



Bladder Cancer Patient Held Record

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Patient Held Records

- Commonly used in other healthcare specialities e.g.
 - Antenatal care
 - Personal Child Health Record
 - Diabetes and other long term conditions

Benefits of Patient Held Records

- Increased satisfaction with information and communication
- Patients feel more involved in their care
 - Acts as an aide memoire
 - Empowers patients to ask questions
 - Somewhere to record thoughts and feelings
- Source of information
- Tool for sharing information across the healthcare system

Disadvantages of Patient Held Records

- May increase anxiety for some patients
- Patients may feel that they have unwanted responsibility
 - HCP's not asking for it to record episodes of care

BAUN Bladder Cancer Patient Held Record (PHR)

- Aims to:
 - Be used by patient and clinician to incorporate all aspects of clinical information and the treatment summary
- To ensure:
 - A single, accurate and up to date record

Objectives of the Bladder Cancer PHR

- To improve communication between healthcare professionals (HCP's) and patients
- To provide a record of discussions for patients about their care
- To act as an aide memoir to HCP's
- To act as a prompt to patients
- Help patients to feel more in control
 - **It is not intended to be a comprehensive source of patient information**

Development of the PHR

- NICE contacted BAUN – Quality Standards development
- BAUN appointed a working group and lead
 - Content agreed
 - Work divided up
 - Submitted work reviewed by the Lead and draft drawn up
- Consultation with key stakeholders
 - BAUS
 - Fight Bladder Cancer
 - Action on Bladder Cancer UK
 - NICE

Contents of BAUN Bladder Cancer PHR

- Key worker and other useful contacts
- Diagnosis and staging information
- Holistic Needs Assessment (HNA) care plan
- Record of information given
- Record of Assessment information completed e.g. HNA, Treatment Summary
- Space for patient questions
- Record of appointments
- Smoking cessation advice record

How to Use the BAUN PHR

- Patients should be offered a copy of the PHR
- Trust/Hospital Name can be inserted
- Patient details can be inserted
- Can be electronically completed or printed
- The contents of the PHR should be explained to patients
- Add any other specific information
- Patients should be encouraged to bring the PHR to appointments for completion
- Remember to ask for the PHR so it can be completed

References

- BAUN (2016) Your Diagnosis and Treatment Record [Online] Available at: http://www.baun.co.uk/files/9114/9440/8889/Bladder_Cancer_PHR_core_document.pdf
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- Sexton F (2017) Patients Have Rights. How Will The Bladder Cancer PHR's Benefit You? *Fight Magazine* pp. 18-19.
- Sartain S, Stressing S, Prieto J (2014) Patients' views on the effectiveness of patient-held records: a systematic review and thematic synthesis of qualitative studies [Online] Available at: <http://onlinelibrary.wiley.com/doi/10.1111/hex.12240/full>