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Implementation of Patient Engagement in the Netherlands: A Stimulating Environment within a Large Academic Medical Centre

Déploiement de l'engagement du patient aux Pays-Bas : un milieu stimulant au sein d'un grand hôpital universitaire

Marjan J. Faber, Thomas W. Vijn, Marja C.M.C. Jillissen, David Grim and Jan A.M. Kremer

Abstract

Patients are the official third party of the Dutch healthcare system, apart from healthcare providers and insurers. Radboud university medical center (Radboudumc) is a regional centre for specialized secondary care in the Netherlands. Here innovation is recognized as a decisive factor when it comes to the implementation of patient engagement. Therefore, all employees are invited to innovate, experiment, fail and implement promising innovations into practice. In this paper, we demonstrate how this stimulating environment led to a rich collection of patient engagement activities in organizational (re-)design and in educational programs for students and employees.

Résumé

Les patients sont une tierce partie officielle du système de santé néerlandais, en plus des prestataires de soins de santé et des assureurs. L'hôpital universitaire Radboud (Radboudumc) est un centre régional de soins secondaires spécialisés des Pays-Bas. L'innovation y est reconnue comme un facteur probant du déploiement de l'engagement du patient. Tous les employés sont donc invités à innover, à expérimenter, à échouer et à mettre en pratique des innovations prometteuses. Dans cet article, nous montrons comment ce milieu stimulant a conduit à une abondante collection d'activités relatives à l'engagement du patient dans la conception ou la refonte organisationnelle, ainsi que dans des programmes de formation destinés aux étudiants et aux employés.

KEY MESSAGES

1. Support the non-homogeneous evolution of engagement in which employees are free and motivated to experiment. Allow initiatives to fail.
2. Build long-term relationships with patients by involving them from the beginning until the end.
3. Create an environment that is comfortable and makes involvement meaningful:
 - For patient engagement at the organizational design and governance levels, ensure that patients stay in their role of patient, guaranteeing that they make a unique and complementary contribution.
 - For patient engagement at the level of direct care, ensure that each patient is seen as a person, with a unique and complementary perspective on healthcare.
4. Prepare patients for their efforts in patient engagement and organize patient engagement in a professional manner to ensure that it is valuable to the organization.

Background

The Netherlands, with 17 million citizens, is internationally known for its affordable and accessible healthcare system (Osborn et al. 2016). Primary care is the cornerstone of this success; that is, the primary care physician is the first point of contact. Consequently, people have a close and long-standing relationship with their primary care physician. In addition to primary care, secondary care is offered in 89 general hospitals, including eight university hospitals, and 231 (small-scale) private and non-profit treatment centres whose services are limited to same-day admissions for non-acute, elective care (Wammes et al. 2018).

Patients are the official third party of the Dutch healthcare system, apart from healthcare providers and insurers (Helderman et al. 2005). National legislation is designed to support patients in executing this role, both as individuals and as a group. For example, the *Medical Treatment Contracts Act* (WBG0, since 1995) governs the relationship between the individual patient and the healthcare provider. Important aspects of this legislation are the right to receive comprehensible information and the right to give consent to or refuse treatment. The right to view and amend your own medical file is also defined in the WBG0. The legislation “Elektronische gegevensuitwisseling in de zorg (*Clients’ Rights in Electronic Information Processing*)” (since July 2017) was introduced in anticipation of the digitalization of healthcare (including electronic patient records) and the European Union’s General Data Protection Regulation. The collective rights of patients are defined in the *Clients’ Representation Act* (WMCZ, since 2010); by law, hospital boards are obliged to consult a client council for advice about each policy decision.

Radboudumc: A hospital where patients are included

Radboud university medical center (Radboudumc) is a regional centre for specialized secondary care. With 600 beds, 50 departments, nearly 11,000 employees and 3,300 students, it serves a population of 2 million people. In 2006, an investigation found that death rates after cardiac surgery were close to three times the national average at Radboudumc. This wake-up call pointed out the importance of monitoring the

quality of patient care. Dr. Melvin Samson, who became the chief medical officer of the hospital in 2007 and chairman of the executive board in 2011, used his influence to increase the quality and safety of patient care. He also created opportunities for active partnering with patients (Richards 2014). This decision to involve patients as partners in their healthcare was not driven by any legislation. Instead, intrinsic motivation was the driving force behind these efforts, in line with deontological ethical theories positing that patient engagement is good in and of itself (Duggan et al. 2006).

Currently, the hospital’s mission is to have a significant impact on healthcare, with two cornerstones: person-centredness and innovation. The patient is seen, listened to and respected as an equal stakeholder. The story of the person behind the patient and his or her life is the beginning and end point of care, and thereby respecting differences between people. Innovation is recognized as a decisive factor when it comes to the implementation of patient engagement at Radboudumc; all employees are invited and enabled to innovate, experiment, fail and implement promising innovations in patient engagement in medical research, education and practice. Every department defines patient engagement strategies in its annual plans, and all participate in the collection of standardized patient experience surveys. The REshape Center (<http://radboudreshapecenter.com>) is available to support the design and testing of e-health and m-health solutions. Finally, dedicated implementation experts are available for departments that need support to bring patient engagement into practice. As a university medical centre, the hospital’s mission and focus areas not only apply to patient care but are also reflected in the training of medical and nursing students. Consequently, after revision of the Medicine and Biomedical Sciences curricula in 2014, patient engagement became a fundamental part of the educational program.

In this paper, we demonstrate how this stimulating environment led to a rich collection of patient engagement activities in organizational (re-)design and educational programs for students and employees. Table 1 provides insight into a broader selection of initiatives.

TABLE 1.
The multi-dimensional continuum of patient and family engagement at Radboudumc (Carman et al. 2013)

Level of engagement	Consultation	Involvement	Partnership and shared leadership
Direct care	<ul style="list-style-type: none"> • CMylife: Online information tailored to the individual patient's circumstance (www.cmylife.nl) • MediMapp: Digital travel guide for patients treated at Radboudumc (www.medimapp.nl) 	<ul style="list-style-type: none"> • Direct access to electronic medical records is available for all patients since 2012; it started on a small scale, for patients treated for an infertility-related problem in 2003 (Tuil et al. 2007) • Patients who have experienced a complication during hospitalization participate in the meeting with the involved professionals to evaluate the complication and identify the lessons learned 	<ul style="list-style-type: none"> • Welearn: An interprofessional and person-centred educational program wherein patients, medical and nursing students and different professionals learn together (Vijn et al. 2018) • "Ask 3 Questions" campaign: Every patient visiting Radboudumc is invited to ask questions and become actively involved in decision-making • First decision aids are integrated into the electronic medical record system
Organizational design and governance	<ul style="list-style-type: none"> • Annual patient experience surveys: Results are fed back to departments and are used during internal audit visits to identify areas for improvement • Mirror meetings: Open discussion between patients about their care experiences, led by a professional mediator; involved healthcare professionals sit in the back of the room, listening to patients' stories; they are not allowed to interfere 	<ul style="list-style-type: none"> • FoodforCare: Redesign of the meal service for hospitalized patients (van den Berg 2017) • Patient advisory board: Provides solicited and unsolicited advice to the hospital board • Educational patient advisory board: Patients are consulted for advice on educational policies 	<ul style="list-style-type: none"> • Co-redesign of care tailored to the needs of young people diagnosed with Parkinson's disease • Patients participate in management teams about educational design and governance

Examples of Radboudumc's Patient Engagement Practices

Patient Advisory Board

Established on January 1, 2013, as one of the first initiatives, the Patient Advisory Board (PAR) emerged as the embodiment of patient engagement at Radboudumc. All PAR members, eight in total plus a chair, are either patients or the parents or caregivers of patients treated at Radboudumc. The rights and tasks of the PAR are defined in a formal arrangement between the PAR and the hospital board and include providing solicited and unsolicited advice about hospital policy and safeguarding the position of patients in care, education and research. This advice is not without consequences: when the hospital board does not commit to acting on the advice, a formal reply with arguments supporting this decision is required. Now, five years after the PAR was established, there is awareness throughout the organization that patients should be included in every decision being made. Fourteen clinical departments established a local PAR for better representation of patients' perspectives in their departmental policies. The central PAR collaborates with the department-oriented PARs to support patient engagement but lets the local PARs determine their own structure and practice. The success of the PAR is driven by an open dialogue between PAR members and the hospital board, with formal and, most of all, informal contact. Although PAR members have a mandate to advise the board, the PAR chair emphasized

that PAR-members should understand the politics involved and be able to deal with them in order to be effective. This requires certain competencies and skills.

A separate education PAR was established for the Radboudumc Health Academy. The education PAR is responsible for representing the patient's voice in various educational curricula: Medicine, Biomedical Science, Dentistry, Master in Molecular Diseases, Master in Quality & Safety and postgraduate education for medicine and nursing professionals. For example, the education PAR advised on the definition and practical shaping of person-centred care in different programs. Moreover, members of the education PAR actively contribute to the education of medical students by giving lectures and leading working groups for students. Education PAR members have various backgrounds, but all have completed higher education and have an affinity for education and healthcare.

Patient participation in internal audits

The installation of a hospital-wide system of internal auditing was one of the measures taken after the 2006 discovery of the high death rates after cardiac surgery. The auditing model consists of independent, objective assurance and consulting visits to all hospital departments. To guarantee the patient's perspective, a small group of patients who showed interest in representing this perspective were trained to become members of the audit team. Training focused on interview techniques

and they were taught how to represent diverse patient perspectives. After a few years, the sobering conclusion was reached that patient-members found their task to be very difficult. They did not succeed in representing the entire patient population. Therefore, an alternative level of patient engagement for internal auditing was selected. Currently, annual patient experience surveys, completed by patients from both in-patient and out-patient clinics, provide input for the audit visit. Also, observations of the patient's journey, combined with interviews with professionals and patients, are part of the auditing model. As a third pillar, checklists based on the patient-centred Joint Commission International (JCI) accreditation standards are used to assess the patient's perspective.

Redesign of meal services for hospitalized patients

Food is vital for recovery from illness. Nevertheless, too often hospital food is unappetizing, and patients are unable to choose what and when to eat during hospitalization. As part of the redesign of care for young oncology patients (in 2012), a so-called "food dream team" was created, including patients, dietitians, facility management and one of the leading catering firms in the Netherlands. Their task was to determine what hospital food should look like and how to organize food delivery when you can start from scratch. The team designed an innovative concept, named FoodforCare: nutrition assistants serve freshly made, appetizing meals at the bedside. Although the servings are small, they are served up to seven times during the day. During each serving, a patient can choose from at least two different meals. Nutrition assistants not only serve the meals: a new and major task for them is to provide proactive advice, taking the risk of malnutrition into account and nudging the patient toward his or her individual nutritional needs. The impact of the concept is impressive: compared to the traditional three-meals-a-day service, the intake of proteins and energy increased significantly (Dijxhoorn et al. 2017). In particular, patients appreciated the appearance and smell of the meals. Also, from a management perspective, FoodforCare was positively evaluated as food waste dropped from 37% to 11%, which counterbalanced the increased costs (van den Berg 2017). The concept is currently implemented throughout the entire hospital. Patients are still involved; for example, patient satisfaction is being collected continuously and used to optimize the selection of meals so that they can be personalized to the needs and preferences of the individual patient.

Within this team, all members had equal rights: information flows were bidirectional, and decision-making responsibility was shared.

Principal clinicians: Supporting doctors with ideas

In 2014, the concept of a principal clinician was introduced by the hospital board, honouring doctors who have a strong vision and innovative ideas on how to accelerate the implementation of person-centred care with an investigator award. One of those principal clinicians, Bart Post, MD, PhD, is a young neurologist who treats many young people diagnosed with Parkinson's disease. His training and the organization of patient care were based on the notion that Parkinson's disease mainly affects the elderly and so did not meet the needs of his younger patients, who work and have families with children living at home. To change the approach to their care, Dr. Post first installed a project team with two people living with Parkinson's disease and two healthcare professionals. Within this team, all members had equal rights: information flows were bidirectional, and decision-making responsibility was shared. In all meetings with patients and professionals, the 50:50 representation of patients and professionals was safeguarded. These meetings resulted in priorities for change in clinical practice, with patients electing the four topics to start with. For each topic, separate groups were initiated, again with patients in the lead and clinicians following. One group focused on case management, where the case manager becomes a personal "coach" who, for example, can answer simple questions, offer triage, support self management, organize dedicated referrals, and coordinate care. Another group focused on the relationship between work and Parkinson's disease, for example, by listing the legal rights of patients and identifying knowledge gaps in employers. Group meetings were used to share the results of the project, raise new questions and discuss the road ahead. The impact of the methodology was founded on the principles of partnership and shared leadership, supporting the power of individual people with Parkinson's disease to change clinical care into an environment that is driven by the needs of patients.

Welearn: Patient and family engagement in medical education

From the notion that training healthcare professionals and patients separately significantly improves patient-centredness of care came the idea for a co-learning model, called Welearn. Welearn is an interprofessional and person-centred educational program wherein patients, medical and nursing students and different professionals learn together. The educational program, consisting of five educational sessions and meetings in the care practice or at home, provides patients, students and professionals with the opportunity to meet each other, exchange knowledge and experiences and practice care situations, such as consultations, in a safe environment. In Welearn, patients, as well as students and professionals, co-design, co-produce and co-evaluate educational activities

(Vijn et al. 2018). Several pilot studies were executed with Welearn wherein medicine and nursing students jointly learned, together with patients and/or family members and professionals in the field, about rheumatoid arthritis, low health literacy and congenital anomalies. Evaluation showed that through Welearn, patients acquired disease and treatment knowledge and developed a responsible attitude toward their disease and treatment. Students learned about the patients' perspective, which further enhanced their communication and shared decision-making skills. After the positive evaluation and high recommendation from participants, Welearn was implemented in a Bachelor research minor course on vulnerable groups and diversity in healthcare and a minor on human embryology at the medical school.

Discussion

Lessons learned

Over 10 years of leadership within the Radboudumc, supporting an engagement environment for patients, has provided lessons for implementation. Consistent leadership on the importance of patient engagement at the board and middle-management levels, innovators who dare to fail and financial support for those with innovative ideas contributed to an environment that currently fosters patient engagement. The most important lessons learned are:

- The essential culture change should be advocated by the hospital board, whereas bottom-up initiatives give meaning to the patient engagement policy.
- A non-homogeneous evolution of engagement in which employees are free and motivated to design engagement activities that reflect their own drives and ideas and set up experiments that are allowed to fail should be supported.
- With new initiatives, patients should be involved from the beginning to prevent decisions being made that do not align with patients' preferences.
- It takes years to implement a new stakeholder, that is, the patient, in an existing governance model.
- For both professionals and patients, role models, who inspire and motivate their peers, should be used.
- Patient engagement may lead to resistance, for example, in areas of management where patients engage closely with professionals.
- Patient engagement should be organized and facilitated to ensure its quality.

Next Steps for the Future of Engagement

The examples presented here show that a small critical mass of innovators is enough to bring change to an entire organization. Numerous innovations with impact typically started small, and some of those will result in hospital-wide implementation. To further strengthen engagement, successful initiatives should be identified and spread throughout the organization. To achieve this, the hospital board organized speaker corner sessions with every department. Departments shared their achievements with, concerns for and wishes about the implementation of person-centred care. From these sessions, best practice teams will now further support the implementation of patient engagement and create hospital-wide learning communities. Education for patients is imperative to address the tension between the patients' professional deformation (i.e., the tendency to look at things based on previous professional roles instead of the patient perspective). Education can ensure that patients know how they can maintain their perspective and reduce (1) the anxiety they feel given their position, which is partly due to (implicit) power differences, (2) professional deformation, and (3) copying behaviour due to patients' lack of skills, knowledge and experience in the healthcare setting.

To conclude, patient engagement is no longer tokenism. It has become part of Radboudumc's identity, and practice will gradually mature toward partnership and shared leadership as the preferred engagement model. **HQ**

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