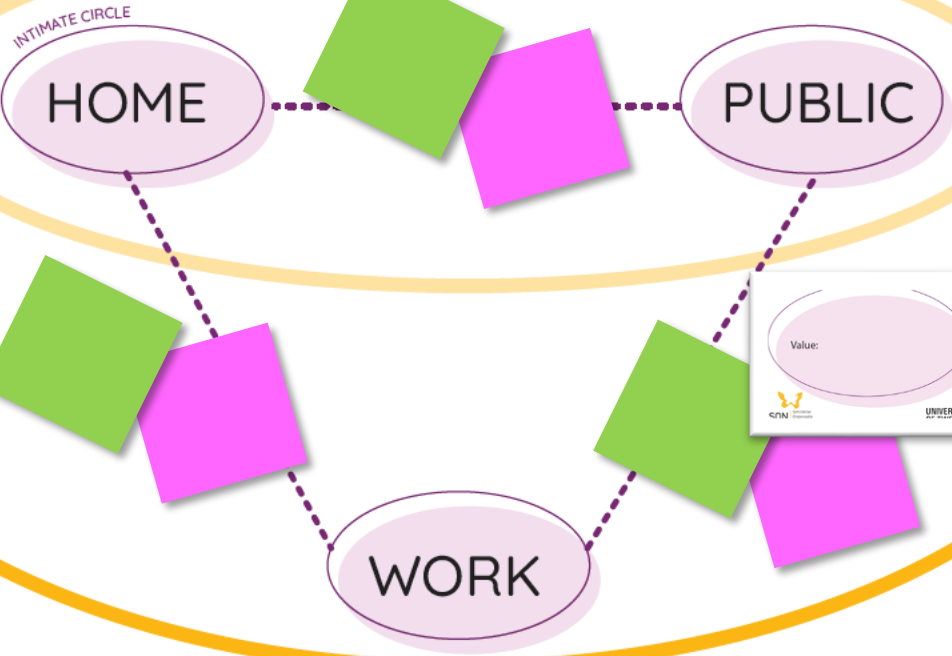
- 1 min time per person (use the timers!)
- Share your name, your profession and what brought you to the workshop
- Be open and non-judgmental
- What comes out in the workshop, remains in the workshop!

Activity 2

- 1 volunteer from SON per table
- Share personal story with thyroid
- Before/after: write on post-its of different colours the activities that each person does, and how they have been affected from the diagnosis
- Place the post-its on the canvas on the table
- Identify which values from the list are connected to the previous activities
- Discuss it in the group

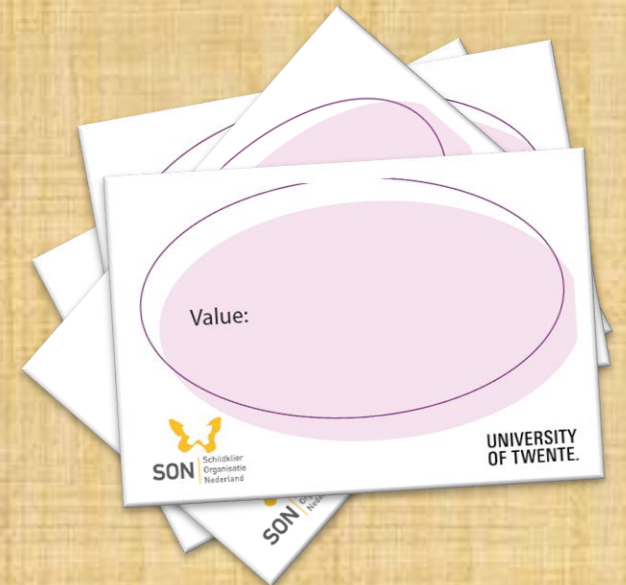
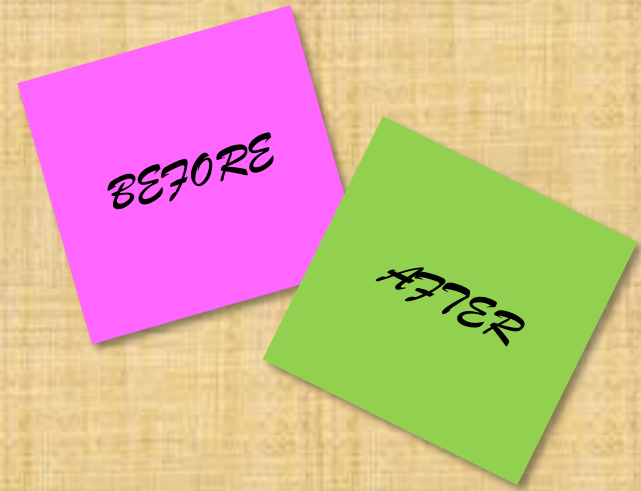
OUTER CIRCLE

INNER CIRCLE



INTRA INDIVIDUAL

INTER INDIVIDUAL





Activity 3

- Identify 1 value and couple of actions to use as a basis for this exercise
- Get your hands dirty!

Use the materials on the tables to imagine a technology that can support the person in dealing with the activities connected to the value you selected.

You can draw, glue, make small models to transform your idea in something visual.

Pick one person per group to share the result in the bigger group!

Our group:

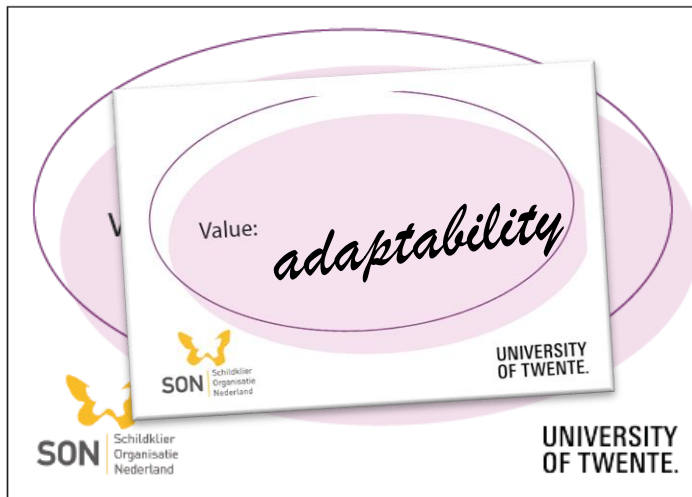
Francesca,
designer

Esther, volunteer
from SON

Matthijs,
designer

Femke,
gerontheologist

Hilde,

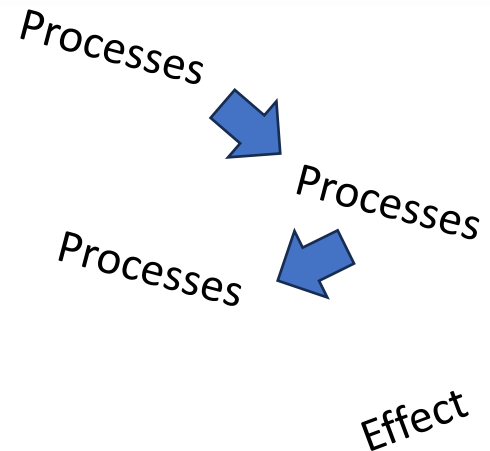


Problem statement:

After receiving her diagnosis of hypo-thyroidism, Francesca finds it hard to adapt to new environments: she's often cold, and crowded environments make her feel very tired. Also, she does not like to explain every time this to her new colleague, so she rather avoids going into new places with strangers.

Our solution:

Technology Experience



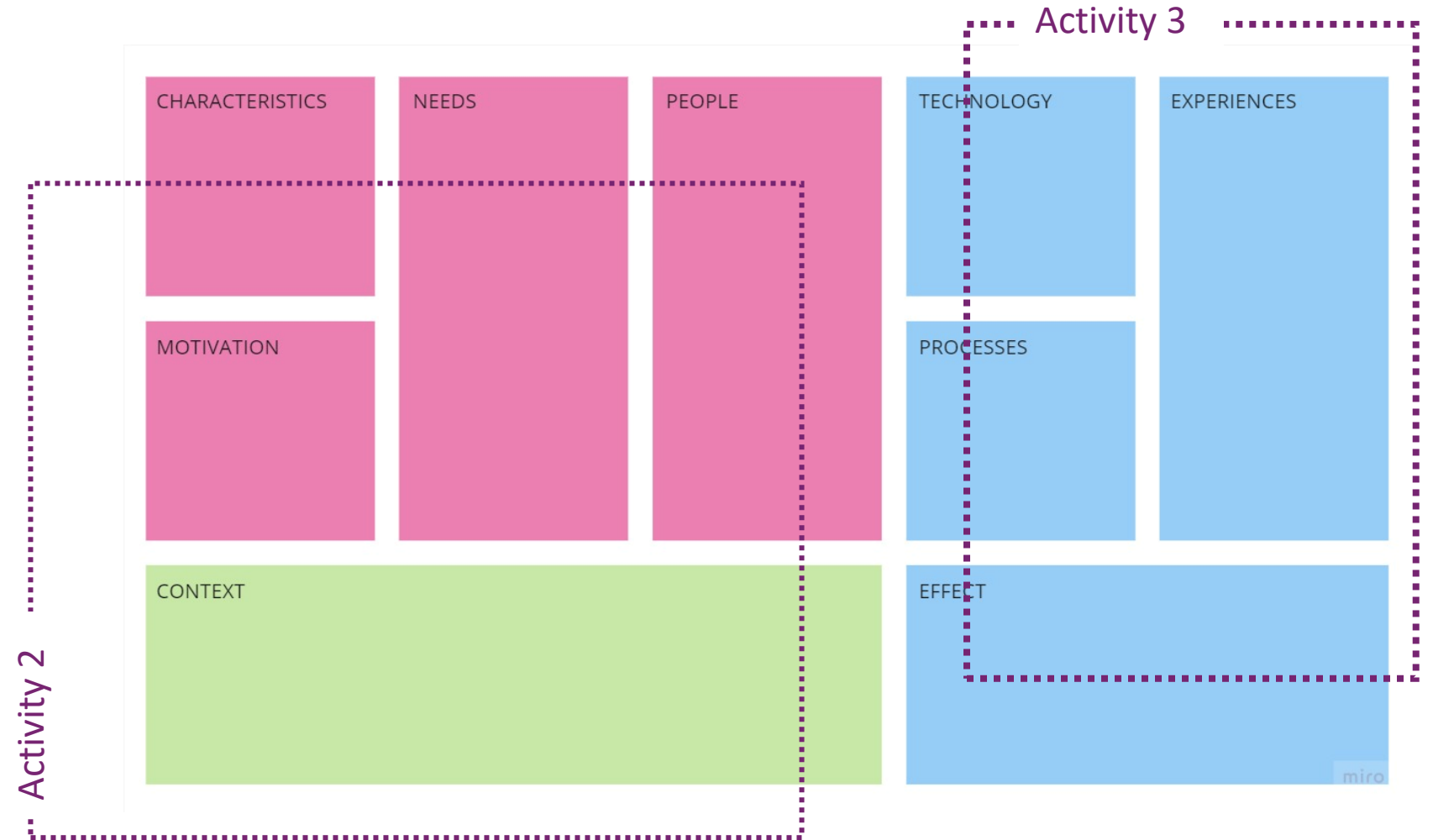
Citizen science and participatory design

- Participatory design and co-design as tools to empower underrepresented voices in design processes
- Roles in the design process: power dynamics, politics and positionality
- Top-down vs bottom-up innovation
- Living Labs and other forms of participation
- Stakeholder mapping, problem definition, needs and wishes

Theoretical framework

People value canvas

(Wildewuur et al.)



Call for PhD

PHD POSITION ON DESIGN METHODOLOGIES FOR CO- CREATION OF TECHNOLOGIES IMPROVING THE QUALITY OF LIFE OF PEOPLE WITH CHRONICAL ILLNESS

<https://utwentecareers.nl/en/vacancies/1487/phd-position-on-design-methodologies-for-co-creation-of-technologies-improving-the-quality-of-life-of-people-with-chronical-illness/>

Before
saying
goodbye...



Thank you for joining
the workshop
and...let's keep in touch!

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