

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission

Low -energy contact X-ray brachytherapy for locally advanced, inoperable rectal cancer IP1724

Thank you for agreeing to give us your views on this procedure or operation and how it could be used in the NHS.

When we are developing interventional procedures guidance we are looking at how well a procedure or operation works and how safe it is for patients to have.

Patient and carer organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of having the procedure or operation
- the outcomes of the procedure or operation that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the impact of the procedure or operation on patients and carers. (What are the benefits to patients and their families, how does it affect quality of life, and what are the side effects after the procedure or operation.)
- the expectations about the risks and benefits of the procedure or operation.

To help you give your views, we have provided this template. You do not have to answer every question — they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.

About you	
1. Your name	██████████
2. Name of organisation	PAPS (PAPILLON AND PATIENT SUPPORT)
3. Job title or position	LEAD VOLUNTEER
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	DIRECT VOLUNTEER SERVICES, MACMILLAN FUNDED SUPPORT GROUP WE HAVE 10 BUDDIES WHO ARE ALL MACMILLAN TRAINED AND WHO ARE EITHER EX PAPILLON PATIENTS OR CARERS
<p>5. How did you gather the information about the experiences of patients and carers to help your submission?</p> <p>(For example, information may have been gathered from one to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.)</p> <p>FACE TO FACE AT CLINICS, TELEPHONE AND INTERNET SUPPORT AND ANNUAL PATIENT MEETINGS</p>	

Living with the condition

6. What is it like to live with the condition or what do carers experience when caring for someone with the condition?

THE FEAR AFTER BEING TOLD YOU HAVE CANCER AND ON TOP OF THAT BEING TOLD THAT YOU ARE TO HAVE YOUR ENTIRE COLON REMOVED AND A PERMANENT STOMA FITTED.

PATIENTS CONTACTED FEAR THIS OVER CANCER ITSELF.

PATIENTS ARE THE ONES EXPERIENCING THE TREATMENTS AND ALL THE PAIN AND EMOTIONS THAT GOES WITH THAT BUT THEY ARE IN CONTROL AND USUALLY THEY ARE BUSY GETTING ON WITH GETTING BETTER.

VERY OFTEN IT IS THE CARER AND WIDER FAMILY MEMBERS WHO SUFFER AS THEY ARE ANXIOUS AND FEARFUL FOR THE PATIENT BUT CAN'T DO ANYTHING ABOUT IT. THE PATIENT ALSO MAY KEEP RESULTS ETC, FROM THEM TO PROTECT THEM FROM EVEN MORE SUFFERING.

Advantages of the procedure or operation

7. What do patients (or carers) think the advantages of the procedure or operation are?

THERE ARE MANY ADVANTAGES OF PAPILLON TREATMENT:-
FIRSTLY THE FACT THAT ANOTHER OPTION OF TREATMENT HAS BEEN OFFERED GIVES PATIENTS EMPOWERMENT AND HELPS WITH ANY MENTAL HEALTH ISSUES THAT MAY HAVE ARISEN AFTER CANCER DIAGNOSIS.

NO SURGERY INVOLVED, DAY CLINIC PROCEDURE, NO LASTING SIDE EFFECTS, NO STOMA TO CONTENT WITH, NO AFTERCARE REQUIRED,

Disadvantages of the procedure or operation

8. What do patients (or carers) think the disadvantages of the procedure or operation are?

THE MAIN DISADVANTAGE IS THE MIS INFORMATION GIVEN TO PATIENTS ABOUT PAPILLON TREATMENT BY CLINICIANS WHICH ONLY ADS TO THE STRESS TO PATIENTS AND FAMILY.

Patient population
<p>9. Are there any groups of patients who might benefit either more or less from the procedure or operation than others? If so, please describe them and explain why.</p> <p>THE MAIN AGE GROUP WE SPEAK WITH ARE AGE BETWEEN 50-90 YEARS OLD WITH THE MAJORITY BETWEEN 70-85. OVER THE LAST 5 YEARS WE HAVE SPOKEN TO OVER 500 PATIENTS WHO GIVEN THEIR AGE OR HAVE OTHER RELATED HEALTH ISSUES CANNOT HAVE SURGERY WOULD HAVE ONLY BEEN OFFERED PALLIATIVE CARE. THERE HAS BEEN AN INCREASE OF PATIENTS IN SCREENABLE AGE RANGE WHO DO NOT WANT SURGERY AND THIS HAS BEEN THEIR ONLY OPTION.</p> <p>PAPILLON GIVES THE PATIENT THAT OPTION AND ALLOWS THEM TO LOOK AT LIFE VERSUS QUALITY OF LIFE WITHIN OUR PATIENT COHORT.</p>
Equality
<p>10. Are there any potential equality issues that should be taken into account when considering this topic?</p> <p>AVAILABILITY OF TREATMENT ESPECIALLY FOR VUNERABLE PATIENTS WHO MAY NOT BE ABLE TO TRAVEL TO ONE OF ONLY 4 PAPIILLON CENTRES IN THE UK.</p>
Other issues
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>THE COSTS INVOLVED ARE OBVIOUSLY IMPORTANT BUT WHAT IS MORE IMPORTANT IS THE PSCHOLOGICAL AND EMOTIONAL COSTS OF HAVING RADICAL TREATMENTS WITHOUT BEING GIVEN A CHOICE. ALL OUR CONVERSATIONS WITH OUR PATIENTS ARE ABOUT THEM BEING GRATEFUL FOR BEING GIVEN THAT OPTION.</p>
Key messages
<p>12. In no more than 5 bullet points, please summarise the key messages of your submission.</p> <ol style="list-style-type: none"> 1. NONE SURGICAL OPTION ALLOWING VUNERABLE PATIENTS TO BE TREATED 2. IMPORTANT FOR PATIENT QUALITY OF LIFE AND MENTAL

HEALTH.

3. OFFERS CLINICIANS AND PATIENTS ANOTHER SOLUTION IN
MANAGEMENT OF COLORECTAL CANCER.
4. TREATMENT AS AN OUT PATIENT REDUCING TIME IN
HOSPITALS.
5. OVERALL FEEDBACK FROM OVER 500 PATIENTS IS OF
GRATEFULNESS AND HOPE OF BEING GIVEN THIS OPTION.
WITHOUT THIS CURATIVE OPTION PATIENTS WOULD BE GIVEN
JUST PALLIATIVE CARE.

Thank you for your time.

Please return your completed submission to jp@nice.org.uk