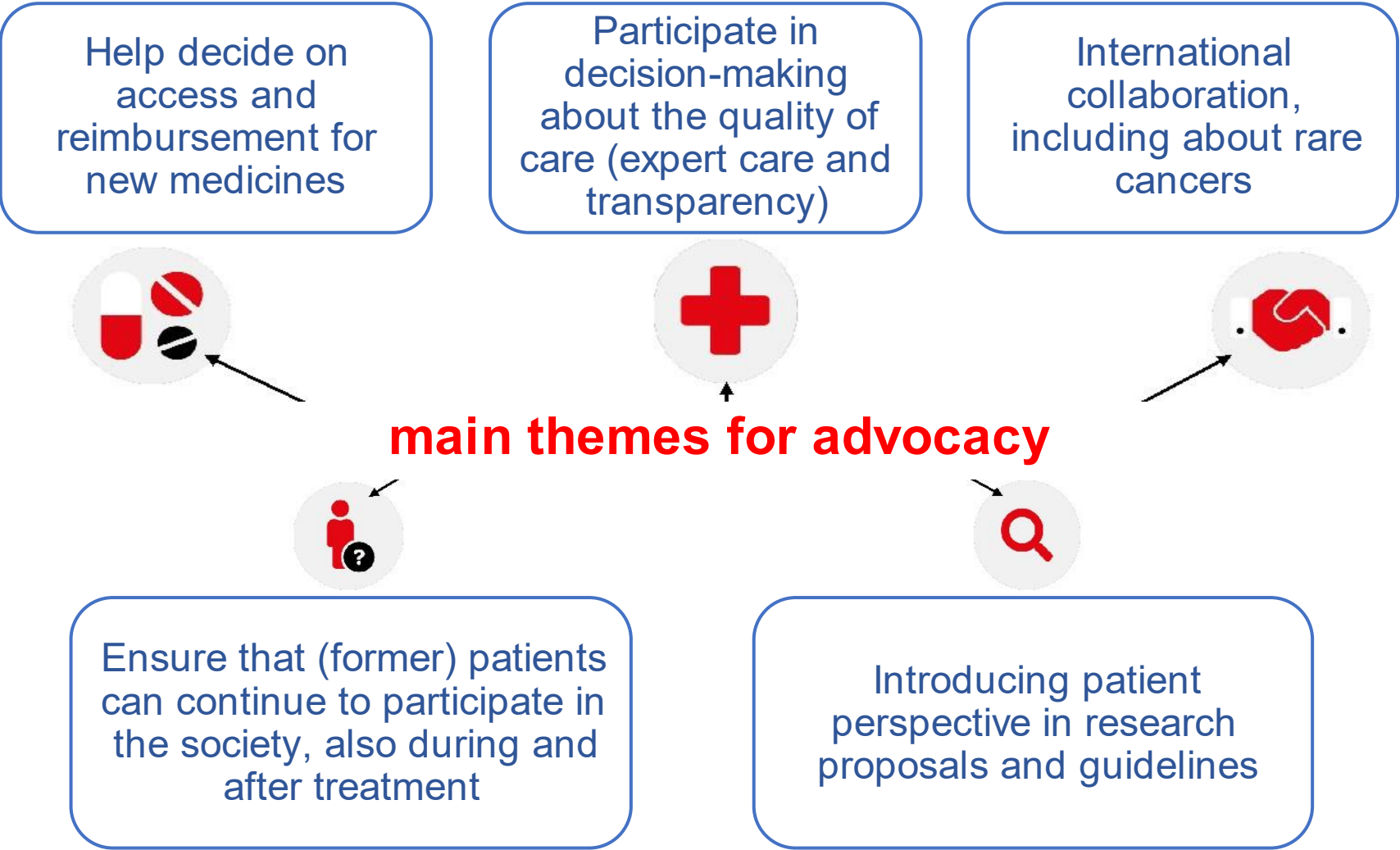
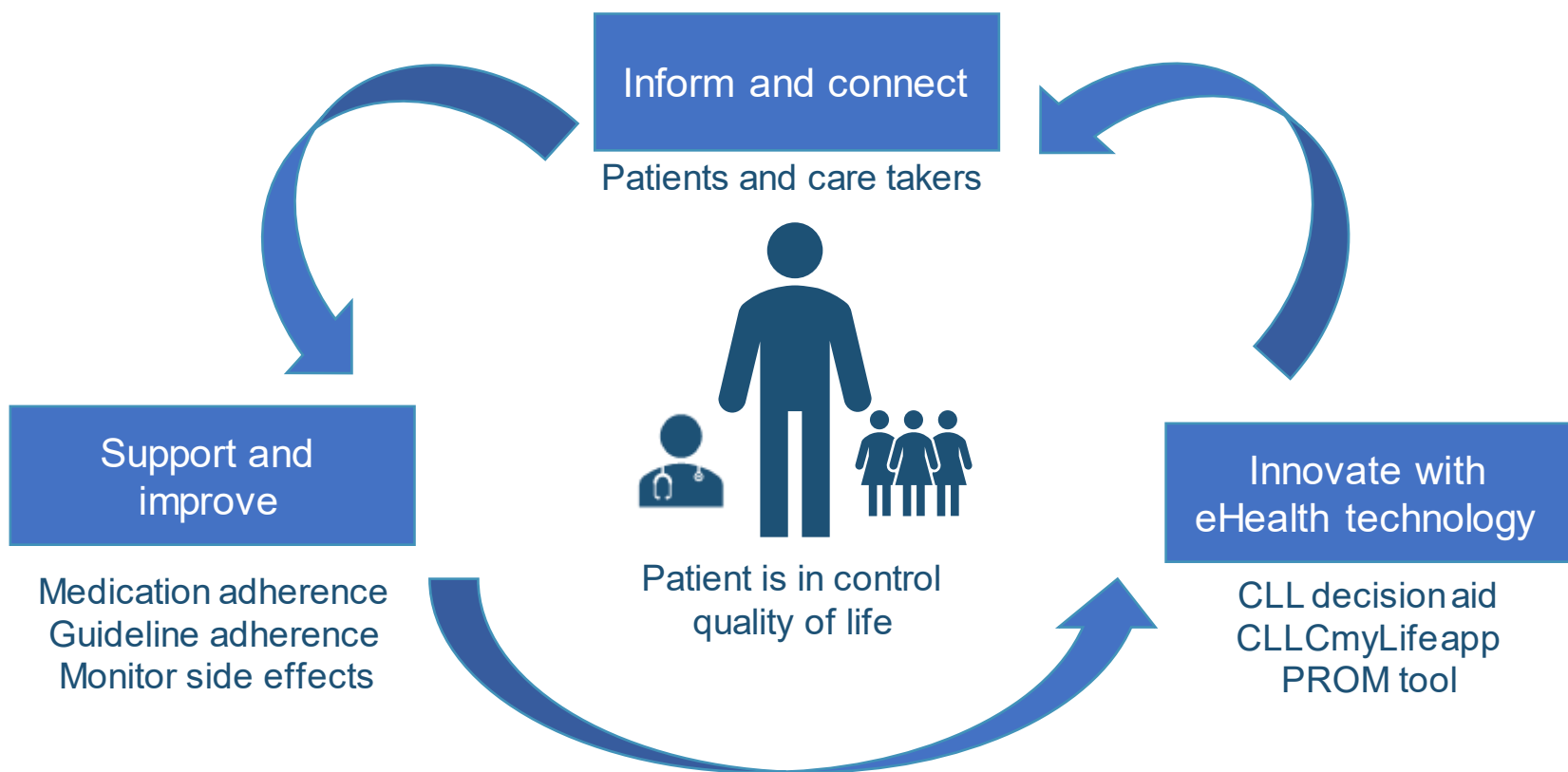


Hematon, what does the advocacy stand for?



CmyLife, what do we stand for?

- ✓ Patient is in control
- ✓ The place where care comes together
- ✓ Collaboration between healthcare provider and patient for more efficient care and better quality of life



THE DUTCH WAY

Hematologists and patients create a decision aid for newly diagnosed CLL patients

CHARACTERISTICS CLL-DECISION AID

Accessed through cmyCLL.com, a website with information about the CLL disease, contact with peers and much more.

Information based on the latest CLL guideline in the Netherlands.

Designed in a unique way with collaboration between patients and healthcare provider.

FREE

Free-to-use for CLL patients and their healthcare providers.

In easy-to-understand language.

Guidance based on medical data as well as personal wishes.

Data securely stored in a Personal Health Environment.

Outcome useful as preparation for conversation between patient and healthcare provider.

Makes collaborative decision making easier.

Always viewable and adjustable.

Contributes to improving quality of care.

Funded by Foundation for Quality Funds Medical Specialists.

With thanks to the Dutch Internists Association, Hematon and the Dutch Society for Hematology.

CLL-DECISION AID

Your healthcare provider invites you to complete the CLL decision aid. This decision aid will explain your treatment options. To help you with making the best choice, you will need the following information:

Name patient:

Date of birth:

Practitioner:



IGHV mutation:

I do not have an IGHV mutation

I do have an IGHV mutation



17P deletion:

I do have a 17P deletion

I do not have a 17P deletion



TP53 mutation:

I do have a TP53 mutation

I do not have a TP53 mutation



Fitness:

The doctor does rate me fit

The doctor does not rate me fit



On Youtube:
Explanation CLL choice aid
(in Dutch)

	Treatment A	Treatment B	Treatment C
Treatment frequency	★ Take a pill twice a day	Take a pill once a day	The first month 4 days of infusion. The following 5 months 1 day of infusion and then build up to taking pills daily, until 1 year
Experience with this treatment	★ 2020	2014	2019
Side effects	Serious infection: Similar between treatments High blood pressure: Risk of high blood pressure, increases with duration of treatment Fatigue: Occurs in more than 10% Diarrhea: Occurs in more than 10% Headache: Occurs in 35%, does not go away as a result of which 20% stop treatment Cardiac arrhythmias: Occurs in 10%, can lead to cardiac arrest in 1% Joint complaints: Occurs in more than 10% Other types of cancer (especially skin cancer): Occurs in some cases and it is mainly skin cancer that can be treated well	Serious infection: Similar between treatments Bruising: Occurs in more than 10%. Can be large, may temporarily get worse Diarrhea: Occurs in more than 10% High blood pressure: 78% develop high blood pressure, increases with treatment duration Cardiac arrhythmias: Occurs in 15%, can lead to cardiac arrest in 1% Joint complaints: Occurs in more than 10% Fatigue: Occurs in more than 10% Headache: Occurs in 20% Other cancers (especially skin cancer): Occurs in some cases and it is mainly skin cancer that responds well to treatment Peripheral neuropathy (numbness in hands and feet): Occurs in more than 10%	Severe infection: Similar between treatments Infusion reaction: Only with the first course Diarrhea/constipation: Occurs in more than 10% Nausea: Occurs in more than 10% Malignant bone marrow diseases: 1% acute leukemia and myelodysplastic syndrome Other cancers (especially skin cancer): Occurs in a few cases and it is mainly skin cancer that is easy to treat
Treatment duration	Continue treatment until the disease worsens or the side effects become intolerable.	Continue treatment until the disease worsens or the side effects become intolerable.	1 year or until the disease worsens or the side effects become intolerable.
Method of administration	swallow	swallow	Swallowing and via an IV (tube in your arm, ask your healthcare provider whether this is done at home or in the hospital)
Time to disease recurrence (PFS)	No information available yet	6-7 years	4-5 years
Options for follow-up treatments	1 more option with known effectiveness and 1 option where the degree and duration of effectiveness is definitely determined by research. In some cases there is a more drastic 3rd option, the stem cell transplant	1 more option with known effectiveness and 1 option where the degree and duration of effectiveness is definitely determined by research. In some cases there is a more drastic 3rd option, the stem cell transplant	1 more option with known effectiveness and 1 option where the degree and duration of effectiveness is definitely determined by research. In some cases there is a more drastic 3rd option, the stem cell transplant
Medication	❶ I am not taking any of these medications	I am not taking any of these medications	I am not taking any of these medications
Supplements	❶ I don't use any of these supplements	I don't use any of these supplements	I don't use any of these supplements
Other conditions	❶		
Diabetes	●	●	●
	Choose treatment	Choose treatment	Choose treatment

● Definitely not causing any problem with this treatment

● (may) cause a problem with this treatment, discuss the options with your doctor