



ATIPP Request: 24-732

**Source of Records: Insured Health &
Strategic Policy and Planning**

CONFIDENTIAL

Information Note

Drugs for Rare Diseases

2025Insured Health
Services

Current Situation:

Provinces and Territories have been working with the federal government on terms and conditions for bilateral agreement funding announced by Canada in March 2023.

Terms and conditions are now set, and bilateral agreement funding is available for three fiscal years beginning this 2024/25 fiscal year.

Signing after March 31, 2025, does not guarantee 2024/25 funds.

As of January 31, 2025, six provinces have signed on, including Ontario, British Columbia, Alberta, New Brunswick, Saskatchewan and Newfoundland and Labrador.

Background:

A “common set” of 12 drugs for rare diseases (DRDs) is established for the PTs. These are new and emerging therapies coming on to the market and were chosen for their potential to provide valuable evidence and evaluation in a real-world setting.

Each PT entering into an agreement would be required to list or ‘elect’ at least one of the 12 DRDs identified at any given time.

In the 2024/25 and 2025/26 fiscal years, 100% of funds from the agreement can be applied to eligible expenditures related to DRDs. This includes any qualifying drug for rare disease as well as expenses related to implementation of this agreement.

In the 2026/27 fiscal year, at least 50% of funds from the agreement must be applied to eligible expenditures elected from the “Common Set” DRD and at least 10% of funds must be invested by the Yukon into eligible expenditures elected from the “Common Set” DRDs.

The territories negotiated an additional \$1.3M of supplementary funding per territory for the 2025/26 and 2026/27 fiscal years. (\$2.7M total supplementary funding in addition to the \$1.9M/yr)

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Information Note


Drugs for Rare Diseases

2025

Insured Health
Services

Recommendation:

s.74(1)(a)



From: Josephine.Afful []
To: Prev.Naidoo [Prev.Naidoo@yukon.ca]
CC: Shauna.Demers [Shauna.Demers@yukon.ca]
Subject: RE: Drugs for Rare Disease
Date: Wednesday, March 12, 2025 11:32:22
Attachment 1: image001.png

Thanks Prev.

I picked a few bullets on that from the feds news release. I will update the note with this information.

Josephine Afful

Policy and Issues Analyst

Health and Social Services | IMU

| C. 867-334-7637 | Yukon.ca

I respectfully acknowledge that I work within the Traditional Territories of the Kwanlin Dün First Nation and the Ta'an Kwäch'än Council.

From: Prev.Naidoo <Prev.Naidoo@yukon.ca>
Sent: March 12, 2025 11:28 AM
To: Josephine.Afful <Josephine.Afful@yukon.ca>
Cc: Shauna.Demers <Shauna.Demers@yukon.ca>
Subject: Re: Drugs for Rare Disease

Hi Josephine,

Yukon has elected Yescarta (a CAR-T) therapy as the first drug to be covered under this agreement.

There are 11 drugs on the list and we will phase in the rest as the program develops.

Thanks,

Prev

From: Josephine.Afful <Josephine.Afful@yukon.ca>

Sent: Wednesday, March 12, 2025 8:28 AM

To: Prev.Naidoo <Prev.Naidoo@yukon.ca>

Cc: Shauna.Demers <Shauna.Demers@yukon.ca>

Subject: Drugs for Rare Disease

Good morning, Prev,

I have prepared the following key message for the minister on the bilateral agreement with the feds on the above:

- Our government remains committed to ensuring that Yukoners have access to the best possible healthcare.
- Our government remains committed to ensuring that Yukoners have access to the best possible healthcare. The Government of Yukon has signed a bilateral agreement with the Government of Canada to increase access to effective drugs for rare diseases.
- Under this agreement, Yukon will receive \$ 8.5 million in federal funding over the three years to support better access to these expensive but important treatments.
- This funding will help ensure that more patients receive the medications they need without

facing insurmountable financial barriers.

- In Canada, 1 in 12 people live with a rare disease. People with rare diseases have faced challenges in accessing specialized medications. These treatments are often expensive and difficult to obtain, significantly impacting a patient's quality of life.
- This new investment will improve coverage and access to both new drugs for rare diseases and existing drugs for rare diseases. It will also be used to enhance screening and diagnostics for rare diseases to improve early detection and treatment.
- This new funding will also allow the Yukon to better collaborate with federal government departments agencies and other provinces and territories to enhance real-world evidence generation. This will support better decision-making for access to new rare disease treatments.

I am missing the drugs to be covered in this messaging. Can you let me know which drugs will be covered under this agreement?

This is for our daily note this morning. I will appreciate if you can let me know as soon as you can.

Thanks

Josephine Afful


Policy and Issues Analyst

Health and Social Services | IMU

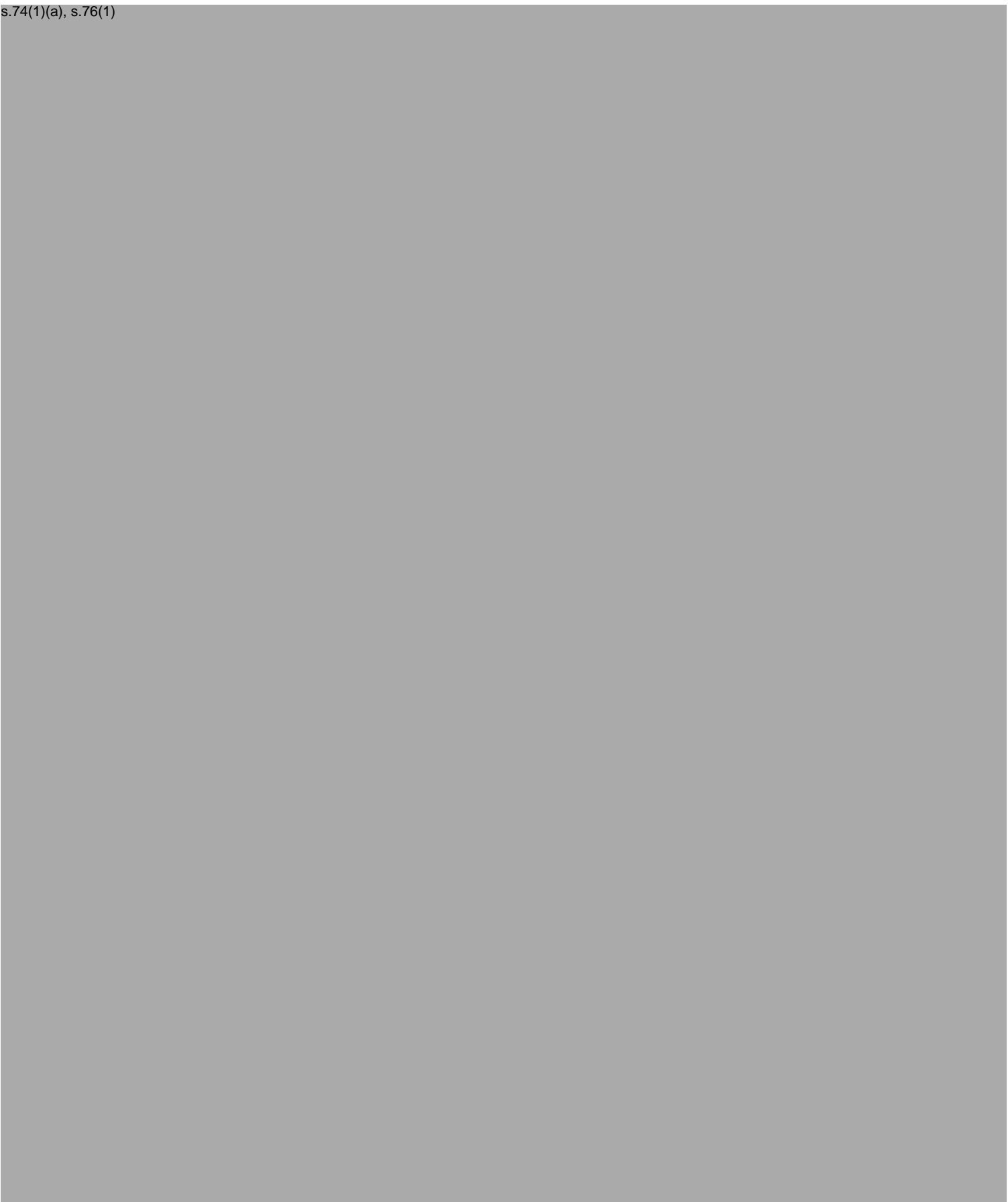
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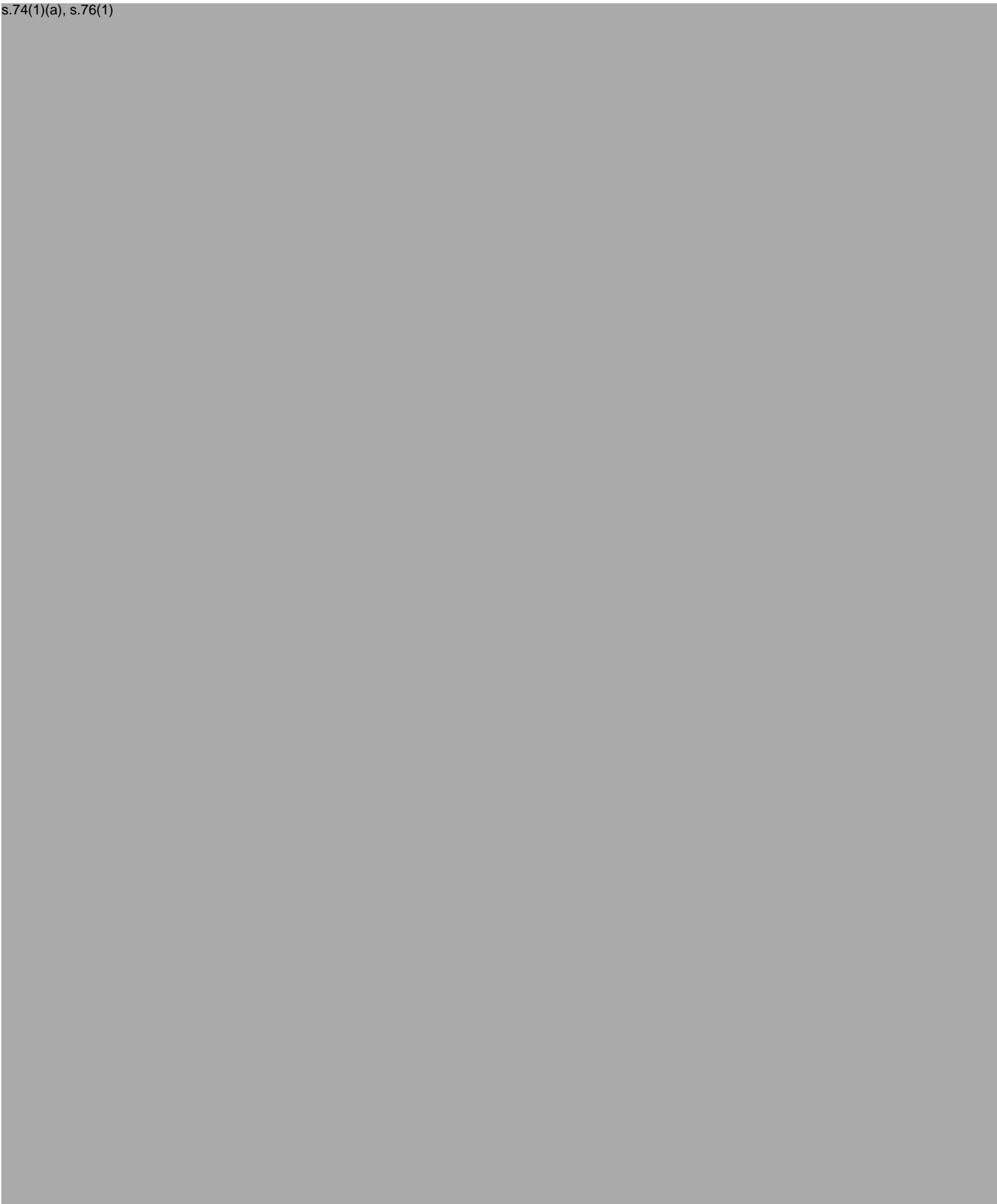
s.74(1)(a), s.76(1)



s.74(1)(a), s.76(1)



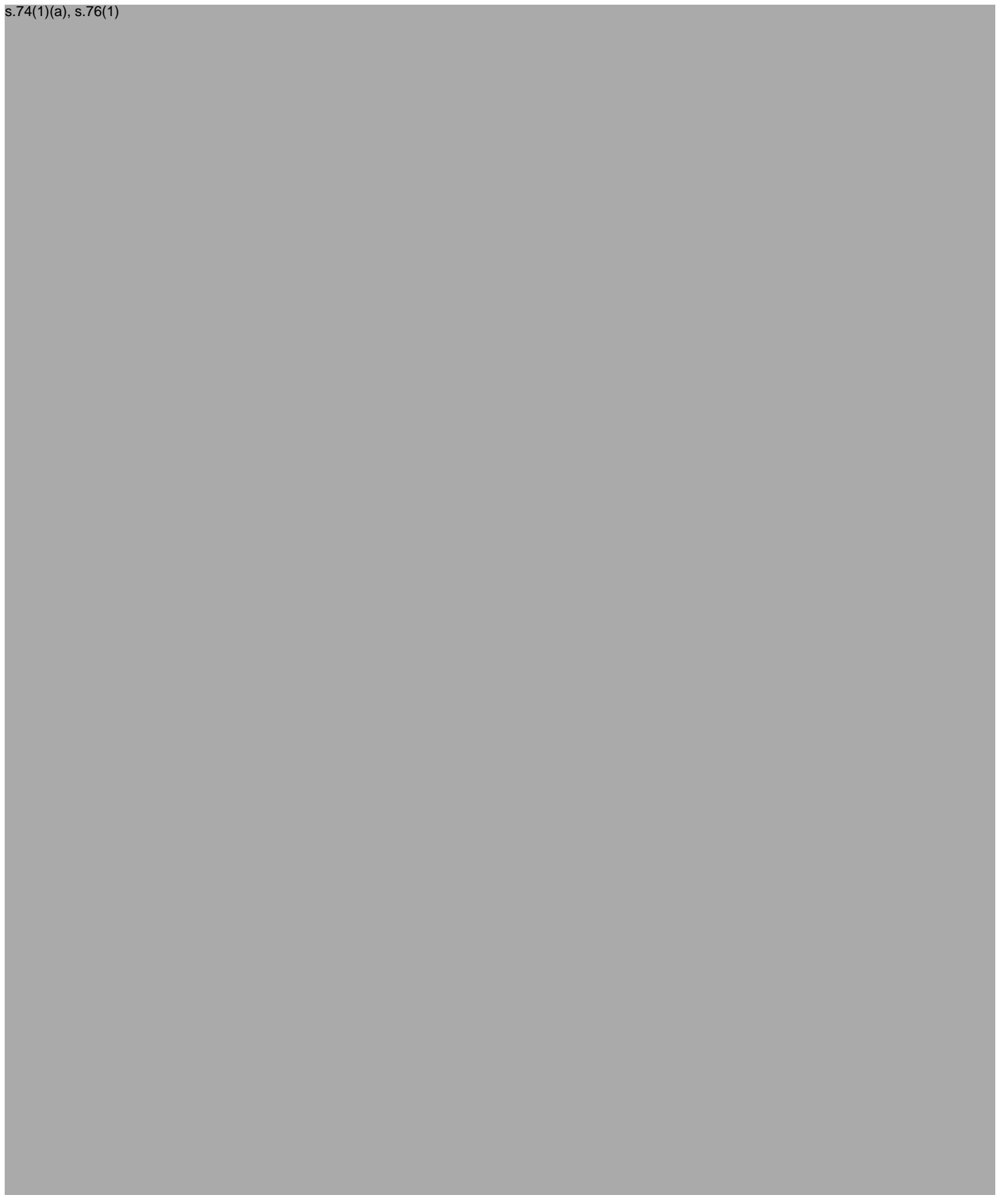
s.74(1)(a), s.76(1)




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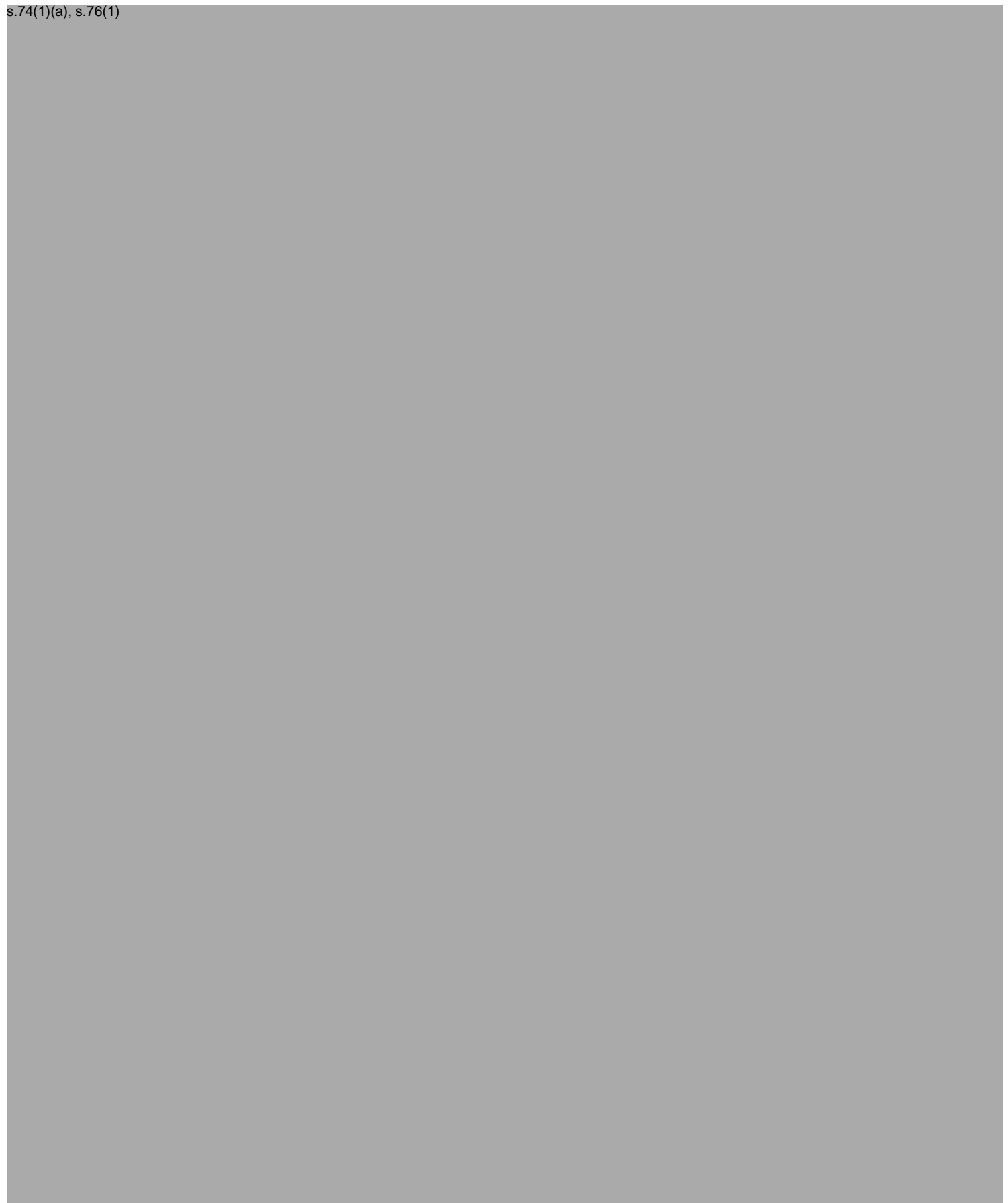





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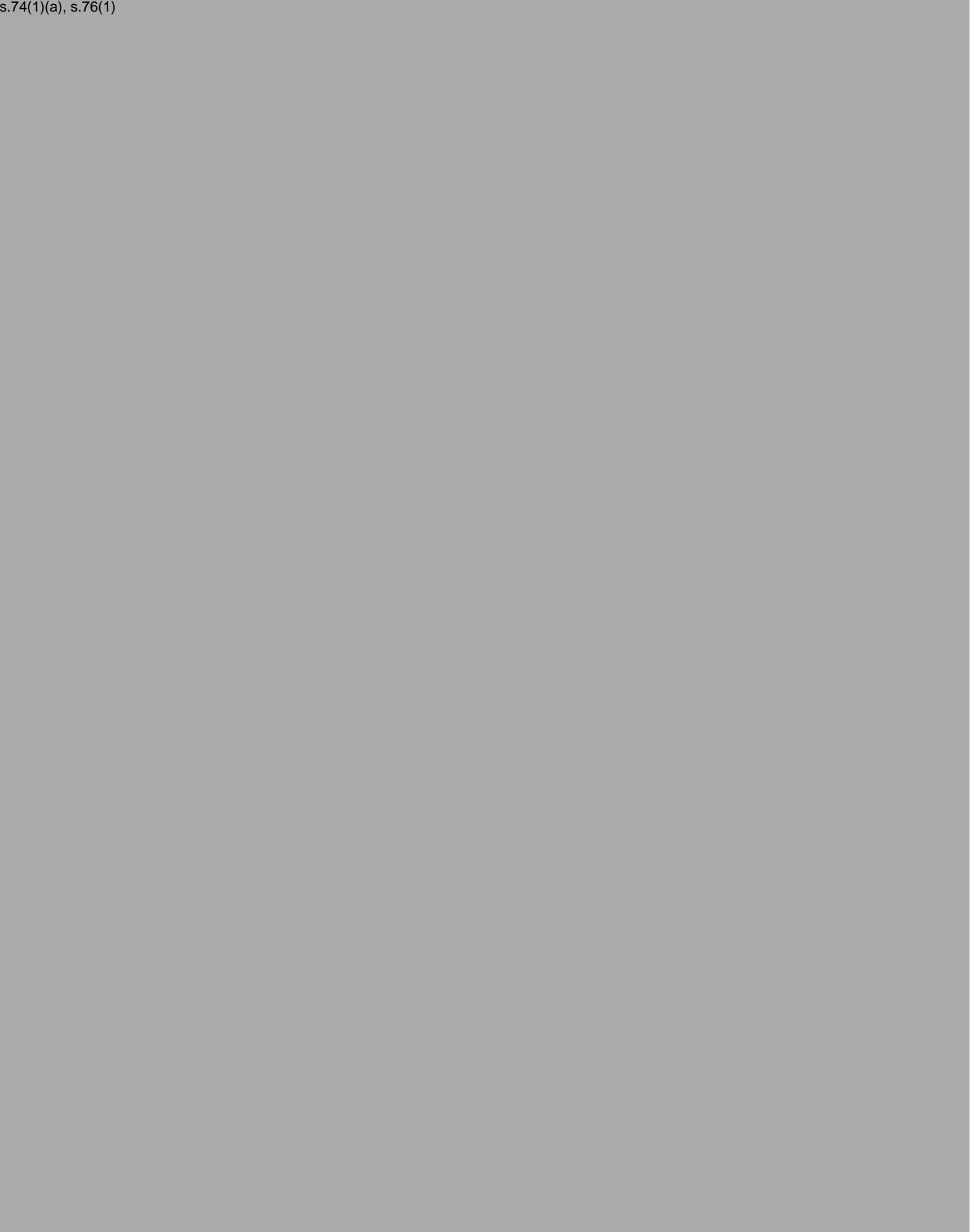


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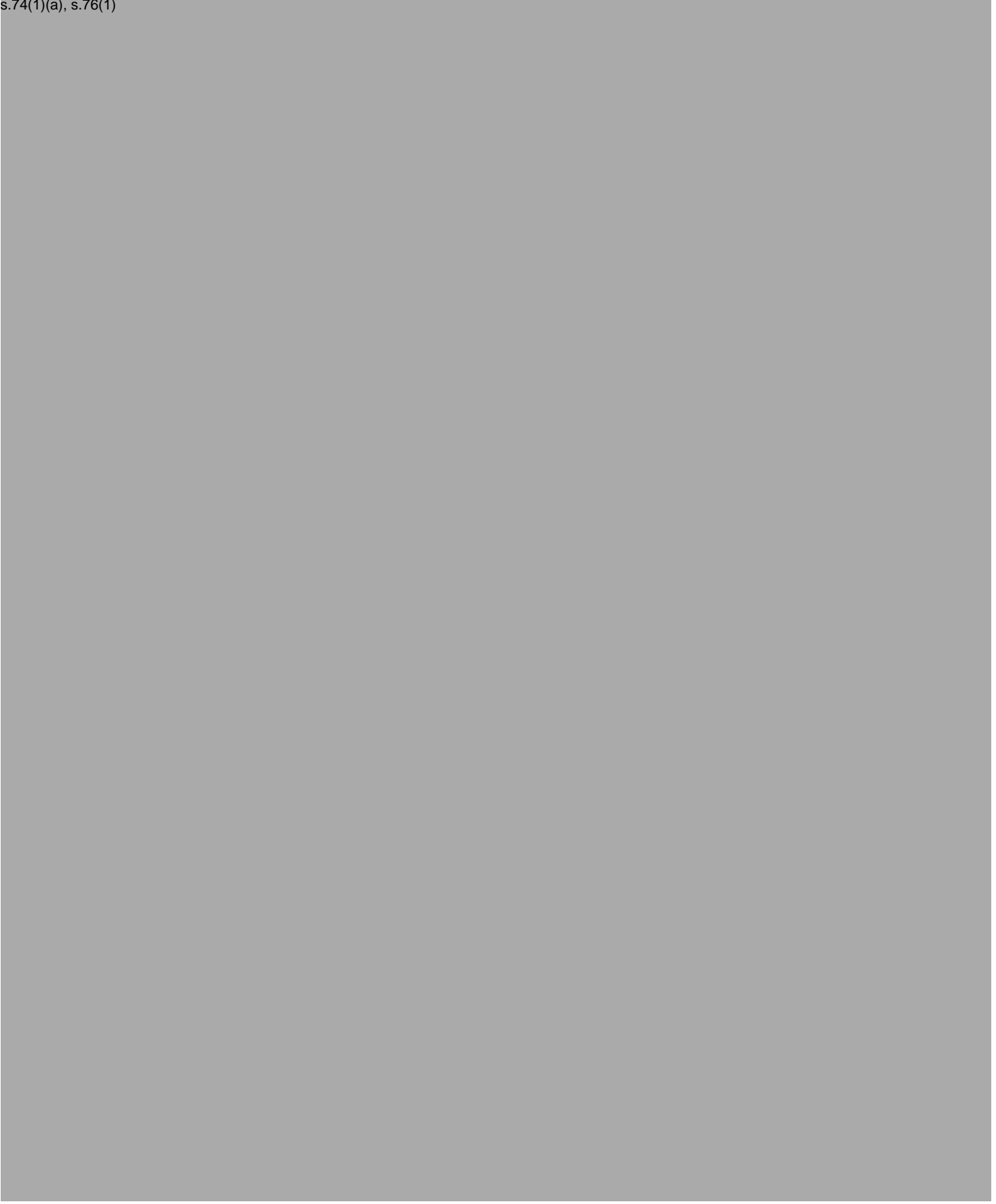
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s.74(1)(a), s.76(1)



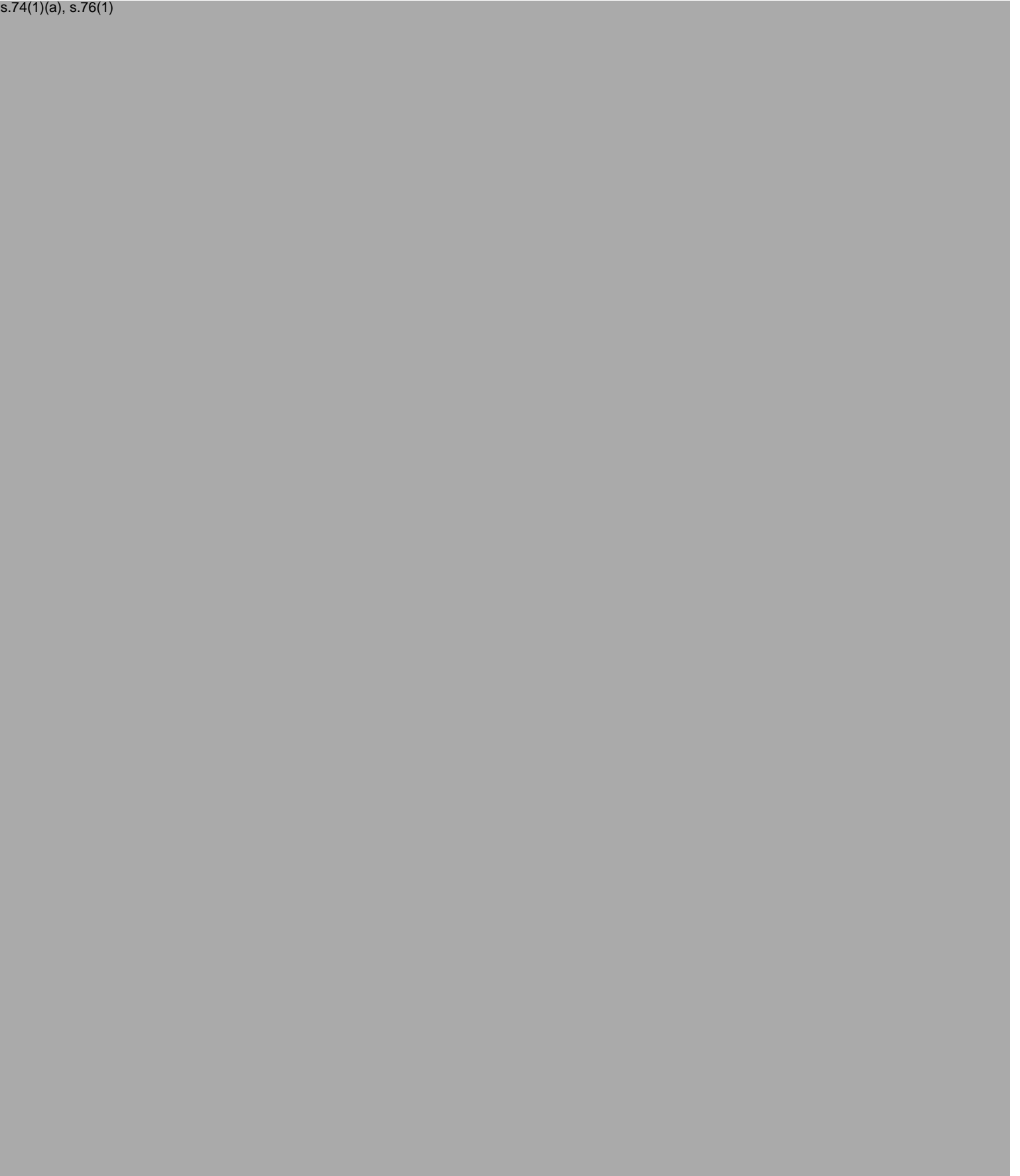
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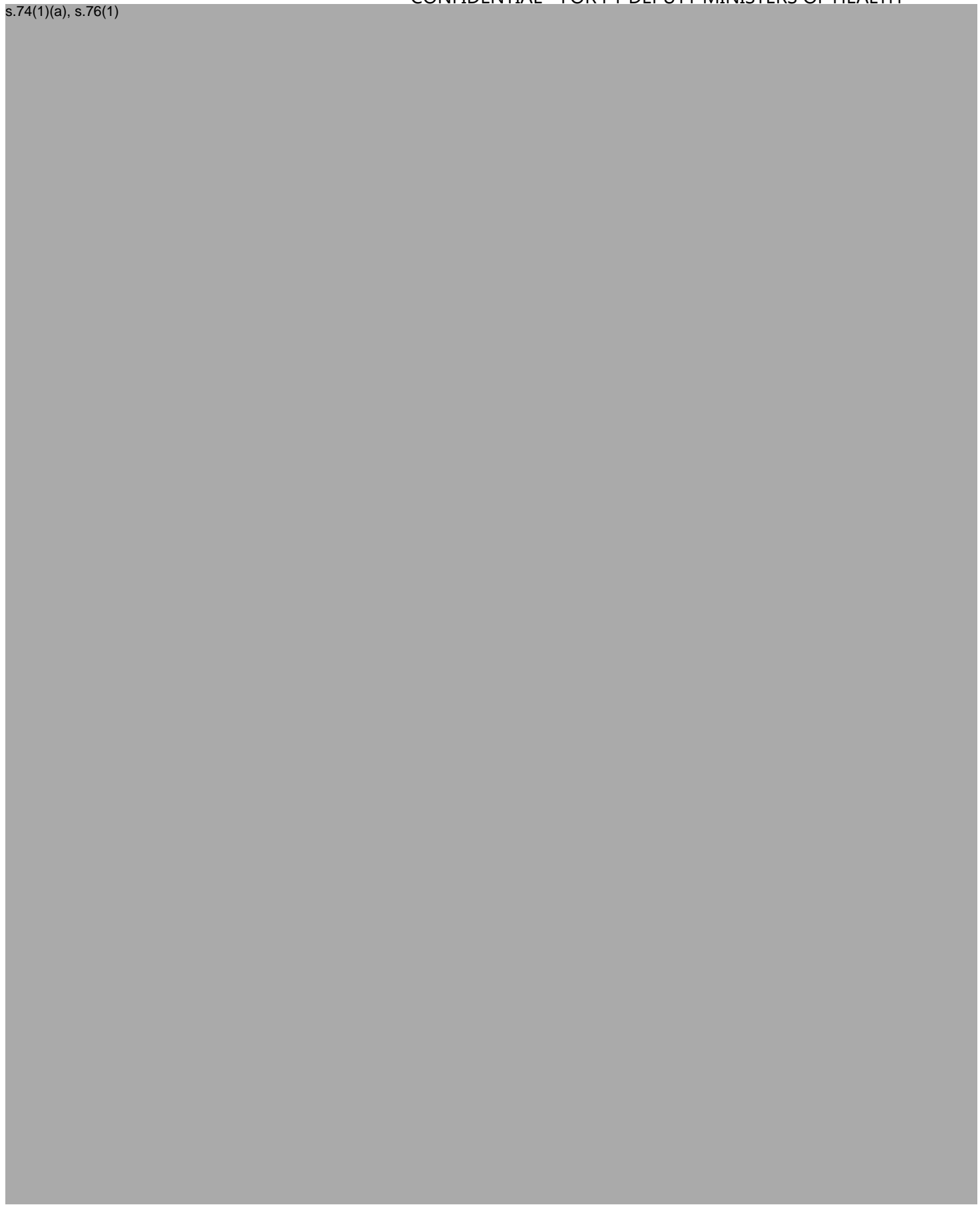
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s.74(1)(a), s.76(1)



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s.74(1)(a), s.76(1)

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s.74(1)(a), s.76(1)


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s.74(1)(a), s.76(1)


s.76(1)




s.76(1), s.74(1)(a)



s.76(1), s.74(1)(a)




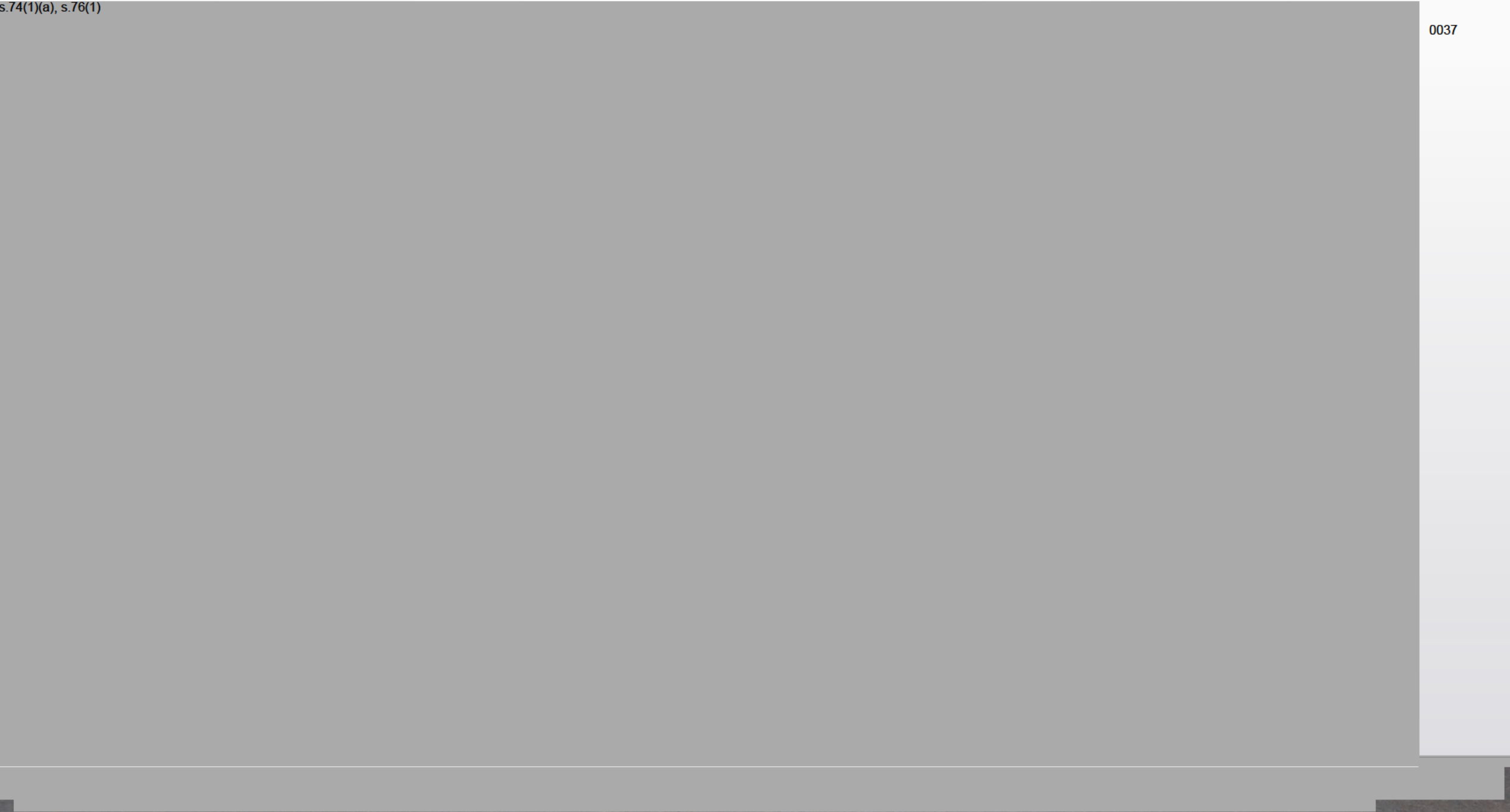
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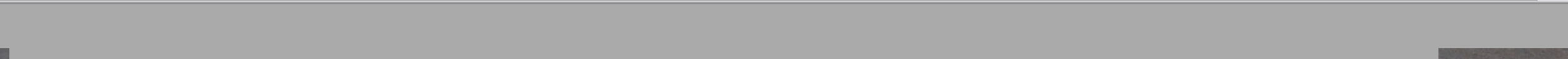





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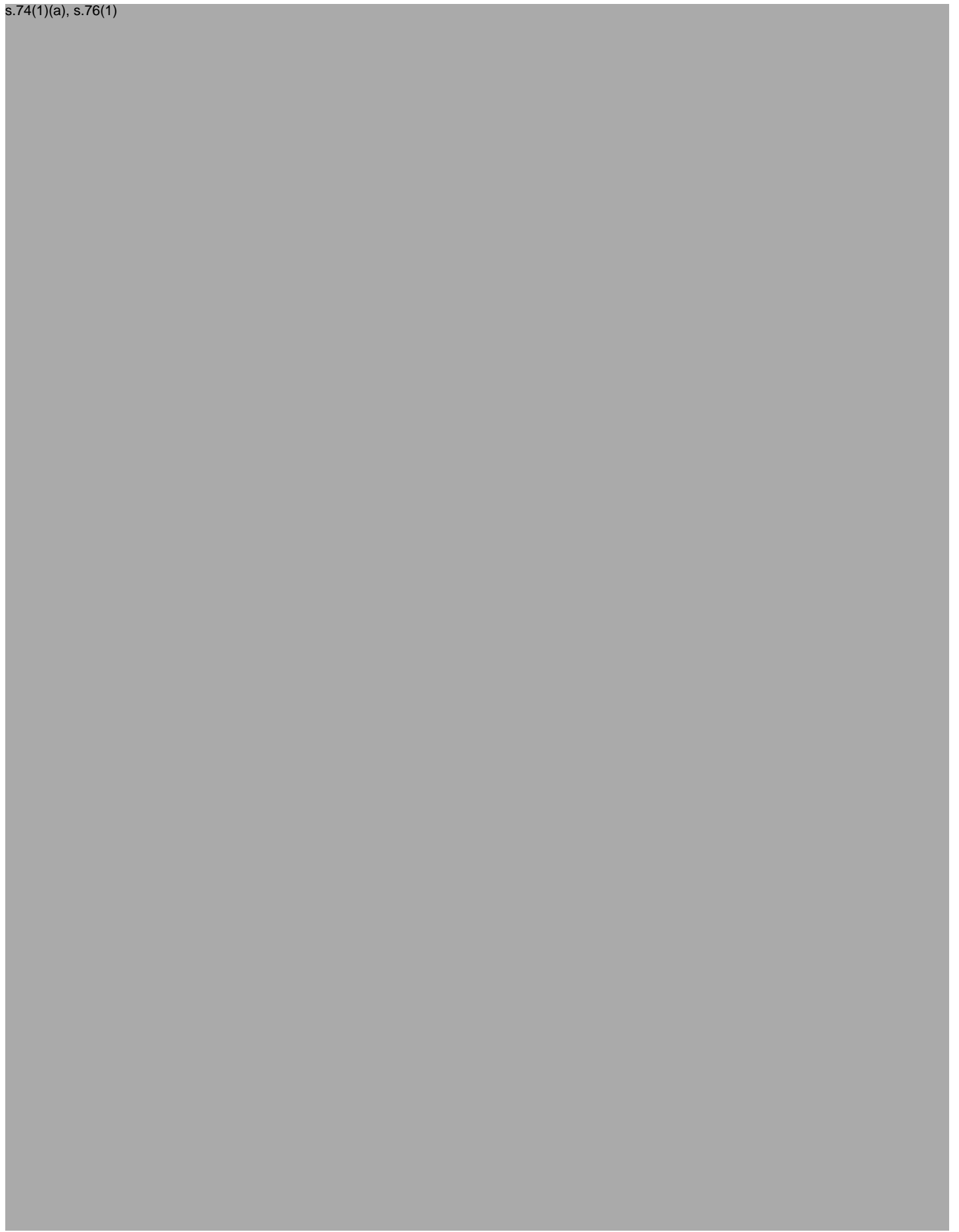




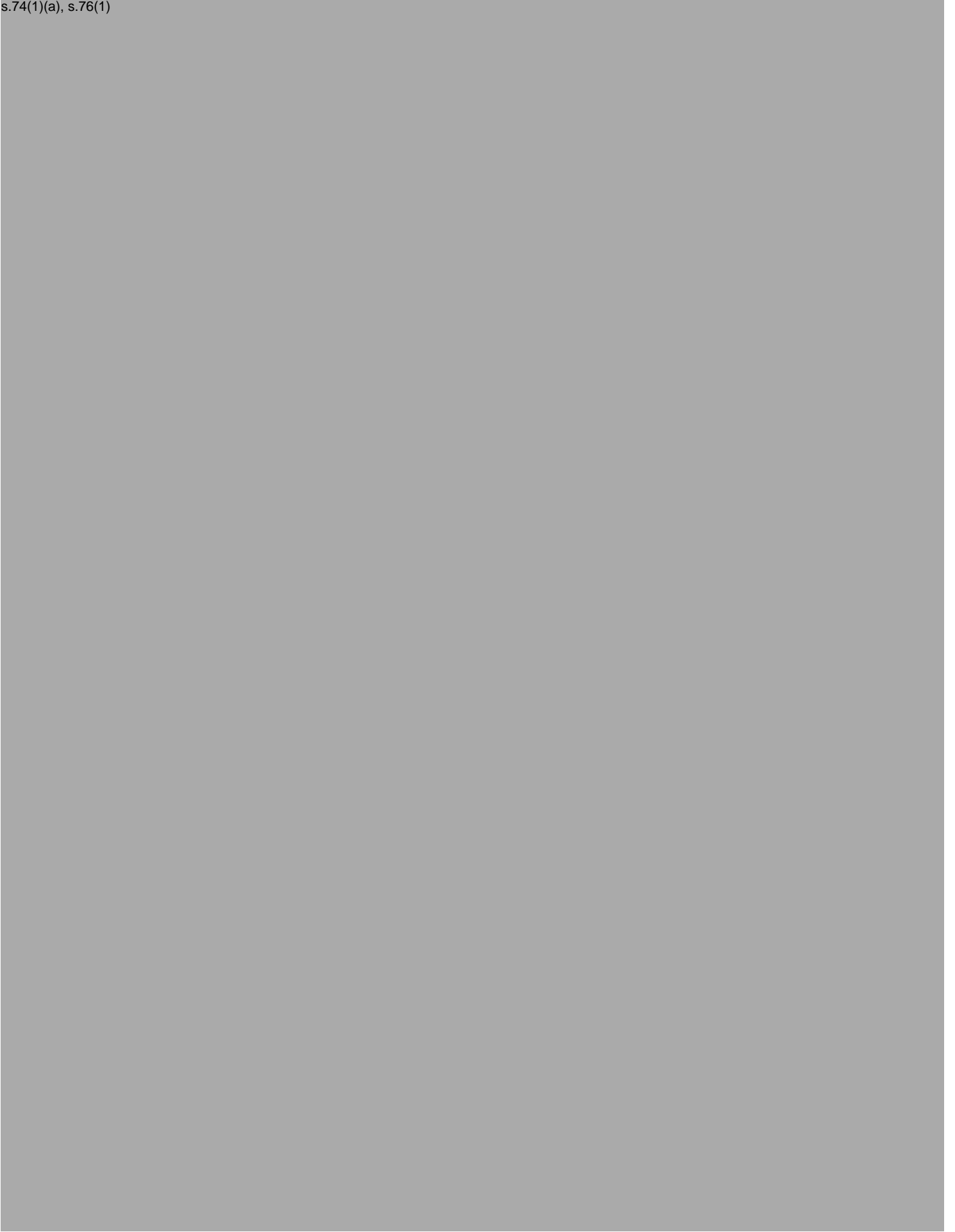
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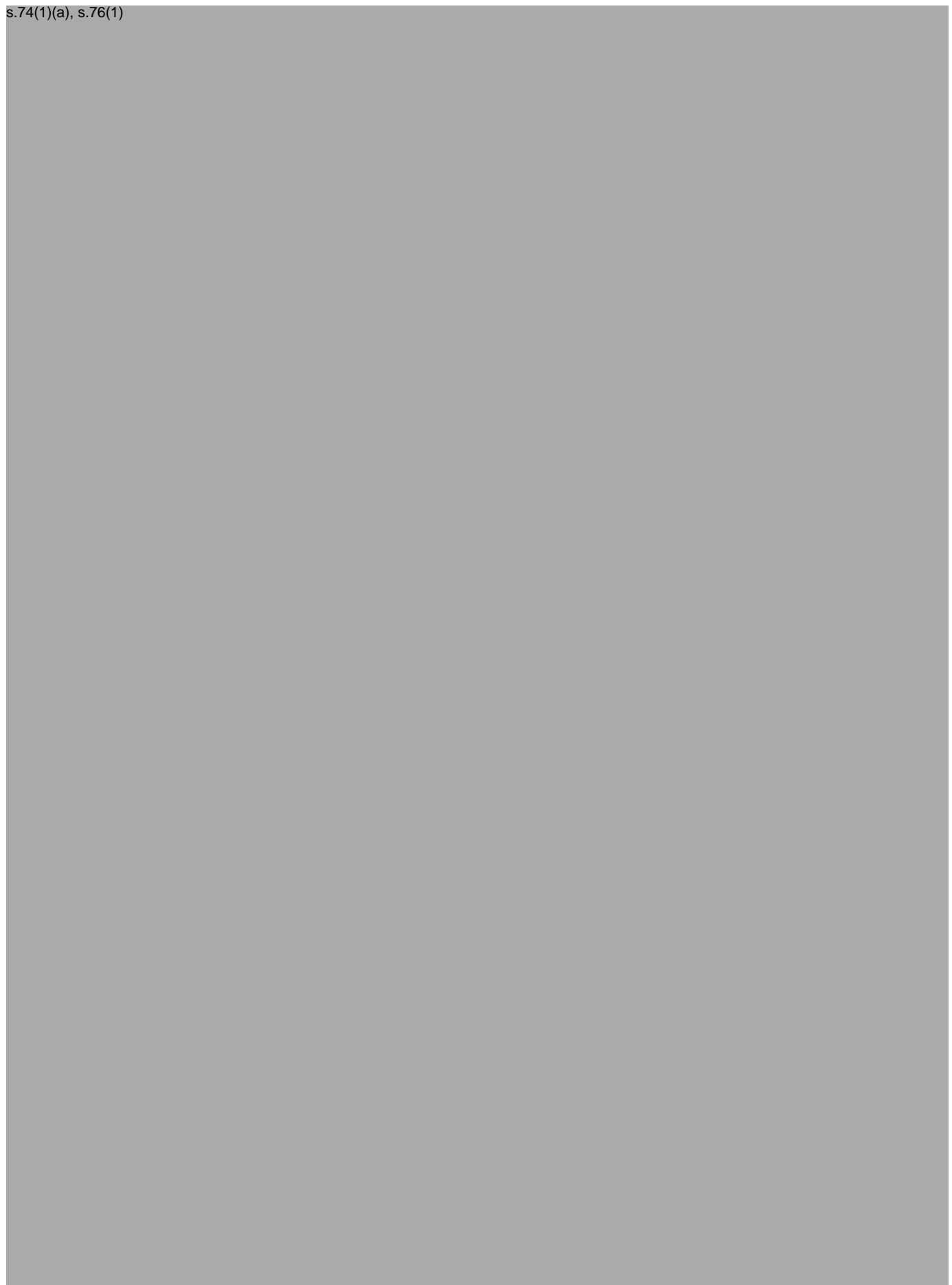
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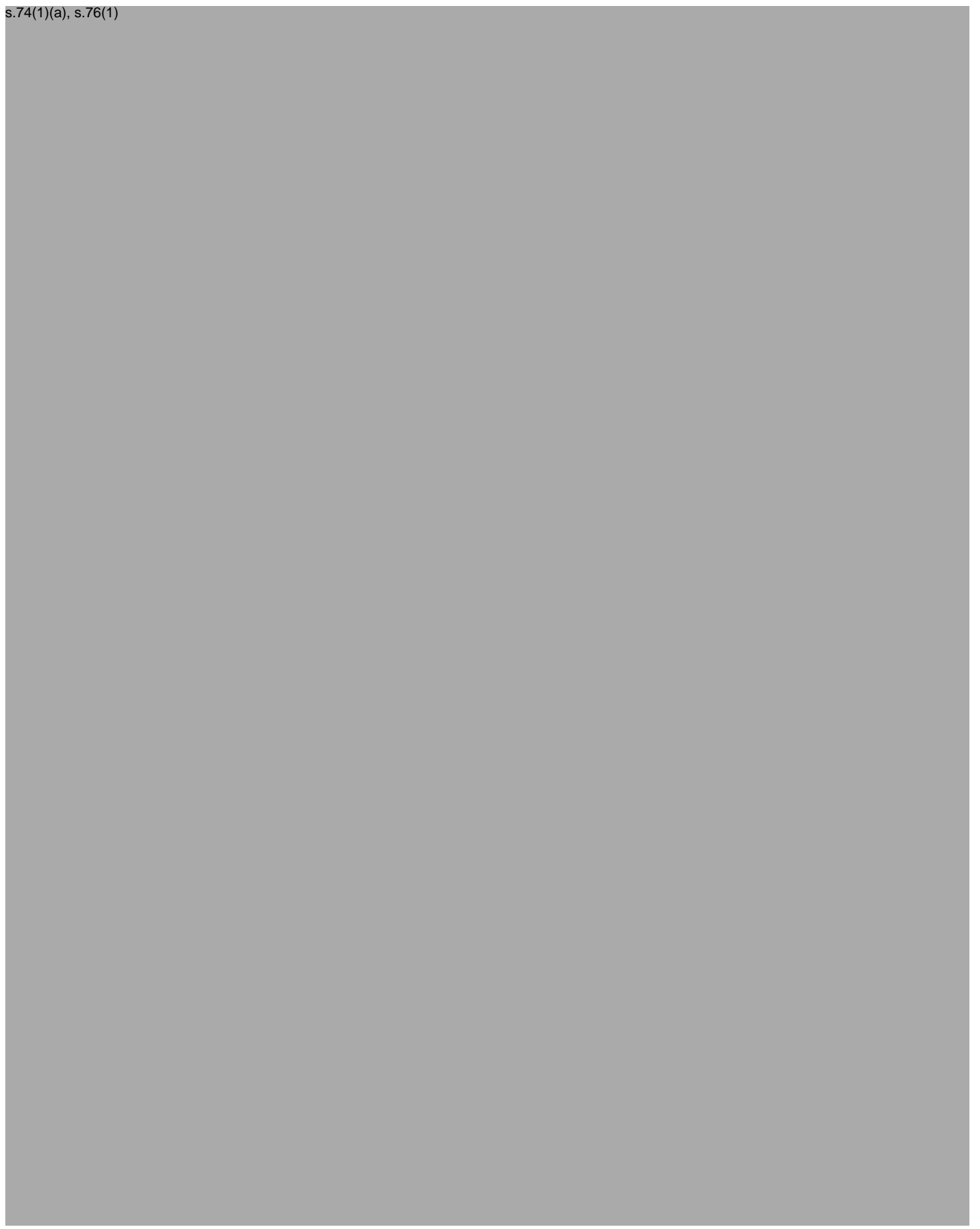
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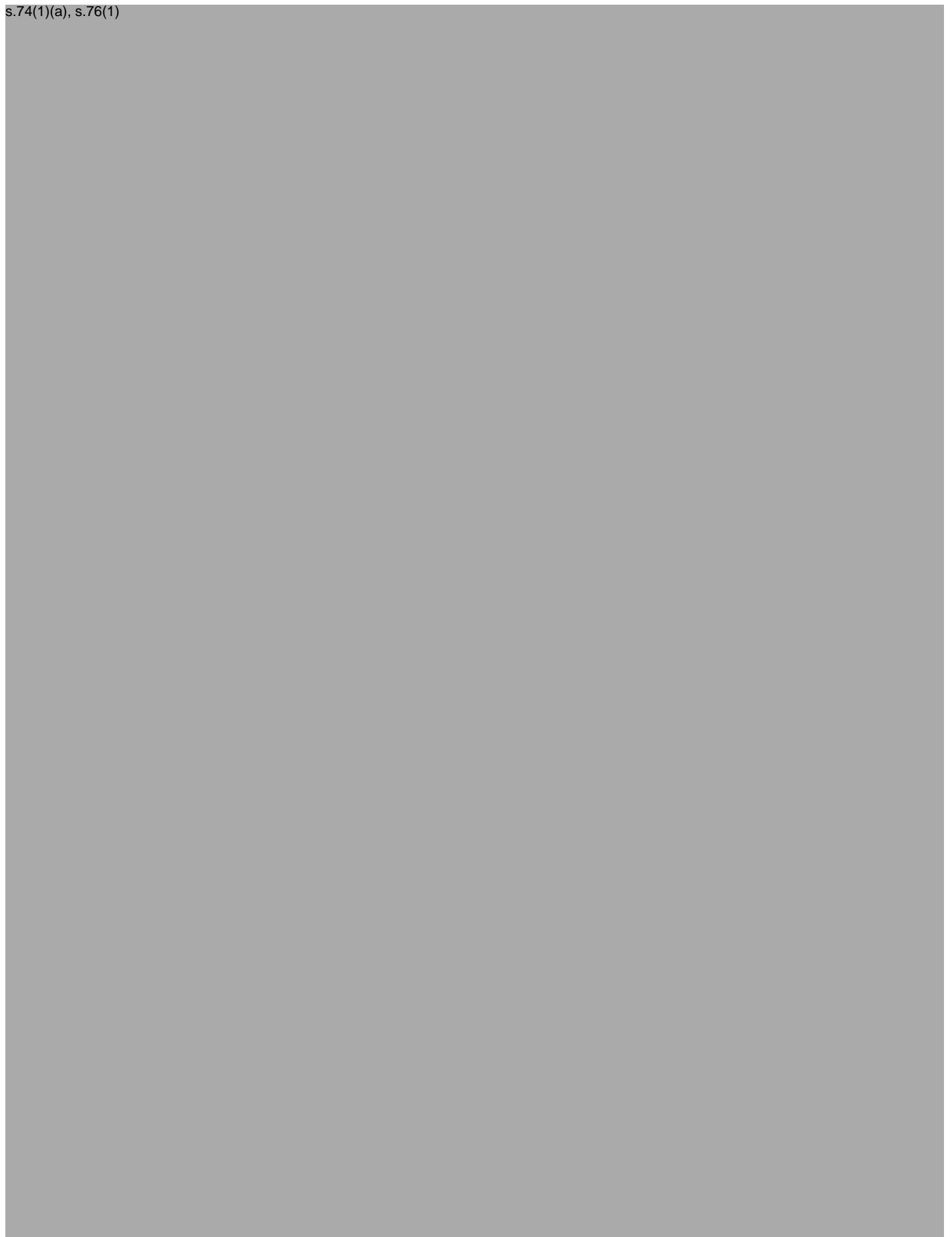
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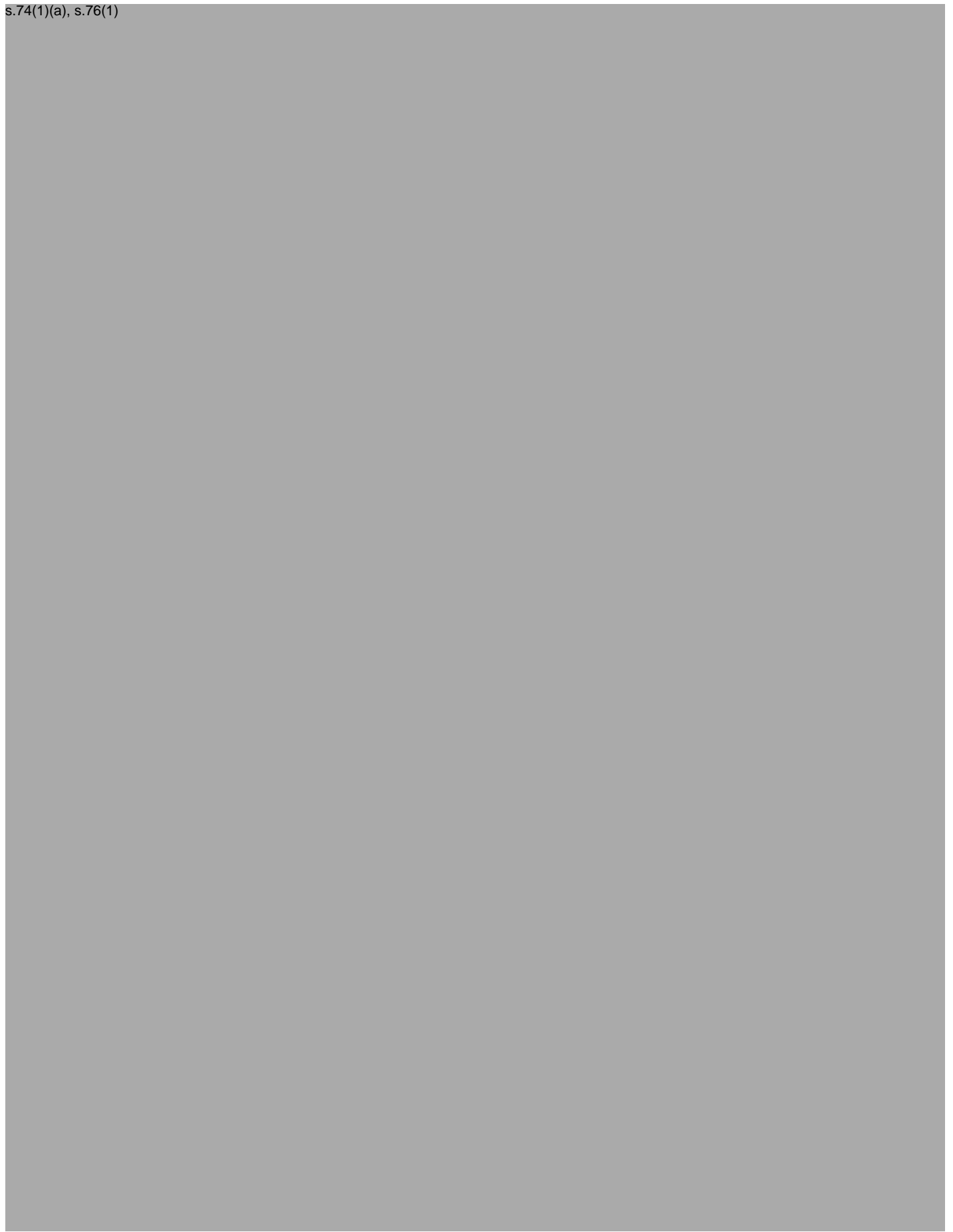
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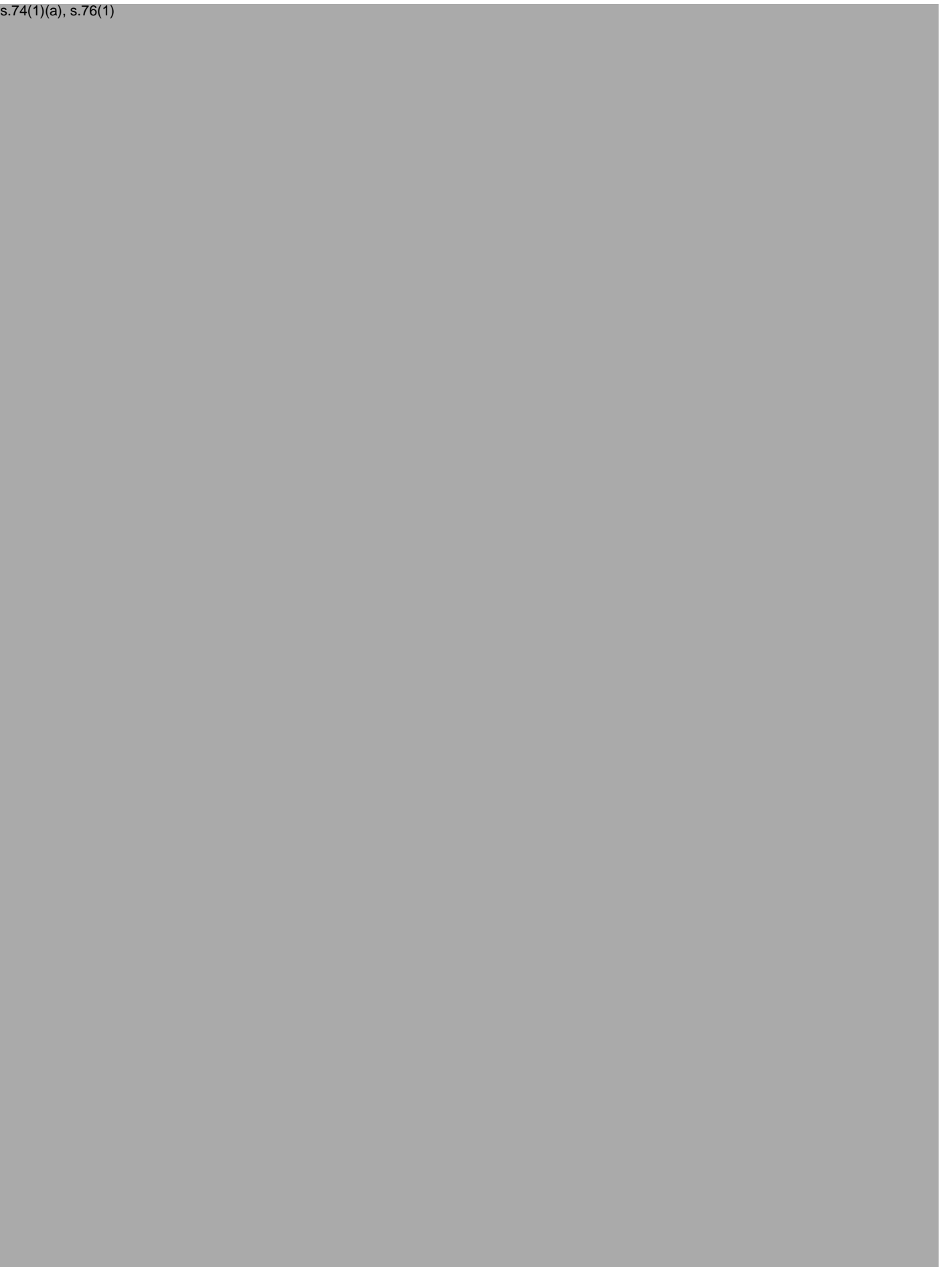
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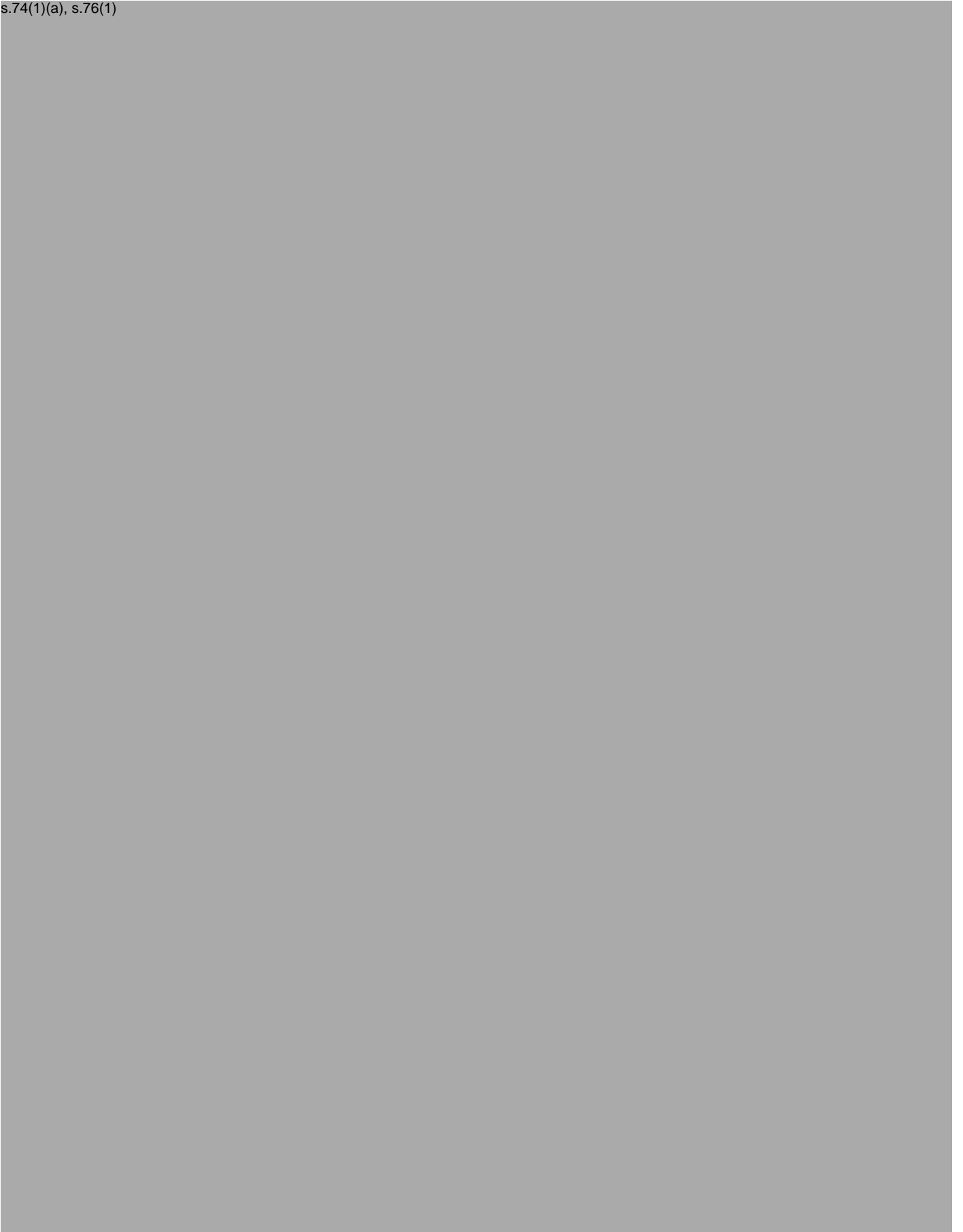
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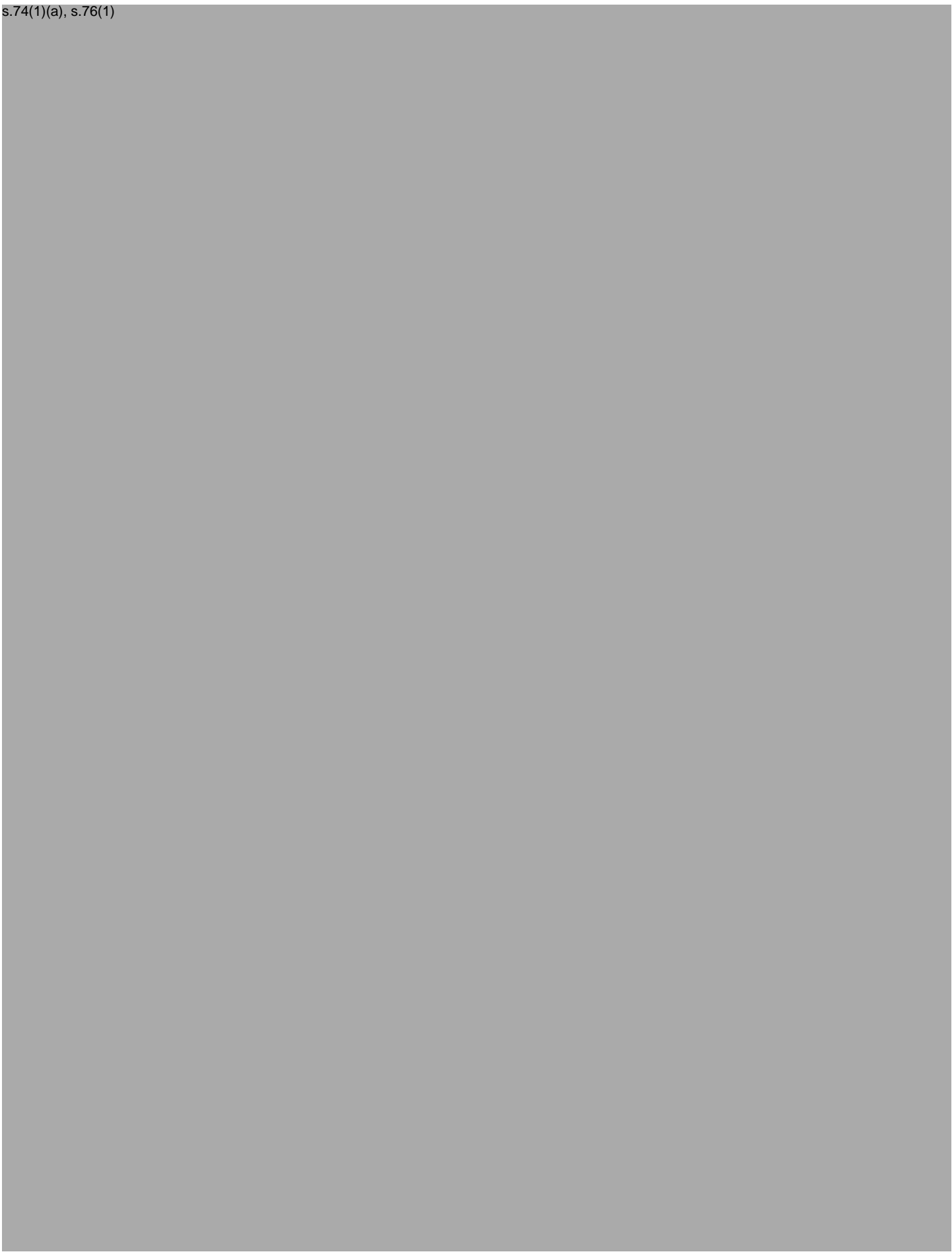
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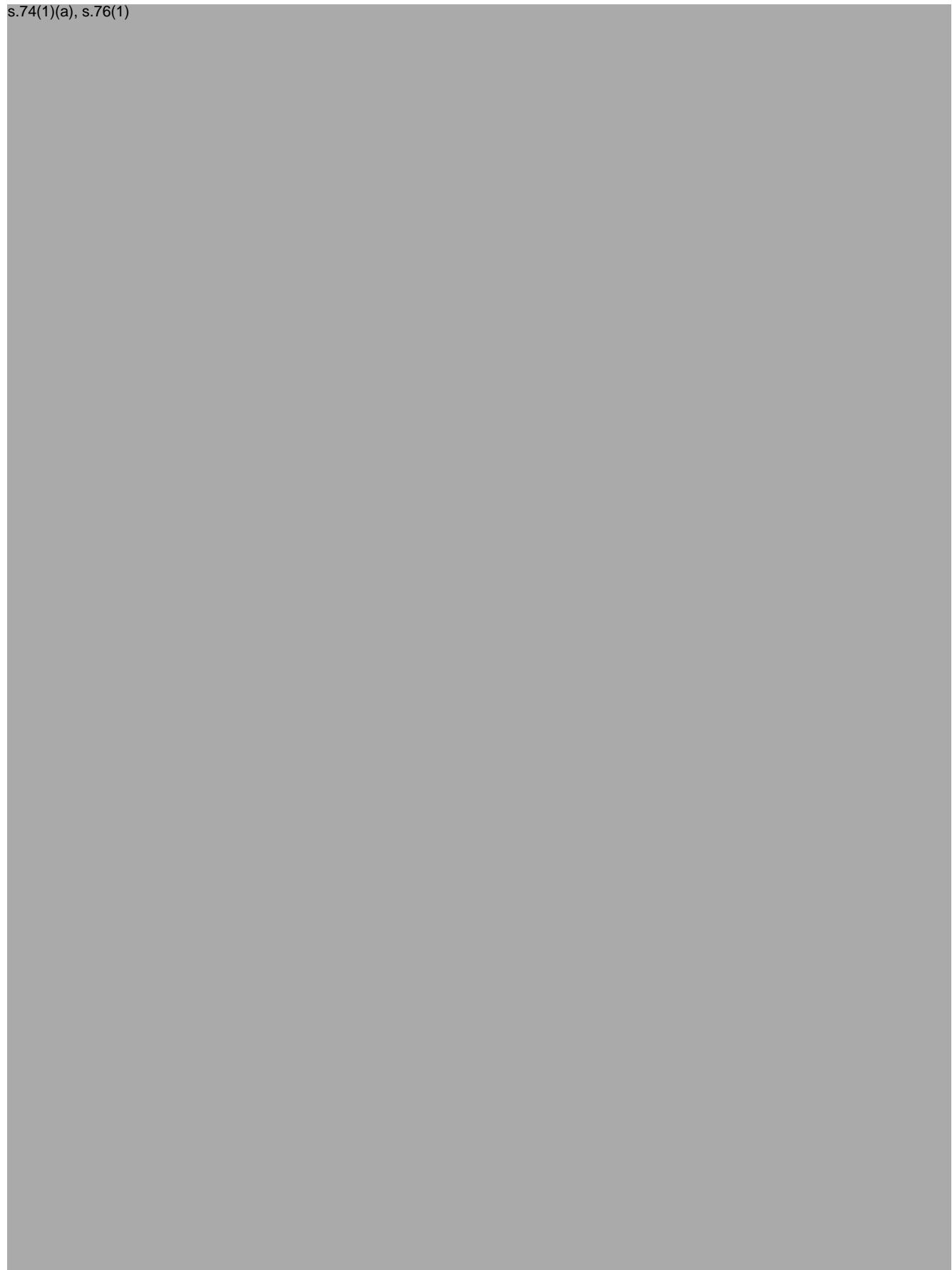
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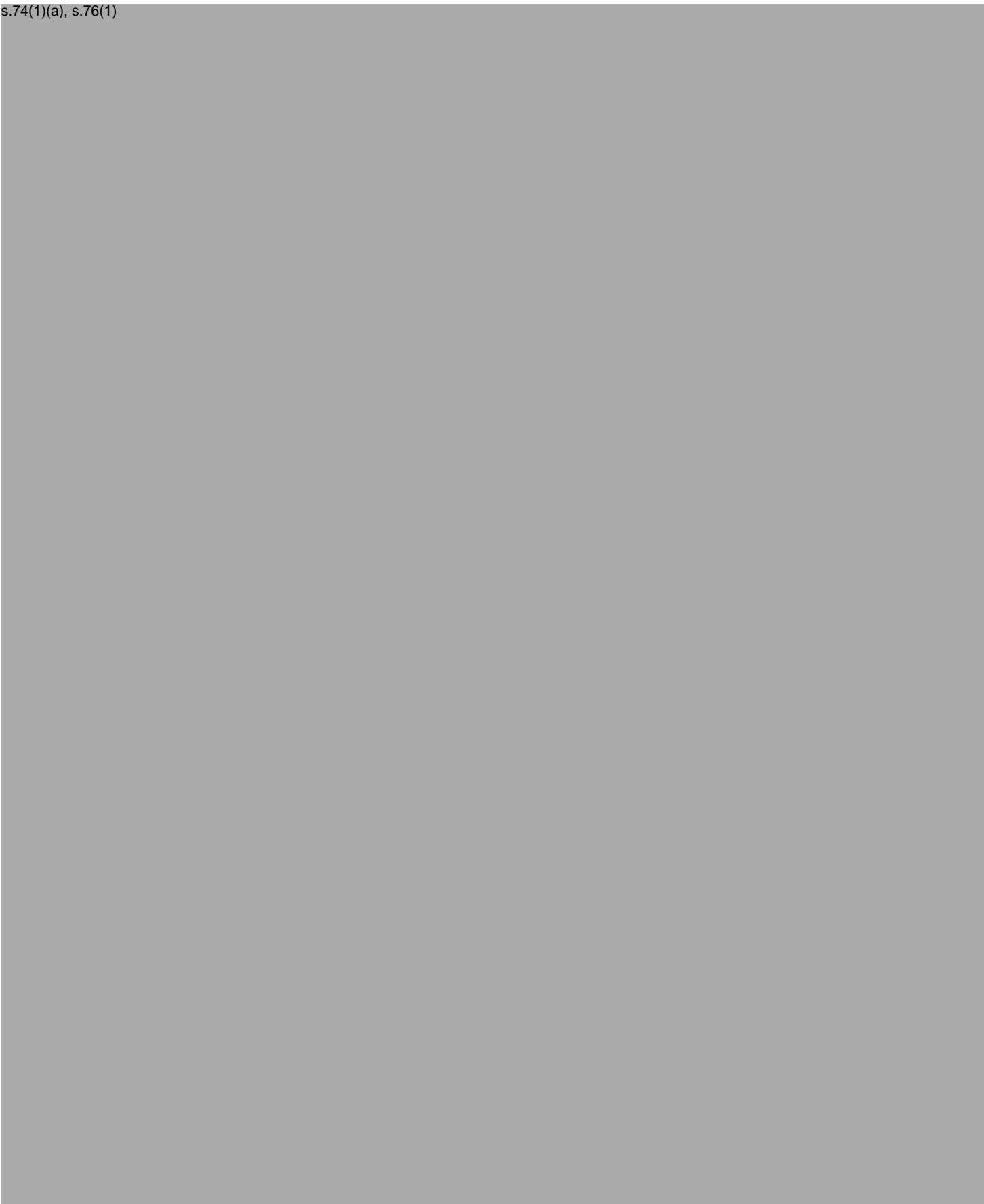


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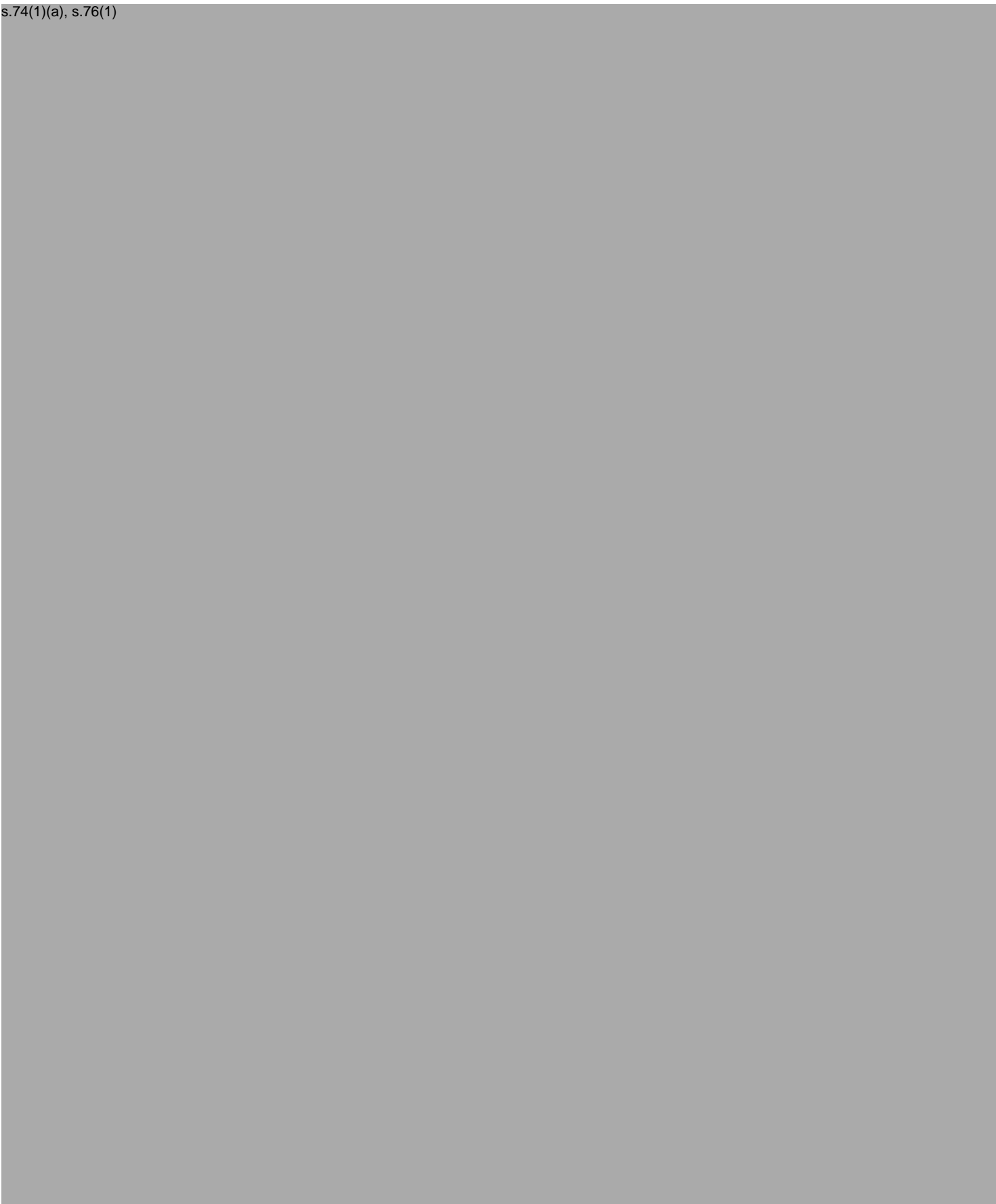
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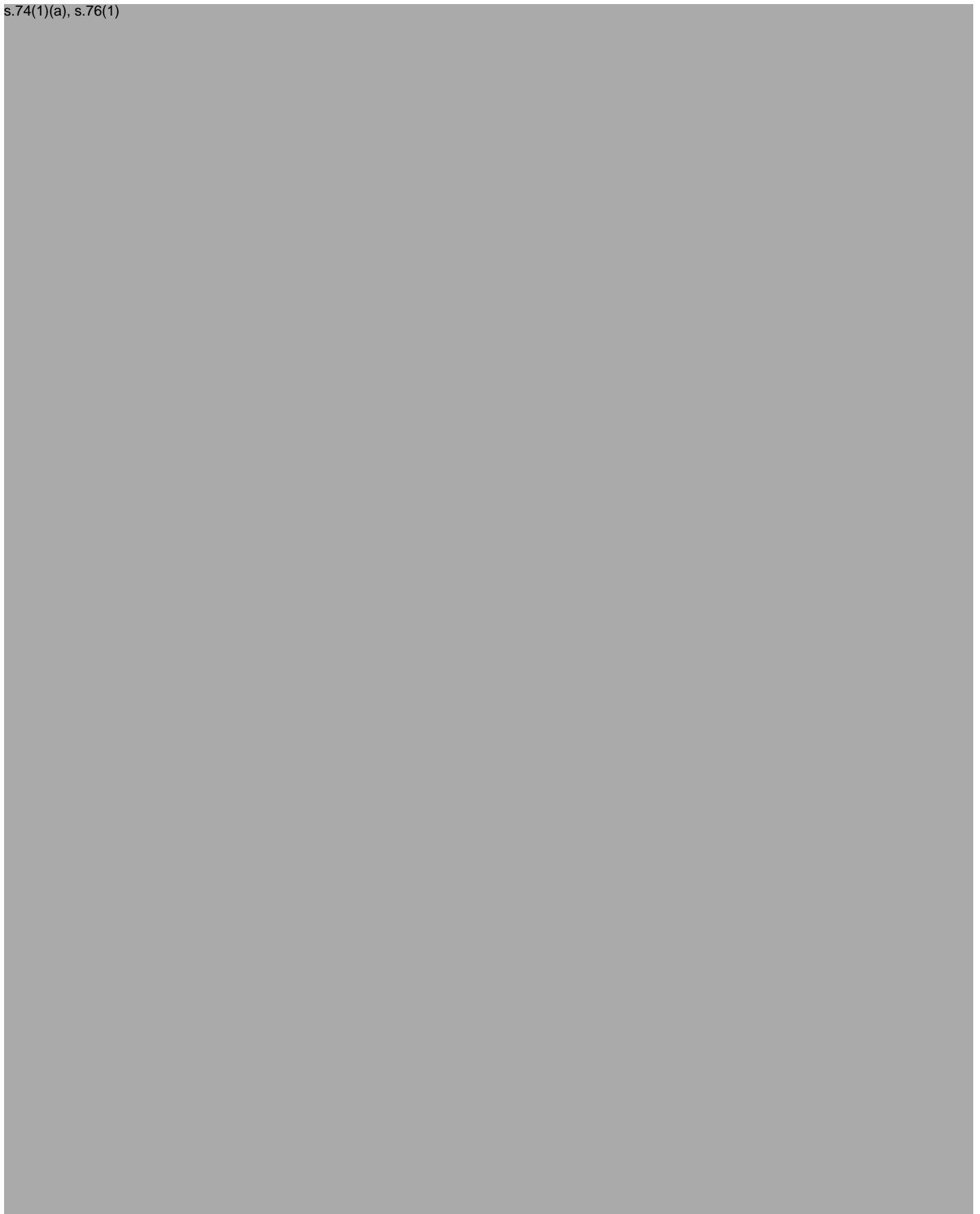
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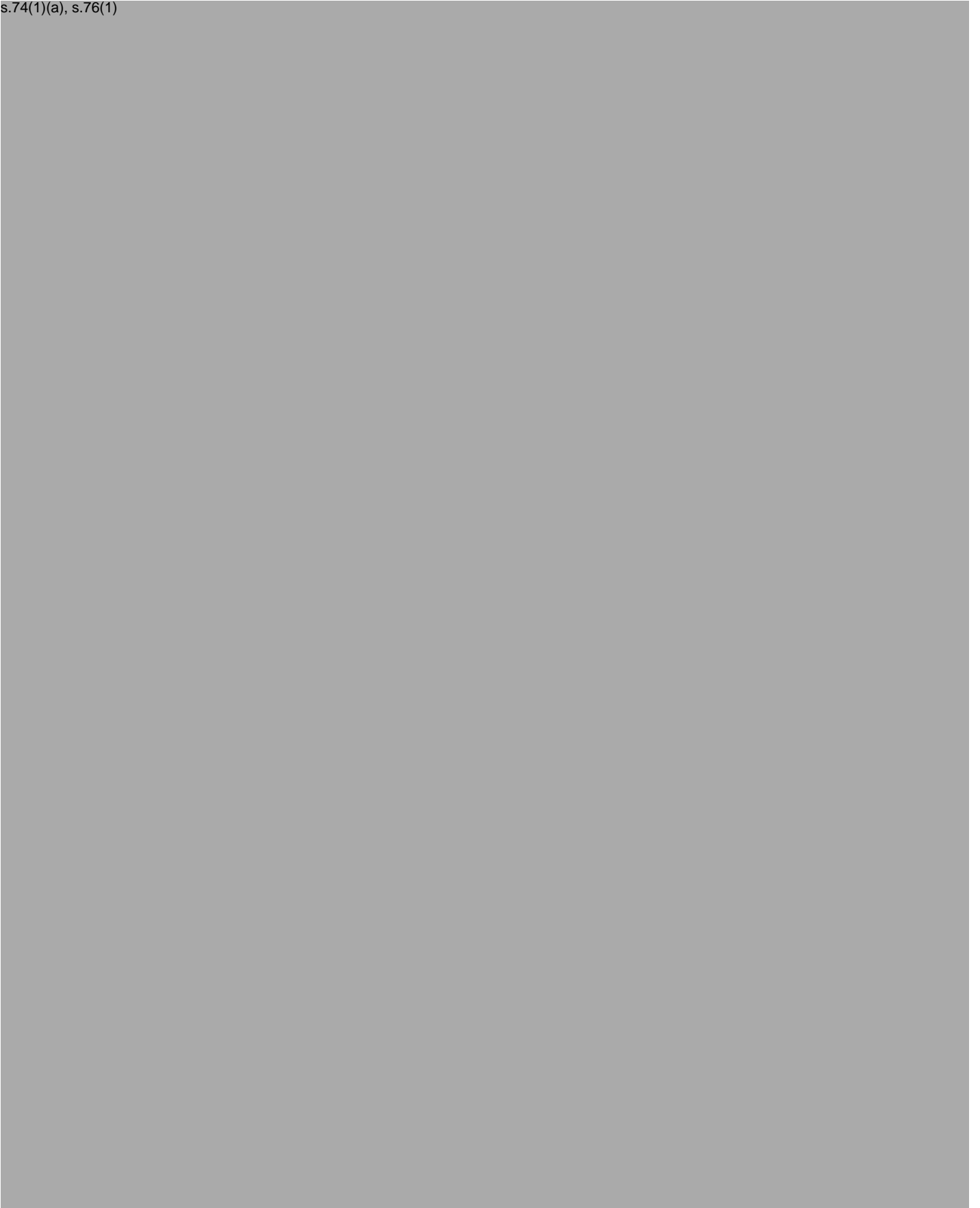
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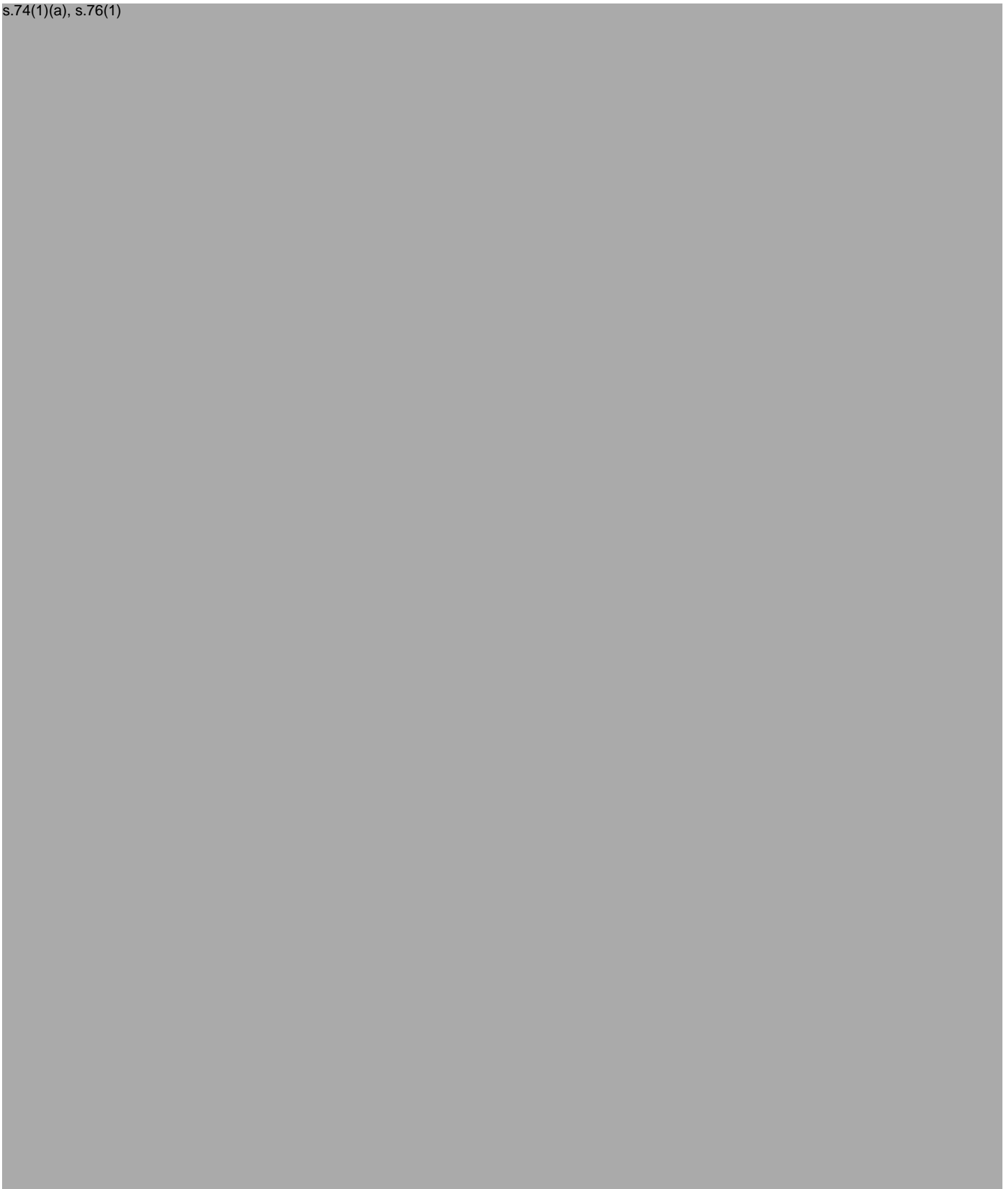
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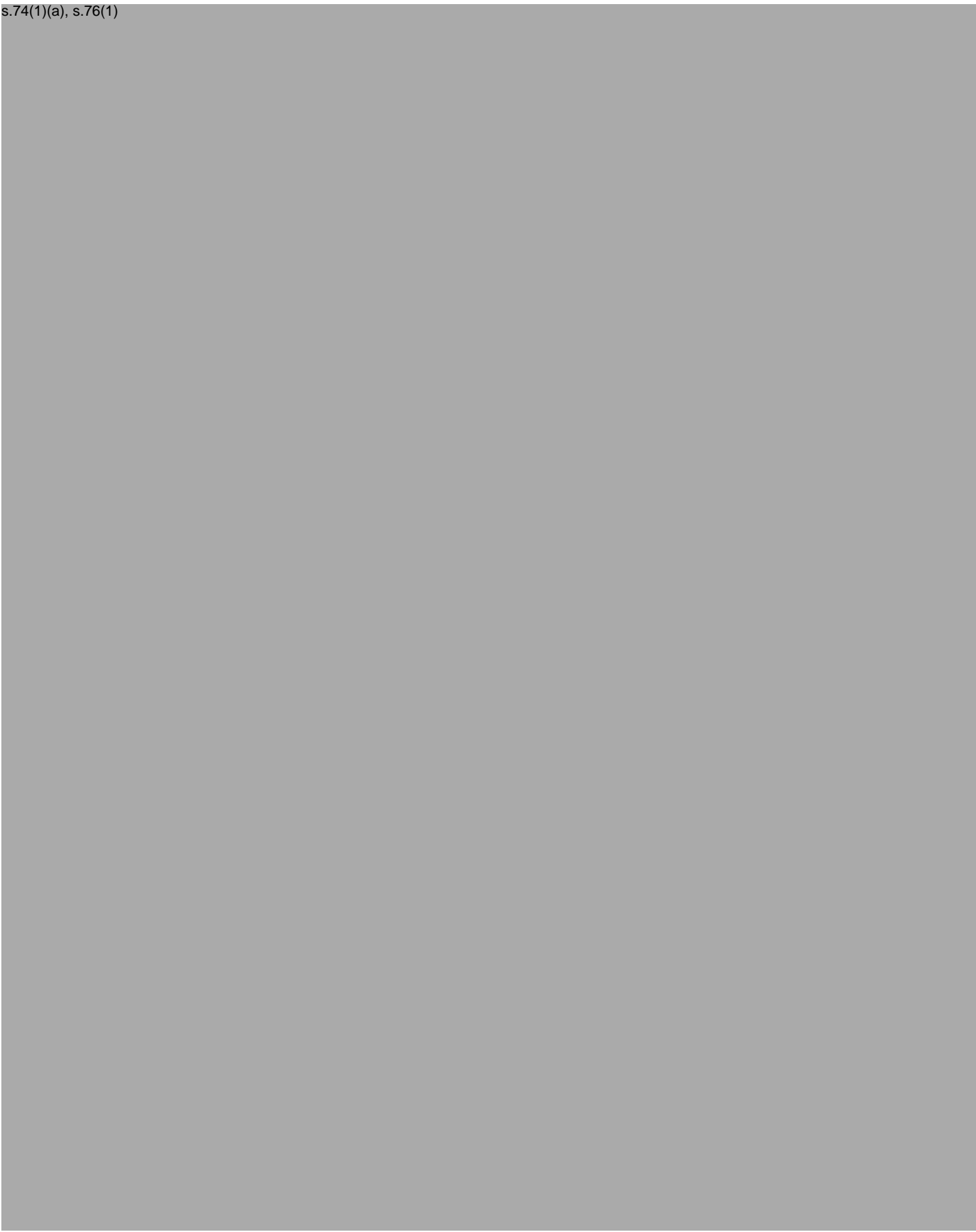
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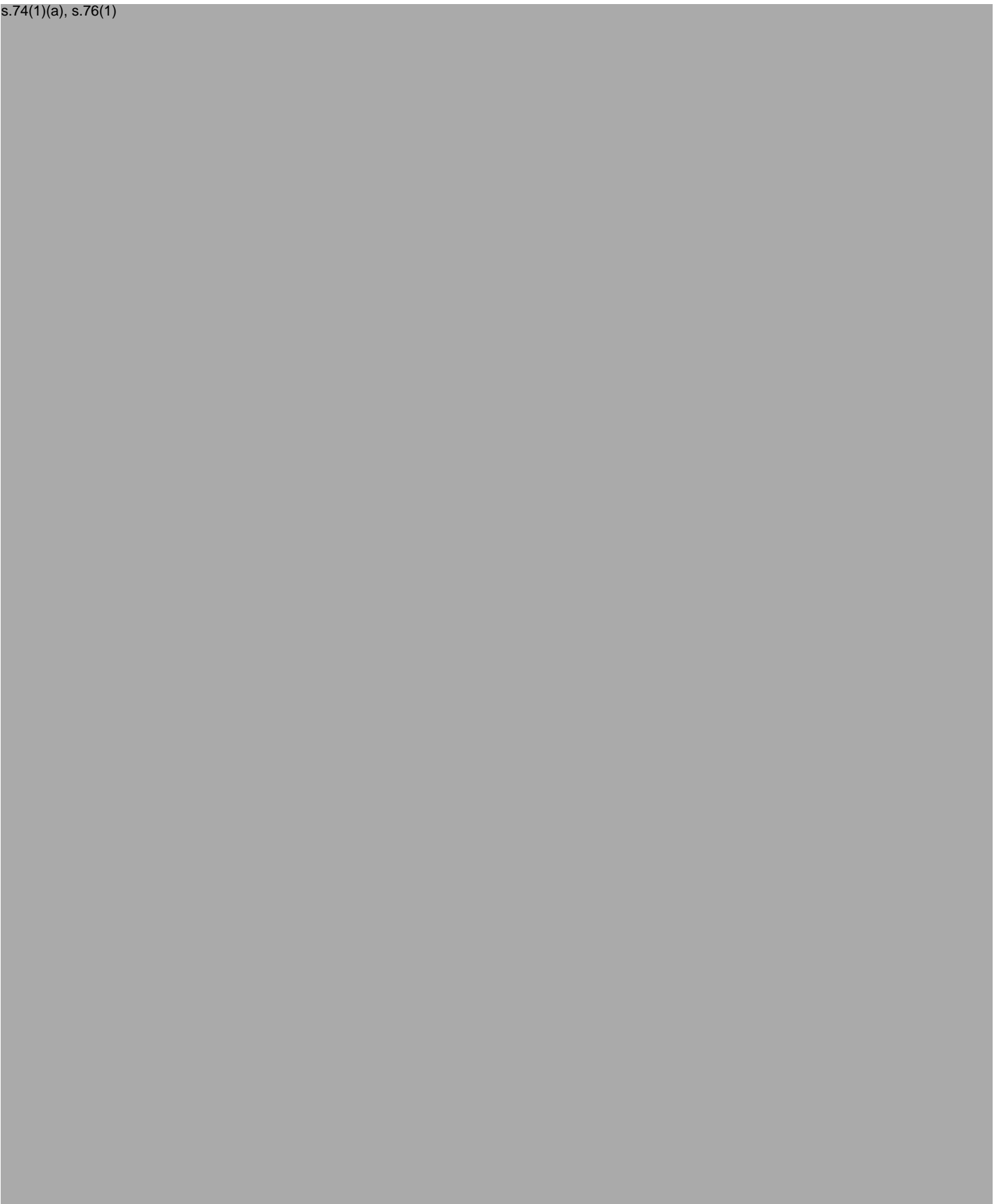
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s.74(1)(a), s.76(1)




s.74(1)(a), s.76(1)




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s.74(1)(a), s.76(1)



s.74(1)(a), s.76(1)























s.74(1)(a), s.76(1)



s.74(1)(a), s.76(1)



National Strategy for Drugs for Rare Diseases

Scoping the universe of drugs for rare diseases (DRD) to inform the short list of new and emerging drugs to be consistently covered and cost-shared

May 24, 2023

FPT Pharmaceuticals Executive Group



Meeting Objectives



1. Begin scoping the universe of DRD to inform the short list of new and emerging drugs to be consistently covered and cost-shared

s.76(1)

Recap: CDM Tasking

- The Conference of Deputy Ministers (CDM) tasked the FPT ADM Pharmaceutical Executive Group (PEG) on March 30 to advance the development of an agreed upon short list of **new and emerging drugs** that will be cost shared and covered consistently across the country by:

s.76(1)



- Advancing these CDM taskings will also inform the advancement of bilateral agreements, which will inform Action Plans and reporting requirements.

Recap: Forward Agenda to Advance CDM Tasking 1 and 2

s.76(1), s.74(1)(a)

Focus of today's discussion

s.76(1)



Defining the DRD Universe

s.76(1)

s.76(1)



s.76(1)



s.76(1)



National Strategy for Drugs for Rare Diseases

Informing the short list of new and emerging drugs to be consistently covered and cost-shared

June 20, 2023

FPT Pharmaceuticals Executive Group



Meeting Objectives



1. Review the **coverage status** of DRD by public plans

s.76(1)

Common Set of Drugs – Progress So Far


- The Conference of Deputy Ministers (CDM) tasked the FPT ADM Pharmaceutical Executive Group (PEG) on March 30 to advance the development of an agreed upon **short list of new and emerging drugs** that will be cost shared and covered consistently across the country

s.76(1)



Common Set of Drugs – Defining the DRD Universe

s.76(1), s.74(1)(a)




Focus of Today's Discussion

Review of Data Collection

- Since the May 24 PEG meeting, HC has worked with PEG to collect information on:

s.76(1), s.74(1)(a)



- Any changes desired to this input data?

s.76(1)




s.76(1), s.74(1)(a)




Horizontal Considerations Related to the List of New and Emerging Drugs

s.76(1), s.74(1)(a)



Discussion Items and Next Steps

s.76(1), s.74(1)(a)



- Also planning a kick off meeting in mid-July to discuss screening and diagnosis (require jurisdictions to confirm contact names for this work if not already provided)