



Dutch Cancer Society (KWF Kankerbestrijding)

19th of May 2016

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CANCER
SOCIETY



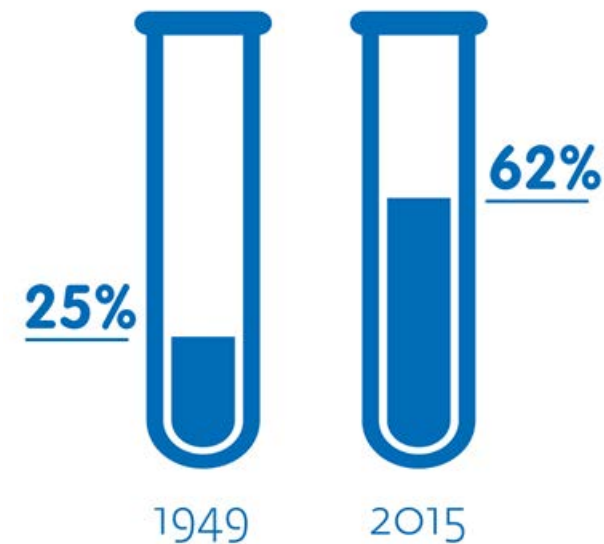
The Dutch Cancer Society is needed

100.000



One in three Dutch people will develop cancer during their lifetime, which amounts to more than one hundred thousand people each year.

Average five-year survival rate



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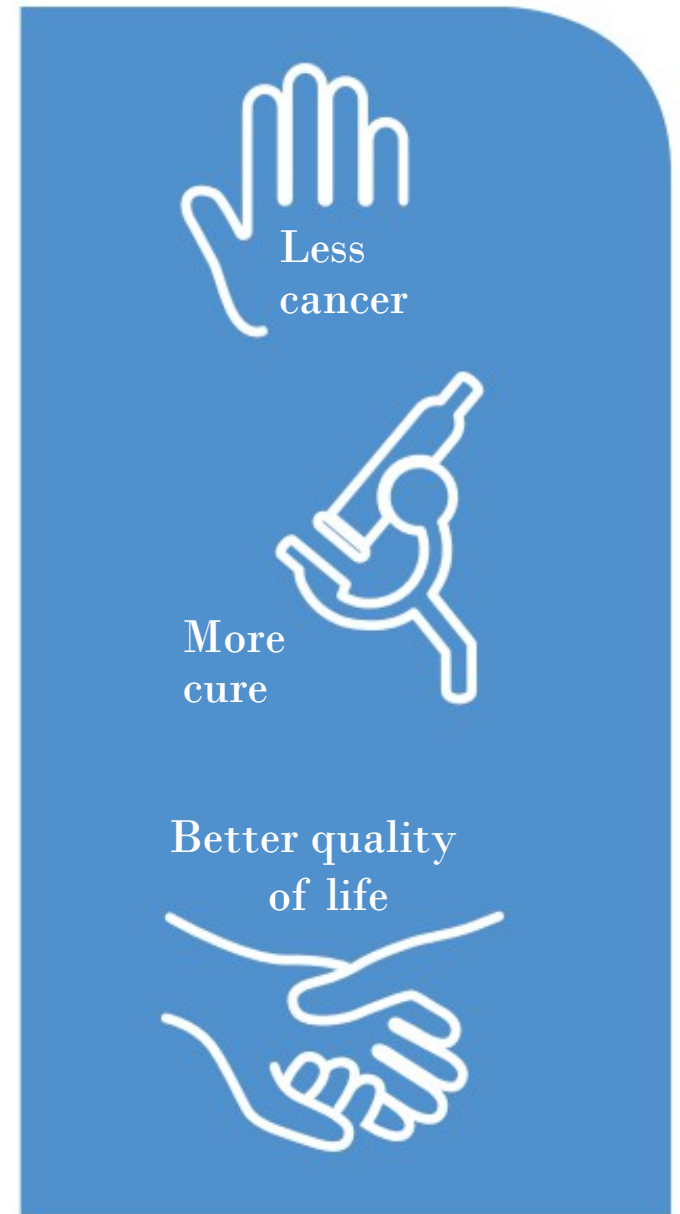
Who are we?

Dutch Cancer Society (KWF Kankerbestrijding)

- Founded in 1949
- At the initiative of Queen Wilhelmina
- Princess Beatrix is the patroness
- 100,000 volunteers
- 1,000 researchers
- 1,000,000 donors
- 200 staff members

Our mission

The Dutch Cancer Society is working to create a world in which nobody dies from cancer ever again.



What we do

- Funding and facilitating scientific research
- Influencing policy
- Sharing knowledge about cancer and its treatment

To make this possible, we raise funds and collaborate with other parties involved in cancer control, both here in the Netherlands and elsewhere.



Less cancer

- Eradicating smoking in the Netherlands
- Protection against UV radiation
- Prevent recurrence
- Early diagnosis



More cure

- Early diagnosis
- Improve treatment and access to treatment
- Using research results to treat patients as quickly as possible



Better quality of life

- Research into the effects of the disease and its treatment
- Make effective interventions available to patients
- Providing reliable and up-to-date information about the disease and its treatment

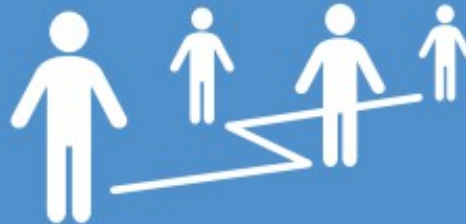


How we fulfil our mission

Three strategic instruments



Funding and
facilitating
cancer research



Influencing policy



Sharing
knowledge



Funding and facilitating cancer research

The Dutch Cancer Society is moving away from a funding role to become a facilitator of, and investor in, cancer research.

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The Dutch Cancer Society funds half of all cancer research projects in the Netherlands

- Each year, the Dutch Cancer Society gives grants to over 100 research projects
- Total portfolio: over 450 ongoing studies



Funding and
facilitating
cancer research

Thanks to years of scientific research:

- Our understanding of how cancer arises and of how it can be prevented is constantly improving
- Cancer can be detected earlier
- Treatments are better targeted, more effective and less stressful
- Quality of life for patients (and former patients) has improved
- Survival rates have increased

Research

Research is assessed in terms of:

- Scientific quality

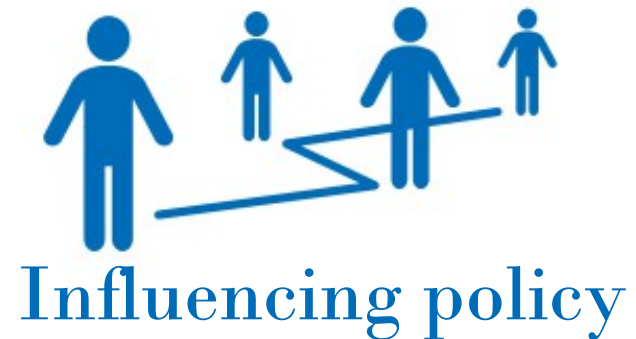
In addition to:

- Contribution to our mission (more, less, better)
- Embedding development translational research
(translation from research result to patient treatment)
- Partnerships

Influencing policy

The Dutch Cancer Society uses its position and network to influence the policies of Government and relevant organizations

- Tobacco Control
- implementation of research results
- psychosocial care



Sharing knowledge

Kanker.nl, accessible
information tailored to
patients, relatives and
their friends



Sharing
knowledge

Using funds
to achieve the
Dutch Cancer
Society's
mission goals.





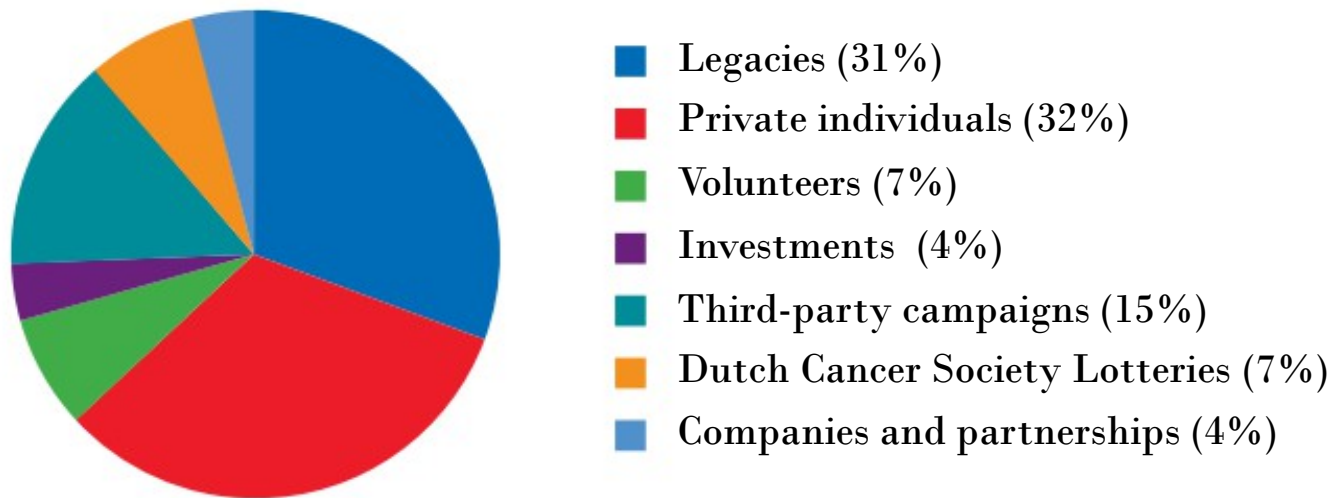
Fundraising and obtaining time

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Where does the income come from?

- Annual revenue in excess of €130 million (no government subsidy)



In partnership with patients

- Formally involve patients
- Patients Advisory Committee
- Levenmetkanker (living with cancer) movement
- Kanker.nl

- **Definition and arguments**

Patients being actively involved, and having influence, in decision-making processes in health research, policy and care

Three arguments:

1. Patients are end-users of health-related decisions, and therefore have the right to be involved
2. Patients have specific experiential knowledge that complements scientific knowledge
3. The legitimacy of health-related decisions increases when patients are involved

- **Scope**



Financieren en
faciliteren van
Onderzoek



Beïnvloeden
van Beleid



Delen
van Kennis

Financing and facilitating research

Influencing policy

Sharing knowledge

- **Scope**



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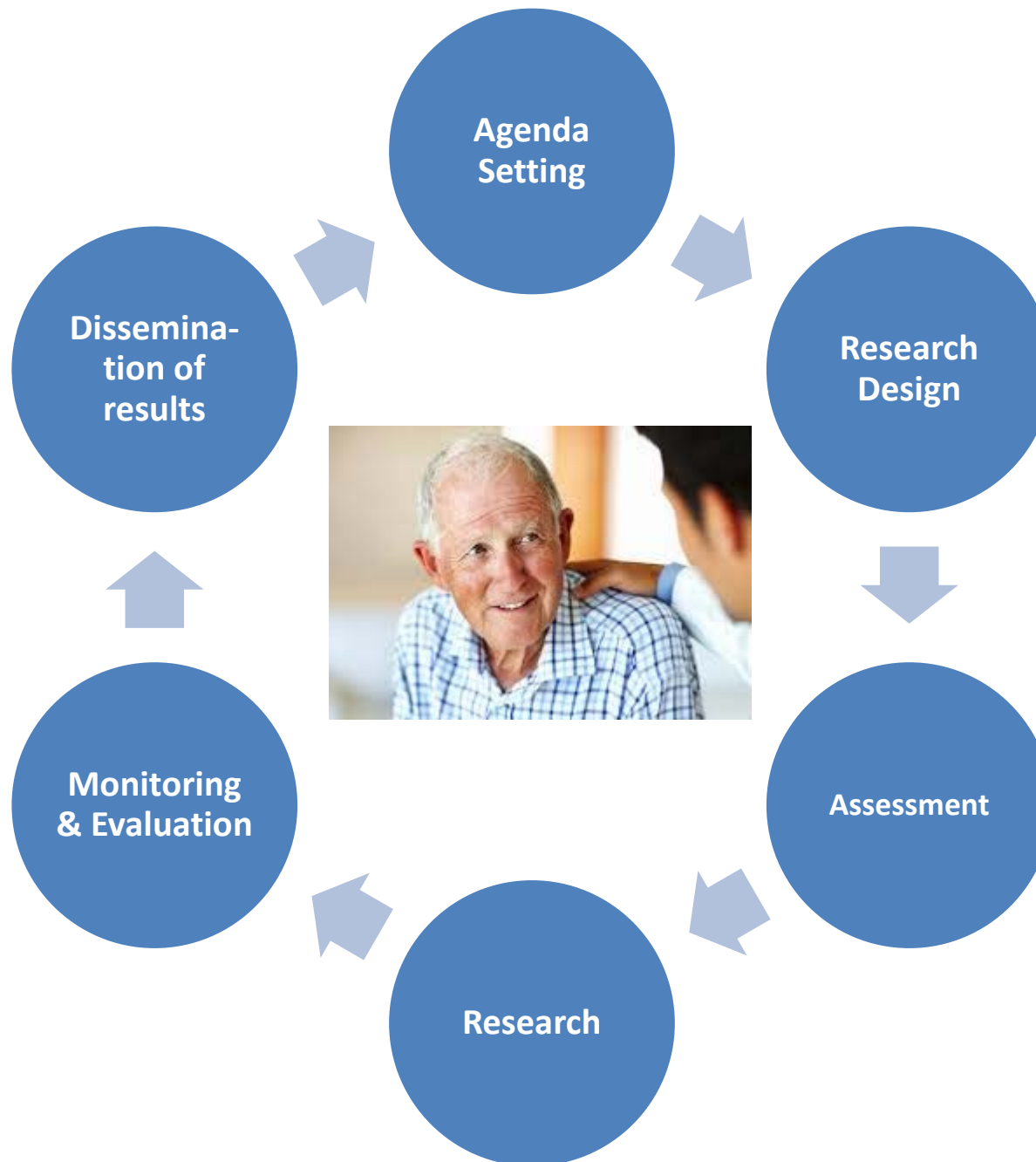
Delen
van Kennis

Financing and facilitating research

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Patient participation in research



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graph TD; AS((Agenda Setting)) --> RD((Research Design)); RD --> A((Assessment)); A --> R((Research)); R --> ME((Monitoring & Evaluation)); ME --> DR((Dissemination of results)); DR --> AS;
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The diagram illustrates a six-stage research process in a circular flow. The stages are represented by circles: 'Agenda Setting', 'Research Design', 'Assessment' (highlighted in orange), 'Research', 'Monitoring & Evaluation', and 'Dissemination of results'. Arrows indicate a clockwise progression from one stage to the next. In the center of the diagram is a photograph of an elderly man with white hair, wearing a blue and white checkered shirt, smiling and looking towards the right. Another person's arm and shoulder are visible behind him, suggesting a supportive or caring interaction.



Ambition

KWF has the ambition to translate results from scientific research **faster and more frequently** into practical applications for patients and the general public.



KWF Programme

Research & Implementation



Funding

KWF offers flexibility within different types of funding



Reviewing

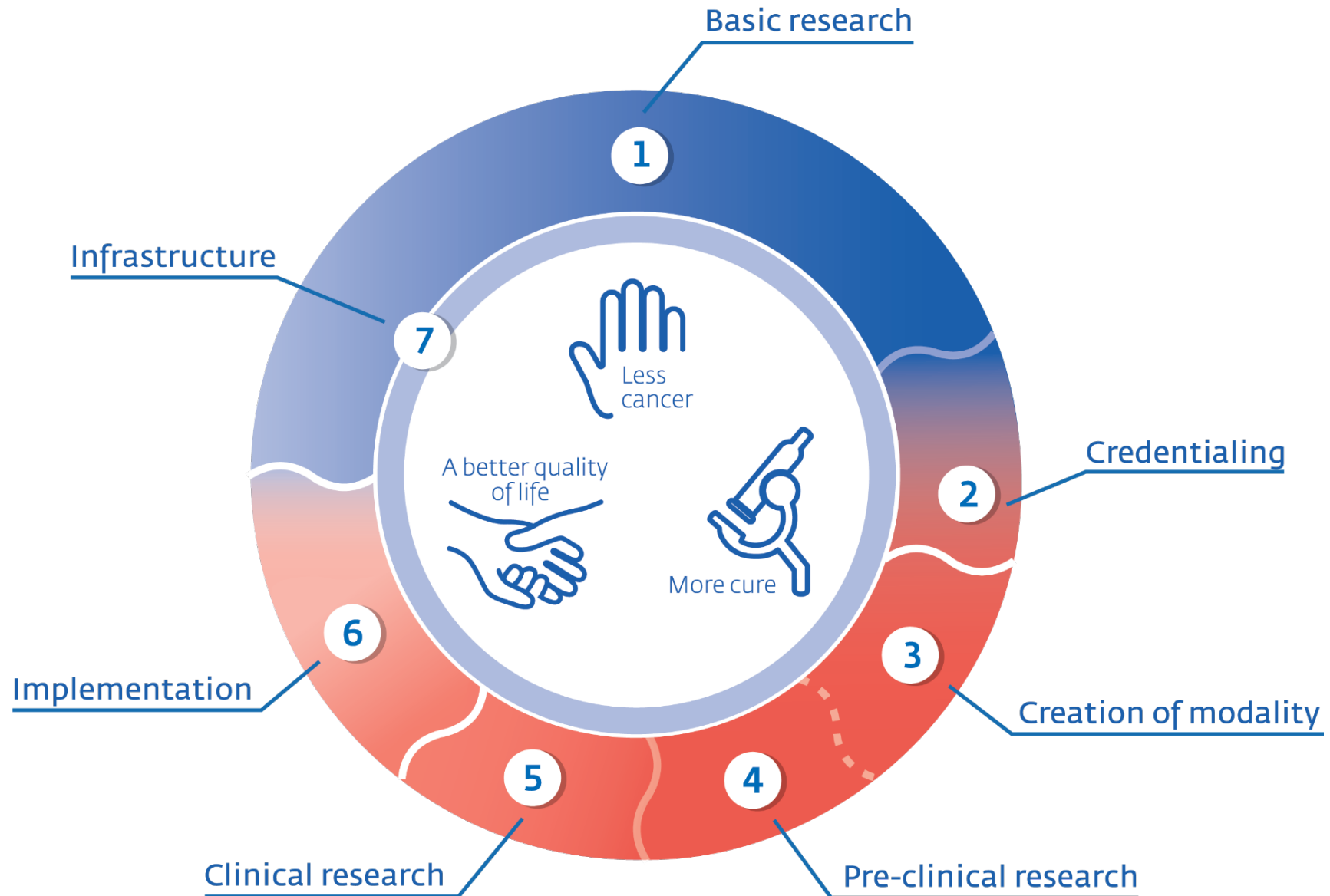
KWF uses three criteria:
Scientific quality
Feasibility
Relevance



Operating

KWF facilitates collaboration and dialogue with and between researchers and other (commercial) parties and patients

From Basic Research to Implementation



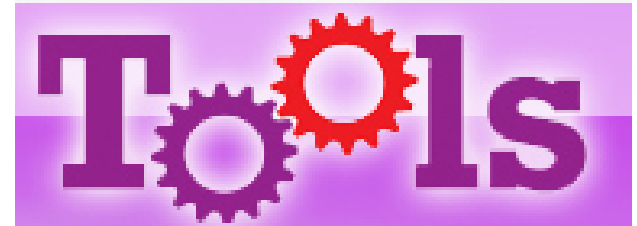
- **Patient Advisory Committee (PACO)**

- Founded in 2011
- 40 members recruited based on profile
- Recruitment together with patient organisations, and through DCS social media
- Technical training in assessing research proposals

• Training for patients

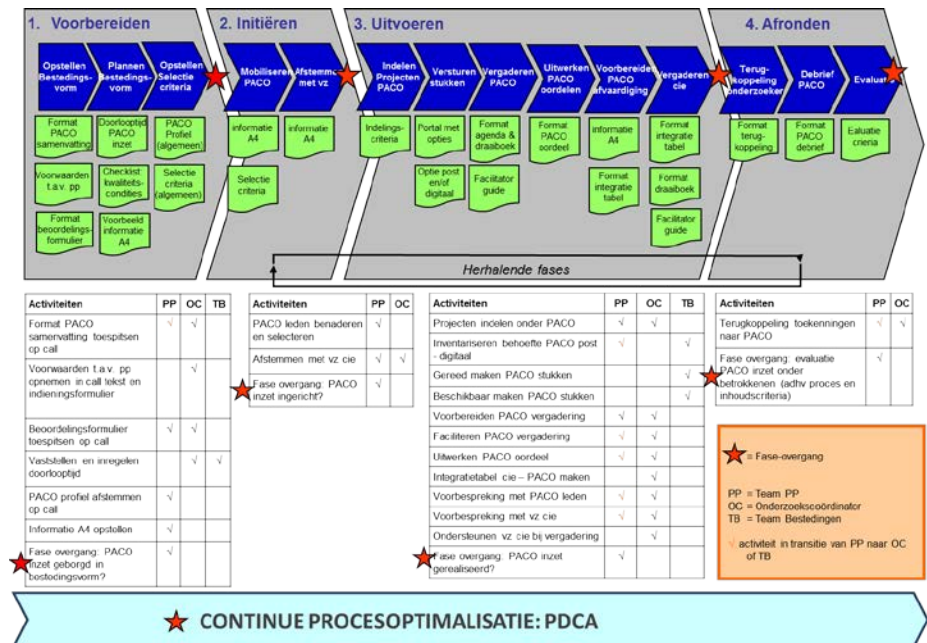
1 training day:

- Introduction to DCS
- Explanation of their role as advisor
- Introduction to the DCS finance structure and assessment procedure
- In depth reflection on PACO assessment form
- Practice in groups with case study

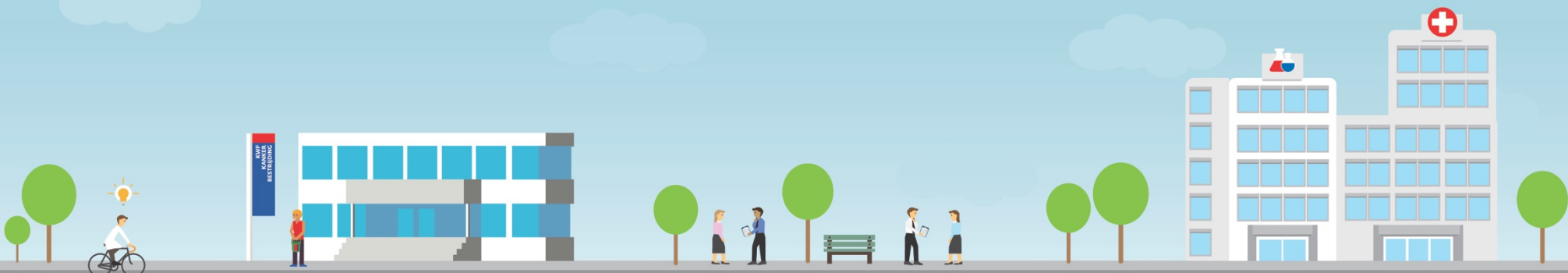
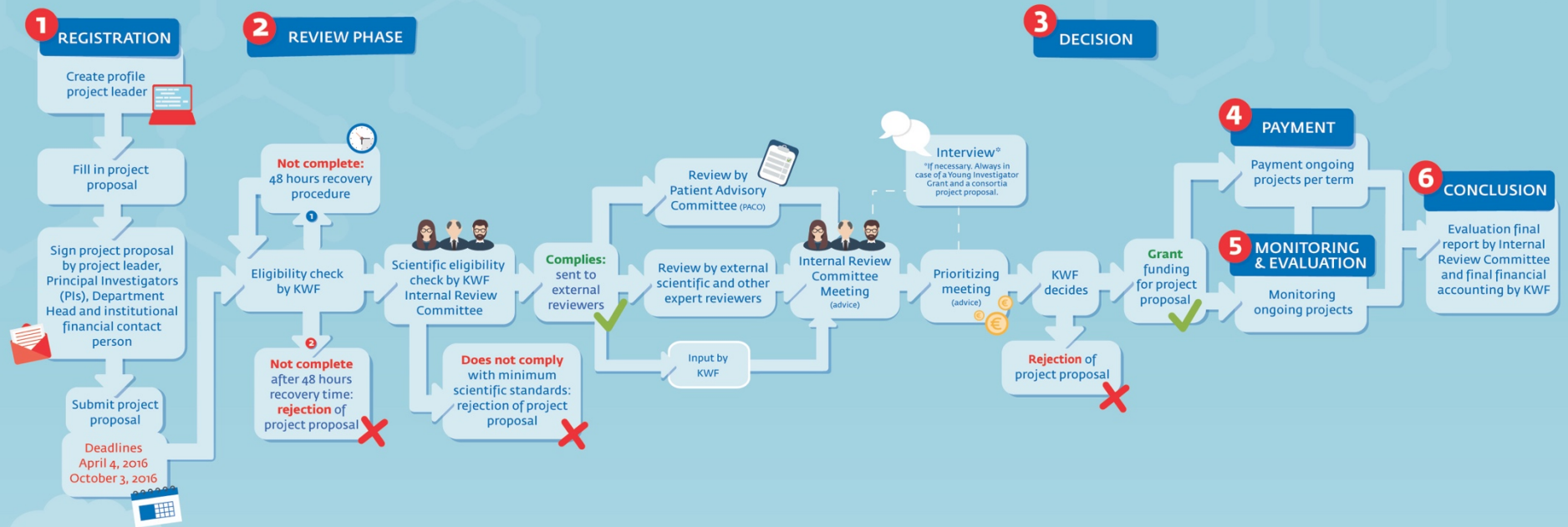


Blueprint patient participation

- Focus: PP in assessing research proposals
- Methodology developed based on 8 pilot projects → PDCA approach
- Dialogue model
- Describes proces steps, supporting templates, and activities
- Serves as a guide for DCS employees



FROM REGISTRATION TO CONCLUSION



We're getting there together



Pitfalls and challenges

- Not engrained in researchers DNA to actively engage patients at an early stage
- Commitment of scientific advisory board
- The holy grail does not exist
- Proto-professionalisation
- Representativeness
- Realising dialogue



Together we
can beat
cancer sooner

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1, We are interested in your initiatives concerning patient involvement in general.

- Better quality of life: patients need research, focus group patients. The health facility isn't going to the patients enough.
- Better quality of life board submit 2 patients. Advice for strategy, stakeholders, research

2, How do you support patients in involving in their own care? Collective.

- Oncokompas.nl/kanker.nl (supporting self-management)

3, Do you have any specific initiatives related to shared decision making between patients and healthcare professionals?

- With the KPO's it's available, financed by KWF. Example video dairy on kanker.nl.
- LUMC supporting shared decision making. Within our patients need research one of the outcomes about shared decision making isn't needed.

4, What are the barriers to patient involvement in the Netherlands?

- (systemic) attitude and mindshift by doctors, researchers, pharmaceutical companies, charities (it starts with the patient!)
- PP is still viewed as an additional step in an already lengthy process of drug development
- The dutch academic system is based on personal merit (4 years for researchers)
- The holy grail does not exist, so PP needs to be incrementally developed, tested, applied – this takes time

5, How do you work to overcome those barriers?

- PP is a key theme in DCS's mission statement 2015 – 2019
- 3 FTE and budget allocated
- Recruiting and training 60+ patients for assesment of research (primarily)< policy influencing
- Patient sounding board for testing 'quality of life' outcomes of market research study among 1400 patients (patient needs & patient information needs)

6, Do the hospitals involve patients on the organizational level?

- Yes, patient boards are up and coming, but are not yet a fully included and operational part of the organisation. Trial and error and in development.

7, In user groups or similar?

- Similar story – sometimes patients included

8, Are there any specific areas where the patients are invited to participate?

- Cancer research
- Strategy for team better quality of life

9, Your study on quality of life sound very interesting. Do you work with patient reported outcomes measures?

- KWF doesn't.
- IKNL/ Lonneke vd Pol

10, And if so, which instruments do you use?

11, And how and for what do you use the data?