Press Release Guide for Genomic Research and Medicine

February 2025
2nd edition

Points to consider in scientific research press releases

Ⅰ Clearly explain the most important element in the first paragraph. Use headlines, summaries, or bulleted lists effectively.

Ⅱ Provide images, figures, or footage to enhance understanding. Ensure compliance with copyright laws.

Ⅲ Create a headline that accurately summarizes the study results. Be specific and concise.

Ⅳ Reflect the research findings accurately. Avoid exaggeration or “hype.” *

* Readers may have expectations or fears that could influence their behavior in ways detrimental to their health. (Refer to p.4)

Ⅴ Clearly distinguish between correlation and causation. (Refer to p.7)

Ⅵ Specify whether the study was conducted in cell lines, animal models, human embryos, or people. Clearly state the research phase.

Ⅶ Include study limitations, supplementary information, and challenges.

Points to consider in genomic research press releases

01 Protect personal information

Ensure that the information does not lead to the identification of a patient or study participant.

02 Avoid detrimental behavior changes

Ensure that the information does not prompt readers to change their behavior in ways that are detrimental to their health.

03 Consider individuals involved

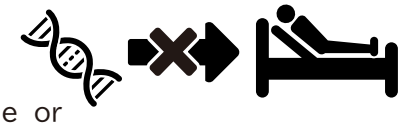
Ensure that the information does not evoke sorrow among readers for their relatives or closely related individuals.

04 Avoid prejudice or discrimination

Ensure that the information does not lead to prejudice or discrimination against specific areas or populations.

05 Avoid “genetic determinism”

Ensure that the information regarding genome or gene-disease associations is not reported in a manner that promotes “genetic determinism.”



From a different viewpoint

01

Protect personal information

Ensure that the information does not lead to the identification of a patient or study participant.

In cases of rare diseases, extra caution must be taken to prevent the identification of patients or study participants. At the same time, consider the potential benefits of disseminating research findings to these individuals.

Note

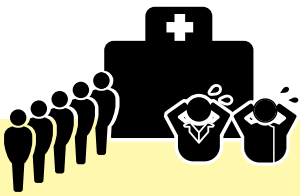
- Do not avoid publicizing study results due to concerns about identifying an individual (especially in cases of rare diseases); instead, carefully weigh the risks and benefits of reporting and highlight significant results that may be overlooked.
- Genomic information that fulfills certain conditions is legally classified as personal data in Japan. However, few researchers and journalists fully understand these conditions. Therefore, the latest legal requirements should be verified before releasing research findings.

For Media

- Be mindful that news coverage based on interviews may unintentionally contain identifiable personal information.

02

Avoid detrimental behavior changes



Ensure that the information does not prompt readers* to change their behavior in ways that are detrimental to their health.

* Readers include patients, study participants, family members, and medical professionals.

"Detrimental behavior change" includes both excessive medical testing due to anxiety and reluctance to consult a physician.

Note

- Even when a behavioral change is desirable for health reasons (e.g., smoking cessation), reports should not encourage such changes unless they are directly supported by research findings.

For Media

- Be aware that news coverage may induce unnecessary anxiety, fear, or unrealistic expectations among readers.

03

Consider individuals involved

Ensure that the information does not evoke sorrow among readers for their relatives or closely related individuals.

Clearly state the study's limitations.

Note

- Scientific facts should not be omitted due to concerns about their potential impact on readers.

  Examples:
  - Do not omit the fact that mitochondrial DNA variants are passed from mother to child when discussing mitochondrial diseases.
  - Do not intentionally exclude disease names with potentially significant emotional impacts when reporting on genetic disorders caused by specific genes.

- Be mindful that certain technical terms may have a strong impact on readers (e.g., founder effect). In such cases, avoid using the terms or explain them carefully in press releases.

For Media

- When reporting study results that could be informative but may also evoke distress, carefully consider whether and how to present them.

04

Avoid prejudice or discrimination

Ensure that the information does not lead to prejudice or discrimination against specific areas or populations.

References to “specific areas or populations” may imply various factors, including geographic location, birthplaces, ancestry, and cultural background.

Note

- There have been cases in which press releases highlighting genetic differences among regions were perceived as discriminatory.
- The use of population descriptors in genomic research is a highly sensitive issue. For further details, please refer to the report by the the National Academies of Sciences, Engineering, and Medicine in the U.S . *

  * Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field (2023), National Academies of Sciences, Engineering, and Medicine
  https://nap.nationalacademies.org/catalog/26902/using-population-descriptors-in-genetics-and-genomics-research-a-new
- Even when press releases and news coverage are carefully crafted to avoid prejudice or discrimination, information may still be misused. Therefore, preventive measures should be considered.

For Media

- If the benefits of reporting research findings outweigh the risks of reinforcing prejudice or discrimination, proceed with caution and careful consideration.

05

Avoid “genetic determinism”

Ensure that the information regarding genome or gene-disease associations is not reported in a manner that promotes “genetic determinism.”

Note that not all genetic diseases are transmitted down the family line (e.g., the difference between somatic and germline variants).

Note

- When discussing genome or gene-disease associations in press releases, carefully consider how technical terminology might be simplified or altered in subsequent news reports.

  Examples: variant, risk of developing diseases, heredity, gene.

For Media

- In epidemiological studies, most findings indicate correlations rather than causation. When reporting such findings, ensure that coverage does not mislead readers into assuming causal relationships. (Refer to p.1, V)

From a different viewpoint

- Following this guide should not prevent the dissemination of research findings or lead to the distortion or suppression of scientific facts.
- Portions of press releases may be misinterpreted or spread on the internet, including social media. Consider preparing proactive measures to address potential misinterpretations or issuing clarifications, if needed.
- To prevent misunderstandings, clearly state any considerations that may affect the interpretation of research findings.
- When reporting on genetic diseases, readers may appreciate information not only on disease causes but also on management strategies. Press officers and journalists should consider including such details while clarifying that they are not directly related to the research results.
- For study results related to genetic diseases, such as “A genetic variant contributes to the risk of developing certain diseases,” it is advisable to explicitly state: “People without the variant may also develop these diseases.”

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