



Techniques for sharing information in a patient-friendly way

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GIST SUPPORT
ÖSTERREICH



How we communicate with patients
has wider effects...

As a result of
good
communication

Patients are more likely to

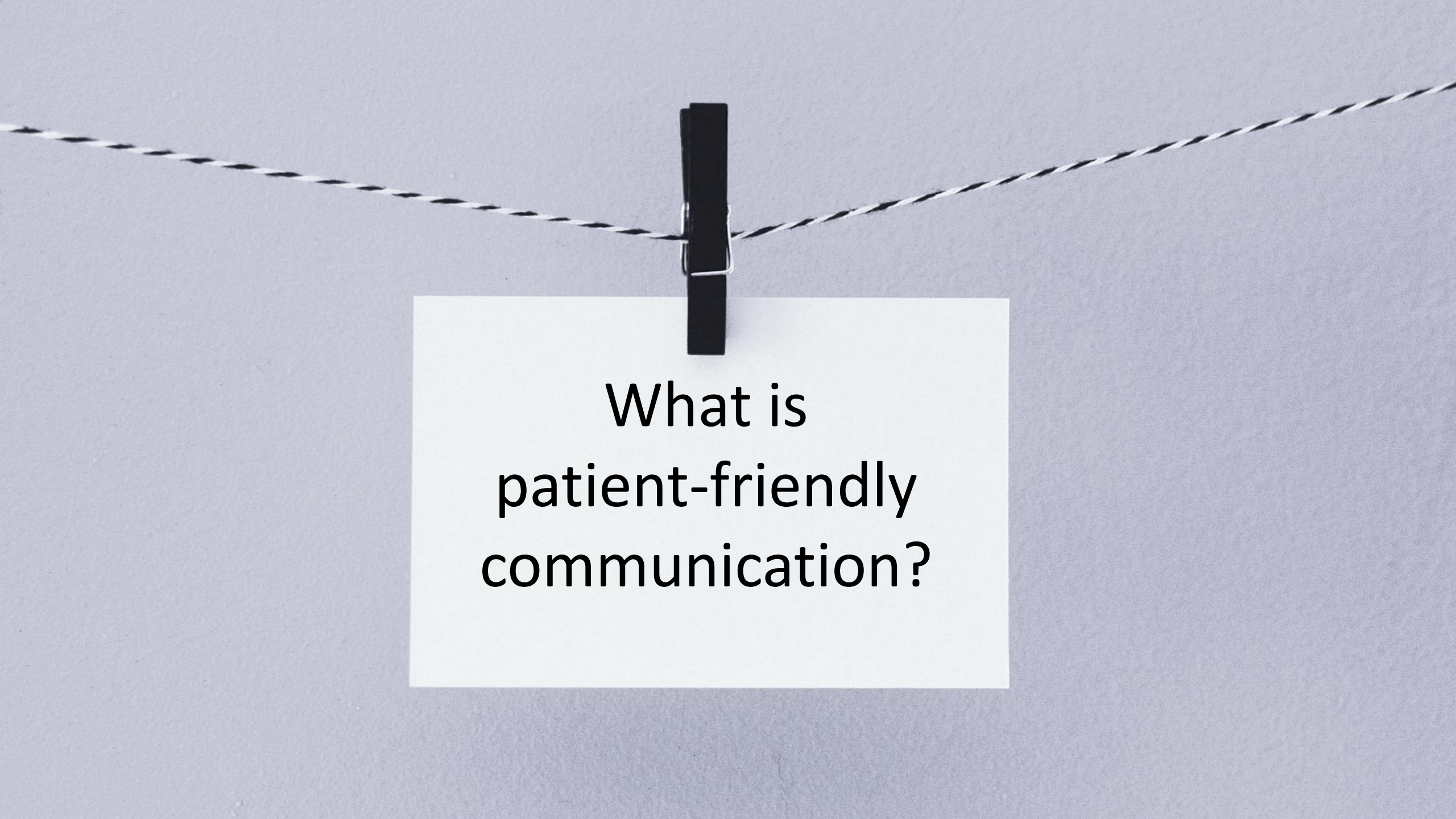
- share information with their physician
- follow advice
- comply with treatment

As a result of
good
communication

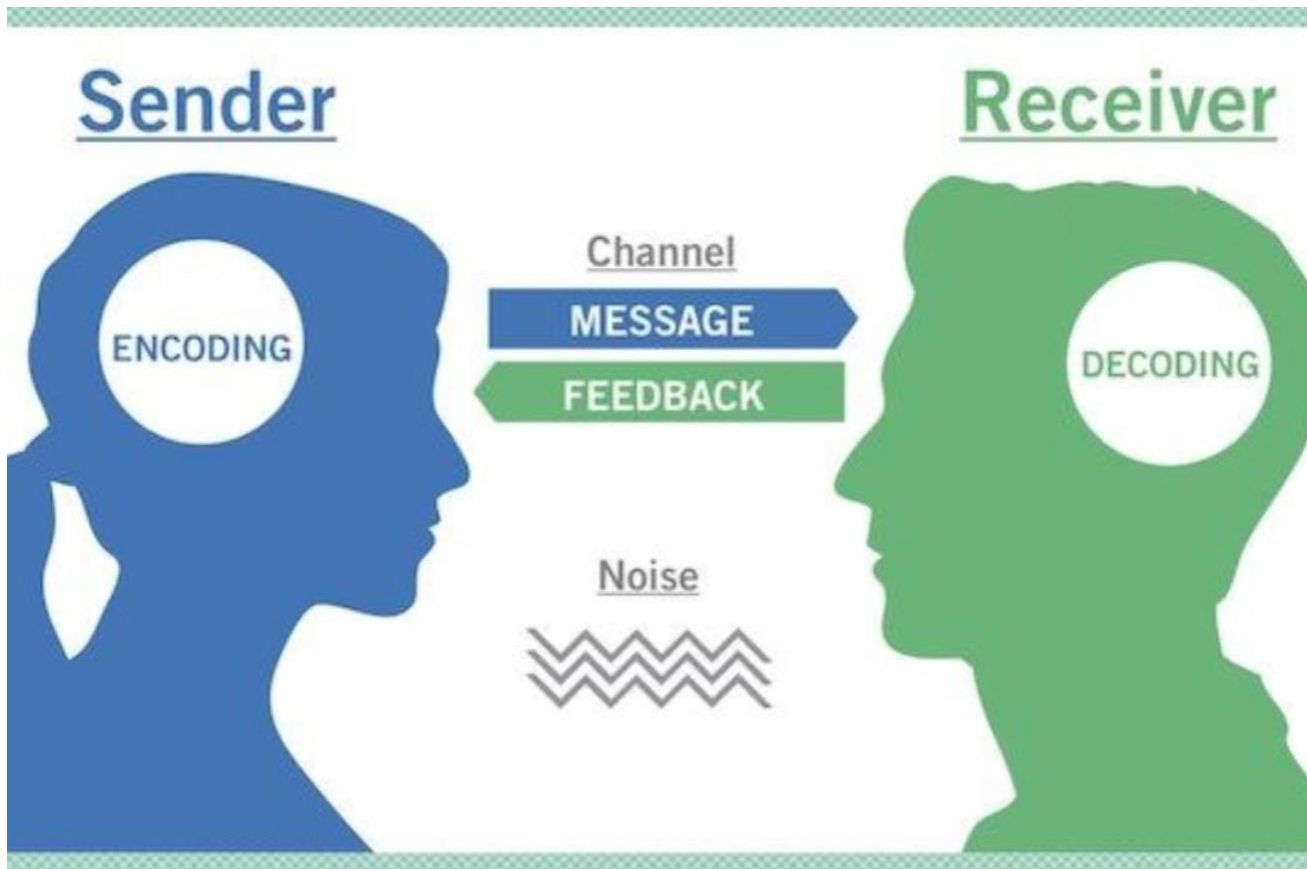
Patients are more likely to

- communicate better with loved ones
- make informed decisions
- feel empowered

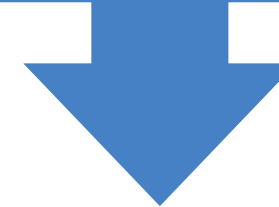
➤ Good communication sets a standard among all involved in patient care

A black clothespin is attached to a thin, dark string that runs diagonally across the frame. The clothespin is holding a white rectangular card. The background is a plain, light-colored surface.


What is
patient-friendly
communication?



Sender/Advocate considers receiver's needs/knowledge when encoding



Receiver/Patient understands information the first time

A black clothespin is hanging from a thin, dark string. The clothespin is holding a white rectangular card. The card has the text "How can we share information in a patient-friendly way?" written on it in a black, sans-serif font. The background is a plain, light-colored wall.

How can we
share information
in a patient-friendly
way?

Principles of patient-friendly communication are applicable...

- in all languages
- in all modes of communication (spoken and written)
- in all channels of communication
- for all patients (regardless of health literacy)



Sharing information in a patient-friendly way

use plain language



Plain language
resembles
spoken
language

- personal pronouns: “you” and “we”
- mostly active verbs
- common, everyday words
- short sentences



YOU + active verb = AGENCY

PASSIVE:

The tablets should be taken after a meal with a large glass of water.

ACTIVE:

You should take your tablets after eating. Drink a large glass of water.



YOU + active verb = AGENCY

- ***You** should speak openly with your physician.*
- ***You** can ask your healthcare team for a copy of all your reports.*
- ***You** need to know your mutation type so you can avoid drugs that do you no good.*

What about
medical
terms?

Medical terms

- cannot and should not be avoided
- should be explained in plain language

Medical terms in patient-friendly written materials

- When using a medical term, **add a synonym:**

Is there evidence of tumour metastasis (spread)?

- When using a medical term, **add a paraphrase:**

What was the mitotic rate (an indication of tumour cell growth rate)?

- Use a medical term and **provide a definition** in a separate glossary

Some examples of patient-friendly language

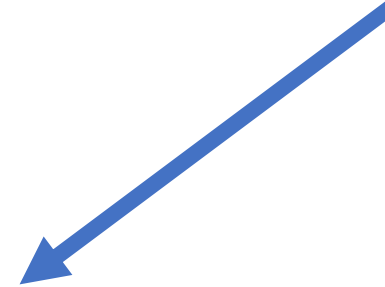
medical terms



paraphrasing



synonym



“Hepatic” refers to your liver.

A “lesion” is another word for a growth, which could be a tumor.



paraphrasing

medical term



personal pronoun

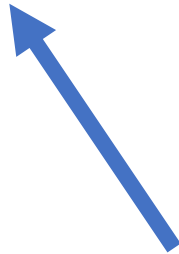


everyday words

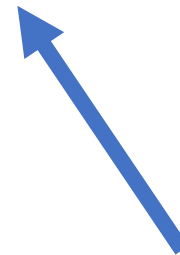


“Adhesions” are when you have scar tissue inside your body. They can come from your operation. Sometimes they cause pain.

short sentence



everyday words



Sharing information in a patient-friendly way

use plain
language

clarify with
mental
images





Clarify ideas with mental images:
Use similes and analogies

Adults learn best
when teaching
progresses from the
known to the
unknown

- new information
seems familiar
- ideas become **visual**



Comparing something unfamiliar
with something familiar

“The active
ingredient of the
drug fits like a key
in a lock.”

Mental image of seed and soil

“When cancer cells have spread, removing visible disease doesn’t mean there are no cancer cells left. It’s like when you remove dandelions from your garden – you may not see all the seeds that are still there.”



Mental image of seed and soil



“GIST cells in the body are like seeds in the earth. Imatinib is winter.”

Positive mental images

"When you participate in a trial you are not a lab rat. You are at the cutting-edge of science, like an astronaut. You receive treatment under the care of leading experts."



Sharing information in a patient-friendly way

use plain
language

clarify with
mental
images

use the
teach-back
method





Check a patient's understanding

- Don't assume everything is clear if the patient doesn't ask a question
- Don't ask ~~"Do you have any questions?"~~
- Ask: What questions do you have?



Use the teach-back method

- “Let me check how well I explained things. Can you go over with me what I said?”
- “I know your daughter is going to want to know about this, so what are you going to tell her?”

Sharing information in a patient-friendly way

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employ
appropriate
visuals





Employ appropriate visuals to explain concepts

- photos, videos
- illustrations, diagrams, graphs

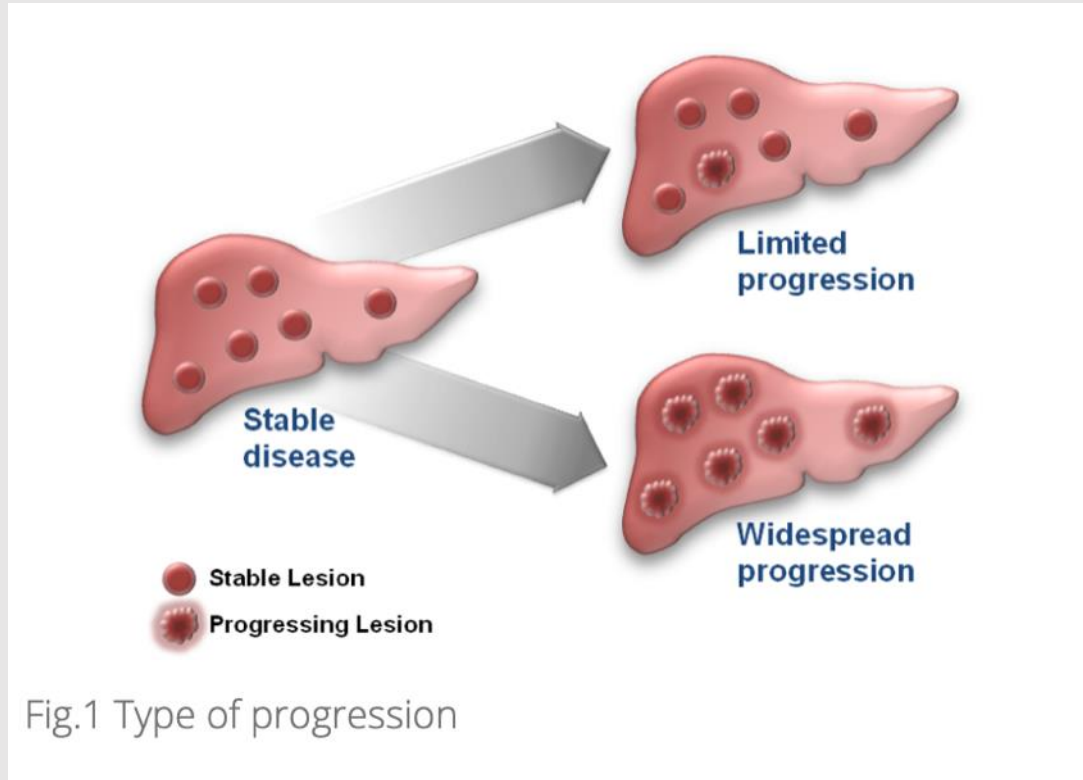
action-focussed or information-focussed visuals



Appropriate
visuals: Photos

Photos for showing what patients
themselves should do, or what they will
experience

Appropriate visuals: Illustrations



- One main point per image
- Explanation in caption

Appropriate visuals: Diagrams

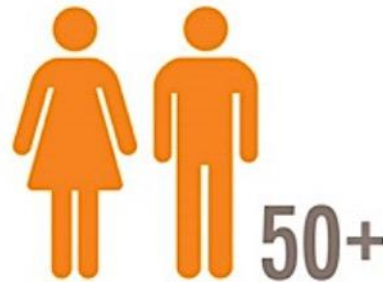
WHO GETS ADVANCED KIT+ GIST?

In the United States, between



10%-25% of these are advanced GIST.

GIST can occur at any age.



However, most people diagnosed with GIST are older than age 50.

The cause of GIST is unknown.



There are no known lifestyle factors that cause GIST (such as diet or smoking).

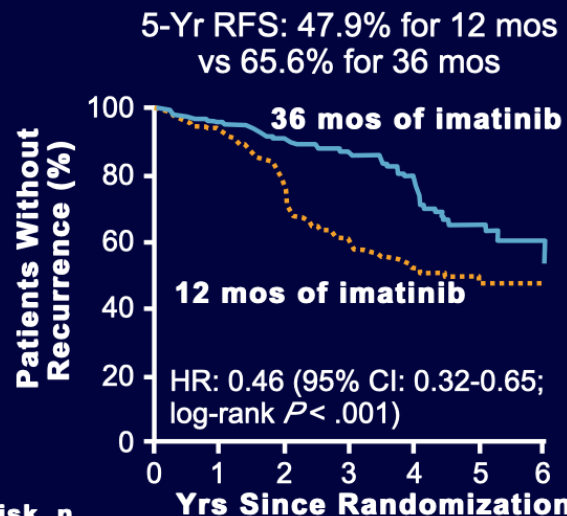
Appropriate visuals: Complex processes

PHASES of a CLINICAL TRIAL

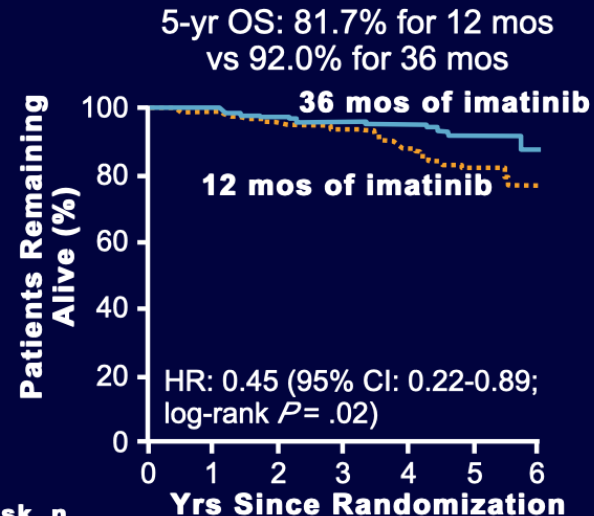


12 vs 36 Mos of Adjuvant Imatinib in High-Risk GIST: Results (ITT Population)

- Compared with 12 months of adjuvant imatinib, 36 months of imatinib improved RFS and OS in patients with resected GIST and a high risk of recurrence



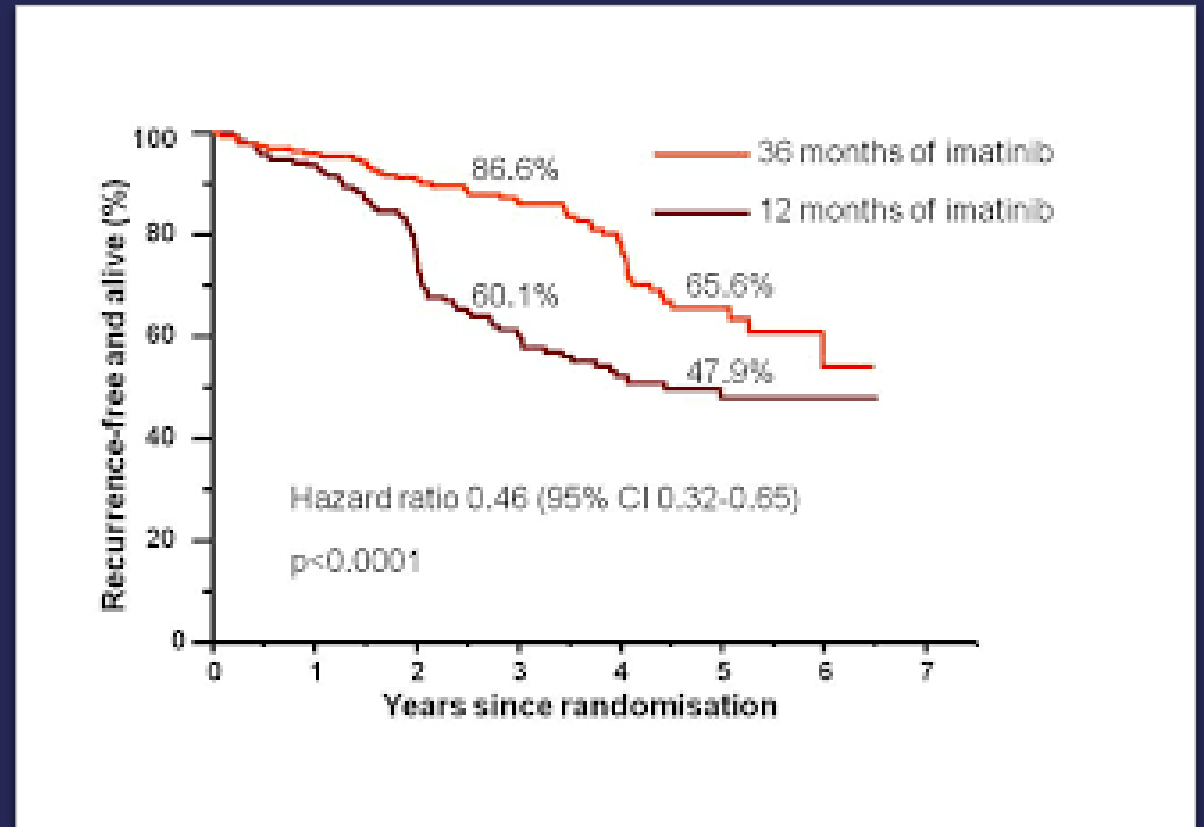
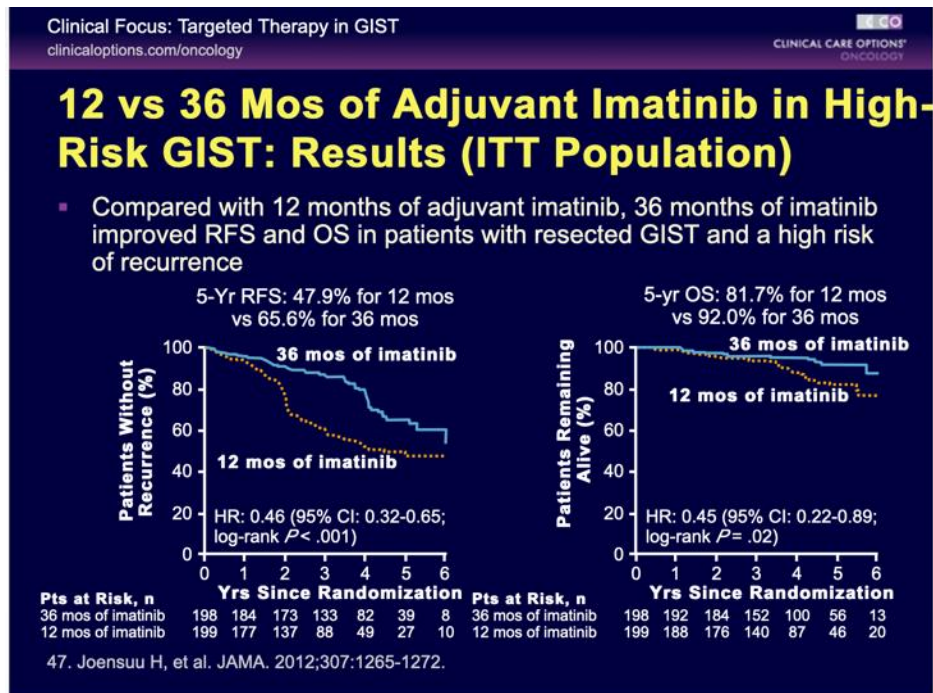
Pts at Risk, n		0	1	2	3	4	5	6
36 mos of imatinib	198	184	173	133	82	39	8	
12 mos of imatinib	199	177	137	88	49	27	10	



Pts at Risk, n		0	1	2	3	4	5	6
36 mos of imatinib	198	192	184	152	100	56	13	
12 mos of imatinib	199	188	176	140	87	46	20	

Appropriate visual?

Opt for non-specialist visuals, not specialist ones!



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structure
written
text

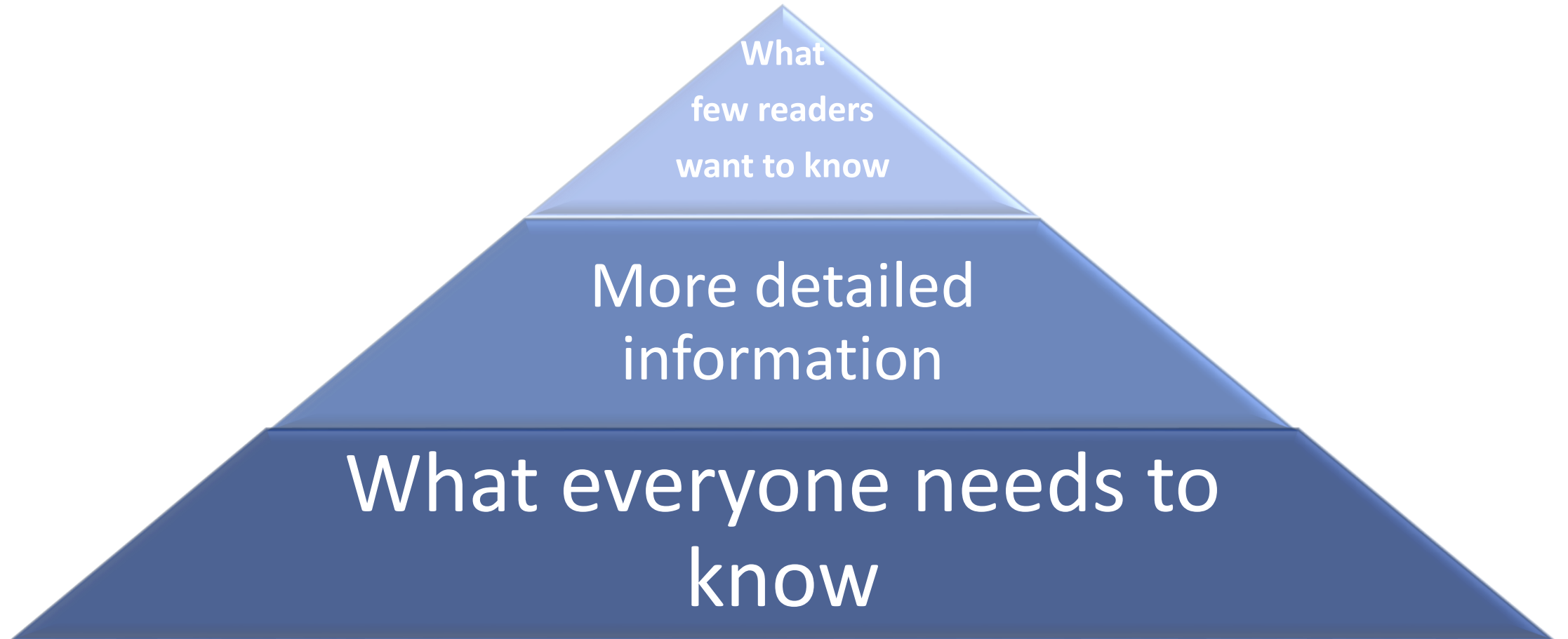


Structure
written text:
Break it up
into smaller
chunks

Use **text structuring devices**, such as

- headings
- bullet points
- tables
- text boxes
- white space

Present info in levels of
increasing specialization or decreasing interest



Headings Are Your Main
Tool for Structuring
Information

3 types of headings

Topic heading:

Mutation Testing

Statement heading:

Mutation Testing is Crucial for GIST Patients

Question heading:

Why is mutation testing crucial for GIST patients?



**Topic
headings:**
For a webpage
menu or table
of contents

What Is GIST?

> Understanding GIST

> Types of GIST

> GIST Diagnosis

> Mutations & Mutational Testing

> Treatments for GIST

> Resistant GIST

> Managing GIST

> Patient Resource Toolkit

Question headings as FAQs

What type of cancer is Gastrointestinal Stromal Tumor (GIST)?

Gastrointestinal stromal tumor (GIST) is a subtype of soft tissue sarcoma. It is a malignancy of mesenchymal origin arising from the gastrointestinal tract (GI). Mesenchymal tissues are part of many organs that help give the organ shape and strength. Most GISTs originate in the stomach, but can also be found in the small intestine, colon, rectum and esophagus.

How are GISTs formed?

“Cancer” is a term for a large number of diseases characterized by uncontrolled cell division and metastasis (the spread of cancer cells to different parts of the body). Cancer is created when normal cells acquire genetic mutations which trigger unhealthy levels of cell growth and division.

Table 4: Follow-up care after surgery

Surgery Results	Follow-up Care
All cancer removed	<ul style="list-style-type: none">• Medical history and physical exam every 3–6 months for 5 years, then repeat every year• Imaging of abdomen and pelvis every 3–6 months for 3–5 years, then repeat every year
Not all cancer removed (persistent or metastatic disease)	<ul style="list-style-type: none">• Medical history, physical exam, and imaging of abdomen and pelvis every 3–6 months

Use tables to structure written text



Use bullets points to...

- list items
- break up blocks of information
- present summary before/after a text
- serve as a to-do list

Which set of bullets is clearer?

How to use bullet points

- You should emphasize the beginning of a bullet
- always make them parallel in structure
- also it is important to try to keep them short

Using bullet points

- **emphasize** the beginning
- **structure** them in parallel
- **keep** them short

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structure
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repeat
key
messages





Key messages are essential points your audience should remember

Repetition makes messages memorable



What are the key messages of your organization?

- “Ensuring no one has to face GIST alone”
- “GIST belongs in the hands of experts”
- “Travel with us on the path to survival”



Key Messages for Core Topics

Clinical trials

"Clinical trials are the way progress against cancer is made."

Mutation testing

"Understanding the role of mutations and mutational testing is one of most important things that patients need to learn."

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Aims going forward...

- ✓ Communicate key messages
- ✓ Help all parties use patient-friendly language
- ✓ Foster patient agency through patient-friendly language



References

- Shared decision making: why the slow progress? Neal Maskrey; *BMJ* 2019;367:l6762
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- <https://www.us.gleevec.com>
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