Cancer Services Collaborative
‘Improvement Partnership’

Patient-held records toolkit
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(available via www.modern.nhs.uk/cancer)

Templates include:

- introductory page template (template A)
- about me template (templates B and C)
- example questions template (template D)
- outline plan template (templates E, F and G)
- bodychart template (template H)

- care team contact details sheet template (template I)
- current medication record sheet template (templates J, K, and L)
- test results record sheet template (template M)
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Appendix 1: table containing information about a selection of patient-held records developed across the Cancer Services Collaborative ‘Improvement Partnership’

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References
Welcome to the patient-held records toolkit.

This document has been developed by a core group working across the Cancer Services Collaborative ‘Improvement Partnership’ (CSC’IP’) to assist teams wishing to produce or develop a patient-held record.

Background to this work

One of the main objectives of the CSC’IP’ is to improve the experience and outcomes for patients with suspected and diagnosed cancer. In relation to this, a number of CSC’IP’ project teams have set about work to develop and implement patient-held records as both a means of involving patients/carers in their care and also to improve information flows and communication between the different groups of people involved in their care - including links between the hospital and the community.

Alongside the widespread activity ongoing across the CSC’IP’ in relation to developing patient-held records, it has also been recognised many other CSC’IP’ teams wish to produce this type of resource locally.

In response to this, the CSC’IP’ National Patient Experience Project, in collaboration with the CSC’IP’ National Primary Care Project, agreed to undertake a piece of work to facilitate the future development of patient-held records across the CSC’IP’. One of the key aims of this work was to draw on and learn from the experiences of those teams that have already produced, implemented and evaluated patient-held records at a local level. From the outset it was envisaged that in order to share good practice a series of templates would be developed. These could be customised locally, to assist teams wishing to develop patient-held records in the future.

The first stage of this work involved collating and examining examples of patient-held records already in use across the CSC’IP’ (refer to appendix one) and to summarise the main features and functions of each. Information was also gathered about the type of techniques that have been used to evaluate these materials and also any barriers to implementation that CSC’IP’ teams might have faced in the past.

The next stage was to bring together key people who had been involved in developing patient-held records. Details of who attended this meeting, and also of those individuals that have been involved in developing this toolkit, are set out in appendix two.
**Aims of this document**

- To assist CSC’IP’ teams wishing to develop patient-held records - by taking account of, and building upon, the work already ongoing and the lessons learnt across the wider CSC’IP’
- To provide examples of items that could be included within a patient-held record

**Who is the toolkit for?**

The toolkit is for anyone who wishes to develop a patient-held record for cancer patients and carers. This may include CSC’IP’ facilitators/managers, service improvement leads, clinical nurse specialists, network lead nurses, doctors, GPs, etc.

**Structure of the toolkit**

**Section one: practical information**

This section of the toolkit contains information about the following:

- practical issues/general guidance to consider when developing a patient-held record
- hints and practical advice in relation to implementing and evaluating a patient-held record

Please note that in pulling together this section of the document we have drawn on some of the key material contained in ‘Patient-held records toolkit’ (1) developed by the Coronary Heart Disease Collaborative.

**Section two: templates**

This section of the toolkit can be found on the CSC’IP’ website. It contains a series of templates/example items that you might want to make use of when developing a patient-held record, e.g.

- a body plan
- information about national support groups
- some example questions
- a glossary of medical terms
- a sheet detailing future appointments

A selection of a few, or all, of these items can be downloaded from the website and customised locally in order to assist with the local development of a patient-held record.

Please note that all of the items contained within this section of the toolkit have been taken from patient-held records developed across the CSC’IP’. Agreement over the items to include as templates was sought amongst patients/carers and health professionals during the developmental stages of this document.
This section contains practical information for teams wishing to produce a patient-held record.

**What is a patient-held record**

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.

**Basics**

It is important to think carefully about the purpose of the record and who will use it. Within this, consideration needs to be given to who will be expected to complete each of the sections within the document (i.e. the patient/carer and/or a health professional). Careful thought in relation to this at the outset should help to determine what information to include within the record.

Furthermore, early consideration should also be given to basic quality issues underpinning the information to be inserted in a patient-held record. For example, is the information:

- up-to-date and who will be responsible for ensuring this on an ongoing basis?
- clear and straightforward
- accessible - avoiding jargon
- respectful

It can be very beneficial to form a small team made up of representatives of the individuals who will be using the record, including healthcare professionals and patients/carers, to develop the record. This will help to ensure that the finished product is appropriate for those using it.

**Case Study:**

One of the difficulties it seems with developing a patient held record is whom the record is being developed for - patient or health professional. A group of health professionals in Oldham from primary up to tertiary care who are involved in a Primary Care Project for the CSC’IP’ developed two questionnaires to seek the views of patients and health professionals. The project is exploring the values and merits of formalising patient held information and the impact this will have on communication.

This work was patient driven and therefore before developing what the health professionals thought patients would want, ideas were sought directly from a group of 400 patients, randomly selected, with or who have had cancer. In order to take this forward, a questionnaire was developed which gained local ethical committee approval. At the same time a questionnaire was developed for use with a group of 400, randomly selected, health professionals involved in the care of the same group of patients. All questionnaires were confidential and anonymous. The aim of this broad approach was to explore common themes which could be used to inform the future direction of the project.

Please note that both questionnaires used in this piece of work have been included in appendix four (available via [www.modern.nhs.uk/cancer](http://www.modern.nhs.uk/cancer)).

Over the past five years the National Cancer Alliance has conducted extensive work with professionals, patients and carers to develop the Teamwork File - part of which incorporates a patient-held record. [www.teamwork.org.uk](http://www.teamwork.org.uk)
Content of the record

Before deciding what a record should contain you will want to decide what level of involvement the record is aimed to promote. You can then ensure that all sections of the planned record contribute to this aim.

Typically, a patient-held record may contain the following information (N.B. Please note that this list is not exhaustive and you should base your record’s contents on your own specific situation and purpose). Example items (derived from actual patient-held records developed the CSC’IP’) from this list can be found, in template form, within section two (available via the website). These can be downloaded and customised locally to assist with the development of a patient-held record:

i) space for health professionals to record details about:

- diagnosis
  A sheet containing basic, summary information about the diagnosis can be helpful - and a diagram, where appropriate might be used as a specific way of highlighting this information.

- treatment plan (refer to templates E, F and G)
  Many patient-held records contain a sheet to record basic information about any treatments that may be planned (e.g. chemotherapy, radiotherapy, surgery, etc.) alongside details of any possible side effects. Providing a quick overview of the patients’ pathway can be particularly useful to the Primary Health Care Team for anticipating the patient’s supportive care needs.

- ongoing care record
  A sheet outlining information about ongoing care can be utilised to provide a summary of both outpatient and GP appointments. This section should be locally designed to reflect the aim of the patient-held record. Many teams have chosen to suggest that patients, carers and professionals write in the same section so providing a ‘diary of events’ approach. The most recent entry can then be easily read and noted and responded to. Other teams have chosen to separate out the section into professional and patient entry. The potential drawback to this is that the patients’ entry may get overlooked.

- current medication (refer to templates J, K, and L)
  This section can act as a reminder for patients about their medication and provides an at-a-glance record for health professionals. It may be particularly helpful to record changes in doses and the reasons for these changes and to keep information about medication, and possible side effects, in one place.

- test results (refer to template M)
  A sheet containing basic information about test results (e.g. blood tests, x-rays and scans) can be a helpful summary for patients and health professionals.

- care team contact details (refer to template I)
  Information about how to contact key professionals involved in a patient’s care could be stored on a single sheet within the record. Alternatively the record could also include space to insert the business cards of key health professionals.

- forthcoming appointments (refer to templates N and O)
  This section might contain details of all forthcoming outpatient and GP appointments - the information recorded could include date, time, nature of appointment and details of the department to attend.

ii) space for the patient to record:

- about me - personal details (refer to templates B and C)
  An issue, often identified by patients, is the necessity of providing the same basic information at each appointment. A page in the record can help to avoid this.

- specific questions
  Space for patients to record specific questions that they wish to ask health professionals during their consultations can be helpful.

iii) other information

- introductory page (refer to template A)
  This section should aim to provide basic information, including:
  - the aim of the record
  - how the patient might benefit from it
  - what is expected from the patient/health professionals in relation to the record
  - who to contact for further information
example questions (refer to template D)
A sheet containing a sample of questions frequently asked by patients to members of the care team might be helpful as a prompt. The examples included on this template may be a helpful starting point.

• glossary of medical terms (refer to templates P)
A sheet outlining some of the key terms that patients/carers may come across might be helpful. The type of items included on this list could be adapted to suit the needs of the patients/carers that will be using the record in practice.

• a body plan (refer to template H)
Presented as a complete body plan, many teams have added to this with a more detailed diagram of the area specific to the relevant cancer. This could be inserted onto the same page.

• map of the hospital
Provision of a map of the local hospital illustrating the location of all relevant departments can be a helpful addition to a patient-held record.

• details of national support groups (refer to template Q)
Contact details for various national tumour-specific and/or generic support organisations can act as a helpful signpost to further sources of information and support for patients and their carers.

• specific information (e.g. about a particular treatment, etc.)
Provision of specific pieces of written information, which is relevant to the individual patient, can also be inserted into the patient-held record.

Size
The size of the record should be carefully considered. It depends on whether the record is a complete document in itself, or if it needs to have information added at different times in the patient’s pathway. In the latter case, pages could be loose leaf, with perhaps a pocket to hold specific information such as test results etc. Many examples of this type of ‘flexible format’ record have been designed and utilised across the CSC’IP’ (refer to appendix one for details). However, it is important to remember all information within the patient-held record should be timely and appropriate to the individual patient pathway.

Consider how and when patients are going to carry their record. Does it need to fit into a pocket, handbag, etc? Do they need to carry it with them at all times? Too small and it could get lost, too big and it will be too cumbersome to carry around.

Design
The record should look inviting, eye catching, easy to read, use and understand. Headings, pictures and colour may be used to accentuate areas of importance and specific areas highlighted to encourage patients’ input into the record. Patients may remember, or find easier to use, picture prompts rather than reading full paragraphs.

The record should be easily identifiable, if possible bearing the NHS logo and standardisation across different areas should be considered to assist this.

It is probably a good idea to discuss the record with the medical illustrations department in your local trust - they may be able to give you a recommendation on layout and cost implications. Local university design departments may also be able to help.

Language
Written information needs to be ‘noticed, read, understood, believed and remembered’ (2). Whatever type of record you are developing, you should consider the user’s literacy levels, ethnic background or visual ability when choosing the language, style and format. It is important to remember that patient-held records may not be appropriate or the best form of communication for some people. Not everyone can see, read or understand written information. Therefore, where relevant, other forms of information provision might be more suitable (e.g. providing patients with an audio-tape of each significant consultation).

Patient information should be evidence-based, as far as possible, peer reviewed, contain references, be dated, give an objective measure of readability and be evaluated (3).
TOP TIP:

• The Department of Health has developed a toolkit for producing patient information. Further details about this document can be found on the internet - www.doh.gov.uk/nhsidentity

Copies can be ordered via the NHS response line on 08701 555 455.

Readability

In order to achieve a wide level of readership, information must be written in plain English. Advice can be obtained from the Plain English Campaign, although this will incur a cost (refer to Appendix 3 for contact details).

It is worth doing a simple readability test. The Gunning Fox test (4) is a simple numerical index of readability.

Proof-reading by patients/carers can help in gaining the balance between writing in a simple manner understandable by most people and a style that is so simple that it sounds patronising and lacking ‘authority’. Always give a deadline for comments to be returned.

Ethnicity

Consideration of the number of users having a different language needs to be borne in mind when planning and developing a patient-held record. Everything should be written with an awareness of cultural sensitivities.

Other considerations include use of short sentences and simple words. Personalise your information by using the ‘active’ rather than the ‘passive’ voice, i.e. ‘you should’ or ‘please’ rather than ‘it is preferable that...’. Correct grammar, spelling and punctuation are essential for credible information.

The Gunning Fox Test

1. Choose a passage of about 100 words, which must end in a full stop.
2. Find the average sentence length by dividing 100 by the number of sentences.
3. Find the number of long words, defined as those of three syllables or more, excluding (a) proper nouns; (b) combination of easy words, like photocopy; (c) verbs that become three syllables when “-es”, “-ing”, and “-ed” are added (for example, committed); (d) jargon that the reader will know.
4. Add the average sentence length to the number of long words.
5. Multiply by 0.4 to get the ‘reading score’.

Comparisons

<table>
<thead>
<tr>
<th>Level of difficulty</th>
<th>Reading score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tabloid newspapers</td>
<td>8-10</td>
</tr>
<tr>
<td>‘Serious tabloids’</td>
<td>11-13</td>
</tr>
<tr>
<td>Learned journals</td>
<td>14 plus</td>
</tr>
</tbody>
</table>

Format

Leading spacing; the space between one line of type and the next (known as leading) is important. As a general rule, the space should be 1.5 or 2 times the space between the words on the line.

Boxes; the use of boxes and tables is a valuable visual representation of results. However, box size is important to consider. If free text is to be placed within a box, consider the space this would take. If a tick, cross, yes or no is required, prompts indicating this are useful. A clear guide for using the record can prove invaluable in the success of a record that requires interaction with a variety of people.

Print guidelines

The principles set out below and on page 8 have been taken from the ‘toolkit for producing patient information’ which has been developed by the Department of Health - for further information about this publication refer to the ‘top tip’ box above.

These basic principles should be applied when you are developing a patient-held record. A large number of patients using the NHS will be over 40, and clear, legible print with the lines not too close together will make documents easier to read.

• font-size: 12 point (minimum) to 14 point but if you are writing information for the elderly or people with sight difficulties always use 14 point or larger
Implementation
It is essential that you ensure all professionals involved in developing the patient-held record are aware of the plans for implementing it in practice. Setting up a multi-disciplinary team at the outset, which includes patients/carers, will be beneficial in this respect. Consideration should also be given to the process underpinning the dissemination of the record in practice - i.e. at which point in the cancer journey will patients/carers be offered a copy of the resource?

Prior to implementation, records need to be approved, and agreed, by all professionals involved. In particular agreement should be sought around who will be responsible for:
• offering the record to patients
• writing information in the record
• updating the record

Often the information entered into the record will mean duplication as hospital/GP records will also need an entry. This should be highlighted before implementation and agreement reached as to the detail and style of entry into the patient held record. It is also important to gain approval and support of the organisation (e.g. acute hospital/primary care trust) where the records will be used.

In the initial phase of development a champion/facilitator is useful to take the process forward and ensure that accurate information is given to patients and carers. It is also important that this champion/facilitator is able to professional participation.

It is often better to carry out a pilot project before using the record widely. This will help address any anxieties. The pilot study can be very small. This may mean trying out the record in one practice or if appropriate trying it out with a small group of patients across a hospital setting. This can be decided locally and will often depend upon available resources.

Prior to final production, thought needs to be given to how many copies of the patient-held record should be produced. Ordering a large amount may be cheaper but it is sometimes more wasteful, as old versions can go out of date quite quickly.

Evaluation
Evaluation of the records can begin as early as three months after they are implemented. It is important to agree on the objective/s of the developed record at the start of the process in order to develop evaluation criteria.

Everyone involved in developing and using the record should be encouraged to take part in the evaluation. Results of the evaluation should then be used to improve the record.

Across the CSC’IP’, teams have utilised a variety of different approaches in order to evaluate patient-held records. The main approaches that have been used to gather patient/carer feedback include questionnaires and semi-structured interviews (refer to appendix one for further details).

Durability
If the record is in regular use it will quickly become shabby, so attention should be paid to the durability of materials used. Record cards and information sheets should be kept in a plastic wallet, and file binders are often used.

Where a particular section of the record is used regularly and soon becomes full (such as the medication section), the use of continuation sheets should be considered rather than a completely new record requiring the copying over of all the information from the previous version.

Costs and funding
Producing a quality product, which is clear and durable, will cost money. Sources of funding should be examined once an estimate of likely cost has been made.

• use a medium weight typeface for example Frutiger roman or Arial
• contrast: use a light background with dark print
• it is acceptable to use a dark background with white print (reversed out) for headings, but not for a large section of text
• use a sans serif font - Frutiger or Arial
• justify the text to the left only
• use one or two colours
• do not write text over background pictures or a design

PATIENT-HELD RECORDS TOOLKIT
Section one
Section one

Practical checklist

Ask yourselves these quick questions before you begin to develop a patient-held record . . .

Basics

• what is the purpose of the record?
• who will be using the record and how?
• who should be involved in developing it?
• is there an existing record that you can adapt/improve?

Practicalities - have you thought about the following?

• size
• design
• use of images
• language
• readability
• ethnicity
• style
• format
• durability
• cost
• confidentiality and ethics

Implementation

• do you have an implementation plan?
• who can help you to implement the record (champions/facilitators)?
• what training will users of the record need?
• when and how will the record be evaluated and who will be involved in the evaluation?
SECTION TWO: Templates

A series of templates/example items that can be used when developing a patient-held record are available on www.modern.nhs.uk/cancer. These items have been taken from patient-held records developed across the CSC’IP’ and include:

- introductory page - template A
- about me - templates B and C
- example questions - template D
- outline plan - templates E, F and G
- bodychart - template H
- care team contact details sheet - template I
- current medication record sheet - templates J, K, and L
- test results record sheet - template M
- appointments record - templates N and O
- glossary of medical terms - templates P and Q
- details of national support groups - template R

Each of these templates is available in Microsoft Word format. It is envisaged that they can be downloaded and customised to suit local requirements.

As indicated in section one, it is important to note that this list of items is not exhaustive and has been pulled together in order to provide an idea of the type of information that you might want to include within a patient-held record. However, final decisions around content should be based on the specific situation and purpose of the record – and should be discussed with all stakeholders involved in the development process locally.
## CURRENT MEDICATION

**Medicines and Remedies**

This page is for you to make a note of your prescribed medicines. You can use it to make notes about what the medicine is for and what to do if you have any side effects. Jot down the names of any over the counter medicines or remedies you take.

<table>
<thead>
<tr>
<th>Date</th>
<th>Medication</th>
<th>Purpose of medication</th>
<th>Possible side effect</th>
<th>What to do about the side effect</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

**Allergies:**

Please write in any medications taken, including those the doctors have not prescribed.

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Body Plan - To help my Care Team explain where my cancer is
## Appendix one

A selection of patient-held records developed across the CSC

<table>
<thead>
<tr>
<th>Contact</th>
<th>Title/tumour type</th>
<th>Use of resource</th>
<th>Summary of contents</th>
<th>Structure/design</th>
<th>Method of evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bolton Hospitals NHS Trust (Greater Manchester &amp; Cheshire Network)</strong></td>
<td>Patient-held record of appointments/prostate patients</td>
<td><strong>When is it offered to patients?</strong> First hospital visit</td>
<td>Contains space for health professionals to record: • Appointments to record: (incl. date and time, nature of the appointment and department to attend) • Comments/results</td>
<td>A5 (4 page) booklet</td>
<td>Plans to do this via the Hospital Information Group</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Who by?</strong> Cancer Nurse Specialist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>How is it meant to be used?</strong> • Patients asked to bring booklet to each appointment • Health professionals encouraged to fill in relevant information.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Contains space for patients to record:</strong></td>
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<tr>
<td></td>
<td></td>
<td>• Useful phone numbers • Names of core members of the team</td>
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<tr>
<td></td>
<td></td>
<td><strong>Contains other info:</strong> • A map showing key departments within the hospital</td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Yeovil Hospital / East Somerset NHS Trust (ASW Network)</strong></td>
<td>Patient Held Diary/lung patients</td>
<td><strong>When is it offered to patients?</strong> At first appointment</td>
<td>Contains space for health professionals to record: • Relevant comments about a patient's progress • Details of the respiratory care team • Details of all appointments (incl. time, date) • Medication information</td>
<td>A5 (4 page) booklet</td>
<td>Questionnaire</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Who by?</strong> Lung Nurse Specialist</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td><strong>How is it meant to be used?</strong> • Patients are encouraged to bring the diary with them when they visit the hospital or GP. • Members of the healthcare team are asked to enter details in the diary if treatments or drugs are changed.</td>
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<tr>
<td></td>
<td></td>
<td><strong>Contains space for patients to record:</strong></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>• Any of the above information</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td><strong>Contains other info:</strong> • Information about having a bronchoscopy/CT scan/lung biopsy • Information about radiotherapy, chemotherapy, surgery &amp; palliative care (incl. useful phone numbers) • National support/info services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Doncaster &amp; Bassetlaw Hospitals NHS Trust (North Trent Cancer Network)</strong></td>
<td>Personal Health Record/lung patients</td>
<td><strong>When is it offered to patients?</strong> Around the time of diagnosis</td>
<td>Contains space for health professionals to record: • Information about patients' illness • Details of hospital appointments • Information about health professional visits • Medication • Health events</td>
<td>A5 booklet</td>
<td>Using a questionnaire</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Who by?</strong> Macmillan lung CNS/member of Palliative Care Nursing Team</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td><strong>How is it meant to be used?</strong> • Patients are asked to bring the record to their appointments • Patients can use it to keep a diary of events/concerns about their illness. • Health professionals are also encouraged to fill in relevant information.</td>
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<td><strong>Contains space for patients to record:</strong></td>
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<tr>
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<td></td>
<td>• Any of the above information</td>
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</tr>
<tr>
<td></td>
<td></td>
<td><strong>Contains other info:</strong> • A plastic folder to store contact cards</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact</td>
<td>Title/tumour type</td>
<td>Use of resource</td>
<td>Summary of contents</td>
<td>Structure/design</td>
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<tr>
<td>Trafford Healthcare NHS Trust &amp; Salford Royal Hospitals NHS Trust (Greater Manchester &amp; Cheshire Network)</td>
<td>Patient communication record/lung patients</td>
<td>When is it offered to patients? After diagnosis - at home visit</td>
<td>Contains space for health professionals to record: • Info about the diagnosis (including diagrams to add info to)</td>
<td>• A5</td>
<td>Postal questionnaire</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Who by? Specialist Nurse</td>
<td>Contains space for patients to record: • personal info (including space to draw a family tree)</td>
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<td></td>
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<td>How is it meant to be used? • Patients are encouraged to bring the record to their appts and show it to health professionals involved in their care</td>
<td>Contains space for patients to record: • details of key health professionals • info about specific questions to ask • key symptoms • space to make notes about problems or concerns • details about ongoing communication with health professionals • info about treatment plan &amp; current medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Milton Keynes General NHS Trust (4 Counties Network)</td>
<td>PSA and treatment log/prostate patients</td>
<td>How is it meant to be used? • Patients are encouraged to bring the card with them to every visit (incl. to the GP) so that any relevant info can be filled in</td>
<td>Contains space for health professionals to record: • Info about PSA level/relevant treatment</td>
<td>• Folded A5</td>
<td>Postal questionnaire</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Contains space for patients to record: • Personal details</td>
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<td></td>
<td>Contains other info: • Contact numbers for consultants and specialist nurses</td>
<td></td>
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<tr>
<td>Northern Cancer Network</td>
<td>Chemotherapy record/generic</td>
<td>How is it meant to be used? • Patients are encouraged to carry the booklet with them at all times whilst they are having treatment (and to share it with other health professionals such as GPs, chemists, etc.)</td>
<td>Contains space for health professionals to record: • Information about a patient’s treatment and who to contact in an emergency</td>
<td>• Half A5</td>
<td>Postal questionnaire</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Contains space for patients to record: • Info about infections • Details of side effects • Info about medications • Info about appointments</td>
<td></td>
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<tr>
<td>Derby Royal Infirmary (Derby Burton Cancer Network)</td>
<td>Clinic Record Sheet/prostate &amp; gynaecology patients</td>
<td>How is it meant to be used? • The sheet is completed in clinic and returned to the patient following each consultation</td>
<td>Contains space for health professionals to record: • Date of appt • Who patient was seen by • Test results • Date of next appointment • Details of information given • Contact details for nurse specialist/local support organisations • Details of other support organisations/websites</td>
<td>• A5 style</td>
<td>Questionnaire</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Contains space for the pt to record: • Questions to ask clinical team</td>
<td></td>
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</tr>
<tr>
<td>Contact</td>
<td>Title/tumour type</td>
<td>Use of resource</td>
<td>Summary of contents</td>
<td>Structure/design</td>
<td>Method of evaluation</td>
</tr>
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<tr>
<td>Royal Brompton Hospital (West London Network)</td>
<td>Patient Information File/lung patients</td>
<td>When is it offered to patients? Diagnosis</td>
<td>Contains space for health professionals to record: • Info on blood tests</td>
<td>A5</td>
<td>Questionnaire contained within the file</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Who by? Clinical Nurse Specialist</td>
<td>• Details about investigations • Medication • Treatment • Additional treatment information • Biochemistry</td>
<td></td>
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<td>How is it meant to be used? • Patients are encouraged to take the file whenever they go to see their medical team, GP, etc.</td>
<td>Contains space for patients to record: • Contact numbers for clinical team &amp; other useful numbers • Questions to ask the healthcare team • Any symptoms to report to the healthcare team</td>
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<td></td>
<td>Contains other info about: • Local and national organisations</td>
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<tr>
<td>South Tees Hospitals NHS Trust (Cancer Care Alliance)</td>
<td>PSA and treatment log/prostate patients</td>
<td>How is it meant to be used? • Patients are informed that they/or a member of the clinical team can record information in the record</td>
<td>Contains space for health professionals to record: • Summary of discussions about diagnosis/test results leading to diagnosis • Outline plan of care • Details of medication • Information about any specialist treatments (chemotherapy/radiotherapy/surgery)</td>
<td>A5 design</td>
<td>Extra pages can be added</td>
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<td></td>
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<td></td>
<td>Contains space for patients to record: • Personal details • Useful contacts and numbers • Specific questions to ask at the next appointment (and some examples of topics that patients often ask about)</td>
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<tr>
<td>Leicester Cancer Network</td>
<td>Patient Held Record/lung and gynaecology patients</td>
<td>When is it offered to patients? At diagnosis</td>
<td>Contains space for health professionals to record: • Planned treatments</td>
<td>A4</td>
<td>Interviews and questionnaires</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Who by? Clinical Nurse Specialist</td>
<td>• Information that the patient has been told • Results of blood tests/x-rays/scans</td>
<td></td>
<td></td>
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<td></td>
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<td>How is it meant to be used? • The patient and the care team can add to information</td>
<td>• Current medication (with space to record possible side effects and what to do about them) • Body plan</td>
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<td></td>
<td>Contains space for patients to record: • Personal details (including GP, district nurse, specialist nurse, consultant, condition, hospital record number) • Sources of help - care team • Questions to ask (also contains some example questions) • Allergies, past/current medical conditions/ complementary treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact</td>
<td>Title/tumour type</td>
<td>Use of resource</td>
<td>Summary of contents</td>
<td>Structure/design</td>
<td>Method of evaluation</td>
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</tbody>
</table>
| South East London Network | Patient Held Record of Care/ gynaecology patients | **When is it offered to patients?** Around time of diagnosis  
**Who by?** Clinical Nurse Specialists  
**How is it meant to be used?**  
• For the patient to carry with them and contains space for the patients, and others involved in their care, to make notes and record other information relevant to the patient’s care | Contains space for health professionals to record:  
• Treatment to date/treatment plan  
• Information about treatment progress  
• Information for other health professionals  
Contains space for patients to record:  
• Contact details for GP/ consultant/nurse specialist  
• Significant past medical history  
• Details of appointments  
• Thoughts/comments/questions/side effects  
Contains other info about:  
• Written contact detail for each Trust across the network (with specialist nurse/ward details) | • A5 photocopied version | Questionnaire |
| Surrey & Sussex Healthcare NHS Trust | Patient-held record /generic | **How is it meant to be used?**  
• For patients and healthcare professionals to write new clinical info or questions about cancer treatment and care | Contains space for health professionals to record:  
• Clinical update - info or changes about treatment or care  
• Medication list  
• Chemotherapy/radiotherapy record  
• Blood test/scan results  
Contains space for patients to record:  
• Contact phone numbers for health professionals  
• Thoughts, feelings or questions  
Contains other info:  
• Contact numbers for support organisations | • A5  
• Extra pages can be added | Looking at how records had been completed plus questionnaires to patient and health care professionals |
| Sussex | Patient-held record /generic | **When is it offered to patients?** As close as possible to diagnosis, as judged appropriate  
**Who by?** Specialist nurses  
**How is it meant to be used?**  
• For the patient to carry with them and contains space for the patients, and others involved in their care (GP, hospital staff, district nurses /other community staff), to make notes and record any changes in medication, etc. | Contains space for health professionals to record:  
• General info on comments page  
• List of medications  
• Chemotherapy/radiotherapy treatment record  
Contains space for patients to record:  
• Personal details  
• Summary of previous medical history  
• Personal notes  
• Useful contact numbers  
• Clinic appointments  
Contains other info:  
• Chemotherapy and infection info for patients and health professionals | • A5  
• Extra pages can be added |
<table>
<thead>
<tr>
<th>Contact</th>
<th>Title/tumour type</th>
<th>Use of resource</th>
<th>Summary of contents</th>
<th>Structure/design</th>
<th>Method of evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Devon Healthcare</td>
<td>Patient hand held record/generic for patients receiving chemotherapy</td>
<td>How is it meant to be used? • For the patient to carry with them - to keep a record of their treatment. Health professionals who prescribe any treatment or give any care are asked to write in the record</td>
<td>Contains space for health professionals to record: • Appointment record • List of medications • Clinical information &amp; notes Contains space for patients to record: • Notes / questions to ask at the next hospital visit Contains other info: • Details of the cancer support team (with contact numbers) • Support information and specific contact telephone numbers • Information on fatigue • Information on medical social workers/specialist Macmillan Palliative Care Team • Other relevant local info (e.g. for head &amp; neck cancer patients)</td>
<td>A5</td>
<td>Questionnaire</td>
</tr>
<tr>
<td>Kent and Medway Cancer Network</td>
<td>Patient-held diary</td>
<td>How is it meant to be used? • The purpose of the diary is to enable patients to record information and observations relating to their care and treatment. It aims to help them find out info about how cancer services work, know and understand the services available to them, know how to get the help and support that is right for them</td>
<td>Contains space for patients to record: • Personal details/questions or concerns / things that are important to them • Info about medicines (incl. prescribed and over the counter) - with details of possible side effects • Details of treatments offered • Advice/info given about diet and teeth • Details about consultations • Info about tests and investigations • Contact details for clinical team Contains other info: • Detailed info on local support organisations (incl. addresses and opening times, etc.) • Info about standards of care to expect, etc.</td>
<td>A4</td>
<td>Extra pages can be added</td>
</tr>
</tbody>
</table>
Acknowledgements:

The development of this document has been a truly collaborative process. We would like to thank everyone who has contributed by sharing his or her experiences, knowledge and case studies.

The following list contains details of the individuals who played a key role in developing this toolkit:

Patient-held records group members

Margot Buchanan - CSC‘IP’ Service Improvement Facilitator, Kent and Medway Cancer Network

Katie Burall - CSC‘IP’ National Manager - Patient Experience

Pauline Burton - CSC‘IP’ Project Manager, Cancer Care Alliance

Janet Butterworth - CSC‘IP’ Project Manager, Greater Manchester and Cheshire

Linda Bycroft - CSC‘IP’ Service Improvement Facilitator, Chesterfield & North Derbyshire Royal Hospital NHS Trust

Andrew Casewell - Patient Representative

Catherine Exley - University of Leicester

Andrew Fenton - National Cancer Alliance

Liz Fox - CSC‘IP’ Service Improvement Facilitator, Queen Mary’s, Sidcup

Marie Hewison - CSC‘IP’ National Manager - Chemotherapy

Fiona Howes - CSC‘IP’ Project Manager, Pan Birmingham

Sheelagh Machin - Programme Manager, Coronary Heart Disease Collaborative

Louise North - CSC‘IP’ Project Manager, East Somerset NHS Trust

Maggie Parsons - CSC‘IP’ Service Improvement Lead, Mid Anglia

Marie Patchett - CSC‘IP’ National Primary Care and Palliative Care Manager

Sue Platt - CSC‘IP’ Project Manager, Leicester

Amanda Ramirez - CSC‘IP’ National Clinical Lead for Patient Experience

Greg Tanner - CSC‘IP’ National Clinical Lead for Primary Care

Ian Watson - Cancer Lead, Oldham Primary Care Trust and GP

Helen Woronowski - Project Support Manager, Sussex Cancer Network
## Further reading / useful contacts

### Further reading

- Toolkit for producing patient information, Department of Health, 2002

### Useful contacts

- Plain English Campaign - PO Box 3, New Mills, High Peak, SK22 4QP (tel: 01663 744409 / fax: 01663 747 038) - http://www.plainenglish.co.uk/
- Centre for Health Information Quality. Tel : 01962 872202
1. Coronary Heart Disease
   Collaborative ‘Developing patient-held records toolkit’ Modernisation Agency

   London: Chapman and Hall


   British Medical Journal, 305: 1266-1268
Cancer Services Collaborative
“Improvement Partnership’
NHS Modernisation Agency
3rd Floor
St John’s House
East Street
Leicester
LE1 6NB

web address: www.modern.nhs.uk/cancer

The NHS Modernisation Agency is part of the Department of Health