



Seminar at Stgiles Medical

'All I want for Christmas.....'

**How to write healthcare information
for adults and children
that 'minds the gap'**

10 December 2019



Jane Lamprill RN RSCN FICR
Specialist Healthcare Writer

Please Read Carefully™
Lay Language Communications
www.laylanguage.com

© Talk - Jane Lamprill 2019
© Picture credits - on images



Overview

Gaps in healthcare communication

Plain English principles & legal requirements

How to involve different patient groups:

- Parents in emergency health alerts
- Children/young adults in clinical trials

What's the weather got to do with it?

Mind the gap

“If you or your child do not take part in the research, you and your child’s data will be destroyed”

Baby Lab: Reading University

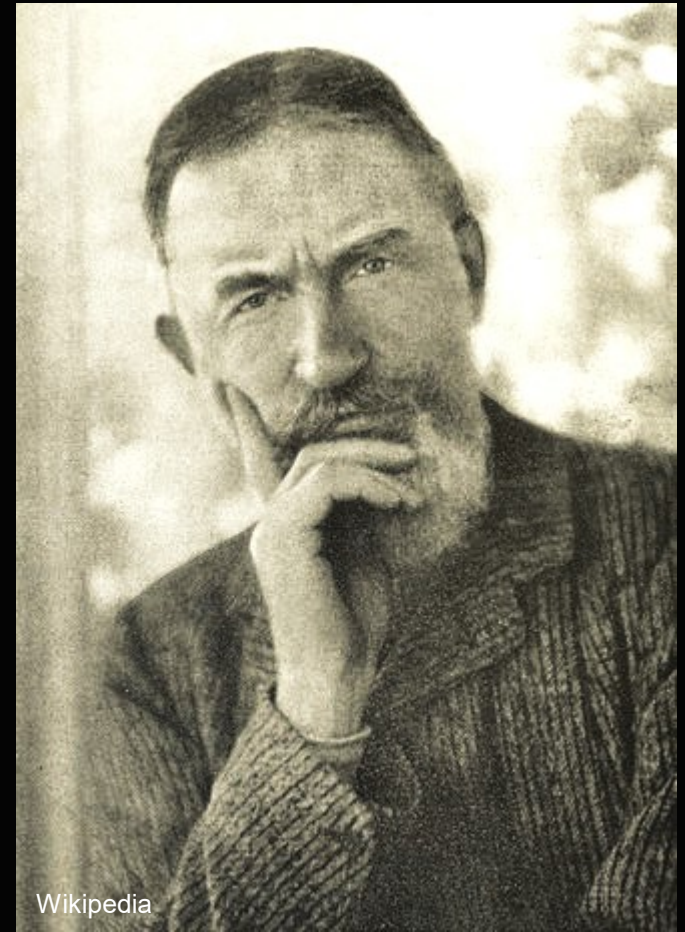
Mind the gap

Clinical trial patient

- Given 4 weeks supply study drug
- Blister packs, one per week
- Came back 2nd week needing more
- Took all Monday tabs on Monday etc
- What did the instructions say?!

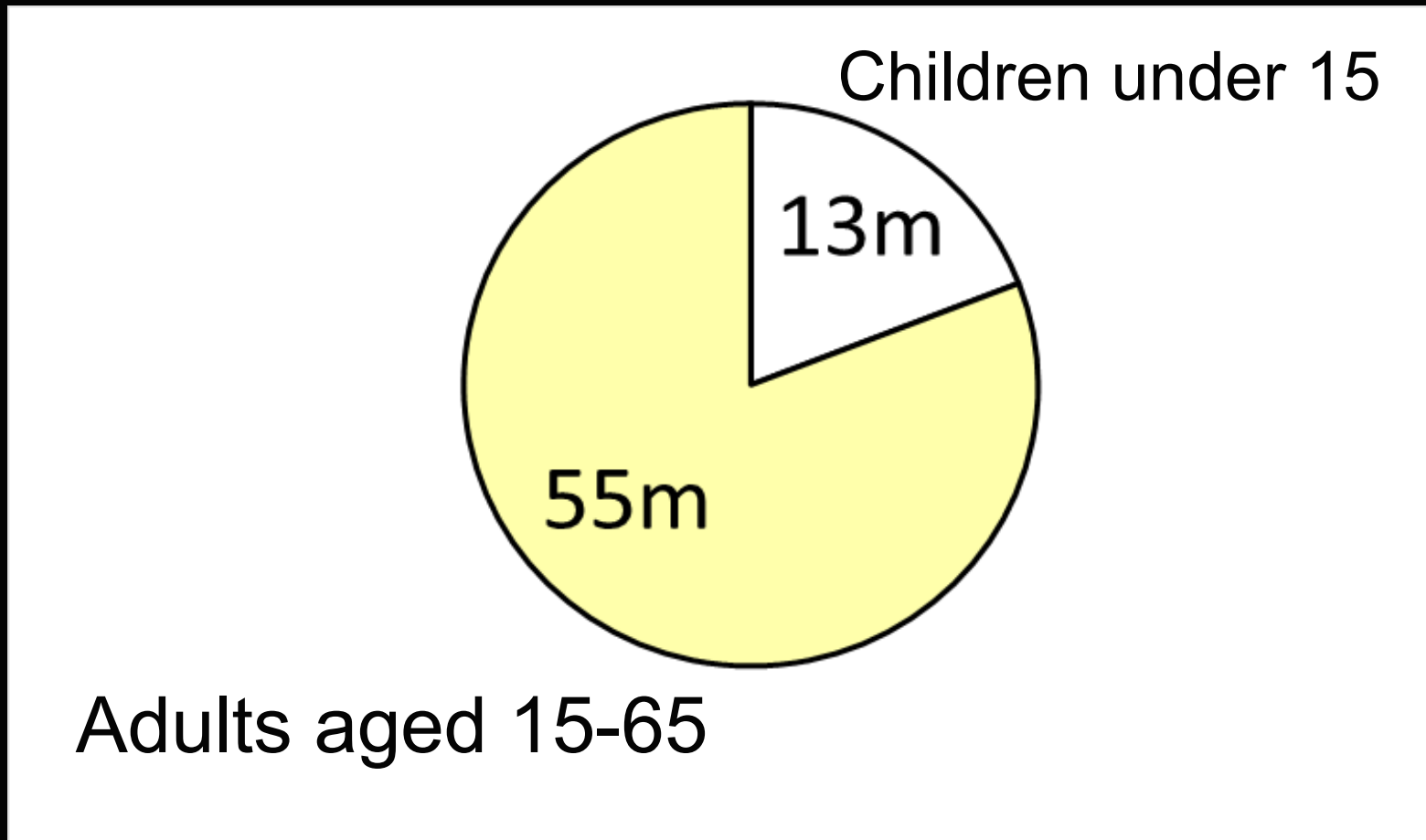
George Bernard Shaw

“The biggest problem with communication is the illusion it has been accomplished.”



Wikipedia

Literacy difficulties in the EU (ELINET 2015)



Poor health literacy = serious risks

If patients misunderstand health advice →

- Increased side effects
- Under or over-dosing
- A sense of **shame** & afraid to ask questions
- A decreased ability to cope with health issues

Overview

Gaps in healthcare communication

Plain English principles & legal requirements

How to involve different patient groups:

- Parents in emergency health alerts
- Children/young adults in clinical trials

What's the weather got to do with it?

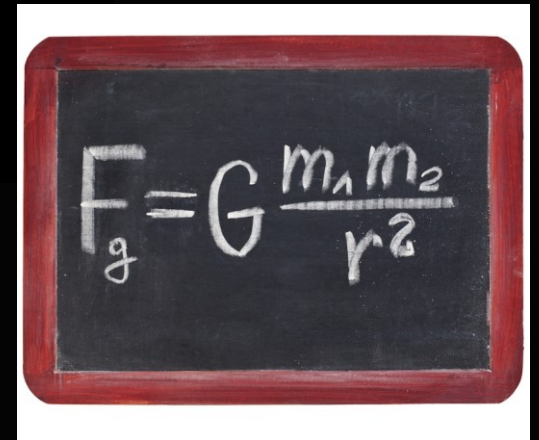
© Plain English Campaign

Plain English is

- “information that gets its meaning across clearly and concisely to its intended audience.
- It must do this with the necessary impact and the most suitable tone.”

3, Plain English Workbook, 2014

Barriers to writing plain English



Writing plain English

Key principles:

1. Use short sentences
2. Use words your audience understands
3. Use a personal touch ('I', 'We')
4. Write with the 'active voice'
5. Don't get nouns and verbs mixed up

Punctuation

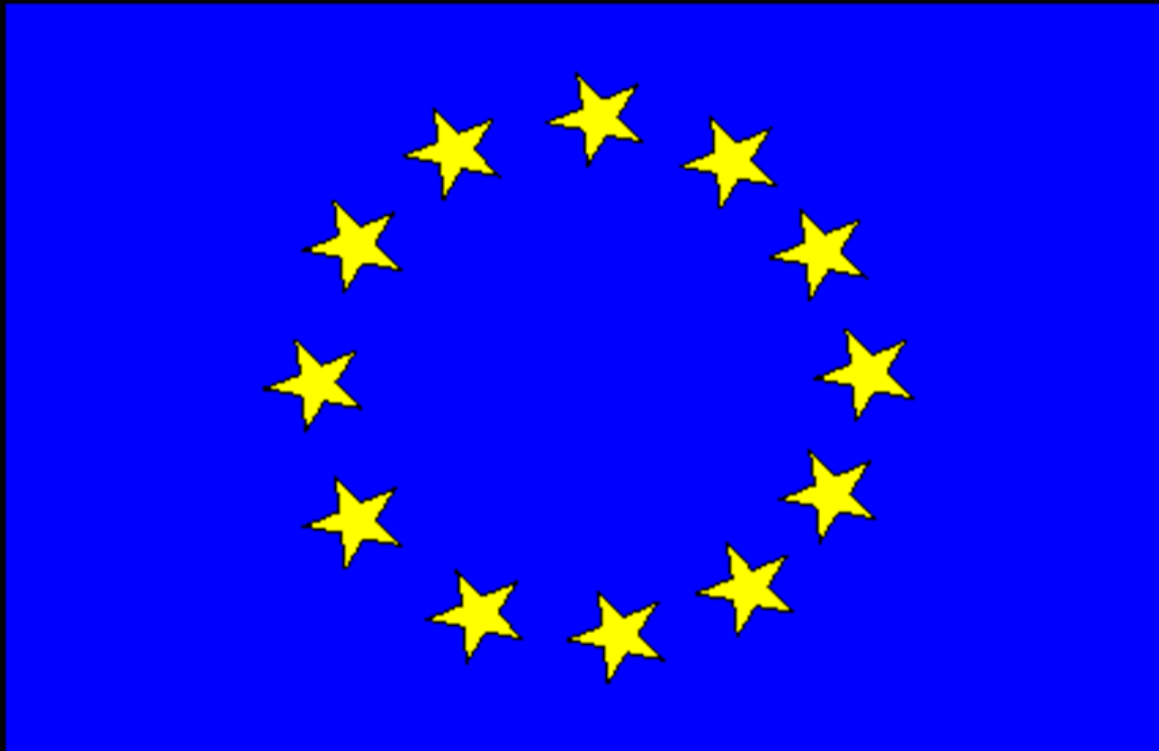


Commas – lost in translation?

- ‘Joseph, Mary, and the baby in the manger’
- Back in the day - one-star stable rooms had a large manger down the middle, separating humans from animals
- All 3 slept together: ‘Joseph and Mary and the baby in the manger’
- So – Christmas cards are wrong?!

Legal requirements for plain language

Clinical Trial Regulation 536/2014/EU



Clinical trials: Informed consent

Article # 29 (2b)

[Research participant] information shall be **kept**

- Comprehensive
- Concise
- Clear
- Relevant
- Understandable to a layperson

Clinical trials: Layperson summaries

Article # 29 (6)

Summaries of clinical trial results

'in terms understandable to a layperson will be made available in the EU database...'

Overview

Gaps in healthcare communication

Plain English principles & legal requirements

How to involve different patient groups:

- **Parents in emergency health alerts**
- Children/young adults in clinical trials

What's the weather got to do with it?

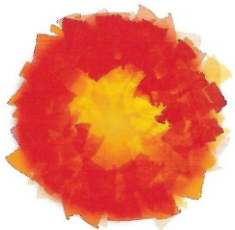
What every parent needs to know about sepsis.

NHS

If your child is unwell with a bug or infection, is rapidly getting worse and you are worried that their illness seems different to any previous illness, it could be sepsis.

Sepsis is a rare but serious complication of an infection.

Use this leaflet to check your child's symptoms and find out what to do next.



THE UK
**SEPSIS
TRUST**

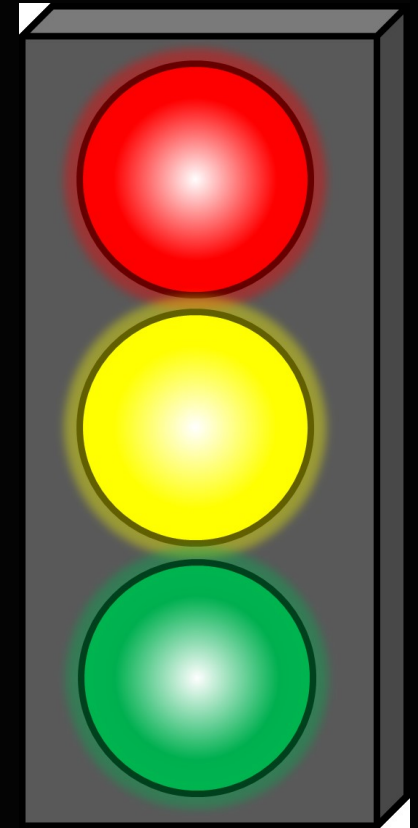
Colour blindness

Globally

- 1 in 12 men (8%)
- 1 in 200 women (0.5%)

UK

- 4.5% (3m)



colourblindawareness.org

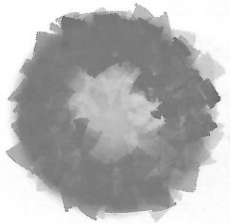
What every parent needs to know about sepsis.

NHS

If your child is unwell with a bug or infection, is rapidly getting worse and you are worried that their illness seems different to any previous illness, it could be sepsis.

Sepsis is a rare but serious complication of an infection.

Use this leaflet to check your child's symptoms and find out what to do next.



THE UK
SEPSIS
TRUST

If your child has any of these symptoms you should take **IMMEDIATE ACTION:**

- ▶ Looks mottled, bluish or pale
- ▶ Is very lethargic or difficult to wake
- ▶ Feels abnormally cold to touch
- ▶ Is breathing very fast
- ▶ Has a rash that does not fade when you press it
- ▶ Has a fit or convulsion

**GO TO A&E
IMMEDIATELY
OR CALL 999**

Sepsis is rare in children, but if your child is unwell with a bug or infection, watch your child closely. These symptoms may be signs of sepsis:

TEMPERATURE

- Temperature over 38°C in babies under three months
- Temperature over 39°C in babies aged three to six months
- Any high temperature in a child who cannot be encouraged to show interest in anything
- Low temperature (below 36°C, check three times in a 10 minute period)

BREATHING

- Finding it much harder to breathe than normal – looks like hard work
- Making 'grunting' noises with every breath
- Can't say more than a few words at once (for older children who normally talk)
- Breathing that obviously 'pauses'

TOILET/NAPPIES

- Not had a wee or wet nappy for 12 hours

EATING & DRINKING

- New baby under one month old with no interest in feeding
- Not drinking for more than eight hours (when awake)
- Bile-stained (green), bloody or black vomit/sick

ACTIVITY & BODY


- Soft spot on a baby's head is bulging
- Eyes look 'sunken'
- Child cannot be encouraged to show interest in anything
- Baby is floppy
- Weak, 'whining' or continuous crying in a younger child
- Older child who's confused
- Not responding or very irritable
- Stiff neck, especially when trying to look up and down

If your child has any of these symptoms, is getting worse, or is sicker than you would expect (even if their temperature falls), trust your instincts and seek medical advice urgently from NHS 111.

For more information visit [nhs.uk/sepsis](https://www.nhs.uk/sepsis) or [sepsistrust.org](https://www.sepsistrust.org)

Great big gaps!

- Passive voice “what every parent”
- The red alerts us, then distracts from text
- Unclear font under headline
- Over-use of capital letters
- What is sepsis anyway?
- Is it dangerous?
- What should parents do?
- Is the target audience clearly addressed?



Friends,
Romans,
Countrymen!

Parents: don't let sepsis kill your child!

Sepsis happens when an infection goes badly out of control. It can kill in 24 hours.

Dial 999 if your child has any of these:

- feels cold to touch
- has stopped passing wee
- is breathing very fast
- has a blotchy rash that **does not fade when you press it**

Overview

Gaps in healthcare communication

Plain English principles & legal requirements

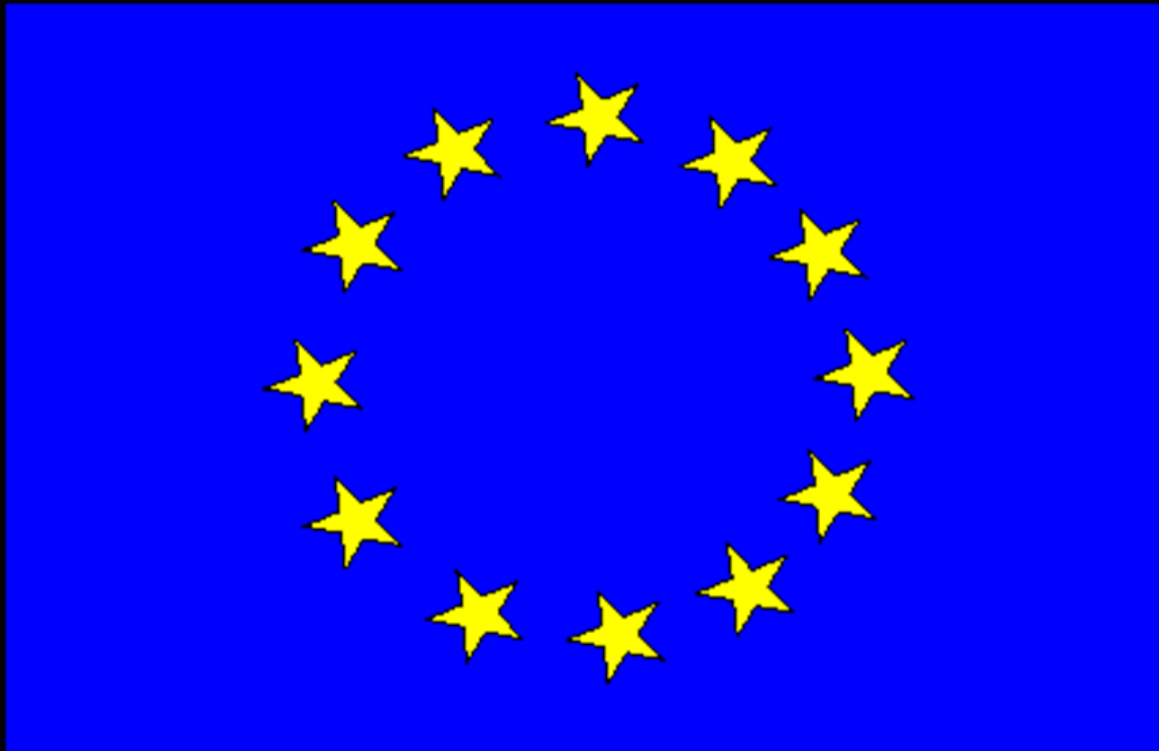
How to involve different patient groups:

- Parents in emergency health alerts
- **Children/young adults in clinical trials**

What's the weather got to do with it?

Legal requirements for plain language

Clinical Trial Regulation 536/2014/EU



Asking for a child's involvement

Article 32 1(b)

Children can **only** take part in research if they [have parental consent &]

- 'have received the information
in a way **adapted to their age
and mental maturity**'

Involving little children in research

Children may misunderstand their anatomy, diagnosis & medical tests → fear

- Don't understand research
- Can **verbally assent** (or **dissent**) before and during each procedure
- **Voluntary**, with parental written consent

Kids need factual info to help allay fear

- **procedure** based
- simple drawings e.g. ECG. CT etc
- very short text

Child's eye view – help!



Children have immature

- **Capacity** to understand cause and effect of risks and benefits
- **Competence** to make informed choices
- Both vary with age, **cognitive ability**, educational level and disease experience

Children in diabetes research

Written information needs to help kids 'join up' their **cognitive gaps**, to manage their diabetes.

- Goal and priority setting
- Planning, multi-tasking
- Impulse inhibition
- Awareness of danger
- Ability to make good judgements

Cognitive ability / executive function

**Does not fully mature
until early twenties**

Prof Sarah Jayne Blakemore UCL

Cognitive ability not linked to intelligence

Every Mayday morning

- Oxford students jump off Magdalene Bridge
- Quite a drop
- Freezing shallow water
- Crash land on uneven sharp stones
- Not wearing a lot
- Serious injuries every year
- Lessons learned?

No!



Wikipedia

Health info teens/young adults

- **Online** information that is 'eye-catching' and brief.
- **Positive focus** around how behaviour affects health:
 - benefit and risk
 - cause and effect
- **MHRA may require you to register app software as a medical device, if you are collecting health metrics etc**

Show respect!

- Use 'I' and 'we' but 'you will' is tricky as can be a statement or command
- People are not subjects (unless you are the Queen!)

CAPITAL LETTERS ARE HARD TO READ FOR

- People with English as second language
- Children

Capitals are 'SHOUTY'

- Suggest using **bold** for emphasis

Children

Information and pictures

- **Laser-focussed** for their reading age and illness, study age and country information age-bands
- Honest but not frightening
- Explain procedures : **why** we ask them to do strange things

Why the bath hats



Imagestate

User testing

“Nothing about us, without us!”

- Children's research groups
- Review paediatric protocols
- User test research info

UK ethics committees

- often require user testing prior to approval

→ Allow enough time!

Nouns, verbs and technical language

Avoid using words with

- Double meanings
- Those used as verbs or nouns
- Double, technical meanings

Study

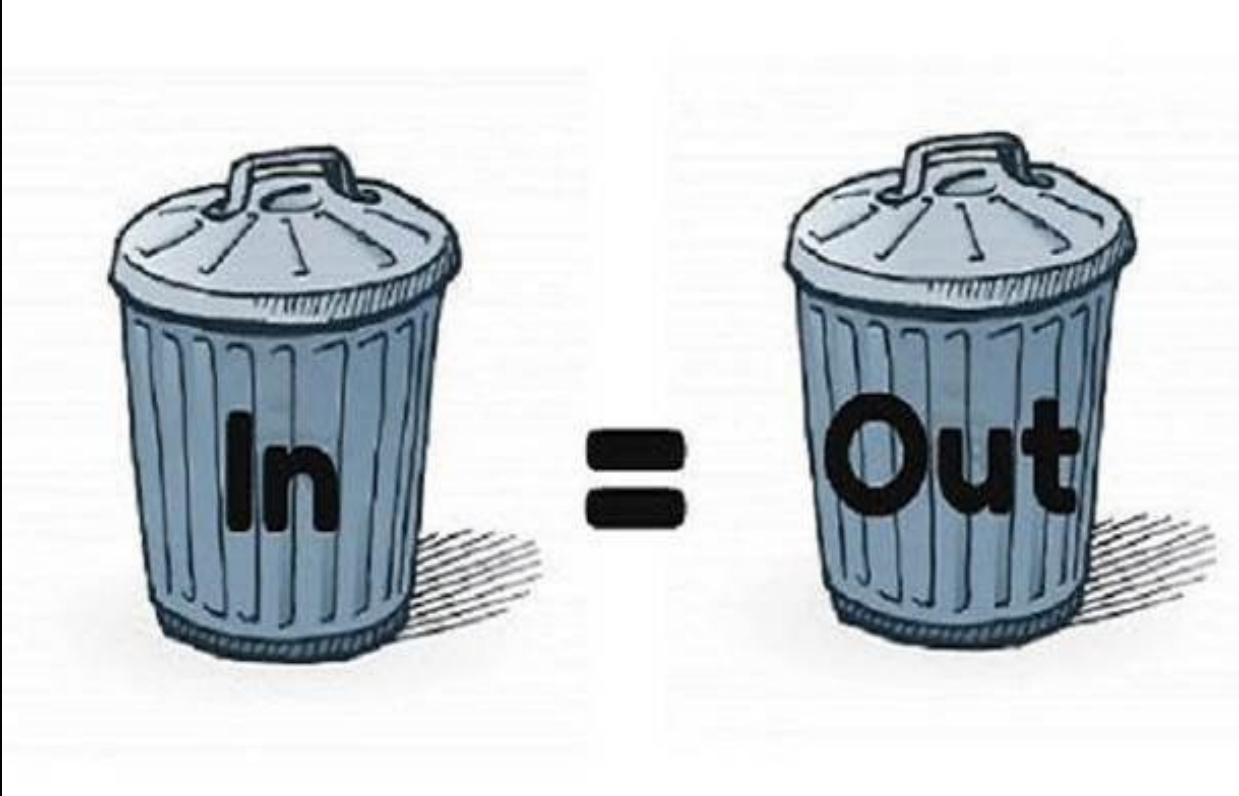
Airways

Blood draw

Trial

Subject

Bug



Overview

Gaps in healthcare communication

Plain English principles & legal requirements

How to involve different patient groups:

- Parents in emergency health alerts
- Children/young adults in clinical trials

What's the weather got to do with it?

“We take very complicated science and try to make it **interesting** and **usable** for the public....

.... [so that] people can **properly understand it** and use it to make **their [informed] decisions**”

Absolutely!

As medical writers:

- Whatever the weather
- We can together
- Help to bridge the gaps

Happy Christmas!



yesofcorsa.com



Thank you

Questions any time to

prc@laylanguage.com