I am just a patient

Breast Cancer organisation Netherlands

sep 2022

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Introduction

- Who is Cristina
- BVN
- What defines a patient?
- What does a patient need?
- How can we get into the system?

Who am I? Cristina Guerrero Paez

Why is **Breast Cancer organisation Netherlands (BVN)** needed?

Our aim: Each breast cancer patient receives the best personalized treatment for them.

17,000 women and 120 men per year.

Helping with questions, concerns and considerations by sharing our experiences.

Every patient can receive tools, equipment and idea's to decide what's important for them in a treatment and can discuss this in detail

We support and relieve the health care professional in her / his work

The BVN mission

Mission

We fight every day for people affected by breast cancer to receive personalized, tailored and appropriate treatment, care and support.

Vision

To achieve this, advocacy for good quality of care and of life is essential. Just like information provision and contact with fellow sufferers. Quality of care focuses on diagnosis, treatment and aftercare. Quality of life concerns the physical, psychological and social functioning of (former) breast cancer patients and people with hereditary/familial predisposition.

They need good information, which is reliable and according to the latest developments. This allows them to make well-considered choices about their treatment and how they want to deal with their disease or hereditary/familial predisposition. BVN is a strong supporter of Shared Decision Making. This is the process that leads to you deciding together with care providers about which care, in what form and in what way, suits you best.

BVN proactively influences breast cancer care by discussing topics with decision making forums in hospitals, with researchers, health insurers and other important stakeholders to improve the quality of care and life. In addition, we respond to current developments, decisions by government and policy makers.

What do we do?

We provide reliable information

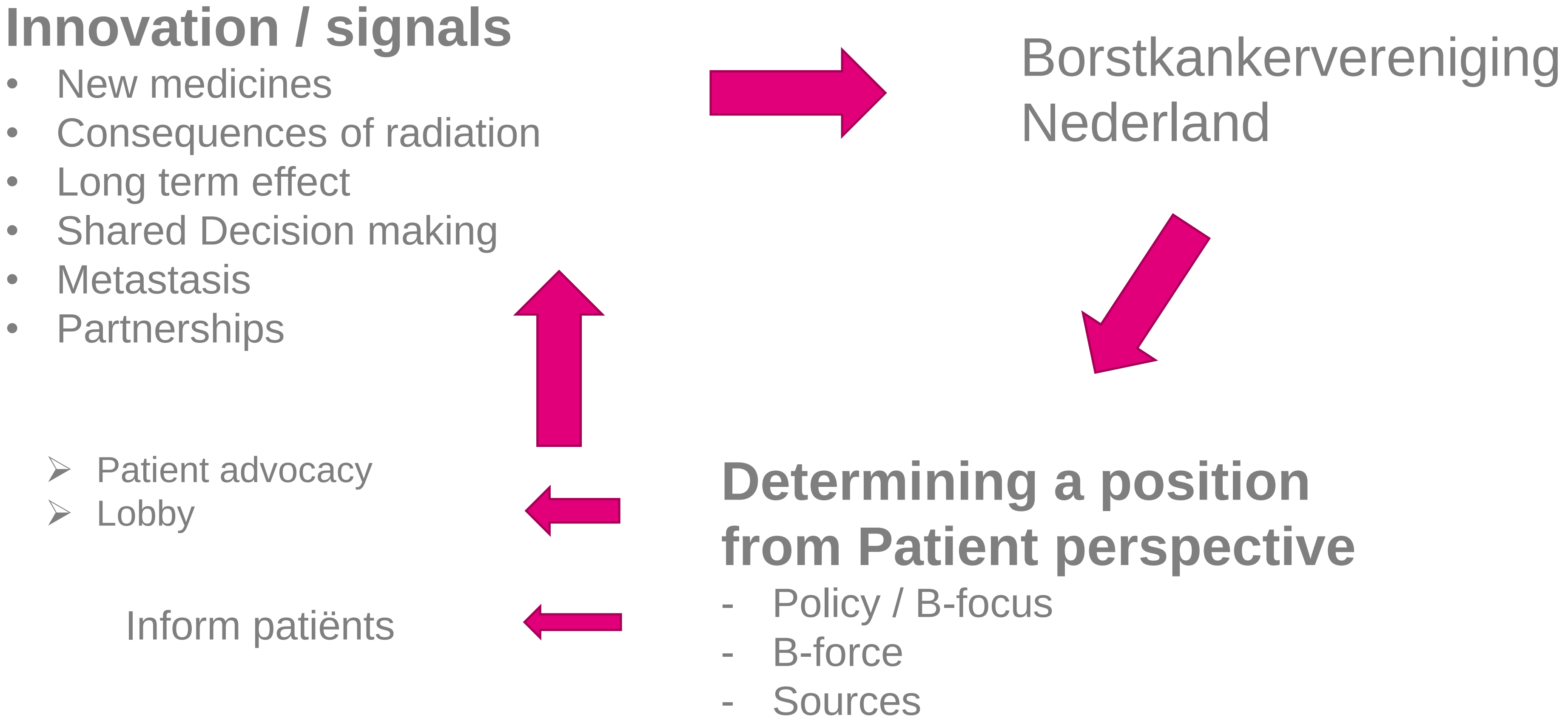
We provide peer contact

We provide support in making decisions

We stand up for the patient's interest

Funding for our goals and projects

How do we work?



Innovation / signals

- New medicines
- Consequences of radiation
- Long term effect
- Shared Decision making
- Metastasis
- Partnerships

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Determining a position from Patient perspective

- Policy / B-focus
- B-force
- Sources

➢ Patient advocacy
➢ Lobby

Inform patiënts

We will stay as long as we are needed

200+ volunteers

40 years experience

6000 members

What are we aiming at (B-focus) 2020-2025

1. Access to the best (after)care and expertise (national)
2. No over- and under-treatment
3. Conscious choices through (among other things) time and attention in the care path
4. Metastatic breast cancer
5. Early detection and hereditary/familial predisposition

We are a network organisation

- All hospitals in the Netherlands
- NABON
- BOOG (Borstkankeronderzoeksgroep), in PAG (patiëntenadvicegroup to review research applications)
- NFK = Nederlandse Federatie van kankerpatiëntenorganistaties en Patientenfederatie
- IKNL
- KWF Kankerbestrijding/Pink Ribbon
- Farmaceutical industry
- Kanker.nl
- Other (breast)cancer organisations AYA, Jong en Kanker, MammaRosa

Our products and services

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BVN products and services

For patients:

Information for patients:
- Website Borstkanker.nl
- Various brochures (hardcopy and online)
- Our online magazine Blad B , (for members)
- Newsletter general (twice a year), newsletter for members

Providing information and contact with fellow sufferers:
- All kinds of contact options; by telephone and online (‘Service team’)
- Breast cancer agenda, contact with fellow sufferers and regional and local activities ('B-actief')
- Discussion groups and individual guidance (buddy)

Support in making choices:
- Monitor breast cancer care with website
- B-bewust, better prepared with different tools on our website
- Online Support Overview
- Videos for patients

BVN products and services

For healthcare providers:

- Newsletter healthcare professionals
- Patient advocates in hospitals
- Support in improving breast cancer care (projects)
- Advocacy on our B-focus points
- Possibility of requesting B-force
- Themed meetings

For researchers:

- Provide a patient perspective to research proposals and ongoing studies

Based on:

B-force: the voice of fellow sufferers who participate in our panel (over 4000 members)

I am just a patient

Am I just a patient?

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Breast cancer patients; a great variety

- Young women
- Elder breast cancer patients
- People with genetic predisposition
- People with metastases
- Non-native speakers & low-literate
- Men with breast cancer

Each group has its own unique problems, dilemmas and priorities in care and information.

Types of patients

- We have defined 4 types of different patients
- With different needs
- And different qualities and emotions

(sorry, the next slide is in Dutch)

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Key leverage points patient journey borstkanker

Pfizer samhealth

Daphne

- Rationeel, taakgericht en extravert
- Grootste angst: controleverlies
- Focus op regie en controle (mBC = terugvechten)
- Proactief en leidend in behandeling = ik beslis

Iris

- Emotioneel, mensgericht en extravert
- Grootste angst: afwijzing door anderen
- Focus op kwaliteit van leven(ontspanning)
- (mBC = moeite positief te blijven)
- Proactief, maar wil samen beslissen over behandeling

Suzan

- Emotioneel, mensgericht en introvert
- Grootste angst: verlies van zekerheid
- Focus op beperken van stress en lijden (mBC = isolement, overleven in kleinere wereld)
- Reactief en volgend in behandeling = arts beslist

Charlotte

- Rationeel, taakgericht en extravert
- Grootste angst: kritiek van anderen
- Focus op managen van spanningen (mBC = erbij neerleggen)
- Reactief en kritisch in behandeling = feiten beslissen

Informatie over bijwerkingen, praktische zaken, late gevolgen, seksualiteit, werkhervatting en lotgenotencontact

Daphne	Iris	Suzan	Charlotte
Hoofdlijnen, voordelen en resultaten	Praktische tips	Gehoord worden	Feiten, onderbouwing, eenduidigheid

Communicatie

Daphne	Iris	Suzan	Charlotte
Directe benadering = zakelijke zorgverlener, helder en concreet	Positieve benadering = gezellige zorgverlener met tijd voor emotionele aspecten	Relationele benadering = aardige zorgverlener met tijd voor persoonlijke aandacht	Analytische benadering = deskundige zorgverlener met tijd voor details

Begeleiding & ondersteuning door een vast contactpersoon (mammaverpleegkundige, ook voor mBC), buddy of lotgenoten

Daphne	Iris	Suzan	Charlotte
Case manager als ondersteunend contactpersoon	Case manager / buddy als contact-persoon. maar moet ook voorzien van (praktische) informatie & ondersteuning	Case manager / buddy als contact-persoon, maar moet ook voorzien van (praktische) informatie en ondersteuning	Case manager als ondersteunend contactpersoon

Breast cancer patient driven research agenda

1. Tailored treatments based on tumor and patient characteristics.
2. Long-term effects of the various treatments (including fatigue, (nerve) pain, effects on other organs).
3. Improve communication about the effects of treatments, side effects and late consequences.
4. The best sequence, length and intensity of treatments in patients with metastatic breast cancer (aiming at living longer).
5. The best sequence, length and intensity of treatments for survival in the first treatment of breast cancer (targeted at cure).
6. Effectiveness of follow-up and self-monitoring in early detection and recurrence of breast cancer.
7. Psychological consequences of living with genetic predisposition, also for children and family.

More information on: [BVN stelt lijst samen met 7 onderwerpen voor onderzoek | Borstkankervereniging Nederland]()

Why should a patient be included ?

- The patient is the client; s/he decides if s/he needs the "product"
- The patient is the only one who can tell if the treatment helps
- The patient knows if it is worth the "price"(Qualy)
- It is more fun to work together from different perspectives

How can a patient be included?

Qualitative representation of a patient group:

- Through the patient organisation; N does not equal 1
- On a level playing field; a patient is not a doctor
- With the necessary means; time, budget and coaching
- From the very start to the very end
- In a role that suits the project and the patient representative

BVN has a successful PAG working together with the BOOG (Breast Cancer research group)

Quantitative participation

Through our B force panel; more than 4000 breastcancer patients that are willing to fill out questionnaires

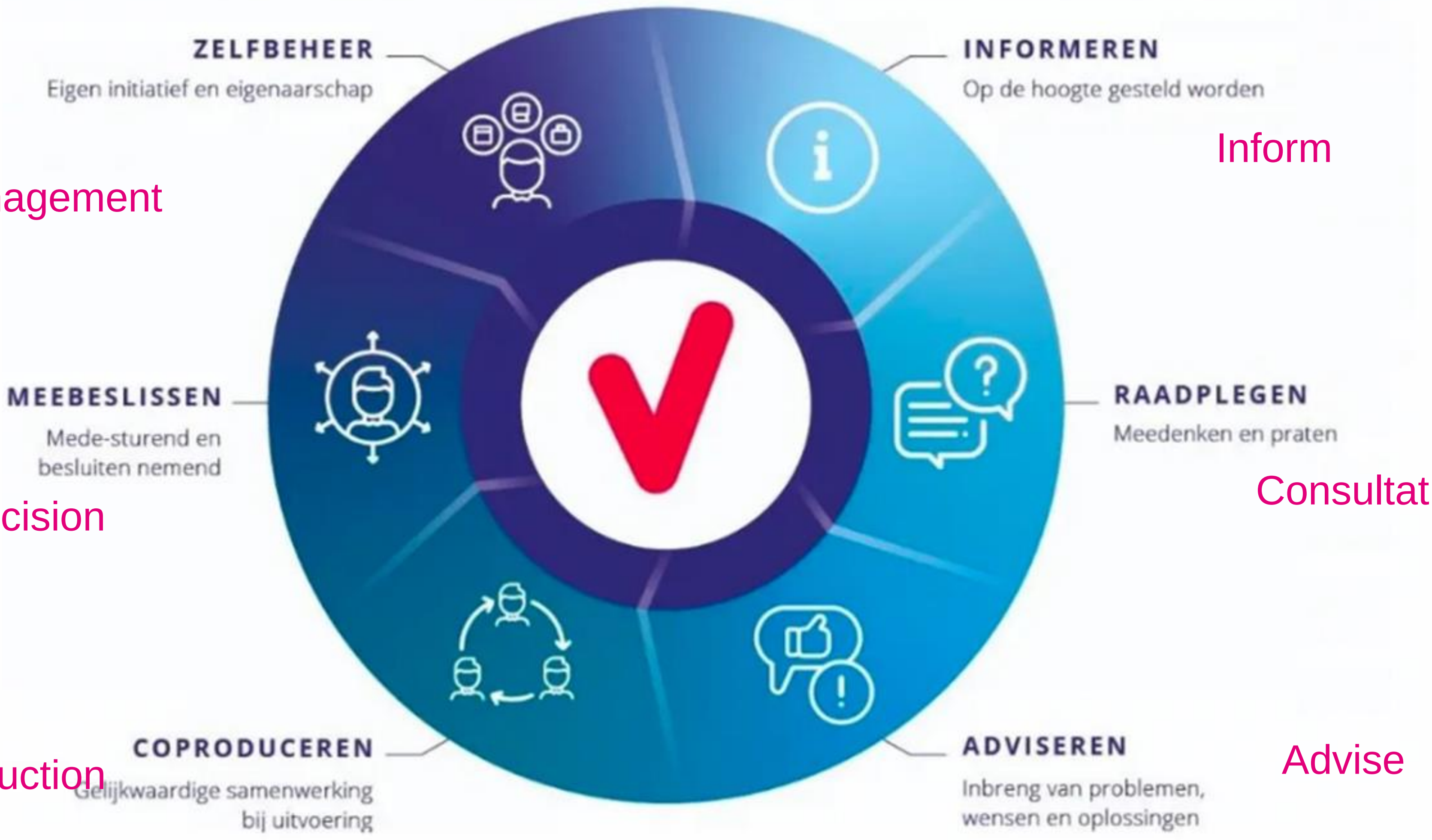
What does it take to include patients?

- Matching; the right patient representative; skills, expertise and competences
  - Volunteers
  - Training
  - Coaching

- Conditions;
  - Time
  - Budget
  - Education/ coaching

- Relevance & Quality of the project; Is it a project that patients want? Understandable topic?
  - Improvement of quality of care and/or the quality of life?
  - Short term or long term improvement?
  - Direct effect on patients?

How should a patient be included?



Self management

Inform

Joint decision

Consultation

Co-production

Advise

A few examples of how BVN works together with regulatory sciences?

- NABOR: a consortium with 6 parties that are going to research how the follow up after breast cancer treatment is provided
- BREAST: a study focused on a new method for breast reconstruction, in which we participated in the steering committee
- LORD study with 2 volunteering participants in a study about DCIS
- SONIA study Zonmw parel

Every researcher that wants us to participate can reach us through the PAG/BOOG

Thank you for your attention

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