

TRUST POLICY/PROCEDURE/STRATEGY AMENDMENT SHEET

DOCUMENT TITLE	Provision of Information for Patients Policy
DATE OF INITIAL AUTHORISATION	27 February 2014
DATE OF THREE YEAR REVIEW	27 February 2017, extended to 29 Feb 2020
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AUTHOR	Steve O'Brien, Associate Director, Quality Amended by Louise Parkinson, Trust Policy Administrator

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6 March 2018	N/a	Review date extended to 31 August 2018
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13/08/2019	All	Extension agreed, Sept 2019 PDRG. Form No: 398

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PROVISION OF INFORMATION FOR PATIENTS POLICY

THIS POLICY SETS OUT THE TRUST STANDARD FOR PROVIDING INFORMATION RESOURCES FOR PATIENTS AND SERVICE USERS, INCLUDING INFORMATION LEAFLETS, AUDIO-TAPE, AUDIO-VISUAL MATERIAL AND IMAGES.

AUTHOR.	AUTHORISED BY	DATE AUTH	POLICY REFERENCE NUMBER
NAME Steve O'Brien	NAME Karen Partington	6 March 18	TP-03
SIGNATURE	SIGNATURE	REVIEW DATE	
ASSOCIATE DIRECTOR QUALITY	CHIEF EXECUTIVE	29 Feb 2020	

TRUST POLICY

This Policy has general application throughout the undertaking of Lancashire Teaching Hospitals NHS Foundation Trust. It represents the governing principles outlined within the document which are fully supported in every respect by the Board of Directors.

All members of staff are required to adhere to the principles involved as outlined within this document, together with any related procedures, which are enabled by this policy.

This Policy was produced in consultation with:

Directorate PI Leads	Chief Librarian
Clinical Governance Co-ordinator	Head of Medical Illustration
Equality and Involvement Lead	Governors

Other Trust Policies/Procedures associated with this document include:

Consent Policy, Communications Strategy, Copyright Policy, Intellectual Property Policy

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Lancashire Teaching Hospitals NHS Foundation Trust Impact Assessment Screening

Policy Title: Information for patients policy **Impact Assessment approved by:**
Policy Author: Steve O'Brien

1.	Does the policy/strategy affect one group more or less favourably than another on the basis of:	Yes/No	Evidence in support of either positive or negative impacts, including references to research and national documents must be provided for the sections below
	1. Race	No	Policy identified action taken to ensure needs relating to race (language) and disability are equally met
	2. Disability	No	
	3. Gender	No	
	4. Sexual Orientation	No	
	5. Religion or Belief	No	
	6. Age	No	
	7. Marriage and Civil Partnership	No	
	8. Gender reassignment	No	
	9. Pregnancy and Maternity	No	
2.	Is there any evidence some groups will be affected differently?	No	
3.	If potential discrimination has been identified is this justifiable (you must explain why)?	NA	
4.	What methods of consultation have you used and with whom please describe?		Consultation with Patient information group members, Governors, staff colleagues, equality and involvement lead
5(a)	Is the impact identified likely to have a negative impact on the Policy/Strategy?	No	
5(b)	Can the impact be avoided?	NA	
5(c)	Are there alternative ways of achieving the aims of the Policy/Strategy to remove the impact?	NA	
5(d)	Can measure be put in place to reduce the impact?	NA	
Comments			Action to be taken (or not applicable) None

Name and designation of person completing this form Steve O'Brien Date 13th December 2013 (If anyone reading this form identifies any potential discriminatory impact that has not been identified on this form, please contact the Policy Author named above, along with suggestions how the impact can be eliminated or reduced.)

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POLICY FOR THE PROVISION OF INFORMATION FOR PATIENTS

1.0 AIM

The provision of good quality information is central to the patients' ability to make valued decisions and informed choices about medical treatment and care. This provision should be accessible to all and include, where appropriate, information about their condition, all possible treatments/investigations and their risks and benefits (including the risks/benefits of doing nothing). They also need to know whether additional procedures are likely to be necessary as part of the procedure, for example a blood transfusion, or the removal of particular tissue. Once a decision to have a particular treatment/investigation has been made, patients need information about what will happen: where to go, how long they will be in hospital, how they will feel afterwards and so on.

Lancashire Teaching Hospitals NHS Foundation Trust is committed to the production of good quality information that is;

- Clear
- Relevant
- Evidence-based
- Authoritative
- Complete
- Secure
- Accurate
- Well designed
- Readable
- Accessible and up-to date

The Trust is also committed to support and uphold the aims of the Information Standard and will ensure that information produced by the Trust and its representatives

- Meets the requirements of the Information Standard
- Will be reviewed regularly and updated as necessary to ensure its ongoing suitability

The Trust will be able to demonstrate that representatives involved in the production of patient information will be aware of and compliant with policy and the requirements of the Information Standard.

2.0 SOURCES OF PATIENT INFORMATION

Information produced by the Trust and its representatives (staff) will be relevant to healthcare services provided by the Trust to the population of Preston, Chorley and South Ribble and to the wider community supported by specialist health services. The following sources of patient information are available in the Lancashire Teaching Hospitals NHS Trust and will be produced, approved and updated in accordance with the standards defined in this policy and associated procedures:

- **Internally produced Patient Information Leaflets**
- **Patient Consent forms**
- **Internally developed Audio- visual materials/interactive materials e.g. iBooks**

In addition the Trust makes available to patients other externally produced information sources that are not subject to the rules and processes described in this policy and associated procedures. These include published information from

- Relevant professional and credible external bodies such as the Department of Health, NHS choices, NHS Evidence, and NICE
- Recognised patient organisations and support agencies,
- Royal Colleges and societies
- Product information leaflets supplied by manufacturers of medicines

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3.0 ROLES AND RESPONSIBILITIES

3.1 Individual Staff

Patients and those close to them will vary in how much information they want: from those who want as much detail as possible, including details of rare risks, to those who ask health professionals to make decisions for them. There will always be an element of clinical judgement in determining what information should be given. However, the *presumption* must be that the patient wishes to be well informed about the risks and benefits of the various options. Where the patient makes clear (verbally or non-verbally) that they do not wish to be given this level of information, this should be documented.

All healthcare staff have a responsibility to ensure that patients are provided with clear, relevant, credible and accessible information to assist patients in making the right decisions about their care and treatment. Staff who provide information resources or direct patients to sources of information as part of their care and treatment should document this in the clinical records.

3.2 Authors of patient information leaflets

Patient information will vary depending on who it is for and what it is about. Authors of patient information will give consideration to the target audience and provide information in a style that is:

- Clear
- Relevant
- Evidence-based
- Authoritative
- Complete
- Secure
- Accurate
- Well designed
- Readable
- Accessible and up-to date

Appendix 1 provides guidance for the production of written information.

3.3 Directorate Patient Information Lead

Each Clinical Directorate has an identified Patient Information Lead who acts as the point of liaison between Directorate staff and the Patient Information Group, and is responsible for collating draft patient information leaflets and submitting them to the Patient Information Group for approval. Following initial approval the lead is responsible for ensuring that periodic review of leaflets (including a review of the supporting evidence) is undertaken in a timely manner to ensure that review and approval takes place before the document expires

3.4 Patient Information Group (PIG)

The Patient Information Group, chaired by the Associate Director Quality meets on a monthly basis to:

- Quality assure and ratify all information for patients that has been produced 'in house'.
- Oversee the review process for all patient information leaflets produced 'in-house'.

Membership consists of Directorate Leads, one Patient Governor, selected by the Chair of the Governors Patient Experience Group and the Patient Information archivist

3.5 Cancer Patient Information Group (PIG)

The cancer PIG team for cancer services will mirror the responsibilities of the Trust Patient Information Group in:

- Quality assuring and ratifying all cancer specific patient information leaflets that are produced 'in house'.
- Oversee the review process for all cancer patient information leaflets that are produced 'in house'.

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The team will meet on at least a monthly basis. Minutes of the meeting will be presented to the Patient Information Group for approval. The process of quality assurance and ratification of new and revised leaflets will be consistent with guidance within this policy.

3.6 The Archivist

The archivist will:

- Facilitate the patient information group meetings.
- Establish the agenda with the Associate Director Quality.
- Maintain an electronic directory of “in-house” produced information on the Trust Internet and intranet sites.
- Maintain an archive of material produced “in house,” once ratified by the PIG.
- Liaise with authors of all leaflets three months prior to the review date to request a review of the leaflet content, prior to review by the PIG.
- Liaise with medical illustration to ensure consistent leaflet production.
- Ensure that the availability of new, or amended, patient information leaflets is circulated to all staff by formal notification in the Trust’s monthly Team Brief communication.

4.0 PROCESS FOR PRODUCTION, APPROVAL AND REVIEW OF PATIENT INFORMATION LEAFLETS

Authors of patient information leaflets should follow the guidance in appendix 1 that sets out the required standards for style and format in line with national standards as defined in the NHS Institute for Innovation and Improvement¹, and relevant elements of the Information Standard. The Trust has developed an information leaflet template to assist authors to develop information resources which meet the quality standards. These are available on the Trust intranet site in the Patient Information Leaflets section of the Intranet, accessible via the homepage.

Following development of the leaflet, the author will consult with patients from the target audience to seek their views on content, style, accessibility. The author will then forward the leaflet and completed Patient Information Quality Assurance (PILQA) Checklist (Appendix 2) to the Directorate Patient Information lead who will in turn present it to the Patient Information Group for approval.

The PIG will either approve the document (through the process described in appendix 4, or return the document to the author with recommendations for any revisions. Once approved, the archivist will upload an electronic version of the leaflet to the Trust website.

The PIG archivist will maintain a central library of internally produced information leaflets for patients that are accessible via the Trust’s Intranet and Internet homepage.

All approved leaflets will be reviewed at a minimum of three yearly intervals to ensure information is up to date using the PIL QA Checklist for Existing In-House Leaflets, presented in Appendix 3. The process for review is described in appendix 3

5.0 AUDIO-VISUAL MATERIALS

All internally developed audio-visual information including images or audio material for patients must be:

- Approved through the process set out in appendix 3, and
- Reviewed at three yearly intervals to ensure information is up to date using the QA Checklist for Existing Information Materials, presented in Appendix 3.

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6.0 ELECTRONIC INFORMATION (WEBSITES)

There is a wealth of information, often condition-specific, available via the internet. These websites can be valuable sources of information that are peer reviewed and provide up-to-date patient information sheets on a wide variety of disease specific topics and procedures and formats such as videos and images. However, Staff sharing information from websites must first be confident that the site is credible and reliable. Details of a number of such reliable websites can be found in appendix 6 but please note that the list is not exhaustive.

When viewing web content with a view to sharing the information with patients and relatives, staff should consider the following:

- Is it clear who has written the information?
- Is the site relevant?
- Can the information be checked?
- How up-to-date is the site?
- Is the information biased in any way?
- Does the site tell you about available choices?

When downloading information it is important to consider whether there are any copyright issues, particularly if you are going to incorporate information or images into internally produced information. All information sources should be referenced.

7.0 ACCESSIBILITY OF INFORMATION, TRANSLATION AND INTERPRETING SERVICES

All printed information should be made as easy to understand as possible through the use of plain English and by minimising length of sentences in order to reduce the reading age score of material produced.

The Trust is committed to ensuring that all patients receive the information they require in a way that is best suited to their needs. A multilingual communication guide can be found on all wards, clinical departments and on the Trust intranet site. This provides a range of phrases in a number of commonly spoken languages. Where there is a requirement for leaflets in another language, this can be arranged through Capita translation services. Contact details are available on the Trust intranet.

A ward based communication book guide is available in all clinical wards and departments in an easy read format to assist with communication with people who may have a communication need such as a learning disability.

The Trust subscribes to Sign Medical, which is a British Sign Language web-based translation and interpreting service. The tool also provides web-based translation in twelve other commonly spoken languages. Sign Medical can be accessed directly from the Trust's intranet site via the following link http://intranet.xlthtr.nhs.uk/Multi_Multilingual_phrasebook/

8.0 CONTROL OF INFORMATION MATERIAL

Approved printed information material will be made available in PDF or "read only" format on the Trust intranet/internet site.

Information leaflets must be archived for the minimum period as set out in the Trust's Record Management Strategy.

9.0 MONITORING ARRANGEMENTS

Audit of compliance will be underpinned by annual Information Standard surveillance and accreditation processes, including self-audit.

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GUIDANCE FOR AUTHORS OF INFORMATION RESOURCES FOR PATIENTS

Consideration should be given to the following points when developing information resources for patients and service users.

1. What is the reason for producing the leaflet?

This should be based on the key priority areas identified in the Trust policy, i.e.:

- To provide a complete and comprehensive range of information resources for patients and service users in the clinical specialty or Directorate
- In response to issues arising from patient feedback, and
- Identified through local need

2. Are there any other leaflets/resources made available about the same condition or topic?

It is important to ascertain what information is available across the Trust to ensure that there isn't already a good quality resource in use. Check with other departments such as outpatients, day case units, and other specialties that may also perform the same procedure.

It is also crucial to check what information is produced externally to the Trust as this can be preferable to producing "in-house" material. Most external sources ensure that their information has been peer reviewed and reviewed by the public. External sources of information include: NICE who provide printed information brochures on every piece of guidance issued by them; Royal Colleges and Associations; patient support groups such as Patient UK and Diabetes UK; NHS Direct has also produced a range of information for patients, some of which is produced in several languages.

3. Will the new leaflet/resource replace those in existence or accompany them?

An objective of the Trust is to eradicate duplicate leaflets for the same condition/procedure and have one high quality leaflet for each need. It should be able to be used on all sites. This will also help you decide the key people who should be involved in developing the content.

4. At what stage in the pathway of care should the information be given out?

If the leaflet is about a procedure or what happens afterwards, the patient or carer may need to know this at an early stage. It will be necessary to consider where it will be given to the patient and which staff groups will need to be included in communications. It will be important to develop links with staff in these areas to ensure that they prepared to handle questions and they can help to flag up when things change and the leaflet needs reviewing?

5. Are there a significant proportion of service users with visual impairment?

This will help you decide if other media such as audiotape needs to be developed.

Information may need to be provided in large print. It may be useful to contact local organisations who have experience in this field, such as Galloways or Action4Blind when considering designing resources for partially sighted people.

6. Are there a significant proportion of service users who require an easy-read format?

This will help you decide if other media such as a picture book needs to be developed. There are already a number of resources that can be purchased from support groups or other organisations which may be a more appropriate option to developing a local resource.

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7. Are there a significant proportion of service users whose do not understand English?

This will help you consider whether the leaflet needs to be made available in picture book, other languages or audiotapes. For translation of written documents into alternative languages, quotations can be obtained from: Applied Language Solutions (see Trust Intranet Site)

8. Is the information leaflet designed for patients on discharge?

The leaflet should explain what danger signals to watch out for; when to return to normal activities such as driving, work etc. or other activities related to the specific to condition or treatment; and when and where to seek advice.

9. When to involve patients in developing the information resource?

The Trust Patient Information Group has representation from a patient Governor and provides a robust system for review of patient information. Prior to submission of a patient information leaflet for approval, the views of a sample of the target audience should be obtained to ensure that the use of language is appropriate and free from technical or other health related jargon and in helping to inform any changes to the leaflet.

10. The information contained in the leaflet must be evidence based where evidence exists.

Assistance with evidence searches can be obtained from the knowledge and library services manager on extension 2717. References should be included on the leaflet and the PILQA checklist that accompanies the leaflet

11. Information for patients should include the risks and benefits of treatment, and the alternatives to treatment including having no treatment.

12. Proof Reading.

Ask another person to proof read the information to ensure that it does not contain any typographical errors.

13. Improving accessibility of information

It is important that all information produced is as accessible as possible in order not to disadvantage any member of the public.

a) **Try to write from the patient's point of view**

Put yourself in the place of someone who may have little or no knowledge of what you are talking about.

b) **Use everyday language**

Use plain, everyday language to make your information easier to understand. Avoid jargon and acronyms at all times. Remember, as many as seven million people (roughly one in five adults) in England have difficulties with basic literacy and numeracy

c) **Use patient-friendly text**

Using personal pronouns such as 'we' and 'you' will help to create a sense of inclusion and trust. Avoid using language that may cause alarm. If you have to use medical terminology, explain clearly what these terms mean.

d) **Be relevant**

Make sure your information is relevant to and appropriate for the patient group it is aimed at

e) **Make sure information is consistent**

Your information should reflect and reinforce other information received by patients, such as letters, leaflets, appointment materials and all information delivered at local clinics.

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- f) **Be helpful**
Help people to make decisions by giving them the facts: facts about the benefits, risks and side-effects of treatment options or medical interventions.
- g) **Don't confuse people**
You should avoid discussing several different treatments and conditions in the same leaflet. Too much information on different subjects could cause confusion. Try to limit your leaflet to one or two subject areas and associated issues
- h) **Signpost additional resources**
Include other sources of information and support.
- i) **Highlight alternative formats**
Let patients know if the information you are providing is available in other formats, for example in Braille or on audiotape.
- j) **Use of diagrams**
Diagrams should be used in context. For example a cross section of an organ or vessel should be shown in relation to its location in the body, and copyright permission must be obtained.

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Patient Information Group - Quality Assurance Checklist

Request for new information to be reviewed

The checklist below is to be completed for all requests for **new information leaflets**, audio visual resources or procedure specific information to support consent to be reviewed by the Patient Information Group (PIG).

This form must be accurately completed and submitted to PIG, together with a copy of the new material, to ensure review by the group. Failure to return the checklist may result in a delay of the review process.

Title:	
Who is the information intended for and what is the purpose of the leaflet?	
Lead Directorate:	
Author contact details:	
If the leaflet is to support formal or informal consent to treatment, does it include the risks, benefits and alternatives to the procedure/ treatment including the option to do nothing?	yes / no / not applicable
If the information is designed for patients on discharge, does it explain when to return to normal activities such as driving, work or other activities related to the specific condition/treatment?	yes / no / not applicable
Is the clinical information contained in the leaflet evidence based where evidence exists?	yes / no / not applicable
If copyright applies, has permission been received regarding text and images	yes / no / not applicable
If copyright permission has been received, is this referenced?	yes / no / not applicable

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Please give details of sources of evidence supporting the content of the leaflet including references, websites etc.:

Please state if potential users (patients and carers) have had the opportunity to read/comment on the information; specify any changes that have been made as a result of this consultation:

Approved by: <i>PI lead</i>	<i>Name:</i>	<i>Signature:</i>	<i>Date:</i>
Approved by: <i>Senior Clinician</i>	<i>Name:</i>	<i>Signature:</i>	<i>Date:</i>
Approved by: <i>Directorate Committee Chair</i>	<i>Name:</i>	<i>Signature:</i>	<i>Date:</i>

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Patient Information Group - Quality Assurance Checklist

Request for existing information to be reviewed

The checklist below is to be completed for all requests for review of **existing information leaflets** or audio visual resources that have been previously approved by the Patient Information Group (PIG).

This form must be accurately completed and submitted to PIG, together with a copy of the revised material, to ensure review by the group. Failure to return the checklist may result in a delay of the review process.

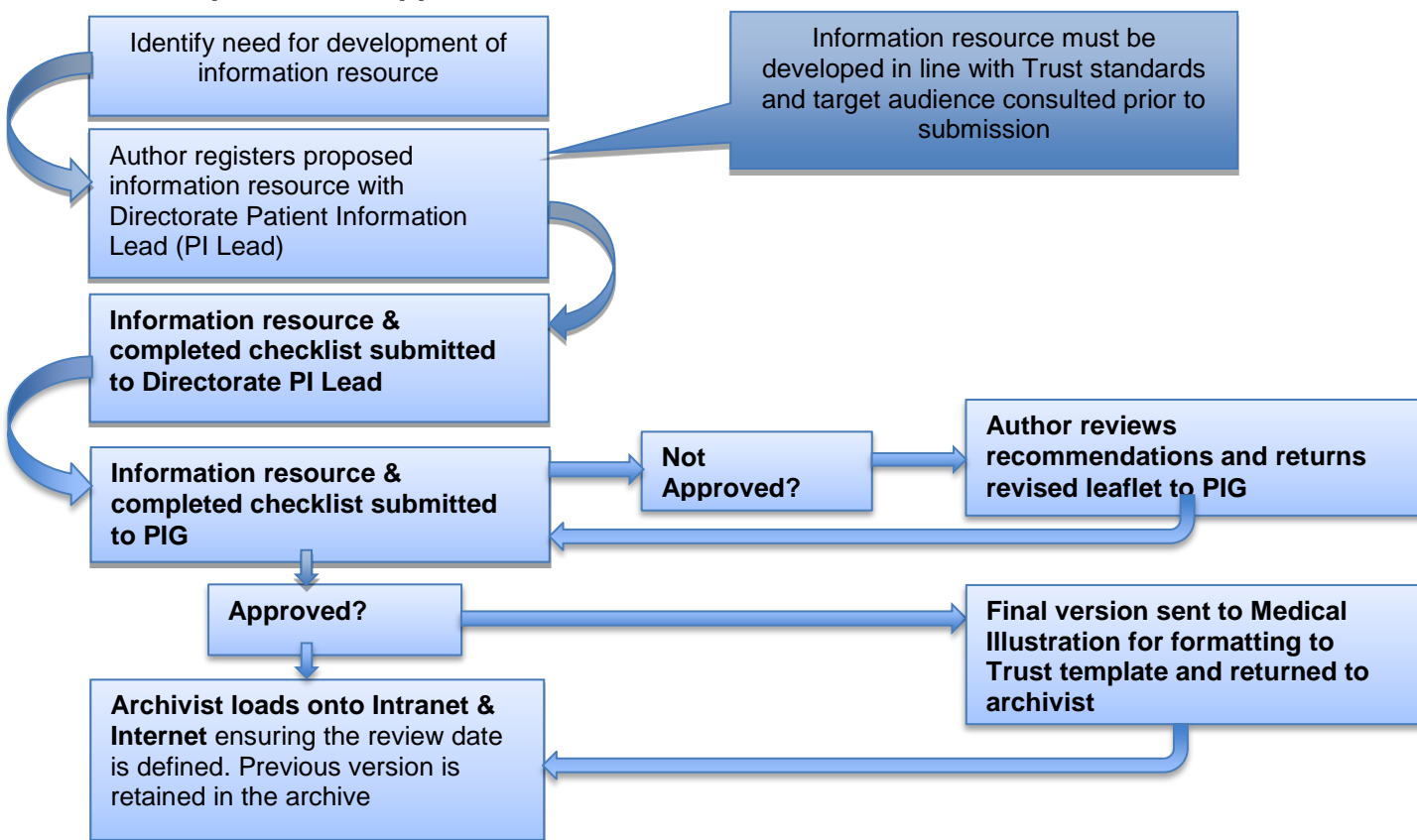
Title:	
Document reference: <i>(shown on back of leaflet)</i>	LTHTR/Tr/
Lead Directorate:	
Author contact details:	
Changes identified as a result of: <ul style="list-style-type: none"> • new research/evidence • changes in practice • patient feedback 	
Source material used to support the changes e.g. website addresses, references etc.:	

Approved by: PI lead	Name:	Signature:	Date:
Approved by: Senior Clinician	Name:	Signature:	Date:
Approved by: Directorate Committee Chair	Name:	Signature:	Date:

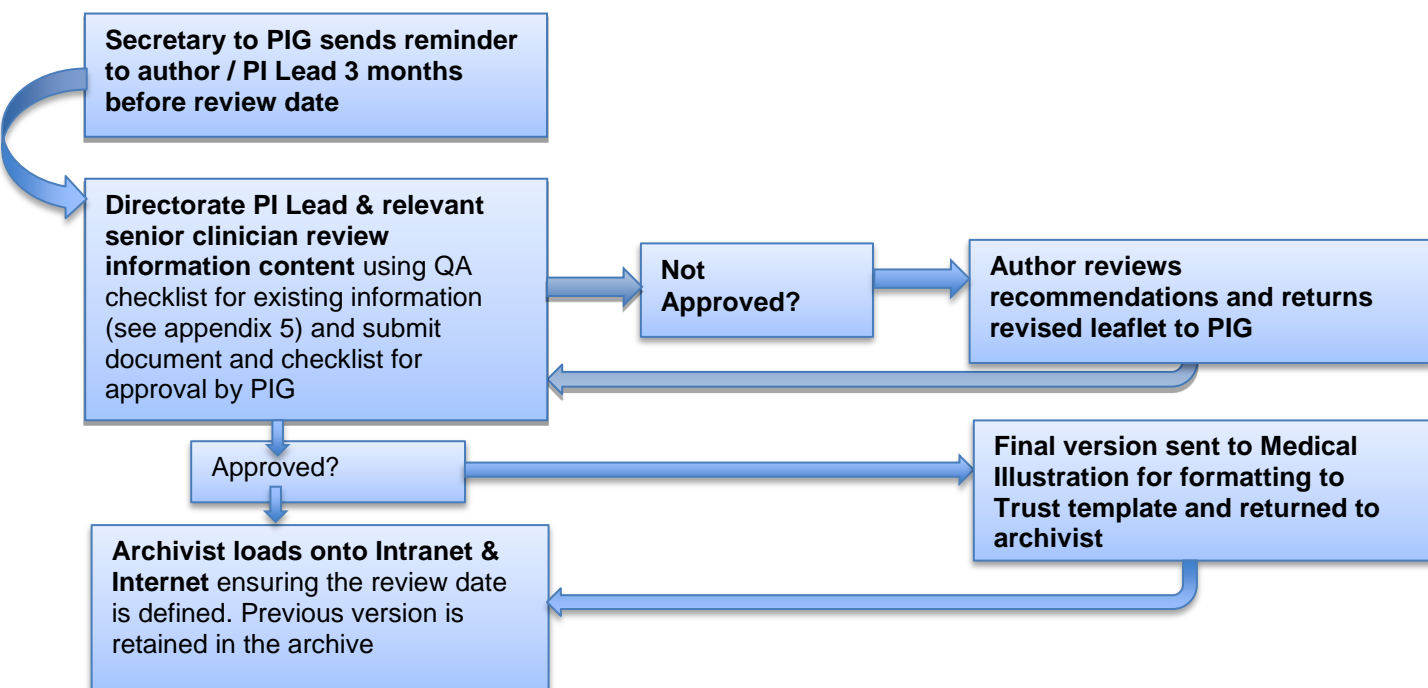
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Process for development, approval and review of patient information resources

Development and approval



Review and approval



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Evidence-based Medicine and Patient Information Websites

AHCPR: Agency for Health Care Policy and Research	This website provides access to research findings into better patient care and provides policymakers and other health care leaders with the information needed to make critical health care decisions.
Best Health	Best Treatments help patients and doctors work together by providing the best research evidence about the treatments for a range of medical conditions
Contact a Family	Contact a Family is a UK charity providing support and advice to parents whatever the medical condition of their child.
EQUIP: Electronic Information for Patients	This is a gateway to quality health and social care information for UK patients, their families and carers.
Care Quality Commission	The Care Quality Commission is the independent watchdog for healthcare in England and promotes continuous improvement in the services provided by the NHS and independent healthcare organisations. Patients, carers, service users and the public can view information about how well their local services are performing and other highlights from the assessments.
NHS Evidence	NHS Evidence is a service that enables access to authoritative clinical and non-clinical evidence and best practice through a web-based portal. It helps people from across the NHS, public health and social care sectors to make better decisions as a result. NHS Evidence is managed by the National Institute for Health and Clinical Excellence (NICE).
NHS Direct	NHS Direct Online: A range of reliable health information resources to help the public make informed choices about their health and lifestyle. Resources include: Online Encyclopaedia with a comprehensive guide to common medical conditions. Contains sections on diagnosis and treatments along with explanatory diagrams and images. Self Help Guides: advice on what to do next for a range of common symptoms, plus background information on minor ailments and guidance on what you should have in your medicine cabinet.
NICE: National Institute for Health and Clinical Excellence	NICE have developed guidance on a range of specific health topics which are useful for patients, carers and healthcare staff.

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NHS Institute for Innovation and Improvement	This tool gives you guidance on writing information about conditions, treatments, procedures, examinations, surgery and services. It doesn't tell you 'what' to write, but 'how' by highlighting points about writing style. It also makes links to checklists relevant in specific clinical settings.
Patient.co.uk	This website is edited by two General Practitioners from Newcastle upon Tyne. The aim of this site is to direct non-medical people in the UK to good quality information about health and disease. The majority of the links provided are to UK sites.
Patients Association	This website provides patients with an opportunity to share their experiences of health services and then uses the knowledge gained from patients to work with the NHS and other healthcare providers in improving services
Clinical knowledge summaries (cks)	cks provides an up-to-date source of clinical knowledge that can help healthcare professionals and patients in managing the common conditions generally seen in primary and first-contact care. The knowledge is practical and reliable, supporting safe and effective clinical practice.
TRIP	The TRIP Database brings together a wide range of 'evidence-based' healthcare resources available on the internet and is updated monthly.

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