

Patient safety

Paving the way for progress

← → N°11
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Making the patient a partner in treatment safety



Newsletter for
radiotherapy professionals



> Editorial

The patient is at the centre of the mechanisms to ensure the safety of radiotherapy treatments, but is not yet really considered as a partner by the care team.

Yet the analysis of events notified to ASN shows that patient vigilance detects errors and mitigates their consequences. Furthermore, having a good understanding of the treatment protocol contributes to the delivery of safer and more effective treatments.

This issue of the patient safety bulletin aims to echo the ongoing reflections on the role of patients as actors in their own treatment safety. In Canada, the Montreal University Hospital Centre introduces expert patients to accompany oncology-patients. In France, the Gustave Roussy Cancer Centre in Villejuif (Paris region) gives patients a booklet to encourage their personal involvement in the prevention of adverse events.

Building a relationship of confidence, improving the clarity and the observance of instructions and explanations, encouraging cooperation: the editorial committee presents three lines that foster patient involvement. The recommendations in this respect result from the work of two ergonomics specialists - Adeline Pernet and Vanina Mollo, and two radiation oncologists from medical centres in Bordeaux - Veronique Vendrely and Christèle Breton-Callu.

We wish you enjoyable reading.

The Editorial Team

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> Deciphering the events notified to ASN

Between 2014 and 2016, forty-four (non-exhaustive figure) significant radiation protection events (ESR) were identified in which patients contributed to their detection or their occurrence. Over the same period, 530 ESRs (criterion 2.1 - see link <http://www.french-nuclear-safety.fr/Media/Files/00-Guides-de-declarations/Anglais/Guide-no-16-Significant-radiation-protection-events-affecting-patients-in-radiotherapy-criterion-2.1-notification-and-ASN-SFRO-scale-rating?>) were notified to ASN.

1. Contribution of the patient to error detection (16 notifications):

- location (10, including 4 laterality errors):
 - by reporting the incorrect location of a radiation boost for the treatment of a breast (wrong quadrant / wrong scar - 5 cases) or other location;
 - by reporting a pain or secondary effects in a zone that does not correspond to the zone to treat;
 - by reporting an unexpected treatment duration.
- identity (2): 1 by reporting an unexpected treatment time, 1 by verification of the name displayed in the treatment room;
- positioning (1): question via the interphone during the session;
- fractionation (1): erythema reported during the follow-up consultation;
- in the treatment phase (1): by reporting an unexpected treatment time;
- in the number of sessions (1): reported during the follow-up consultation.

2. Malfunctioning of care management associated with:

- patient identification (19):
 - Patient early or late (11): the radiographers selected the patient expected according to the schedule in the R&V system, but installed the patient in advance;
 - Patient in waiting room who stands up when another person's name is called (5);
 - The patient's physiological state is not in conformity with the treatment protocol and necessitates returning to the waiting room before conducting the session (time to allow filling of bladder/rectum) (2);
 - Patient who does not speak French - no photograph taken (1).
- patient positioning:
 - the patient gets up during the session (due to a need to urinate) (3);
 - the patient erases the marks on his/her skin between sessions (1);
 - patient pulls out the treatment device during PDR (pulsed dose rate) brachytherapy treatment (1);
 - the patient has a haircut (difference between mask and skin) (1);
- interruption of treatment: the patient insists on going away on vacation (1);
- unknown and unplanned pregnancy during treatment (2).

Teleservices.asn.fr, ASN's new website for on-line notification of ESRs in all medical applications

As of April 2017, teleservices.asn.fr has replaced the vigie-radiotherapie.fr portal set up in July 2011 for radiotherapy professionals.

The new ASN teleservices portal is open to all medical applications that use ionising radiation: nuclear medicine, fluoroscopy-guided interventional practices, computed tomography, conventional and dental radiology, and radiotherapy. The website enables health professionals to upload their event notifications to the relevant authorities.

The notifications for all events concerning patients are sent automatically to ASN and to the ARS (regional health agency), while events relating to medical devices vigilance or drug safety monitoring are sent to the ANSM (health products safety agency).

[Teleservices.asn.fr](http://teleservices.asn.fr) is integrated in the portal for reporting adverse health events (<http://www.signalement-sante.gouv.fr>) opened on 13th March 2017 by the Ministry of Health and covering all health-related vigilance issues.

Any health professional who notifies a radiation protection event, whether it is related to another vigilance issue or not (medical devices vigilance for devices emitting ionising radiation or drug safety monitoring for radiopharmaceuticals) will be redirected to the ASN on-line notification website.

> Steps for progress

1. Good practices, recommendations

The good practices and recommendations presented in this section stem from the reflections of the working group conducted in collaboration with Adeline Pernet, Ph.D. in ergonomics and Vanina Mollo, teacher-researcher in ergonomics.

They concern management of the patient (from the 1st consultation until the end of treatment):



Recommendations for the medical personnel



What must be explained to the patients



Proposed aids

Build a relationship of trust



Put the patient in a position where he or she can cooperate and feels free to ask questions or report anything:

- Organise a time for discussion outside the medical procedures

• Humanise the care

- Address the patient by their name so that they feel recognised and respected;
- Inform the patient that they will be asked regularly to give their identity;
- Consider the person has a whole, with his/her professional and private life, not just as a patient.

• Exercise active listening

- Always verify any doubt reported by the patient, no matter how unlikely it may seem;
- Do not consider questioning of the treatment procedure as challenging the competence of the medical personnel.

• Exercise a careful watch

- over the emotional and physical state of the patient;
- for secondary effects of the treatment.



Do not hesitate to ask any questions

Improve the clarity and observance of instructions and explanations



Give the patients clear and tailored explanations concerning their treatment (particular treatment, personalised immobilisation devices, importance of positioning, etc.),

Insist on the importance of complying with the advice and/or instructions given.

Explain to the patients that although the medical staff (doctors, interns, radiographers) may change, treatment continuity is ensured.

Do not hesitate to ask for the services of a translator.



Follow the advice and instructions provided by the medical staff:

- dates and times of appointments;
- advice intended to minimise the occurrence of secondary effects (diet, pain management, aesthetics, etc.)

• instructions to ensure the effectiveness of the treatment (do not to move during the session, do not to erase marks on the skin, comply with the bladder / rectum preparation instructions, etc.)

• allow the use of identification procedures (photographs, fingerprints, etc.)



Provide an automatic communication system (sms, e-mail, etc.) to inform patients of unforeseen events (failures, change of appointment date or time) and tell them what to do (not to come to the appointment, time of resuming treatment, etc.).

Provide information screens (delays, failures, etc.)

Provide the patient with a booklet/brochure summarising the verbal explanations.

Encourage cooperation



Encourage the patients to play an active role in their treatment and ask them:

- to keep their hospital identification card ready and available;
- to check their indicated identity;
- to memorise and reproduce the required treatment position;
- not to move during the session;
- to ask questions and point out anything they find unusual.

Involve the families, particularly with patients who do not speak French or who physically cannot be actively involved.



Encourage patients to report:

- any information that could interfere with the treatment (schedule, any prior medical history, pregnancy during treatment);
- any concerns or unusual factors (identity, positioning, zone to irradiate, immobilisation devices, secondary effects, number and duration of treatment sessions, etc.)

Encourage patients to write down any questions they might wish to ask in order not to forget them.

And not to hesitate to ask to speak to a doctor.



Organise a "radiographer consultation" or "paramedical consultation" to supplement the information provided by the doctor.

Provide the patient with a dedicated means for communicating any proposed improvements

and/or reporting any malfunctions.

2. Innovative initiative



Patient advisors partnering the health care team in Québec

Doctor Israel Fortin, radiation oncologist, presents the *PAROLE-Onco* project currently being implemented at the Montreal University Hospital Centre (CHUM) in collaboration with Dr Marie-Pascale Pomey (CHUM)

It can be easier for patients to discuss certain subjects with other patients who have experienced similar situations and problems. The Patient Advisors (PA) who have acquired know-how through experience can provide emotional, educational and informational support to enable new patients to regain control of their condition and improve their healthcare experience. Patient advisors have been introduced in the hand surgery clinic of the Montreal University Hospital Centre (CHUM) to improve the rate of adherence to the occupational therapy treatment and the success of hand replantation or revascularisation surgery.

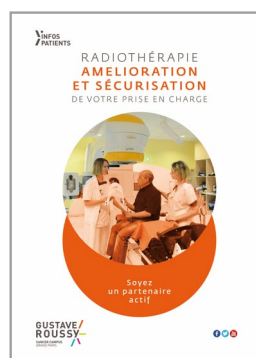
Jointly "walking through" the treatment procedure with former patients has revealed the following benefits:

- 1. for the patients:** improvement in the adherence to the treatments, in the mobility of the hand, in the treatment experience and a reduction in depression syndromes;
- 2. for the PAs:** a role that gives meaning to their experience;
- 3. for the care teams:** improved interdisciplinary coordination in relation with the PAs.

The PAROLE-Onco project for its part proposes that expert patients with first-hand knowledge of cancer problems be integrated in the clinic and be able to meet patients on a voluntary basis.

The patient advisors can support the patients, provide information, and ensure that they understand the treatment and play an active role in the decisions. This is a need expressed by more than 90% of the health professionals and a large number of patients. The PA is a key player in the partnership between the care team members and the patients. The PA facilitates each person's understanding of the knowledge of the others (the patients' knowledge through experience and the medical staff's clinical knowledge) and becomes a "knowledge transmitter". PAROLE-Onco is proving to be a promising means of fostering a better health care experience for the patients and increasing the quality of treatment, the feeling of effectiveness and the work satisfaction of the persons involved. A pilot project will be deployed at the CHUM in Autumn 2017.

> The experience of the radiotherapy centres



A booklet to involve the patient as an active player in his/her own radiotherapy treatment safety

Experience of the Gustave Roussy Cancer Centre (Villejuif)

In the context of the patient safety week which ran from 21st to 25th November 2016, the radiotherapy department of the Gustave Roussy Institute produced two posters on the participation of the patient as an active partner in the prevention of adverse events associated with the treatments.

In order to ensure the continuation of the procedure and the dialogue with the patients over the long term, a booklet intended for the patients was produced in the 1st half of 2017.

The booklet incorporates contributions resulting from proof-reading by doctors, radiographers, the department management and above all the patients via the patients and families committee.

Interview with a patient treated for breast cancer in 2016.

« The informed patient is more relaxed and able to be a vigilant and active player in their own treatment »

Is it important for radiotherapy patients to be able to play a role in their own safety?

Yes, because this enables the patients to play an active role in their treatment. The better informed the patient is of the future treatment and manipulations, the more vigilant he/she can be.

Do you consider that being involved is a source of anxiety?

Personally I always ask a lot of questions because I need to understand what is being done. Being well informed enables you to be more relaxed and not get worried about symptoms that are associated with the treatment. Some patients are afraid to ask questions, in which case the medical personnel has to initiate the dialogue. This being said, it is just as important to respect the desire of people who prefer to put themselves entirely in the hands of the medical staff. Some people do not want to know the treatment details, and never will.

In your opinion, what is the best way of informing the patient of their role in their radiotherapy treatment?

Verbal information is to be favoured in the carer/patient relationship; talking is often enough to dispel any concerns. Written information can constitute a good medium for engaging a discussion. The Gustave Roussy Institute brochure encourages the patient to ask questions. The brochure also provides a written reminder of information that patients might have forgotten.

What moments are conducive to having a discussion with the patients?

The start of care before the 1st computed tomography scan is a key moment when the patient often feels worried and rather alone. I will never forget that intimidating machine that rotates around us... A new place, new people, a new treatment ...

Personally, I would have appreciated having a meeting prior to and separately from the medical procedure, because it all adds up to a lot of emotion and information in a single day.

The taking of a photograph showing your body disfigured by scars can also be "difficult" for one's personal image and identity...

A few explanations would suffice: don't worry, nobody else will see the photograph, it is simply a means of identification... When I had my treatment, another person with a similar name was also being treated, hence the interest of this additional safety measure in radiotherapy. The 1st treatment session is also a difficult moment. You enter a room full of machines, screens and people you don't know, you are positioned on the machine, and then everybody disappears into a back room to start the radiation treatment.

I really was very ill at ease on that day. Things were running late, everything was going too fast and no explanations were given. The machine rotates around you and dozens of questions come flooding into your mind: the risks of an excess dose, having the radiation go through your lungs... A pre-treatment explanation of the way the radiotherapy sessions proceed would be reassuring and help reduce the stress. Afterwards, you get used to it. Lastly, the weekly visits with the doctor can be a bit destabilising. Sometimes you are faced with a doctor you do not know who is in a hurry and just wants to confirm that you are not suffering from burns or nausea. Patients should be told that they will not necessarily see the same doctor each week, and above all encouraged to write down any questions or worries they have, something that is moreover proposed in the Gustave Roussy Institute's draft booklet.

What experience have you drawn from your involvement in the treatment?

I appreciated having access to my medical file (reports, radiology procedures, blood test results, medical interventions, etc.) via the application "Mon GustaveRoussy". I had no hesitation in asking questions to the care team. On the other hand, the medical staff were sometimes unable to answer my questions. It seems to me that further progress must be made in recognising the patient as a true partner of the care team: I was not warned of a known secondary effect, which was unexpected and stressful for me.

What messages would you like to pass on to the radiotherapy professionals and the patients?

The patients must above all not be afraid to ask questions when they have even the slightest worry. There are no "stupid" questions. I would quite simply ask the medical personnel to explain what they are doing and to keep the patients informed when there are delays (machine out of service, personnel on sick leave, etc.). The waiting times in radiotherapy, which can be very long, are a further source of stress, in addition to the problems of fatigue, pain and nausea... If the patient is kept informed, he or she can relax, go and have a cup of tea or coffee, and the subsequent radiotherapy session will go much more smoothly. Reassuring the patient also means informing them of anything that is new in the sessions: today we are doing another series, from the other side, but this does not change your treatment.

> Further reading

Involving the patient in his/her treatment

Communicating - involving the patient / Toolbox (HAS - French national authority for health)

http://www.has-sante.fr/portail/jcms/c_1660975/fr/communiquer-impliquer-le-patient

- **Getting patients to talk**

http://www.has-sante.fr/portail/upload/docs/application/pdf/2016-02/brochure_fairedire_communiquer_avec_son_patient.pdf

- **Don't be afraid to talk to your doctor**

http://www.has-sante.fr/portail/jcms/c_1695997/fr/oser-parler-avec-son-medecin

Helping to produce safe and effective care: the development of patients' capabilities in radiotherapy

Thesis of A. Pernet, Nov. 2014

<https://tel.archives-ouvertes.fr/tel-01088386/>

Evaluation of patients' engagement in radiation therapy safety

A. Pernet, V. Mollo, J.-E. Bibault, P. Giraud
Cancer radiothérapie, December 2016

Empowering patients for radiation therapy safety: Results of the EMPATHY study

Bibault JE, Pernet A, Mollo V, Gourdon L, Martin O, Giraud P.
Cancer radiothérapie, December 2016

Patient information booklets on the radiation treatment of cancers

Radiation therapy of cancers - better understanding your treatment - 17 thematic booklets - SFRO, January 2017

<http://sfro.fr/index.php/documents/livrets-sfro>

Safety culture and analysis of events

General context for the evaluation of procedures for analysing adverse events relating to treatments

HAS (French national authority for health) - November 2016

http://www.has-sante.fr/portail/jcms/c_2724327/fr/cadre-general-d-evaluation-des-demarches-d-analyse-des-evenements-indesirables-associes-aux-soins

Safety culture conviction: "Organisational silence is the greatest enemy of safety".

ICSI - Institut for an industrial safety culture - January 2017

<http://www.icsi-eu.org/fr/actus/nouvelle-conviction-sur-le-silence-organisationnel.a356.html>

IAEA e-learning course "Safety and Quality in Radiotherapy"

The IAEA recently developed an e-learning course on Safety and Quality in Radiotherapy to help professionals improve their understanding of safety in radiotherapy, learn techniques to reduce and avoid radiotherapy incidents and understand the value and use of incident learning systems.

The course is presented in 12 modules, designed to provide radiotherapy professionals with knowledge and skills to enhance the safety and quality of their practice. As a foundation, the course uses three significant errors that have occurred in radiotherapy to demonstrate the use of these tools and techniques.

https://rpop.iaea.org/RPOP/RPoP/Content/AdditionalResources/Training/1_TrainingMaterial/safety-quality-radiotherapy.htm

Safer Radiotherapy Radiotherapy Newsletter of Public Health England

January 2017, Issue 21

May 2017, Issue 22

<https://www.gov.uk/government/publications/safer-radiotherapy-error-data-analysis-report>

Have you paused and checked? Radiotherapy

<https://www.sor.org/learning/document-library/have-you-paused-and-checked-radiotherapy>

> Previously published bulletins

- N°1 Patient identification (March 2011)
- N°2 The verification session (Nov. 2011)
- N°3 How to analyse your significant radiation protection events? (July 2012)
- N°4 Which events are to be declared to ASN? [Available in French only] (April 2013)
- N°5 In-vivo dosimetry (December 2013)
- N°6 Laterality errors (May 2014)
- N°7 Record and Verify: recording errors! (March 2015)
- N°8 Pulsed dose-rate and high dose-rate brachytherapy (June 2015)
- N°9 High-precision hypofractionated irradiation (September 2016)
- N°10 Protraction / fractionation (January 2017)

www.asn.fr > professionnels > utilisations médicales
<https://www.asn.fr/Professionnels/Activites-medicales/Radiotherapie/Bulletin-La-securite-du-patient>

These publications are also available in English:

<http://www.french-nuclear-safety.fr/Information/Publications/Publications-for-the-professionals>

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