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Patient information; *you'll only see it when you understand it*

-Johan Cruyff

When you reach 89% of your patients with good education and instruction, you lay a foundation for shared decision-making.

The Regionaal Academic Cancer Centre Utrecht (RAKU, part of Oncomid: the regional oncologic partnership of healthcare professionals Utrecht, the Netherlands) has been actively providing video education for several years. Patients, but certainly healthcare workers as well, have been reaping the rewards. In a unique collaboration between patient associations and healthcare workers, the education has been redesigned. This appears to greatly benefit all parties. Among other things, it leads to personalized care in the consulting room.

Millions are being invested in optimizing and developing treatment methods. More and more possibilities come to light.

However, this means, for example; oncological treatment programmes become more complex. This implies more choices for patients as well. In practice, properly conveying this complex treatment information proves to be difficult. There is a diverse range of initiatives to improve communication between healthcare workers and patients, but what really works?

For many hospitals the information provision, which is built on information transference in the consulting room, is supported by written information such as brochures.

Due to a shortage of time, healthcare workers often get stuck at "sending their messages" in conversations with their patients. This is remarkable and undesirable. We know that, among others, concentration problems due to illness or emotions can make the effects of oral information transference on patients drastically smaller. Patients remember 20% of

information about oncological treatment procedures explained in consultation.

Besides, some patients do not understand written information. Healthcare workers recognise the problems, but lack the means to change their ways.

Redesigning communication starts with good patient education.

RAKU faced the challenge of solving this problem.

In 2018, a platform where patients receive the right personalised information through video messages has been shaped and experimented with for two years. A personal playlist of videos, which can be expanded with additional information from healthcare workers throughout the process of treatment. What, at first, was seen as a good new way of informing, soon appeared to lead to a change in the method of procedure ('You'll only see it when you understand it').

Research among healthcare workers and patients carried out by RAKU shows 89% of patients watches the sent information. On average, patients and their loved ones visit the page 3,5 times to take in, and rewatch information. 77% of patients indicate that this way of actively being informed by their caregivers suits their needs..

Together with the patients association and healthcare teams, Patiëntenbegrijpen has been developing a method which does work for patients, and is easily implemented by healthcare teams as well.

This means this platform has been actualized, based on four pillars:

- Video education in messages of an average of 3 minutes, created with patients associations and healthcare workers,
- Control over information transference for healthcare workers,
- A connection to relevant apps, decision aids or websites,
- Awareness for the role of the patients association.



Among others, this platform is active in the RAKU-partnership. In four hospitals, the careteams actively work together to improve communication with patients.

In total, 41 videos, in which healthcare workers provide the necessary information for the patients, have been recorded. That information contains how to reach the hospital, the route to the hospital ward, research, treatments and aftercare. The patient can watch the videos at their own pace at home. On their own device and chosen time. The information is easily shared with family.

Research carried out by RAKU shows 79% of patients who get sent the information, want to keep being informed this way and don't feel the need to search for additional information on their own.

The platform has been designed for regional collaborations. Hospitals can work together on information provision in the platform. So despite a treatment process taking place at multiple locations, the patient will keep receiving the information in one place. The source of information remains clear.



The patient organization (for patients with cancer of esophagus or stomach) SPKS, and Upper GI team RAKU were the early adaptors who committed to this method. Prof. J. Ruurda, together with his colleague Prof. R. van Hillegersberg, made the first educational video. This way they made a complex treatment, a surgery for esophageal cancer, comprehensible.

“The consultation we now have with our patients is much more on an equal level: they know what awaits them and immediately have good questions about the important elements in their treatment.”

Prof. J. Ruurda, surgeon UMC Utrecht Cancer Centre.

Value-driven care

The implementation of video information is a win-win situation, because it wins effectiveness as well as time. Both patients and caregivers benefit from it. Research shows good education leads to better therapy compliance for patients. After all, the patient is informed to a greater degree and can decide, together with the healthcare team, which treatments are valuable in their situation. It fleshes out the idea of

patient participation. The challenge in the implementation of the new way of educating was mainly the breaking of daily routines. The new situation includes checking whether the patient received the information. Depending on the information watched by the patient and their loved ones, this gave the practitioners the opportunity to change the setup of the conversations. Because less time is wasted on

information transference, there is more time to listen, rather than sending.

Changing behaviour can be difficult. This asks for coaching and support.



The benefits lined up:

- **Reducing the duration of consultations by 15 minutes each.** Medics have to explain next to nothing about the treatment proposal to the patient. The patient and their loved ones have already seen the information.
- **Higher quality conversations.** The information is given the exact same way every time, nothing can be forgotten. A well informed patient can participate optimally and the conversation can be led more in depth to the important aspects.
- **The patient is a partner in the conversation (participation).** A well informed patient can ask the medic personal questions and orient themselves on the options.
- **Heightened job satisfaction.** Medics no longer have to explain the same narration all day. Medics report experiencing the conversations as more pleasant. There is more time for personal contact.
- **Fewer telephone inquiries.** The nurses and outpatient staff will encounter a limited number of questions because the preparation for the conversation in the consulting room is better and the patients can remember and rewatch the information.
- **Healthcare workers know exactly from each other what is being told.** This transparency in provision of information minimizes disturbance. It will be clear what is gonna be communicated and what not.
- **The patient association is enthusiastic.** The way of communicating is one of the hot topics for most patient associations. In this collaboration the patient association can think along the improvement in communication. In addition, the platform also provides a space where the patient association can profile themselves. As a result patients will contact them sooner.

Above all we are proud the collaboration between hospitals, patients, patient association and sponsors led to a win-win situation. The collaboration brings happiness for all stakeholders, especially in a time where the workrate is high and financial resources are scarce. It is a warm welcome.

Change is fun!

What can you do?

- Make sure communication with patients is on the agenda with the MDC. Make it a recurring agenda item in your team. What do we tell and in which manner are we doing that? What will be explained in personal conversations, and where can we fit in video education?

- Include the patient association in the shaping of the education.

- Discuss the manner upon which the video education is being shared with the patient.

And now nationwide

The videos for RAKU have a regional character. Healthcare workers from other hospitals and regions showed their wish to improve education and instruction. For us it underlined the need to make the next step towards developing nationwide and make education and information available. Therefore our most recent project has been executed nationwide. Together with the NABON, Breast Cancer patient association Netherlands (BVN) and three hospitals we created video education for the care path Mammacare. The videos will be available on the website of BVN. It is open source and for everyone to

see. Main sponsor Menzis has funded this development. For the year 2022 we have a minimum of three projects already running. For the Colorectal, Upper G-I en HPB pathways there is work in progress with the partners.

If you are interested in participation you can contact Michiel de Klein via info@patientenbegrijpen.nl



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