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# Policy

## Patient Information Policy

### Key messages

- Patient information (whether in written, audio or other formats) must follow the approved Trust [templates](#), [style and format guidelines](#) and [patient information guidelines](#)
- Approved written patient information is valid for **3 years** unless earlier patient or other requirement
- Written patient information is not a substitute for verbal health professional and patient discussion
- the **Reader Panel** must review all departmental leaflets before publication
- the **Advisory Group for Patient Information** must review all Trust-wide leaflets before publication

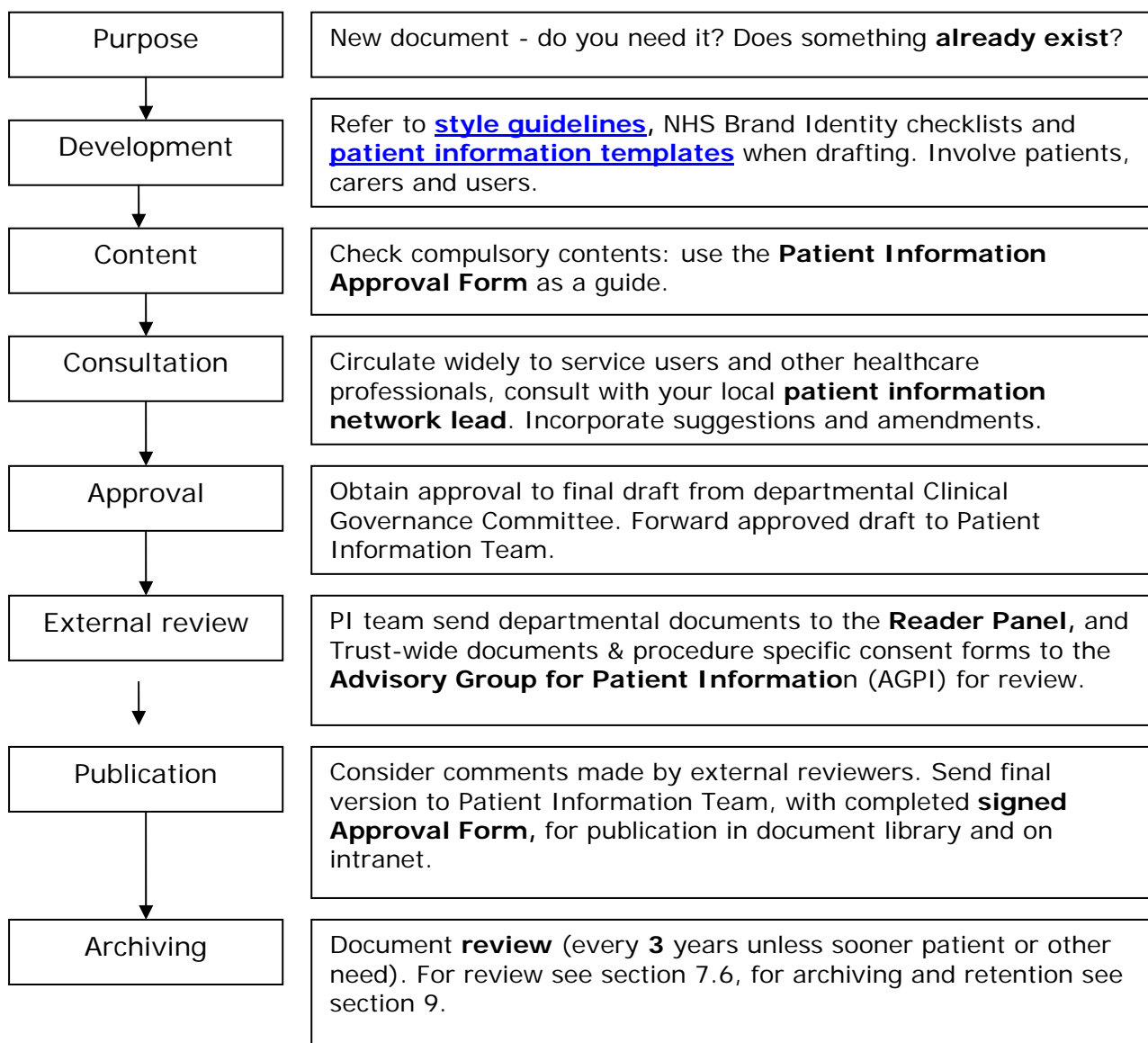
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## Patient Information Team

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### Patient Information summary of process



Numbers refer to section numbers within this policy.

## 1 Scope

Trust-wide.

## 2 Purpose

This policy is intended to define what is meant by 'patient information' and the process by which it is produced, reviewed and monitored within the Trust.

The policy also ensures that the Trust complies with its external obligations to meet the standards laid down by the Care Quality Commission (CQC), the NHS Litigation Authority (NHSLA) and the NHS Constitution.

This policy applies to all staff involved in producing patient information.

The only exceptions are:

- leaflets produced for research projects
- Oncology who use their own review and approval process for written information. Please refer to Oncology's policy document 'Management and Control of Quality Documents' available on Oncolnet (Oncology's intranet):

[http://oncolnet/oncol\\_library/P\\_QS4\\_V7\\_QUALITY\\_DOCUMENT\\_AND\\_DATA\\_POLICY.pdf](http://oncolnet/oncol_library/P_QS4_V7_QUALITY_DOCUMENT_AND_DATA_POLICY.pdf)

- the Rosie Hospital who have their own Rosie Information Committee for developing patient information. For more details contact Chairwoman, Clinical Services Manager (Maternity) on extension 3756.

## 3 Introduction

The [NHS Constitution](#) directs all NHS providers to provide easily accessible, reliable and relevant information to help people make informed choices.

The CQC reinforces this by providing that people who use health care services need to be given information which enables them to make appropriate choices, to make informed decisions about their health and care and which enables them to lead healthier lives.

The aim of this policy is therefore to ensure that the Trust develops high quality patient information, whether it is in written, audio or large print format. High quality patient information will have an accurate clinical content reflecting best practice, it will meet the requirements of patients and carers,

it will have a clear format, be easy to understand and will conform to Trust Style Guidelines.

The Trust has a systematic process for developing, reviewing and monitoring patient information. This process has been developed in accordance with recommendations from the Department of Health and the Kings Fund.

Good quality information is central to the patient journey and also the patient's experience. Quality information improves our communication with patients and their carers, as well as improving the care we deliver to them.

## **4 Responsibilities**

### **4.1 The Patient Information Team**

The Patient Information Team, in conjunction with the Advisory Group for Patient Information (AGPI), is responsible for the co-ordination, development, review and monitoring of patient information across the Trust, as well as maintaining guidelines for the development of patient information.

The Patient Information Team will assist authors from clinical departments in developing and formatting patient information, ensuring that they meet the requirements of the NHSLA and CQC standards. The team will inform staff at the beginning of each month of the patient information leaflets that have been added to the patient information library. This is sent in the form of an e-bulletin which is sent to staff groups using email networks 2,3,4,6,7,9,10 and 12. The e-bulletins are also available on connect at the following link: <http://connect/index.cfm?articleid=16826>

The Patient Information Team will not produce patient information; this is the responsibility of the originating clinical department. Where more than one department is involved in producing patient information it would be good practice to involve all the relevant specialties in developing the information. However, it would be practical if one department led on the development and is noted as the 'owner' of the document.

### **4.2 The Advisory Group for Patient Information (AGPI) and the Reader Panel**

AGPI is responsible for directing and advising on the strategic development of patient information across the Trust (with the exception of the Rosie which has its own patient information process). AGPI provides a framework to:

- enable all forms of patient information to be reviewed for quality and content prior to ratification
- raise the profile of patient information
- enable patient information to be accessible to all patient, user and staff groups.

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AGPI reviews the format and content of Trust-wide patient information leaflets and consent forms, and approves them for publication.

**The Reader Panel** is a sub group of AGPI and consists of lay members who are members of the Foundation Trust and members of the public. Reader Panel members are aged 18 and over and hold office for 18 months.

The function of the Reader Panel is to:

- review the quality and format of all local (ie departmental not Trust-wide) patient information and check it meets Trust style guidelines and adheres to the patient information policy on behalf of the AGPI.
- report back reviews to the AGPI, via the Patient Information Team, for approval.

The Reader Panel members review local patient information leaflets once a month and are given two weeks to complete their review. Any changes to the leaflet following the review are made by the Patient Information Team in conjunction with the author. Once the patient information leaflet has been completed, the author must complete an approval form following which the leaflet will be published.

### 4.3 The network of Patient Information Leads

The network of patient information leads comprises a lead contact for development of patient information from each of the clinical departments.

The lead acts as a point of contact with the Patient Information Team and liaises to co-ordinate the development of patient information and timely reviews of patient information within their department.

The Patient Information Team will work with the lead contacts to ensure good working practice in terms of patient information such as removing out of date leaflets from circulation, printing copies of leaflets as required, using Trust Patient Information Style Guidelines and the principles of plain English.

The lead contacts will also advise potential authors on producing patient information and advise the Patient Information Team of all patient information in use in their department, both local and national leaflets.

The lead contact will be the first point of contact for the Patient Information team in relation to assessing unplanned patient information leaflet requests in conjunction with an appropriate author/specialist in the subject in question.

### 4.4 Clinical staff

Clinical staff are responsible for:

- knowing how to access patient information

- ensuring that their departments keep up to date patient information leaflets available
- giving patients information leaflets appropriate to their condition and/or treatment and ensuring that the latest version is provided
- using patient information leaflets to support verbal information given to patients
- identifying the need to develop patient information in line with service requirements
- working in collaboration with their Lead Contact for Patient Information and the Patient Information Team when developing patient information
- adhering to the Trust patient information policy.

## 5 Definitions

### Authors and owners of Patient Information

The author(s) of the patient information will be the individual(s) writing the patient information but the 'owner' of the patient information will be the originating clinical department.

### Patient Information

Patient information is written information about conditions, treatments (surgery and medications), procedures, examinations and services specifically for patients. It can be in the form of leaflets, booklets, sheets or posters, although these may be converted into other media such as audiotapes/compact discs or videos for people with sight or learning difficulties. References to patient information leaflets in this policy include references to patient information produced in other media.

Patient information is not information about patients such as their medical or personal information which is held in medical notes. Nor is it clinical guidelines, protocols, procedures or GP proformas.

Patient information does not include information given to patients verbally by health professionals. Patient information leaflets should be given to patients to support and supplement verbal communication. Written patient information should not be used as a substitute for verbal communication.

## 6 Does patient information already exist? National and Clinical Network Patient Information Leaflets

It is good practice to use leaflets produced nationally or by clinical networks, where possible.

Consider whether **NHS choices** has patient information already available:

<http://www.nhs.uk/Conditions/Pages/bodymap.aspx>

If departments are purchasing or are provided with national or clinical network patient information leaflets eg breastfeeding/cancer then the Departmental Clinical Governance Committee will ensure that it contains the required information. The relevant lead patient information contact should notify the Patient Information Team of the information they are using. This will be recorded on the patient information database. Information should also be available where possible electronically via the Patient Information Library.

If departments are adapting nationally produced leaflets or clinical network leaflets, these will have to go through the same process as locally developed leaflets. It should be noted that some national or network leaflets are copyright and therefore it may not be possible to adapt them.

## 7 Patient Information Process

### 7.1 Development

See the summary of the process for developing patient information leaflets on page two for an overview.

Departments will produce patient information leaflets or information in other media (eg large print or audio). Patient information leaflets (or patient information in other media) regarding conditions, treatments, procedures or services will be developed by doctors, nurses, allied health professionals or managers. Authors will have appropriate knowledge of the condition, treatment, procedure or service.

Departments or clinicians may identify the need for a patient information leaflet. In some circumstances, the Patient Information Team may also identify a need for a patient information leaflet, for example through PALS complaints or patient survey data.

### 7.2 Patient information templates: compulsory content

The **Trust's Patient Information templates** set out the content which must be included in all written patient information leaflets (or other media). This includes the following sections:

- a) department heading, title of information and leaflet heading
- b) who the leaflet is for and the aim of the leaflet
- c) main text of the leaflet
- d) the benefits, risks and alternatives for the treatment or procedure (which is the subject of the leaflet)
- e) contacts or details of further information
- f) statement on privacy & dignity (if applicable to leaflet content)

The templates are available on the Trust's intranet site (within the Patient Information Library) in A4, A5 and DL (3 fold) versions. All templates also

contain the Trust's no-smoking statement and a section entitled 'Help with this leaflet' which contains details of how to obtain translations, audio or large print versions.

### 7.3 Guidance on writing patient information leaflets

When writing patient information leaflets, authors should consider these points:

- the Trust's [corporate style guidelines](#)
  - [Trust style for formatting information](#)
  - [language and writing](#)
  - The Trust's [patient information style guidelines](#)
  - NHS Brand Identity's checklists on producing patient information (set out in [Appendix 1](#))
- the content will be evidence based and reflect current best practice. If reference sources are used, for example the Cochrane library, British Medical Journal, these must be indicated on the information leaflet. If a large number of reference sources have been used in the production of an information leaflet, they can instead be recorded on the patient information approval form (see appendix 4)
  - any conflict of interest, for example alternative views on an aspect of information given, will be highlighted by the author of the patient information leaflet. These must be made clear by the author in the information
  - patient information leaflets do not replace verbal information; they should complement, support and supplement verbal information
  - involve users in the production of patient information, for example, a user could be part of the writing group
  - pilot patient information with users prior to publication, this can be through user groups or by sending patient information to patients for comments.

### 7.4 Process for developing a new leaflet

Before developing new patient information leaflets, authors will liaise with the Patient Information Lead for their area. The authors, the Patient Information Lead and the Patient Information Team will work together to establish whether there is a need for the new patient information leaflet. New authors must have regard to this policy and the style guidelines indicated above.

Authors must use one of the Trust's [patient information templates](#) for development of new patient information.

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The authors' final draft should be submitted to the Patient Information Team who will check that the contents comply with the essential contents of the patient information template. The draft leaflets are then sent, at the beginning of each month, to the Reader Panel for review.

Following evaluation by the Reader Panel, the Patient Information Team may make amendments to the style/format of the information. The author will be informed of all amendments proposed by the Reader Panel and will be asked to confirm agreement.

**Approval of clinical content** will be by the department's Clinical Governance Committee. When the clinical content has been approved, a hard copy of the **signed approval form** should be forwarded to the Patient Information Team. The [approval form](#) is available from the Patient Information Team and also on Connect.

The Patient Information Administrator will use the patient information **approval form** to ensure that all leaflets presented are in the correct Trust style and also have the prescribed contents (as set out in the Trust's [patient information templates](#)).

The Patient Information Administrator prepares a report of all Reader Panel reviews which is presented at the bi-monthly meetings of AGPI.

Requests for unplanned patient information may be raised via a number of avenues, for example comments cards in use in the Trust, the annual patient information survey, focus groups or via the patient information email account. If such requests are received, the patient information network must liaise with the Patient Information Team and vice versa.

An appropriate senior member of staff will be consulted and a decision made to warrant the request made within two weeks, providing feedback to the requestor. If the decision is made to amend a current leaflet, every effort will be made for the amendment to be made within a month. If a new leaflet is to be written, this will proceed through the development process of an information leaflet as detailed in this policy.

## 7.5 Equality and Diversity

When producing patient information, authors will need to consider that the needs of different groups of people. These groups will include people whose first language is not English and people with sight or learning difficulties. People with learning difficulties may need a clinician to go through the leaflet with them, especially if the leaflet has not been specifically designed for people with learning difficulties.

The Trust is committed to providing information to patients in a range of formats. Staff are advised to direct patients or carers to our public website where a range of materials are available in [other languages](#), [easy read](#) and [other formats](#) (including audio).

All patient information will contain a statement asking staff to contact the patient information team if the document is required in a different format or in another language. The Patient Information team consult with CINTRA each year to determine the most widely spoken languages in Cambridgeshire for this purpose.

This follows a legal requirement set out in the Race Relations Amendment Act 2000 and the Disability Discrimination Act 1995. In addition, it is a requirement under the National Service Frameworks and National Strategy for People with Learning Disabilities.

For more information on equality and diversity, contact the secretary of the EIA Review Group on extension 3913.

### 7.6 Fast Tracking Patient Information Leaflets

There may be rare circumstances when it is necessary to develop a patient information leaflet at very short notice in response to a particular need. In this situation, patient information leaflet(s) may be fast tracked for publication.

In such a case the leaflet can be published but will have to contain the following statement:

"This leaflet has been fast tracked for publication and is pending review by the Trust's Reader Panel".

The leaflet will then be reviewed and approved in the two months following publication and no later. The Patient Information Team can agree and document the extenuating circumstances with the author.

### 7.7 Reviewing

The Patient Information Database contains a list of all patient information leaflets in use within the Trust and will include the publication and review dates of the patient information leaflet. Each leaflet will be allocated a Patient Information Number (PIN). Patient information will only be published following allocation of a PIN.

Patient information will be reviewed every three years following publication date or earlier in light of new evidence. The document management system automatically sends an electronic reminder to the Patient Information Team three months before a document is due for review. Reminders are then sent by the team to the author(s) (and copied to the patient network lead contact for that department) and are recorded on the Patient Information leaflet database.

If no changes are made to the leaflet, the leaflet will be published for another three years. If significant changes are made to the leaflet, prior to publication it will require a further review by the Reader Panel if it is a departmental

leaflet, or review by the AGPI if it is a Trust-wide leaflet or procedure specific consent form.

In both instances, a new **signed approval form** must be completed by the owning department (not the author of the information) and returned to the Patient Information Team.

If the author does not respond by the review date with notification of changes or to republish, the leaflet will be deemed out of date. This will be made clear on the leaflet by the addition of a printed watermark to indicate that it is due for review. There will be a consultation with the leaflet owner regarding the expected length of time it will take to review and update the document.

### 7.8 Errors and corrective action

Any errors in information leaflets will be recorded and corrected by the Patient Information Team, with the agreement of the author/patient information network, as soon as possible after notification.

## 8 Patient Information – Publication

When the patient information has been approved for publication and a PIN allocated to it, it will be published electronically on the internet and intranet.

### 8.1 Internet/intranet

The Trust's internal website (intranet) contains a [patient information library](#) and all patient information will be published here including procedure specific consent forms once the Patient Information Team have received a completed approval form from the author.

Trust staff may then print copies of patient information as required. In parallel, subject to confirmation from the author(s), all patient information will be published on the Trust's external website [www.cuh.org.uk](http://www.cuh.org.uk)

This will enable patients and/or carers to print off patient information as needed. Patient information leaflets will be published on the intranet and internet website by the Patient Information Team within a week of receiving the completed approval form.

### 8.2 Hard copies

Authors/staff should print copies of the required patient information from the intranet/internet. This will ensure that up to date patient information is used at all times.

Patients will also be able to obtain printed copies of the patient information leaflet from PALS.

There may be circumstances when it is necessary to pre-print leaflets, in bulk, in A5 or DL format. In this situation, authors should agree this with the

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Patient Information Team. If this is agreed, it is the responsibility of the author to ensure that the finances are available to pay for published leaflets and to contact either media studio or procurement to arrange printing. It will be the responsibility of the Patient Information Lead and the department to remove out of date leaflets from use at the review stage.

### 9 Archiving Patient Information

All patient information leaflets that are out of date and which have been superseded by a newer version will be archived by the Patient Information Team. A copy of each patient information leaflet will be archived including a copy of any revised leaflets which may be electronic or paper copies.

Copies of revised leaflets will be retained in line with the Trust's [records: preservation, retention and destruction](#) policy.

The archive will be managed by the Patient Information Team.

### 10 Sponsorship and Advertising

Sponsorship or advertising on patient information leaflets will be considered on an individual basis. Authors intending to use sponsorship or advertising must discuss this first with the Patient Information Team.

### 11 Website pages

Staff developing websites/pages containing patient information will contact the Online Communications Team to discuss the development of the content and will adhere to the relevant principles of the Style Guidelines for Patient Information and follow the Trust policy throughout.

### 12 Monitoring compliance with and the effectiveness of this policy

#### 12.1 Content, style and format of written patient information

The Patient Information Administrator will use the patient information **approval form** to ensure that all leaflets presented are in the correct Trust style and also have the prescribed contents (as set out in the Trust's [patient information templates](#)). The Programme Manager for Patient Information will conduct six-monthly spot checks on completion of the approval forms to monitor that the policy on monitoring leaflet content is being followed. The results will be included in the annual report which will be presented for review to [the Patient Experience Committee, chaired by the Director of Public Experience and Patient Engagement] who shall oversee any actions needed as a result.

The Reader Panel members complete and return an **evaluation form** (see Appendix 2) for each leaflet reviewed. Reader Panel evaluations are

summarised by the Patient Information Administrator in a regular report presented to AGPI for their review and comments. Any resultant feedback from AGPI to owning departments is conducted by the Patient Information Team and any trends or recurrent comments will also be communicated to the Network Leads.

### 12.2 Requests for alternative formats

The Patient Information Administrator will maintain a database of requests for patient information in other formats, eg other languages or audio or large print. This will form part of the Team's Annual Report (see below) and the information will also be presented to the Patient Experience Committee and Equality & Diversity Steering Group for information, to assist with monitoring the local population's requirements.

### 12.3 Annual Patient Information Survey

The effectiveness of this policy from a patient's perspective is monitored by an annual patient information survey. This survey is sent to 500 patients selected at random by the Information Technology department, aged 18 and over who have been day case, emergency or inpatients at the Trust within the preceding year, to obtain their views on the quality of written information they received.

The results are analysed by the Patient Information Team and the resultant report is sent to the all Network Leads, the Assistant Director of Patient Safety, the Patient and Liaison Service, the Medical Director, AGPI and the Patient Experience and Public Engagement Committee and Director. Highlights and learning points from the survey are also published on the intranet for all staff. The report is available to all participants, free of charge, on request.

The survey highlights are also included in the **Patient Information Annual Report** prepared by the Programme Manager for Patient Information. This report is sent on request to the Trust's lead Commissioner (through the Trust's Commissioning department) and to the Director of Patient Experience and Public Engagement as above.

### 12.4 Archive monitoring

The Programme Manager for Patient Information will conduct six-monthly spot checks to ensure that documents are being archived correctly. Each half year the Programme Manager will look at approximately one dozen patient information leaflets of version 2 or later to ensure that earlier versions have been archived and are easily retrievable. Results of the spot checks will be recorded and summarised in the annual report presented to the Patient Experience Committee (referred to at 12.1 above), which shall be responsible for overseeing any remedial actions needed as a result.

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### 13 Associated Documents

[Records: preservation, retention and destruction](#) policy.

### Equality and diversity statement

This document complies with the Cambridge University Hospitals NHS Foundation Trust service equality and diversity statement.

### Disclaimer

It is **your** responsibility to check against the electronic library that this printed out copy is the most recent issue of this document.

### Document management

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Owning department:	Patient Information		
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### Appendix 1 NHS Brand Identity Checklists

The following checklists are adapted from the NHS Brand Identity website:

<http://www.nhsidentity.nhs.uk/tools-and-resources/patient-information>

They have been produced as guidance to be considered when developing written patient information.

The lists are not completely comprehensive and some things may not be appropriate for certain information leaflets, for example, some procedures do not involve any sort of anaesthetic.

**Please use the Trust templates as the format for your leaflet and use these checklists as guides to help you write the content of your leaflet.**

#### 1. Information about operations, treatments and investigations

- What is the procedure?
- Why is it needed?
- Give facts about the risks, side effects, benefits and alternatives of the procedure, condition or treatment and the likely effects of no treatment so patients know what to expect.
- What preparation is needed, or none at all?
- Does the patient need a general anaesthetic, sedation or local anaesthetic?
- What happens when the patient arrives at the hospital, who will they meet?
- Does the patient need to sign a consent form or is verbal consent sufficient?
- What does the procedure involve? How long does it last? What does it feel like?
- What happens after the procedure – pain control, nursing checks, sutures.
- How long will the patient stay in hospital?
- Does the patient need someone with them or any special equipment when they go home?
- What care is needed at home?
- What follow-up care is needed? Does the patient need to visit their doctor?
- What can go wrong, what signs to look out for and what to do if something goes wrong.
- When can the patient start their normal activities again, for example, driving, sport, sex or work?

#### 2. Information about conditions and treatments

- What condition is being described?
- What causes it? Or, if the cause is not known, say so.
- Does anything increase the risk, for example, age, sex, ethnic origin

or a family history of the condition?

- What are the signs and symptoms?
- Are there any tests or examinations needed to confirm the diagnosis?
- What treatments are available? Give brief descriptions.
- Give facts about the risks, side effects, benefits and alternatives of the treatment and the likely effects of no treatment so patients know what to expect.
- What are the next steps?
- What can patients do for themselves?
- Are there other implications, for example, infecting other people?

### **3. Information about services, for example, cardiac rehabilitation classes or a GP skin clinic**

- Describe the service.
- Start at the beginning where the patient would start, for example, a leaflet about transport might start with how to book it, with a phone number (but check if the patient will already have received the 'Preparing to come into hospital' leaflet which has these details)
- Who is eligible?
- Details of how to access the service.
- Is equipment or special clothing needed?
- Where to go for it, how to find it.
- Is a map needed?
- When is a service available?
- Is there a waiting time?
- How often does a patient need to attend?
- Does the patient need to bring any documents?
- Who to contact if they cannot attend.
- What is or is not available, for example, transport.
- Is an interpreter needed? Can language line be used? Any costs?
- Are there any advantages or disadvantages that need to be explained?

### **4. Information about medication for patients**

- Explain that any information given in a leaflet should be read with any patient information leaflet provided by the manufacturer.
- What medication are you describing and what is it for?
- How is it given?
- How often should it be given?
- What should be avoided or added when taking a particular medication, for example, certain foods.
- What are the side effects? Make sure that you mention that everyone is different so may react differently to medication.
- What to do if medication is not given properly.
- Remind patients to tell the clinician who prescribes the medication about any other medication they are taking.
- Advice on storing medication out of the reach and sight of children, in the fridge and out of the sunlight.

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- Advice on where to get repeat prescriptions.
- A contact number (of the pharmacy, specialist nurse, doctor or NHS Direct) for more information and to check on any concerns about side effects.