



## FEATURE

## CHRISTMAS 2017: LANGUAGE AND LITERACY

# Santa's little helpers: a novel approach to developing patient information leaflets

Asking children to design information leaflets may improve patient understanding of surgical procedures, say **Catrin Wigley and colleagues**

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Obtaining valid consent before any intervention is a legal and ethical principle that underpins patient autonomy.<sup>1</sup> For consent to be valid, the patient must have received sufficient information and understood the nature and purpose of the procedure.<sup>2</sup> Emphasis is placed on providing information in a variety of formats that is comprehensible and free from technical jargon, which the average patient cannot reasonably be expected to understand.<sup>3</sup>

One solution to increasing patient understanding and capacity for self determination is using patient information leaflets. Time constraints on clinicians and the growing importance of providing patient information have made patient leaflets a popular adjunct to verbal communication, particularly where consent is required.<sup>4</sup> Studies have shown that patient satisfaction correlates strongly with the amount of information received.<sup>5,6</sup>

But using patient education tools to help patients make informed decisions has its own disadvantages, particularly regarding readability.

Readability is defined as “the ease with which written materials are read” and is crucial in assessing how well a patient resource might be understood.<sup>7</sup> Over 40 formulas exist for measuring the readability of text, the most widely used of which is the Simple Measure of Gobbledygook (SMOG).<sup>8,9</sup>

The average reading age in the UK is 9 years.<sup>8,10</sup> This places the UK around 17th worldwide with regard to literacy, lagging behind Australia, Canada, Germany, and the US.<sup>11,12</sup> Some studies, however, show that the average readability required for patient information leaflets is beyond 9 years.<sup>9,13</sup> Many studies have shown that information resources for surgical procedures are too complex and ineffective in educating and in gaining informed consent.<sup>14-16</sup>

## Reading age of 9 years

This led us to ask the question, what does a reading age of 9 look like and how does it compare with the patient information leaflets in current use? To answer this question, we assessed the average readability of several patient information leaflets for one common orthopaedic procedure and then revised these leaflets with the help of a group of very bright and helpful children.

Our analysis of six NHS patient information leaflets from across England for total hip arthroplasty showed a mean SMOG readability of 17.0 with a range of 15.2 to 18.1—well above a reading age of 9 years.

We recruited 57 school children aged 8-10 at a local primary school to determine how the content could be revised. An educational lesson on total hip arthroplasty was delivered by the lead author, teaching about the anatomy, technique, and indications for and risks associated with total hip arthroplasty. They were then asked to write their own patient information leaflet based on what they had been taught under four headings: indications for surgery, complications of surgery, before the procedure, and the procedure. They were also asked to draw one image of their choice, to include in the leaflet.

↓ shows the alternative patient information leaflet constructed by children at the national average reading age of 9 years (↓).

## Honest and to the point

Better patient information is associated with greater patient satisfaction and compliance and fewer questions that start “I was on the internet and . . .,” particularly regarding elective surgery.<sup>17</sup> The Montgomery case in the UK has made it more crucial than ever to ensure that we are providing thorough and

clear information before undertaking any intervention.<sup>18</sup> Patient information leaflets reinforce these standards. But they also pose a risk of assumed understanding and might hamper communication between patient and clinician.

Our readability assessment showed that six patient information leaflets for total hip replacement were too complex for the national average reading age of 9.

What better way to write a new leaflet than by engaging with 9 year old children, so that we can begin to appreciate the disparity in the language we use to convey information through formal patient information leaflets. Although reading age doesn't necessarily equate to comprehension, we should consider adopting an approach of "saying it as it is" that gets lost with the cynicism and social constraints of getting older.

Let's take our cue from the children and begin speaking honestly and to the point with our patients in a language they understand. Mohammed puts it very plainly indeed by explaining what has gone wrong: "Your hip is old and rotten." Jamie adds: "It is past its sell by date." We are not suggesting that patients should be likened to supermarket food with a "best before" label, but this is language that patients use every day and are familiar with.

The complications of surgery require adequate explanation so that patients can give informed consent. Children don't sugarcoat these, so why should we? Maria and Sarah clearly convey that you can "get a chest infection, blood clot, or hip infection." We hope that our patients would not "wake up during the operation," but the risk of death is real, as Mohammed explains.

When we tell our patients that there is a risk of neurovascular injury, we are essentially saying, "The surgeons may make a mistake and cut the wrong thing" (Jamie). So why don't we say what we mean as our bright young children do?

The children's pictures are intelligent and informative and are sure to put a smile on any patient's face (J).

## Simple, relevant communication

One way to improve patient information leaflets would be to enlist the help of 8-10 year old children to formulate a standardised document. Any child who suggests that the preoperative instructions should say to "turn up on time" deserves a dedicated booster seat on a patient liaison group. Payment in Haribo would also align with the government's NHS budgeting, and child labour laws might even be more sensible than the European Working Time Directive. We should keep a watchful eye on these talented young students for future recruitment to medical school based on the excellent advice they provided.

However we choose to impart knowledge and information to our patients, our duty as clinicians is to ensure that patients have all the facts in a format that is easily digestible. Enlisting children to help formulate these leaflets may seem whimsical. But our experience has shown us that the child can become the

tutor, teaching us the value in simple relevant communication. We think these children deserve an extra special gift this Christmas, and we will be sure to let Santa know . . .

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No financial or confectionary based incentives were used to persuade the children to participate in the process. No incentives from parents to include their child in the publication were accepted by the authors.

Provenance and peer review: Not commissioned; not externally peer reviewed.

Consent: We sought consent from the students' guardians using information sheets sent home and returned with signatures, and we used pseudonyms. A selection of direct quotes were chosen by the authors and combined to draw up a novel patient information leaflet.

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# Figures

**PATIENT INFORMATION FACTSHEET**

## Total hip arthroplasty

**Indications for the surgery**

**Mohammed:** Because your hips are old and rotten. When you played football, it was weak and it broke. You told me you cannot walk. That is because it is old and you need to have hip surgery.

**Jaimie:** Because yours is rotten. Because it's painful. Because you can't run and you want to be a sprinter. Because yours is wasting away like an old pair. It's past its sell by date.

**Calvin:** Your hip is rubbing and is not good, because if you do not get the operation it could get worse and cause some problems and start to rot, which could stop you from walking in future.

**Richard:** Because your hip bone is part of your legs, and without your hip bone you will flip around.

**Complications and risks**

**Mohammed:** You can die!!!!!!

**Mark:** The danger is you could wake up and it could harm your body and you could get a chest infection; you could feel so dizzy that you could fall off the bed later. Hip infection and blood clot also.

**Jaimie:** The surgeons might accidentally make a mistake and cut the wrong thing.

**Sarah:** Set off metal detector, lung infection, water infection, too much anaesthetic, a vessel might pop, wake up in the operation.

**Emily:** The bone could be put in badly. The replacement bone could be dirty, and you could get blood poisoning.

**Prior to the procedure**

**Lilly:** What is not allowed—Coca-Cola, fries, chocolate, and warning because of dangers of infection. No smoking. Stop eating foods that are hot, when this happens go to the doctor.

**Mark:** Don't smoke. Lose weight. Balance food/weight. Be there on time!

**Amelia:** Stop smoking or your blood will turn black.

**The procedure**

**Oliver:** So what we do is make you sleepy then make a long scratch and then make a deeper scratch and then we saw out the old bone and shove it back to make a new socket and put the new one in and it's a new hip and then we clip it back up.

**Amber:** Cut open the leg chop off bone, put metal in the bone, put cement in the leg, so the metal doesn't move.

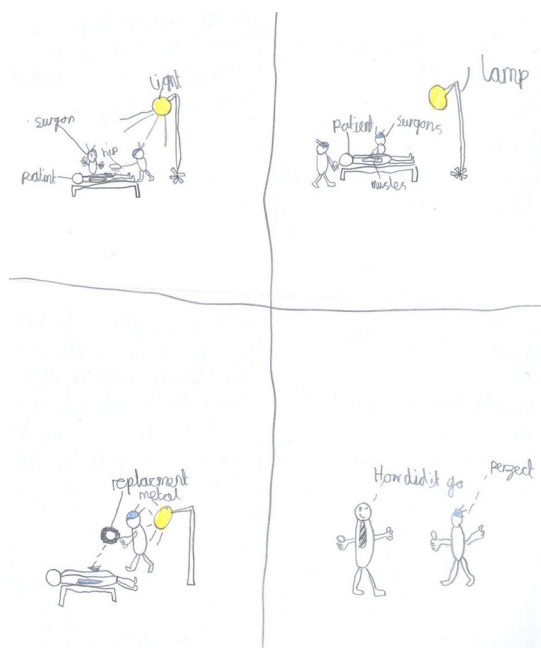
**David:** We're going to take out the part of your hip bone that needed to be taken out but don't worry you will be asleep. When you wake up it will be all done. The metal won't give your blood poisoning because we cleaned it with lasers.

**Avia:** We are going to cut on the side of the muscle using a sword and put the metal thing inside after we grate it and put cement inside. Then stitch.

**Postoperative**

**Jaimie:** You might feel nauseous and not walk properly. Your hips will be good as new after the operation.

## Alternative patient information leaflet



Clear four step diagram including positive feedback postoperatively



Weight loss and exercise advice is vital, pre-operatively



Patients should all be encouraged to bring a teddy along, pre and post op



"Happy patient and all finished"



Image showing essential orthopaedic tools