

Bladder Cancer PHR Introduction

Background on PHRs

According to the NHS modernization agency, a patient-held record “can take a number of forms, from a dynamic tool used by the patient and all healthcare professionals providing care to the patient, to a print out from the patient’s medical record or general information sheets. It is designed to inform and involve patients in their care and to facilitate communication between the different groups of people caring for the patient.” ⁽¹⁾

Although successfully implemented, for example in obstetrics and diabetes care for many years and positively evaluated in numerous studies, RCTs and meta-analysis ^(2, 3) have failed to show a clear scientific benefit to implementing a PHR in the cancer care setting. Patients however, with the support of NHS England, believe that if they had access to their clinical record they would become more involved in their own care ⁽⁴⁾.

This PHR intends to be an important part of how patients and the healthcare team looking after them will record discussions about their care, to ensure that they are informed about everything they need to know in a timely manner. We also hope the information provided, which will be updated as treatment progresses, will make patients feel more in control of their bladder cancer and follow up care.

Aims of this PHR

The aim of the bladder cancer PHR was to produce a patient held record for bladder cancer, to be used by both the patient and the clinical team responsible for their care, which incorporates all aspects of clinical information to ensure a comprehensive, accurate & up-to-date record is kept:

1. of clinical information
2. of the treatment summary
3. of quality assurance measures.

With objectives of:

1. improving communication between HCP and patient
2. acting as aid memoir to HCPs
3. acting as a prompt to patients
4. providing ease of access to data for quality assurance measurement.

It is **not** intended to be a comprehensive source of patient information.

How it was developed?

A facilitator was appointed and a working group set up, based on a call to the BAUN membership to get involved with this project. At this stage we also engaged with the NICE quality standards department regarding potential endorsement of the document. Once a decision was made regarding what content was required, people were allocated content to write. This took into account who would be expected to complete each of the sections within the document (i.e. the patient/carer and/or a health professional).

The submissions were collated and reviewed by the co-ordinator and the first draft completed. At this stage we formally engaged with external groups for feedback. There were four rounds of feedback, document update and review. The organisations involved included BAUS, BAUN, Fight Bladder Cancer, Action Bladder Cancer UK, NICE, Individual Oncologists, and individual patients. Draft 5 was sent for professional formatting in A5 and A4 format to be hosted on the BAUN website. The final draft has sent to NICE for endorsement (decision pending at time of writing). A review date has been set to ensure the document continues to comply with best evidence.

The bladder cancer PHR will be launched formally at BAUN conference 2016 and will be promoted through the BAUN Newsletter and social media, also FBC magazine and via BAUS and TUF.

Contents of the PHR

The bladder cancer PHR contains sections on:

- Diagnosis and other clinical information
- Keyworker (usually a Clinical Nurse Specialist (CNS) or other Healthcare Professional (HCP)), and other useful contacts
- The Multi-disciplinary team (MDT)
- Record of Information booklets provided
- Space for patients questions
- Record of appointments
- Record of any bladder cancer related medication
- Support groups (local and national)
- Clinical trials for cancer that are available for particular types of bladder cancer
- Holistic Needs Assessment (HNA) Questionnaire and care plan
- Treatment pathway
- Proposed follow up schedule and treatment record for each treatment type
- Symptom scoring sheets used for assessing any treatment related symptoms and the planned treatment to deal with these

Structure/design

The bladder cancer PHR is designed to be used flexibly. It is produced in a printable PDF format, which it is intended the patient will keep and bring to each subsequent appointment. An electronic or paper copy can also be held in the hospital, if desired, by the care giving team. It is proposed that the template PHR be downloaded from the BAUN site and customised to incorporate each Trust's logo, local MDT and support groups. It can then be personalised with the individual patient's name and NHS number prior to printing.

The PHR contains core pages for all newly diagnosed patients (introduction, assessment tools, MDT, support groups, record of assessments, care plans and patient information given, appointments, clinical trials for bladder cancer, Holistic Needs Assessment and care plan, symptom questionnaires, clinical information at diagnosis). Additional inserts can then be printed and record pages added to suit the appropriate treatment and follow-up according to the agreed treatment plan (e.g. initial treatment plan, surveillance cystoscopy record, intravesical treatment record). Additional pages for HNA's, questions and comments and treatment records can also be added.

How to use this PHR

The core PHR should be offered to the patient at diagnosis by the keyworker having been personalised with the patient's details.

The keyworker will discuss the contents of the PHR along with any patient information booklets offered and will help the patient complete the clinical pages of the PHR and explain how it will be used. Supplementary sections and assessment forms can be printed as and when required and added to the PHR which the patient will bring to each appointment. The keyworker will help complete the relevant sections at each visit or when appropriate.

Care was taken during the development of this PHR to incorporate all aspects of the care of a person with bladder cancer that are subject to quality assurance measures. The PHR will therefore also provide a rich source of data for audit and quality control e.g. NICE Quality Standards ⁽⁵⁾ and NICE diagnosis and management of bladder cancer ⁽⁶⁾.

1) *Patient held records toolkit*. NHS modernization agency, cancer services collaborative 'Improvement Partnership' (Available Online) Last accessed 25.8.16 at <http://www.qualitasconsortium.com/index.cfm/reference-material/service-transformation/patient-held-records-toolkit/>)

2) *Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review* 'Health Expectations' Volume 10, Issue 1 March 2007 Pages 75–91 Open Access Marjolein Gysels MA PhD, Alison Richardson BN(Hons) MSc PhD RN PGDip Ed RNT, Irene J. Higginson BMBS FFPHM PhD FRCP

3) *Patient-held medical records for patients with chronic disease: a systematic review* Qual Saf Health Care 010;19:1-7 Henry Ko, Tari Turner, Christine Jones, Caron Hill

4) *Patient Held Record Workshop* with the NHS England Patients Online Group 29 July 2015 <http://rippleosi.org/patient-held-record-workshop-with-the-nhs-england-patients-online-group/> Available online. Last assessed 25.8.16

5) *Bladder Cancer: NICE quality standard [QS106]* Published date: December 2015 Available online. Last accessed 30.08.2016 at <https://www.nice.org.uk/guidance/qs106>

6) *Bladder cancer: diagnosis and management. NICE guidelines [NG2]* Published date: February 2015 Available online. Last accessed 30.08.2016 at <https://www.nice.org.uk/guidance/ng2>

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