Writing and testing lay-friendly health information

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Who are Luto Research?

We specialise in producing user friendly communications through good information design. We test them with real people to make sure the information meets their needs.
Writing lay-friendly health information
Key principles for lay-friendly writing

- Use everyday words
- Use brackets when the use of medical terms is necessary
- Use clear headings
- Use the active voice
- Keep sentences short, where possible, with one message
- Use bullet points to break up complex information
- If possible, use a contents list
Everyday words

- Experience → have
- Problematic → a problem
- Develop → get
- Deteriorate → get worse
- Administered → given
- Occurs → happens
- Promptly → straight away
- Excessive → too much
- Most effective → best
- Contact → talk to
- Data → information

When writing for a lay audience, be conversational
Bracketing of medical terms

- Bracketing works well when the patients may have heard or know the medical term

- Always put the medical term second
  - Collection of pus (abscess)
  - Inflamed gut (colitis)

- In some cases – when patients are unlikely to be familiar with the medical term – it is best to exclude the medical term altogether
<table>
<thead>
<tr>
<th>Original headings</th>
<th>Revised headings</th>
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<tbody>
<tr>
<td>Overview of disease epidemiology</td>
<td>How many people have the illness?</td>
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<tr>
<td>Unknowns relating to treatment benefits</td>
<td>Groups of people where we have less information</td>
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<tr>
<td>Summary of risk minimisation measures by concern</td>
<td>Summary of actions to minimise the risk to patients</td>
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<tr>
<td>Planned post-authorisation development plan</td>
<td>Studies happening now and in the future</td>
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To investigate the in vitro expression and sub-cellular localization of IL-8 and its receptors, the ovarian cancer cells were studied by immunocytochemistry.

We studied the cancer cells in the ovary using labels specific for the cancer cells. This meant that we could look at the production and location of the substance IL-8 and its targets inside the cells.
56 in 100 patients (56%) in Group A (ABC treatment) had tumours that stayed the same, while 12 in 100 patients (12%) had tumours that grew, and 32 in 100 patients (32%) had tumours that shrunk.

This would be much more easily digested and understood as:

The results in Group A (ABC treatment) were:

• 56 in 100 patients (56%) had tumours that stayed the same,
• 12 in 100 patients (12%) had tumours that grew,
• 32 in 100 patients (32%) had tumours that shrunk.
Poor Responders Intervention Trial

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You may want to talk to others about the study before taking part.

Part 1

1. What is the purpose of the study?

There are three commonly used regimens used to suppress the pituitary hormones during In Vitro Fertilisation (IVF). The purpose of this research is to find out which of these is the most effective for women who have shown a poor response in their previous treatment cycle(s). There is currently no evidence to say which gives the best outcome.

It is necessary during IVF treatment to control the reproductive cycle. In order to do this drugs are used to suppress the reproductive hormones released by the pituitary gland in the brain. These hormones are the Follicle Stimulating Hormone (FSH) and the Luteinising Hormone (LH). Both these hormones are stimulated by the Gonadotrophin Releasing Hormone (GnRH).

There are two types of drugs which suppress the pituitary hormones. The first is a GnRH agonist, called Nafarelin. An agonist is a drug which mimics the action of a naturally occurring substance in the body. Nafarelin activates the pituitary just like the GnRH in the body, but while the GnRH triggers the release of hormones by repeated on/off pulses, Nafarelin in IVF treatment delivers a long, sustained burst which keeps the pituitary in the ‘off’ mode.

The second drug is a GnRH antagonist, called Cetorelix. An antagonist is a drug which opposes the action of a naturally occurring substance in the body. In this way, Cetorelix prevents the release of pituitary hormones.

We invite you to take part in a research study.

1. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve.
2. Please take time to read the following information carefully. Discuss it with friends and relatives if you wish.
3. You are free to decide whether or not to take part in this trial. If you choose not to take part, this will not affect the care you get from your own doctors.
4. Ask us if there is anything that is not clear or if you would like more information.

Important things that you need to know:

1. We want to find the best way to treat women who have not responded well to previous IVF.
2. We are testing the use of two different medicines as part of IVF treatment, which are Nafarelin and Cetorelix.
3. Nafarelin can be used in two different ways, so the study has three different groups or treatment options.
4. One medicine is used in the study can cause side effects, but they are short-lived.
5. This study fits into your normal treatment, so there are no extra clinic visits or scans.
6. You do not have to pay for Nafarelin or Cetorelix, but the other medicines used in IVF may have to be paid for.
7. You can stop taking part in the study at any time.

How to contact us

If you have any questions about this study, please talk to the doctor who organises it. You can contact us on 01234 567 890.
What is this booklet for?

Lithium is a medicine that can work well for people with some mental health problems. However, for the medicine to work properly and safely, people taking it need to take special care.

Not everyone can take lithium
You need some health checks before you start, to see if it is safe for you to take lithium (see Section 2 ‘Checks needed before you start to take lithium’).

- These include checks on your kidneys, thyroid and heart.
- You also need to talk to your doctor if you might become pregnant.

You need to keep the amount of lithium in your blood at the right level
Too much lithium in your blood can make you very ill.

- You need to know the signs of a high level of lithium in your blood (see Section 6 ‘What happens if the level of lithium in my blood is too high?’).
- You need to know how to stop the level of lithium in your blood getting too high (see Section 7 ‘What can make the level of lithium in my blood get too high?’).

• Headings that stand out
• White space
• Bullets
• Non-justified text
Testing health information
User Testing at Luto Research – iterative design
User Testing at Luto Research – iterative design
Criteria for User Testing

90% of participants tested should be able to find the information in the material.

90% of participants who find the information should also be able to understand it.

These test criteria are applied to the User Testing process – each question is marked individually against these criteria.

These are consistent with accepted readability rates for User Testing of Package Leaflets in Europe.

In practice this means that across 10 people:

- 9 must be able to find the information
- 8 of those that find it must be able to show an understanding of the information.

## Testing on ‘real people’

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Content or layout and design?

When we are testing information for patients, we ask them to:

• Find a piece of information in the document
• Explain it in their own words

Which do you think is the most common reason that a document fails?

• Can’t find
• Can’t understand
Overview

Content

• Short, familiar words
• Use bold lower case for emphasis
• Be conversational
• Short sentences with one message
• Active voice

Layout & Design

• Short headings that stand out
• Leave ‘white space’
• Use bullet points for lists
• Use non-justified text
• Pictures and graphs do not always help
User feedback

"Why is it upside down?"

Raynor DKT et al. “Clinical trial results summary for laypersons: a user testing study.” Ther Innov Regul Sci. 2018
Participant feedback on “in vitro”

“Something to do with babies and wombs”

“...not a trendy word, but it’s a word that’s bandied around”
Participant feedback on “hypertension”

“I think it’s something to do with blood pressure, but I’m not quite sure whether it’s high blood pressure or low blood pressure”

“Well if I was going to take it literally... overstressing?”