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Welcome to the hospital of the patient

High death rates galvanised quality improvement and innovative change in one of the Netherland's largest hospitals, transforming it into a model for patient participation, reports **Tessa Richards**

In April 2006 one of the largest hospitals in the Netherlands hit the national headlines with the exposure of "scandalously" poor results for cardiac surgery.¹ It was a sentinel event for Radboud University Medical Centre in Nijmegen, and parallels were drawn with a similar scandal in the UK at Bristol Royal Infirmary in 2001.² An investigation found death rates were close to three times the national average and ordered the (temporary) closure of Radboud's cardiothoracic centre.¹

The problem was seen, senior staff freely admit, as symptomatic of a wider malaise in a hospital that paid too little attention to the quality and outcome of care and failed to openly discuss problems.

A new chief executive, Emile Lohman, was brought in. One of the first things he did was to fire all the heads of department and audit each unit's performance. The heads were then invited to re-apply for their posts. Over a third failed to regain them.

"It was a terrible time," recalls Hub Woltersheim, a general physician and senior researcher at Radboud's Scientific Institute for Quality of Healthcare. "The exposure of such high death rates and the suffering of patients and families bought a sense of shame which pervaded the whole hospital."

The heads of department were then made responsible for improving and maintaining the quality of care as well as its costs and for



"The staff I met wanted to engage with patients, but some did not know where to start or how best to do it"
Jopie Verhoeven

Box 1 | Chief listening officer

It's not hard to see why Corine Jansen, who has a background in broadcasting, was appointed as Radboud's chief listening officer—a first for a European hospital. She is warm, thoughtful, and non-judgmental.

"My job is to listen to patients, carers, and family members and find out what worries them, how illness disrupts their lives, what they want to know about, and the things they don't share with doctors," she says. "I don't try and solve their problems or tell them what to do; I just listen."

"Listening is a therapeutic intervention in its own right, but regrettably, health professionals are not good at it," she says. "The average doctor, studies suggest, interrupts the patient after 18-23 seconds and then rapidly compartmentalises them into sets of symptoms and diseases."

Jansen advises doctors to spend the first two minutes

of each new consultation listening. "That's how long it takes the average patient to articulate their problems and feel the doctor understands and is on their side. These are essential prerequisites of trust; they take the doctor-patient relationship to a mutually beneficial level and open the gate to shared decision making."

Jansen's approach is systematic. She is involved with all REshape's projects and regularly visits and talks to patients in each department, selected to be as representative a case mix as possible. After an hour and a half with each she can identify common concerns and communicate these to staff.

Take young patients with cancer: "They told me doctors only talk about disease and treatment," says Jansen. "But they want to know about how these will impair their ability to study, earn a living, and have a



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normal sex life." Listening to patients with ovarian cancer revealed that few understood the nature of their cancer and what would happen to them. Jansen helped the oncology department produce a dedicated notebook for them to share with staff and family. It contains factual information about ovarian cancer and its treatment, who is in charge of their case, where to get advice about coping with side effects and psychological problems, appointments, and space to write personal information and put the questions and concerns they want answered.

the quality of training and education. Lohman also stripped out a tier of management between them and the hospital's executive board, and in 2007 appointed a new chief medical officer, Melvin Samsom, a gastroenterologist with a strong research background, to drive quality improvement.

Championing patient participation

Samsom, who later became Radboud's chief executive, is widely credited with leading the hospital's renaissance. His enthusiasm for raising the quality and safety of patient care, for the opportunities and challenges that active partnering with patients provides, and for partnering to be extended is evident.³

Radboud is now consistently ranked high in national comparisons of the quality and outcome of care, with cardiothoracic surgery results among the best in Europe.⁴ The hospital has also acquired an international reputation for innovative ways of working with patients and helping them to take an active role in managing their health and improving care for other patients. Its ratings of patient experience and satisfaction are among the best in the Netherlands.

Along with pinpointing poorly performing departments, Samsom identified strong units and staff with leadership skills. With their help, audit of the quality, safety, and outcome of



CONCEPT IN BEELD

marily on the use of new healthcare technologies to empower people to self manage health and long term conditions. Lucien Engelen, head of the regional emergency healthcare network, designed and now leads Radboud's REshape Centre.⁷ He is passionate about the ability of technology and social media to "migrate healthcare into a joint patient professional venture." He talks about the 4 Ds: democratisation of health information (and with it patient choice); de-location of healthcare delivery (away from hospital); digital innovation; and dollars. Big global players such as Google, Apple, and Samsung are in the wings, he underlines.

The units many initiatives include Hereismydata, an integrated personal e-health record and community platform that gives patients full access to their own data and allows them to connect with other patients. They can also input information (but not remove it) and monitor their conditions. In REdesign 101, patients and health professionals in primary and secondary care meet to codesign new care pathways. FaceTalk is a secure video consultation system.

Engelen also established the post of chief listening officer in healthcare (box 1) and spearheaded the Patients Included campaign,

care benchmarked against national standards became routine. He also spurred a change in culture, with strong emphasis on transparency, good communication, and patient participation.

Several of the hospital's consultants influenced Samsom's thinking, including Bas Bloem and Jan Kremer. Bloem, a neurologist, was pioneering a multidisciplinary model of care for patients with Parkinson's disease based on feedback from patients on what they needed and wanted. ParkinsonNet has now been rolled out nationally after evaluations showed it provides good quality care at lower cost than standard care. Its potential to revolutionise the management of other chronic diseases has attracted international attention.⁵

Kremer, formerly a professor of reproductive medicine, is now Radboud's (first) professor of patient centred innovation. Kremer had long experience of working in partnership with patients and redesigned the hospital's in vitro fertilisation department with their input. A key component of the redesign is patient controlled records and an online platform run by patients through which they support and inform each other.⁶

Healthcare innovation

To promote patient centred innovation Samsom set up a dedicated research unit that focuses pri-

Box 2 | Patient centred innovation

Despite being professor of patient centred innovation, Jan Kremer thinks the term patient should be abandoned.

"It conjures up an image of passivity which is not appropriate in an era where people are—and must increasingly—assume responsibility for their own health. Health professionals are struggling to provide continuity of care and we have to help people to learn to be their own doctor."

He favours a new acronym: TIFKAP (The Individual Formerly Known As a Patient), a take on TAFKAP (the artist formerly known as Prince). It does not roll off the tongue, but the initiatives the hospital has introduced are undoubtedly promoting patient empowerment.

These include the MyRadboud-Data platform, the MyCaret platform for personal health communities (www.mijnzorgnet.nl), patient advisory groups, online communities at both departmental and hospital level, video consultations, regular assessment and joint discussion of patient experience, the development of personalised health indicators, shared decision making, a patient empowerment academy, self management courses, involvement of patients in setting the research agenda, and the codesign of a new undergraduate medical education curriculum.



BART NIJIS FOTOGRAFIE

"Our medical students are coached by patients and patients sit on the committees designing our new curriculum to inform concepts, context, and complexity"
Jan Kremer

which *The BMJ* among others has adopted.⁸ This advocates including patients in every step in healthcare and boycotting medical meetings that don't invite patients to participate. One key element of hospital policy is that all proposed new initiatives must be discussed and agreed with patient groups before implementation.

Radboud's patient advisory groups

Radboud has several patient advisory groups and a patient advisory board. The groups include one for children and another for adolescents and young people with cancer. In addition, several departments have set up patient groups and work with them to define policy and the design and delivery of services.

Jopie Verhoeven chairs the patient advisory board. Like her fellow patients on the board, she work on a voluntary basis, with expenses paid and sometimes a small stipend

"Before I decided to accept the invitation to chair the patient advisory board, I met with the hospital's other advisory boards, medical staff, nurses, paramedics, and employees, and several heads of department," she said. "I wanted to be sure there was support for our work.

"There was. The staff I met wanted to engage with patients, but some did not know where to start or how best to do it. We help with this and make suggestions to the executive board on what changes are required to enable patients to participate."

The patient advisory board has also reviewed

the hospital's patient information products and spurred transformation from an approach that took an organisational perspective to one that now starts with "what patients really want to know."

Glimpse from the ground

Walk through the doors of the average UK hospital and the atmosphere often raises tension. Busy staff to and fro among a catholic mix of brash retail, smart clinical, and drab utilitarian facilities. At Radboud the impression is of order, space, and good design. Staff are friendly. Porters, who take to scooters to traverse long hospital corridors, engender a sense of fun. I spotted what looked like a pale square telephone booth. It contains an iPad, I was told, and passing staff and patients are invited to jot down comments and ideas.

Not all of Radboud's patient participation initiatives have been evaluated, but several have been taken up in other Dutch hospitals and beyond. In particular, many countries are now moving to give patients the opportunity for online exchange with health professionals and full access to, and sometimes control of, their personal health records.

A recent national television documentary about Radboud attracted what Engelen describes as a "social media storm," with many patients coming forward to offer to help the hospital.

In October, REshape is hosting the first ever European Listening and Healthcare Conference. It aims to fuel a move to "transform healthcare through the power of listening." It's a powerful and important message.

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Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

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ANNEMIEK MOMMERS

Box 3 | Patient centred initiatives

"We write clinic letters to the patients and copy the GP in. Patients like it and GPs do too because we avoid jargon and acronyms" **Hub Wollersheim, general physician**

"We can offer patients video consultations rather than face to face meetings; it's helpful if travel is difficult." **Stephanie van den Bosch, surgeon**

"I send my oncology patients an email two weeks before their annual review. I tell them what points I need to run through and ask them to send me their answers, questions, and goals. When we meet we discuss if our goals have been met and agree future ones."

Nicoline Hoogerbrugge, oncology consultant

"Our medical students are coached by patients and patients sit on the committees designing our new curriculum to inform concepts, context, and complexity"

Jan Kremer, head of patient centred innovation

"Mirror talks are where we get patients and medical staff in the same room, sitting back to back to retain anonymity. Staff listen while patients talk about their experience. Their messages really hit home." **Hub Wollersheim**

"All patients should have full access to personal health records and see everything their doctor writes about them." **Jopie Verhoeven, chair of patient advisory board**

"Doctors should listen to patients for longer; it takes two minutes, not 20 seconds to tell your story" **Corine Jansen, chief listening officer**

"In the Patients Academy new patients about to undergo treatment, eg knee replacement, and invited to a coaching day led by patients who have had the procedure," **Jan Kremer**

"We need to shift from doing things to patients, to doing things with them, as we move towards a future when they will champion their own solutions," **Lucien Engelen, head of Reshape Centre**

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