InfAct - Information for Action

WP5; Task 5.3, Milestone 20

Method paper on a Delphi Survey for Health Information Prioritization

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Executive summary

Health information prioritization involves the establishment of methodological standards, and the development of political momentum, in order to reliably track health status and health determinants. Accurate tracking of health and its determinants and consequences at the national level is important in order to strengthen the evidence base for public health policies and facilitate effective delivery of healthcare services.(1)

Task 5.3 aims to answer the following questions:

a) How is health information, for national health reporting, prioritized in EU- and associated countries? How is it linked to health targets, both national and international (SDGs)?

b) Can „good-practice“-approaches in prioritizing health information be identified from answers to a)?

In order to address health information (HI) prioritization processes, an online Policy Delphi survey will be conducted among InfAct project partners and other stakeholders from EU-Member States (MS) and associated countries.

Key points

- Implementation of the 1st and 2nd rounds of the Policy Delphi to scope health information prioritization processes used among Infact project partners and EU-MS stakeholders are planned for March and May 2019, respectively. Field time will be three weeks.
- Final feedback will be sent to participants in July 2019. In addition to the survey results, the final feedback will contain information about the next steps in the research project, e.g. dissemination plans.
- The expected outcome of the Policy Delphi survey is a list of good-practice-approaches to health information development and prioritization at national levels, which could be further developed into a health information prioritization strategy at the European level.
- A final report, containing recommendations for health information prioritization methodologies, will be submitted to the Coordination in February 2021.
- In addition to being accessible on the InfAct Share Point, the final report may also be submitted as abstracts to relevant conferences or as a scientific paper to relevant journals.
InfAct: Method paper on Delphi Survey for Health Information Prioritization

I. Introduction

This paper outlines the methodology for the implementation of a Delphi survey to be conducted in WP5/ task 5.3. A conceptual outline of the Delphi survey was drafted by the task lead (RKI) and circulated among task partners for two rounds of comments, review and approval. The approved version of the conceptual outline is the basis of this method paper. Following the approval of this Milestone by the Coordination, the documents contained herein will be used to implement the Delphi survey on health information prioritization. The method paper is divided into the following sections:

1. Research Question
2. Methods
3. Outcome
4. Discussion and dissemination

It contains the following annexes:

Annex 1: Letter of invitation for survey participants
Annex 2: Project summary for survey participants
Annex 3: Informed Consent and Questionnaire for the 1st round
1 Research Question
Health information prioritization involves the establishment of methodological standards, and the development of political momentum, in order to reliably track health status and health determinants. Accurate tracking of health and its determinants and consequences at the national level is important in order to strengthen the evidence base for public health policies and facilitate effective delivery of healthcare services.(1)

Task 5.3 aims to answer the following questions:

c) How is health information, for national health reporting, prioritized in EU- and associated countries?
How is it linked to health targets, both national and international (SDGs)?
- Are defined methods or structured processes being used for prioritization of health information at national levels? How can such processes be described?
- Which stakeholders are involved in such structured processes? Who leads the processes? In the case that quasi-structured approaches may apply, which is/are the source(s) of unstructured additions to the structured processes?
- Does the development and prioritization of health information for national health reporting follow defined criteria? If yes, which are these criteria? Are they linked to international regulations, laws or priorities? Who is involved in developing criteria for the prioritization of health information?

d) Can „good-practice“-approaches in prioritizing health information be identified from answers to a)?
- Could these be developed into recommendations for EU and associated countries?
- Could they be used towards a European strategy for health information prioritization?

2 Methods
In order to address health information (HI) prioritization processes, an online Policy Delphi survey will be conducted among InfAct project partners and other stakeholders from EU-Member States (MS) and associated countries. We selected the Policy Delphi survey approach as the appropriate scoping survey format, due to its appropriateness for our research question and in view of the lack of alternative methods being described in literature for national health information prioritization processes (see section 2.1 on Literature review, below).

Figure 1, below, illustrates the steps that have been, and will be taken to prepare and implement the survey. They are described in detail in the sections below. The timeline is approximately one and a half years, having started preparations in mid-2018 and expecting to finish by late 2019.
2.1 Literature review

Literature review was based on the search strategy developed in the BRIDGE-Health Horizontal Activity 6 deliverable (HA6): Priority setting methods in health information, BRIDGE Health Technical Report 04/2017 on Recommendations of priority setting methods for an European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy (HIREP-ERIC)(2). Our search strategy took a wider scope, expanding the original BRIDGE search strategy below:

- (((priorit* [Title]) AND (((set*[Title]) OR determin*[Title]) OR develop*[Title]))) OR ((research[Title]) AND priorit*[Title]))

Our search augmented the original BRIDGE search, by including additional terms for health information prioritization:

- OR (((health[Title]) AND information[Title]) AND priorit*[abstract]) AND ((report [title/abstract]) OR (policy[title/abstract])))

In January 2019, we applied our search in the Pubmed and Embase literature databases, and in the OpenGray grey literature database and limited results to publications within the last ten years. We also included results obtained from hand search of bibliographies of included studies and also included studies identified by experts as relevant. For terms related to overall prioritization, we limited our search to article titles only. For terms related to health information prioritization we allowed more flexibility by including results from article titles and abstracts. This approach helped limit the number of search hits and focused our search on articles whose main objective was health information prioritization.

Our search returned 5,010 articles which focused mostly on overall prioritization methods used at the community, or regional level. Articles were de-duplicated, resulting in a total of 2,952 articles for review. In order to narrow our focus, we filtered results by selecting articles whose abstract contained the words “nation*”. By doing so we hoped to isolate articles discussing national prioritization processes. Through a review of the resulting 990 articles’ titles and abstracts we excluded articles that did not outline a prioritization methodology, that were applied among non-human subjects, and articles that did not cover national level prioritization. We reviewed the full text and bibliographies of 182 articles, identifying 111 articles which were relevant for national health information prioritization. Among included studies, 13 studies used the Delphi
method for prioritization of national health information. Figure 2 contains a PRISMA diagram, outlining the procedure for our literature review.

Figure 2: Health Information Prioritization PRISMA Diagram


For more information, visit www.prisma-statement.org.
2.2 The (Policy) Delphi Survey

Delphi exercises have been used in health care and medical research since the 1960s over a broad spectrum of issues, including the development of population health indicators. Since Delphi surveys allow for rankings and priority-setting, their output is considered operational for a variety of actors, including policy-makers. A Policy Delphi is a variation of the anonymous Delphi process. Its objective is not to generate a decision or a consensus; instead, it aims to gather a comprehensive range of options, with supportive evidence, ensuring that all relevant aspects of a research question are taken into account, that impacts and consequences are analyzed, and that the acceptability of a proposed policy option is examined. For a Policy Delphi, topics under discussion are ranked by degree of desirability, feasibility, importance and confidence (see Table 1, below).

2.2.1 Number of survey rounds

A characteristic feature of Delphi studies is their implementation in several rounds, with between-round feedback to participants, and revision of questionnaires based on replies from previous rounds. The number of rounds in a Delphi survey depends on the goal of the survey and on the definition of its endpoint. The choice of the endpoint also determines whether qualitative and/or quantitative methods are used. Endpoints can be:

- To gather experts’ ideas on a problem (purely qualitative);
- To make vague subject-matter more concrete and to forecast specific developments (qualitative and quantitative);
- To collect and quantify experts’ opinions (qualitative and quantitative);
- To reach consensus among experts (purely quantitative).

One round of survey can be sufficient to gather experts’ ideas while several rounds will be required to reach consensus. The endpoint of the Policy Delphi on HI prioritization is to obtain experts’ ranking of national prioritization processes. It was therefore decided to conduct the survey in two rounds. This enables us to obtain qualitative information (round 1) and to quantify experts’ opinions (round 2). By limiting the survey to two rounds, the risk for attrition, which increases with each round, is minimized.

2.2.2 Recruitment Strategy for Survey Participants

Participants in a Policy Delphi study are not a numerical sample of a given population of experts, but a sample of available expertise. Purposive sampling is thus needed for depth and specificity of expertise. Heterogeneity of the panel is of benefit, as it minimizes the risk of overlooking obvious aspects of a question, while homogeneity of the level of expertise is a decisive factor for the validity of a Delphi survey’s outcome.

Participants for the HI prioritization exercise Delphi will be recruited using the network of the InfAct partners from. InfAct project partners will be encouraged to participate in the survey, and to inform the RKI research team of names of stakeholders in public health and in health information for national health reporting who may also be interested in participating. Stakeholder affiliation shall include, but is not limited to:

- National Public Health Institutes
- National Statistics Offices
- National organizations involved in health targets development
- Policy Making
- Stakeholders involved in creation of National health reports

Potential participants will be vetted for willingness to participate immediately following MS identification of contacts. All potential participants will receive a letter of invitation (Annex 1: Letter of invitation for survey participants), a project summary (Annex 2: Project summary for survey participants) and information on anonymity and data protection. Since the aim of the survey is to gather as much relevant information about national health information prioritization as possible, there is no upper limit to the number of participants. Recruitment will begin after completion of the pre-test and continue until achievement of a recruitment target of at least 1 participant for 80% of the included MS.
2.2.3 Questionnaire development

After confirming the survey format and distributing the research question among task partners for review, the questionnaire for the 1st round of the survey was developed. In order to gather as much relevant information about the processes of health information development in MS, the 1st round survey contains mainly open questions. Topics for the 1st round of the Delphi are:

- Existence of structured or formal processes for health information development/prioritization in participating countries
- Any other informal processes to prioritize/develop health information
- Methodologies for structured processes (stakeholder involvement, criteria for HI prioritization)

The 1st round questionnaire will include 19 discrete, (mainly) open-ended questions, which participants will complete online, by clicking to select one among multiple choices, and then by writing corresponding free-text responses in an open text field. The questionnaire can be found in Annex III to this method paper.

Information from the 1st round will be presented in closed question format for the 2nd round. Participants to the 1st round will be asked to rank the collected methods, processes and criteria, according to degree of “desirability”, “feasibility”, “importance” and “confidence”, based on their own expert opinion. (see Section: Analysis Plan below)

2.2.4 Programming of the questionnaire and data protection

The survey will be implemented online using the Voxco Online software. Voxco has been used extensively for health monitoring by the Health Survey Lab at the Robert Koch Institute (RKI) as well as for smaller project-related studies at the RKI. Technical support is available in-house for programming and survey implementation. The benefit of Voxco, compared to other survey software, is its extensive provision for data protection and security. An internal team at the Robert Koch Institute reviews all survey questions before survey administration, according to strict data protection criteria. Additionally, at the beginning of the survey questionnaire, participants will be explicitly asked to omit personal details from their survey responses, in order to maintain survey anonymity vis-à-vis the research team.

Participants will receive an email introduction to the survey, and will access the survey through an online link. Only participants who receive the survey link will be able to access the survey. Participants will be allowed to suspend and resume survey participation at will, until the survey submission deadline.

2.2.5 Analysis Plan

By ranking methods, processes and criteria, we aim to highlight a) „good practice“-approaches for national health information prioritization and b) applicability of the approaches to the development of a European health information strategy. To this end, full-text replies to the 1st round will be analyzed by the research team, using the text-sorting technique by Beywl & Schepp-Winter(13), for simple content analysis. Responses from the first round will serve as the foundation for closed questions in the 2nd round. Participants will then be asked to rank the closed questions according to degree of “desirability”, “feasibility”, “importance” and “confidence”. The categories (Table 1 below) are based on the Policy Delphi Survey methodology by Turoff (2002)(9).

<table>
<thead>
<tr>
<th>Importance (Priority or Relevance)</th>
<th>Very Important</th>
<th>Important</th>
<th>Slightly Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>- a most relevant point</td>
<td>- is relevant to the issue</td>
<td>- insignificantly relevant</td>
<td></td>
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<tr>
<td>- first-order priority</td>
<td>- second-order priority</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- has direct bearing on major issues</td>
<td>- significant impact but not until other items are treated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- must be resolved, dealt with, or treated</td>
<td>- does not have to be fully resolved</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Instead of an additional neutral position on the rating scale, participants will be given a fifth option to choose, labeled “no-judgement”. This option will enable the participants to actively indicate that they did not wish to express an opinion on an item. Adding this category will help distinguish between active non-replies and missing values. For the analysis, participant responses per criterion will be aggregated into positive responses (combining the two highest ranking categories per criterion) and negative responses (combining the two lowest ranking categories per criterion). Replies indicating ‘no-judgement’ will be included in the frequency

| Unimportant       | - no priority  
|                  | - no relevance  
|                  | - no measurable effect  
|                  | - should be dropped as an item to consider  

**Desirability (Effectiveness or Benefits)**

| Very Desirable    | - Will have a positive effect and little or no negative effect  
|                  | - extremely beneficial  
|                  | - justifiable on its own merit  

| Desirable         | - will have a positive effect and little or no negative effect  
|                  | - beneficial  
|                  | - justifiable as a by-product or in conjunction with other items  

| Undesirable       | - will have a negative effect  
|                  | - harmful  
|                  | - may be justified only as a by-product of a very desirable item, not justified as a by-product of a desirable item  

| Very Undesirable  | - will have a major negative effect  
|                  | - extremely harmful  
|                  | - not justifiable  

**Feasibility (Practicality)**

| Definitely Feasible | - no hindrance to implementation  
|                    | - no R&D required  
|                    | - no political roadblocks  
|                    | - acceptable to the public  

| Possibly Feasible  | - some indication this is implementable  
|                    | - some R&D still required  
|                    | - further consideration or preparation to be given to political or public reaction  

| Possible Unfeasible| - some indication this is unworkable  
|                   | - significant unanswered questions  

| Definitely Unfeasible | - all indications are negative  
|                       | - unworkable  
|                       | - cannot be implemented  

**Confidence (In Validity of Argument or Premise)**

| Certain            | - low risk of being wrong  
|                    | - decision based upon this will not be wrong because of this “fact”  
|                    | - most inferences drawn from this will be true  

| Reliable           | - some risk of being wrong  
|                    | - willing to make a decision based on this but recognizing some chance of error  
|                    | - some incorrect inferences can be drawn  

| Risky              | - substantial risk of being wrong  
|                    | - not willing to make a decision based on this alone  
|                    | - many incorrect inferences can be drawn  

| Unreliable         | great risk of being wrong  
|                    | - of no use as a decision basis  

analysis as a source of information, but they will be excluded from calculations of standard deviations and mean values.

2.2.6 Pretest
A pretest shall be conducted in three countries to identify issue of comprehensibility and technical implementation. For this purpose, pretest access to the online survey shall be accompanied by the pretest form, below:

<table>
<thead>
<tr>
<th>Comprehensible (yes/no)? If not, please specify.</th>
<th>Technical problems (yes/no)? If yes, please specify.</th>
<th>General comments? If none, specify 'NA'</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data protection / anonymity information</td>
<td></td>
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<tr>
<td>Letter of invitation</td>
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<tr>
<td>Project summary</td>
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<tr>
<td>Questionnaire</td>
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<td>Section I</td>
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<td>Section IV</td>
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<td>Section V</td>
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<tr>
<td>Section VI</td>
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Please also share the amount of time it took to complete this survey: __________

2.2.7 Implementation
Implementation of the 1st round of the Policy Delphi is planned for March 2019. Field time will be three weeks. Implementation for the 2nd round of the Policy Delphi is planned for May 2019; field time will also be three weeks. Final feedback will be sent to participants in July 2019. In addition to the survey results, the final feedback will contain information about the next steps in the research project, e.g. dissemination plans.

3 Outcome
The expected outcome of the Policy Delphi survey is a list of good-practice-approaches to health information development and prioritization at national levels, which could be further developed into a health information prioritization strategy at the European level.

4 Discussion and dissemination of WP5.3 Results
Final results of the survey will be presented to steering bodies of the InfAct project for discussion. A final report, containing recommendations for health information prioritization methodologies, will be submitted to the Coordination in February 2021. In addition to being accessible on the InfAct Share Point, the final report may also be submitted as abstracts to relevant conferences or as a scientific paper to relevant journals.
Bibliography

Annex 1: Letter of invitation for survey participants

This dual round survey is conducted within the framework of the Joint Action on Health Information (InfAct), Work Package (WP) 5 on the Status of Health Information Systems in Member States and Regions.

InfAct is a 3-year project (2018-2021) funded by the European Commission, involving 40 partners in 28 European countries. Read more about the project here: www.inf-act.eu

The Delphi exercise targets national health information experts and seeks to compile information regarding national prioritization processes used in health information development for national health reporting. The expected outcome of the survey is a list of good-practice-approaches to health information development and prioritization at national levels, which could be further developed into a health information prioritization strategy at the European level.

The online survey contains 19 questions. Participants can pause while taking the survey and resume the survey at any time. During pre-testing, participants finished the survey within x minutes.

The data collected will be treated with confidentiality and used solely for the purpose of the study. The survey answers will be reported in an aggregate, anonymous form.

The survey is conducted by the Robert Koch Institute, Berlin in close collaboration with InfAct-partners from Belgium, Italy, Lithuania, the Netherlands and the UK.

We kindly ask you to finalize your responses and submit the online questionnaire before dd/mm/yyyy.

For further information or to signal any problems, please contact our survey team.

Thank you for your time and contribution.
Annex 2: Project Summary for Project Participants

Delphi Survey on Prioritization of Health Information for National Health Reporting

-Project Summary for Survey Participants-

This survey is conducted within the framework of the Joint Action on Health Information (InfAct), Work Package (WP) 5 on the Status of Health Information Systems in Member States and Regions.

InfAct is a 3-year project (2018-2021) funded by the European Commission, involving 40 partners in 28 European countries. Read more about the project here: www.inf-act.eu/.

The survey targets national health information experts, who are involved in national health information prioritization processes, and seeks to compile information regarding national prioritization processes used in health information development for national health reporting. The expected outcome of the survey is a list of good-practice-approaches to health information development and prioritization at national levels, which could be further developed into a health information prioritization strategy at the European level.

The survey has been developed by six InfAct-project partners (BE, DE, IT, LT, NL, UK) and is implemented by a research team at the Robert Koch-Institute (RKI).

Research design and timeline

The survey is conceptualized as an online Delphi survey in two rounds. Participants are asked to fill in the first questionnaire in March and the second in May 2019. Data will be analyzed by a research team at the Robert Koch Institute and discussed with the WP5.3 task partner before being forwarded to survey participants. Final feedback regarding the results will be disseminated among survey participants in July 2019.

The survey is anonymous. Participants’ identities will not, at any time during the analysis and publication of data, be visible to other survey participants or linked to individual survey results.

Thank you very much for your participation!
Please do not hesitate to contact us if you have any questions about this survey:

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E-mail: infact@rki.de
Annex 3: Informed Consent and Questionnaire for the 1st round Delphi

**Informed Consent:**
Participation in this survey is voluntary. If you chose not to participate, there will be no negative consequences. You can stop and resume the survey at any time, and your responses will be saved. If you start the survey and decide you would no longer like to participate, you may return to the first page of the survey and click ‘no’, that you would not like to participate. By choosing this option your session will be ended and your responses deleted.

In order to maintain the complete anonymity of the survey, **please do not include any personal details in your response to survey questions.** No details will be removed from survey responses, once submitted.

Do you want to participate in this survey?
_ yes
_ no

**Questionnaire on Prioritization of Health Information for National Health Reporting:**

**Rationale:** Prioritization of health information for national health reporting ensures that available indicators and health data provide evidence for effective policy action (agenda-keeping) and / or highlight emerging public health issues (agenda-setting)

Our survey frequently uses abstract concepts, which we define, below, in more detail. Our survey questions are based on the definition of health information prioritization as the establishment and implementation of methodological standards and development of political momentum in order to reliably track health and its determinants and consequences. Accurate tracking of health at the national level is important in order to strengthen the evidence base for policies which target population health, and to facilitate effective healthcare service delivery(1).

National Health Reporting is communication of the results from public health monitoring. Public health monitoring is the regular collection and analysis of individual data on the components of health and its determinants within a population(14).

As you continue the survey, you will find four sections with questions which will help us understand how HI is prioritized in your country. Two additional sections allow you to share insights that we had not anticipated and to provide broad information about your own experience. Thank you, again, for your time!

**Sections I – III; Health Information Prioritization Processes:**

1. **In your country, are structured processes used to prioritize health information topics for national health reporting?** By structured processes, we mean, for example, priority setting partnerships, focus groups, stakeholder meetings or pre-defined national health targets.

_ yes
_ no

b. **If yes, please describe any structured methodologies used to prioritize health information in your country.** If possible, please include information about how long these methodologies have already been used in your country. In the case that quasi-structured approaches may also apply, which is/are the source(s) of unstructured additions to the structured processes?

**If yes, are processes and methods for health information development (or prioritization) documented in national health reports or other relevant publications?**
If no, please describe how health information development for national health reporting, including health indicator development, is usually implemented in your country. This may include any informal processes which influence priority setting in health information development, e.g. strong media focus on certain health issues.

If no, do you consider the current approach to health information prioritization to be a barrier to effective functioning of your health system? Which improvements to health information systems would benefit health information users and policy makers?

II. If stakeholders are involved in health information prioritization processes in your country, please describe the following:

a. Which stakeholders are involved?
b. Who initiates, coordinates and / or leads stakeholder involvement?
c. Did stakeholders use criteria to evaluate a range of prioritization processes before establishing their current methodology for prioritizing health information? Please describe their decision process.

III. In your country, are criteria defined and applied to select and prioritize topics for health information for national health reporting?

_ yes  _ no

If yes, please describe the following:

a. Who is involved in developing the criteria?
b. What methodologies are used to develop the criteria?
c. What methodologies and / or contexts are used to apply the criteria (e.g. stakeholder or experts meetings)?
d. Are criteria linked to national or international regulations, laws or priorities? Which? (Examples are: national health targets, national health strategies, Sustainable Development Goals (SDGs), UN Action Plan to Combat Non-Communicable Diseases, Tobacco Framework Convention)

IV. Health Information Prioritization Good Practices (Short Answer):

Please describe any national efforts to develop a set of national good practices for prioritization of health information.

a. Was there a structured process for establishment of national health information prioritization good practices?

b. How could member state good practices be developed into good practices for use at the EU level?

V. Additional comments

Do you have any additional comments on this survey or the topic that you would like to share?

VI. Background information on survey participants

You have completed the questionnaire. In conclusion, please give us some information about your professional affiliation, background and expertise.

<table>
<thead>
<tr>
<th>Q1</th>
<th>What is your current institutional</th>
<th>Please choose your answer from the drop down menu</th>
<th>If you have selected ‘yes’ or ‘other’, please specify your answer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ministry of Health, Ministry of Research, National Public Health Institute, National Statistical Office,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q2</td>
<td>What is your professional background?</td>
<td>Medicine, Epidemiology, Public Health, Statistics, Political Science, Demography, Informatics, Other</td>
<td></td>
</tr>
<tr>
<td>-----</td>
<td>--------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
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</tbody>
</table>
| Q3  | What is your level of involvement in health information development? | Very high (e.g. in charge of HI development)  
High (e.g. represent key stakeholder in HI development process)  
Medium (participant or consultant in HI development on an irregular basis)  
Low (e.g. observer to HI development process, user of health information) |