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

Catrin Wigley foundation year one doctor¹, Victoria Bucknall speciality registrar², Simon Fleming speciality registrar³

¹University Hospitals Coventry and Warwickshire NHS Trust, Coventry CV2 2DX, UK; ²Victoria Hospital, Kirkcaldy KY2 5AH, UK; ³Barts Health Whitechapel, London E1 1BB, UK

Obtaining valid consent before any intervention is a legal and ethical principle that underpins patient autonomy.¹ For consent to be valid, the patient must have received sufficient information and understood the nature and purpose of the procedure.² 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.³

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.⁴ Studies have shown that patient satisfaction correlates strongly with the amount of information received.⁵ ⁶

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

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 (J).

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.⁷ 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.18 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 everyday 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 (⇓).

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.

8 WashLER, VialeTA. Readability assessment of internet-based consumer health information. Respir Care 2008;53:1310-5.18811992
18 ChertaiDV, CooperE, SmithM, NgJ, NumanJE. Montgomery and informed consent: where are we now? BMJ 2017;357:j2224. doi:10.1136/bmj.j22248650035

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Figures

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