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Development of a PET/CT and PET/MRI patient information films in collaboration with patient representatives previously treated for cancer.

Running head - Development of PET/CT and PET/MRI information films

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Conflict of interest – Pierpaolo Inga is a commercial filmmaker whose services were retained for the purposes of this project, he worked closely with the patient members of the working group to ensure their input was incorporated.

Abstract

Introduction; PET/MRI and PET CT scanning carries an increased psychological burden for patients which may be improved by effective preparation prior to attendance for the procedure. We aimed to devise an online resource for patient benefit prior to PET/MRI and PET/CT scanning.

Method - With the help of patient representatives' the style and content for two patient information films was reviewed at each stage of the process to explain the patient journey.

Results – Two patient information films were produced for patients undergoing PET scanning, Positive feedback from healthcare providers and users was obtained.

Conclusion – Involvement of patient representatives in the production of an information resource has had a positive impact on the finished product, with potential for increased benefit to patients as a result.

Introduction

Scan procedures carry with them potential for anxiety, discomfort and embarrassment, in patients, which contribute to an overall level of psychological burden (*1*) , which may be allayed or amplified by previous experience or knowledge, as well as understanding of the need for the procedure, or lack thereof (*2*). Patient preparation prior to scanning has been shown to reduce anxiety amongst patients undergoing MRI scans (*3*).

In line with the findings of previous studies (*4*), the effect of a preparatory film prior to colonoscopy(*5*), coupled with increased use of the internet by people in search of health information; the concept for a patient information film for viewing online prior to PET/CT or PET/MRI scans was formed.

The aim of the films was to help patients orientate themselves to the scanning department in hospital, improve familiarity with the procedure, and to address the questions patients may have regarding scans. Here we describe our method in the creation of these films, and report feedback from patients involved regarding their opinion of the resulting work.

Materials & Methods - The method used to create and review the videos is summarised in Figure 1.

Firstly public & patient involvement was sought due to the unique perspective that service users can bring (*6,7*). A working group was convened, consisting of a panel of five patient representatives that were previously treated for cancer at University College London Hospitals (NHS) Trust (UCLH), along with two research radiographers, a research nurse, a film-maker and an Operations Manager.

The patient representatives that were invited to take part were part of a of a pre-existing group of 'expert patients' who volunteer to assist our institution by reviewing potential projects as well as documentation for accessibility, or 'usability' by members of the public. The patients included in this

group are involved voluntarily, are not currently under medical care the hospital and did so of their own free will. As this work was conducted as part of service development, rather than research, no ethical approval was sought.

The patient representative panel reviewed the material using still photographs of the scanner to show the various stages of the process involved in preparation for PET/CT and PET/MRI scans. These were combined into a single film.

There were several aspects of the film that the panel addressed as needing improvement

- Emphasis of continuity of care by showing interactions between patients and radiographer.
- Showing the scanners are open at both ends,
- Indication of scanning noise
- Information regarding comfort aids available,

At this stage the group agreed individual PET/CT and PET MRI films should be made to reduce confusion.

The film developers incorporated feedback to create a new script for each modality with minor changes to the script to improve clarity. The subsequent films were re-reviewed by the panel and modifications made.

It was considered necessary to observe healthcare professionals performing their scanner related duties -putting the patient on the scanner, showing images being acquired, and the resultant images (Figure 2).

Once the script had been reviewed by the department, filming took place and scripts narrated.

- Following editing of the footage, the films were presented to the panel and department. further changes were made to refine the tempo, the language, and field of view.

The films received a final edit and were reviewed again. In line with feedback, the films have had English subtitles applied for the benefit of the hard of hearing.

Results

The patient representative group were asked for feedback on the final product. The feedback received from the patient representative group was very positive regarding the resulting films. The feedback was collated and is reported in Figure 3.

Discussion

Feedback from the patient representatives was positive, they considered that the work and effort invested had succeeded in creating a useful tool to help people who are facing potentially serious diseases combined with facing a scan that they have never experienced before.

Additionally, the patient representatives commented that their involvement was rewarding because their comments were taken seriously and genuinely sought. Specifically, 'that the process did not pay lip-service to patient & public engagement (PPI); which could have been an easy trap for the team to fall into.'

The films are posted on our Institutional and departmental sites including subtitles in 11 languages. In patients with early stages of dementia, second language skills are some of the first to diminish, therefore these translations may be of significant help to patients that may need to undergo imaging investigations related to their dementia, a field where PET/MRI imaging is developing rapidly.

Through extensive consultation with previous cancer patients we created a patient information resource to alleviate specific concerns of patients undergoing PET/CT and PET/MRI scans. The task now is to evaluate this resource in terms of its effect on the burden experienced by patients, then to include this

information in patient communications, and to distribute it as widely as possible to achieve greatest benefit.

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Titles and legends to figures

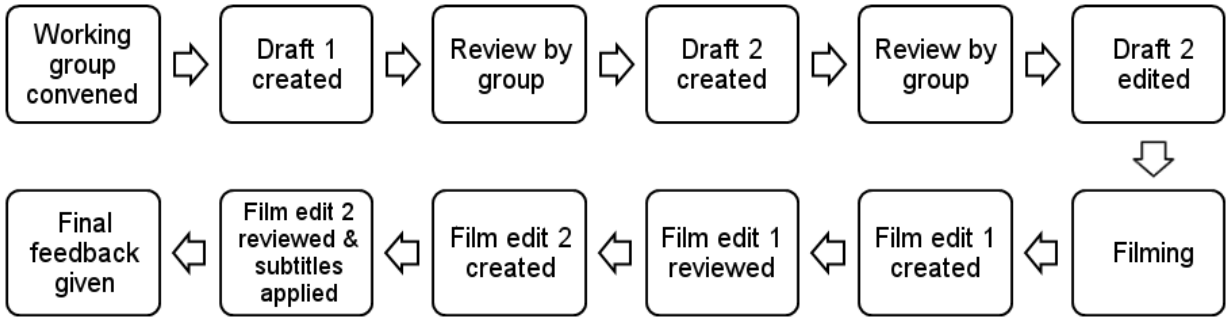

Figure 1 - Flow diagram illustrating the process of creating the videos

Figure 2 - An example of a PET/MRI image shown to demonstrate resultant images in the information film

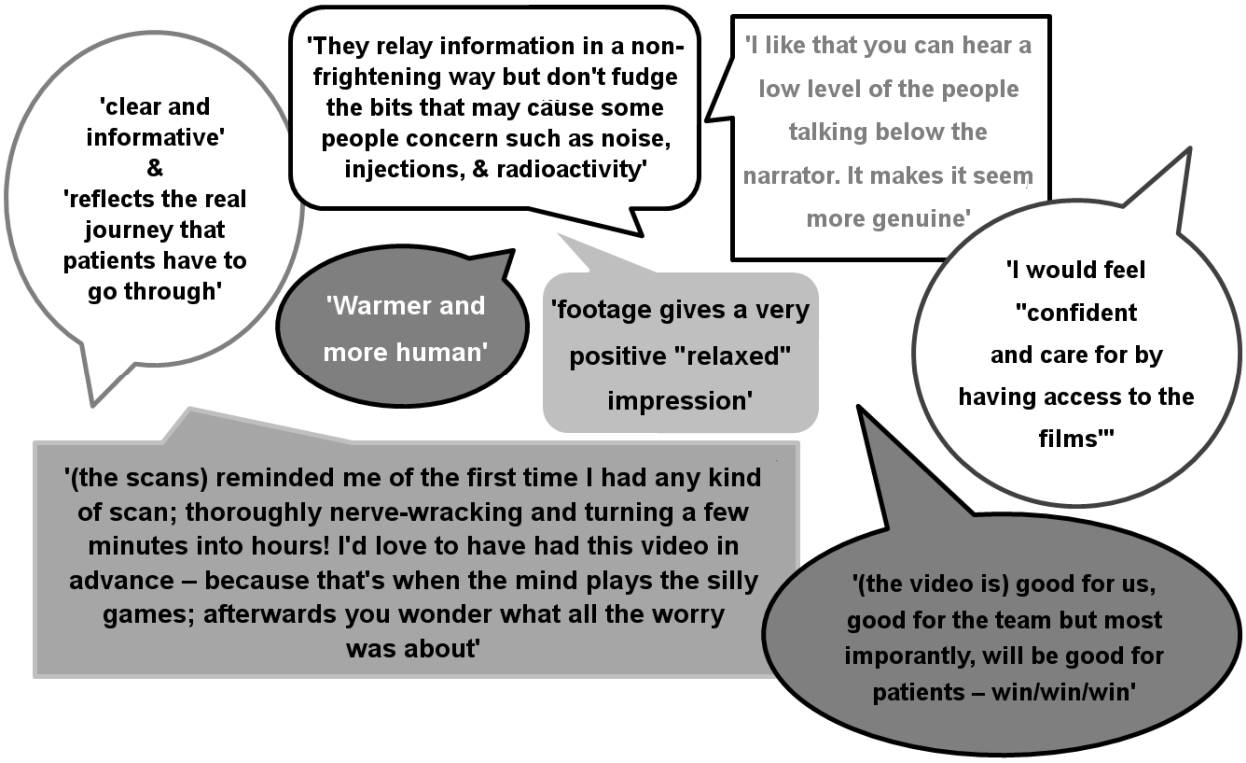

Figure 3 - Feedback of the patient representative panel regarding the final versions of the films