



Prioritization in Health Information Development

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Executive summary

The aim of this study was to broaden the knowledge base on health information (HI) prioritization strategies, encouraging expert exchange towards good practice-models. A specific focus was put on HI for national health reporting, this being a crucial tool for policy advice.

This document is Deliverable number 5.3, prepared within task 5.3 of the Joint Action on Health Information (hereinafter referred to as InfAct) with project number 801553. The document presents the methods and results of a Delphi study on HI prioritization among EU Member States (EU MS). EU countries, including EFTA and EEA countries, share the ambition of reducing health inequalities within and across countries. They aim to improve their citizens' health through targeted prevention and universal access to safe, effective and efficient health care in a financially sustainable way. Such efforts have to be based on reliable and relevant data on health determinants, health status and prevention, and health care. However, while prioritizing health research is discussed widely in the literature, very little information can be found on prioritizing HI.

In a two-round anonymous Delphi study, we explored which processes and methods exist in EU MS and associated countries for the prioritization of HI. In the first round, information about these processes were gathered in semi-structured questions; in the second round, participants were asked to rank the identified approaches for desirability and feasibility. The survey was conducted online. An invitation to participate in the survey was sent via email to InfAct project partners; contact details were provided by the InfAct Coordination. The invitation included a letter, a short project description and the link to the survey. In the first round, we received 17 fully completed and an additional 11 partially completed questionnaires. Both fully and partially completed questionnaires were included in the analysis. As regards participants' expertise, the majority (n=16) of the 23 respondents who answered this question reported a high or very high involvement in national health information development. Of the total number of first round respondents, 6 experts participated in the second round.

In the first round, slightly more than half (n=15/26; 58%) of the respondents to this question confirmed that structured HI prioritization processes existed in their countries. Regarding the organization of such a process, a list of options was presented in the second round from which the respondents gave preference to a formal, horizontal and centralized approach, i.e. an approach which is coordinated, not top-down, and in which stakeholders and experts develop priorities for health information. This approach was also considered a feasible option. A formal, top-down approach, where governments set priorities, ranked slightly higher for definite feasibility, but slightly lower for desirability. About two third (n=17/26; 65%) of the respondents in the first round confirmed that stakeholders are involved in national HI prioritization processes. From a list of potential stakeholders, which should be involved in HI prioritization, national public health institutes ranked top both for desirability as well as for feasibility. These results must certainly be seen in the light of the reported institutional affiliation of the respondents, of whom nearly half (n=11/23; 48%) reported affiliation with a national public health institute.

Limitations regarding the outcomes of our study mainly relate to the small number of participants, especially in the second round. Low response in the second round was presumably due to the fact that its implementation coincided with the onset of the Corona pandemic, giving the majority of public health experts, which were our target group, very little time to participate in research unrelated to COVID-19. We are very grateful for the contributions we did receive in both rounds, and we are convinced that they create a knowledge base for future expert exchange regarding good practices for health information prioritization in EU countries.

Key points

- Little research exists about prioritization processes for health information in EU countries.
- In our two-round Policy Delphi survey, more than half of the respondents reported the existence of structured HI prioritization processes in their countries.
- To prioritize health information, a clear preference was given for a formal, horizontal process which includes different experts and stakeholders.
- National public health institutes were named the desired key stakeholders in this process.
- Owing to a Corona-related low response rate in the second round, results rather reflect individual experts' opinion than the opinion of a broader European public health community.
- Information and results from this survey provide a valuable database for expert exchange on elements for good practice-approaches in health information prioritization.

InfAct: Prioritization in Health Information Development

I. Introduction

EU countries, including EFTA and EEA countries, share the ambition of reducing health inequalities within and across countries. They aim to improve their citizens' health through targeted prevention and universal access to safe, effective and efficient health care in a financially sustainable way [1].

Such efforts have to be based on reliable and relevant data on health determinants, health status and health care. These data shall serve two purposes: on the one hand, they shall provide the evidence base for tracking public health policies (agenda-keeping). On the other hand, health information (HI) should be able to identify emerging issues in population health developments or health determinants. In this function, it shall inform and shape the health policy agenda (agenda-setting) [2]. Eventually, the information can be used to evaluate the effect of policies or in the case of health systems, analyze the performance of the system and monitor and explain the developments in population health. As a consequence, and to ensure that available indicators reflect both current and emerging public health priorities, proper processes for HI prioritization are essential.

As Verschuuren et al. explain in relation to the Data-Information-Knowledge-Wisdom hierarchy: 'Although health data is at the core of population health monitoring, monitoring comprises more than the mere collection and analysis of data. Rather, population health monitoring should be seen as a cycle [...]. Ideally, this cycle starts with a comprehensive health information strategy. Subsequently, data are being collected based on the needs identified in the strategy, [...]' [3]. With our study, we aimed to gather information about these strategic approaches in EU countries which precede the initiation of new data collections and define relevant topics. To this end, our project is 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 [4]. A literature search revealed that indeed very little information can be found on prioritizing HI topics for initiating new data collections. Literature on prioritization in health rather relates to health research topics, to health care and limited resources or to developing priorities for (new) health indicators or indicator sets based on existing data.

To improve knowledge of HI prioritization processes, our study explored which structured methods are used in EU MS and associated countries to decide on the relevance of HI topics. A focus was on HI for national health reporting, as health reporting is a central tool for policy advice.

Our study was guided by the following main questions:

a) Do structured processes exist in EU MS and associated countries for the prioritization of health information? If yes, how are they organized? Structured processes would include defined methods, criteria, stakeholder involvement and possibly links to national and/or international frameworks or regulations.

b) If such processes exist, can good practice-approaches be identified from them?

To answer these questions, we conducted an anonymous two-round online Policy Delphi. This method allowed us to gather experts' input on HI prioritization processes (round one) and have the same experts rank these with a view to good practice-approaches (round two). Potential participants for our study were recruited from the InfAct project partners.¹

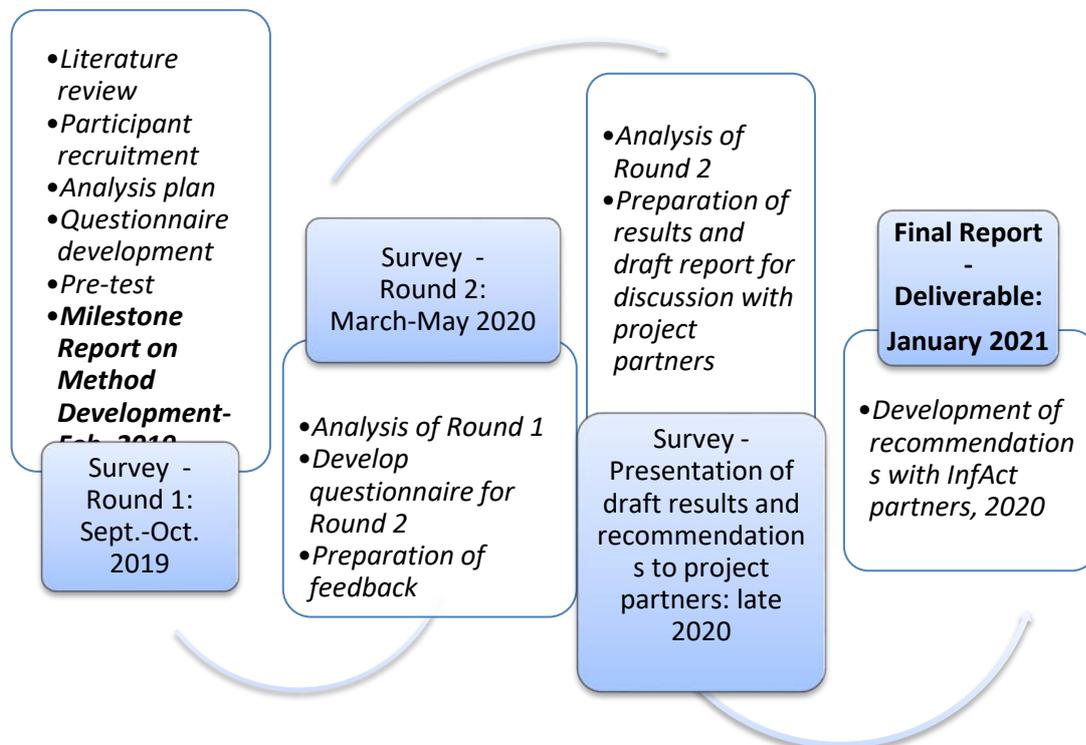
II. Aim

The aim of our study was to improve the knowledge base of national prioritization strategies for HI, thereby facilitating and promoting expert exchange towards the identification of good practices. With the analysis of national prioritization strategies of HI and its connection to health targets and national health reporting, we aimed to contribute to the domains of data collection, health reporting and conceptual frameworks for the assessment of European Health Information Systems (HIS) and the HIS strategy development.

III. Approach

This section describes the methods we used for our research project. Figure 1, below, illustrates the steps that were taken to prepare and implement our research. The literature study and the data collection are described in detail in the paragraphs below.

Figure 1: Timeline Delphi survey – preparation, implementation, analysis, dissemination



¹ <https://www.inf-act.eu/project-team>

A. Literature study

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) [5]. 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:

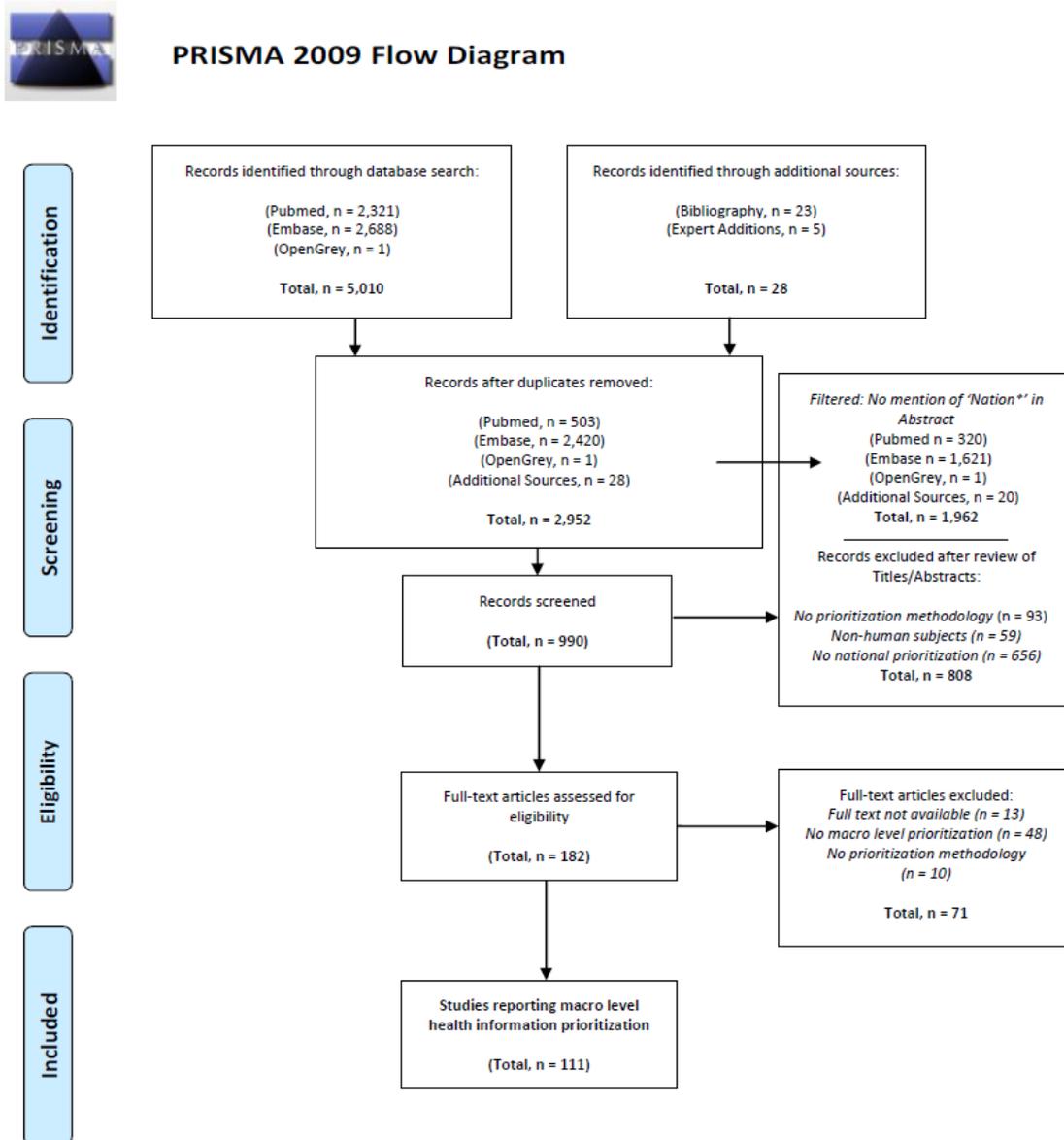
- OR (((health[Title]) AND information[Title]) AND priorit*[title/abstract]) AND ((report [title/abstract]) OR (policy[title/abstract])))

In January 2019, we applied our search in the PubMed and Embase literature databases, and in the OpenGrey 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 as relevant by experts. For terms related to overall prioritization, we limited our search to article titles only. For terms related to HI 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 HI 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 HI prioritization. Figure 2 contains a PRISMA diagram [6], outlining the procedure for our literature review.

Figure 2: Health Information Prioritization PRISMA Diagram

Reported following PRISMA statement recommendations [6]



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Out of the initial set of publications, 13% of our findings referred to procedures and examples of priority setting applied by EU Member States (EU MS), whereas 42% of the

publications focused on national priority setting procedures for developing and emerging countries.

However, examples and frameworks for priority setting, both for developing countries as well as for EU MS, rarely focused on HI. Instead, through the aggregation of our findings to EU MS only, it became apparent that the majority of the European examples focused on the priority setting processes in research or health care. The publications on Europe included reports and examples of prioritization approaches in health care from the Scandinavian countries, the Netherlands, Belgium, Spain as well as Germany and the United Kingdom. Hence, it was decided to complement the initial search by a semi-systematic search for grey literature on the prioritization of HI. The analysis of the initial set of publications revealed national attempts to prioritize HI through the development and implementation of Health Information Systems (HIS), such as in Spain and in the United Kingdom. However, these approaches relate more to a framework for a national exchange of health data. They can thus be considered as a base for a sustainable Health Information Exchange (HIE) but give limited conclusions about the national prioritization of HI.

Through the assessment of the grey literature, it became clear that the majority of the EU MS seem to prioritize and process HI through frameworks of national health reporting, each with its own formats and priorities. Individual member states, e.g. Austria, Germany or the Netherlands, set priorities in HI implicitly through the definition of national health targets and the related procedures of national health reporting. To illustrate, the preparation, operationalization and realization of health targets through the Rahmengesundheitsziele (health targets framework) in Austria started 2010 with a broad participatory approach. Austrian health targets are based on a number of guiding principles like the focus on health determinants, the 'health-in-all-policies approach' or the promotion of health equity. The establishment of Austrian health targets has an indirect impact on health reporting and the prioritization of HI, for instance through the simultaneous integration of the promotion of equal opportunity and social welfare as a health target and a criterion for national health reporting [7].

In Germany, a national health targets process was established in the year 2000. To date, nine health targets have been defined. Topics for potential health targets are selected by a group of experts on the basis of defined criteria, including mortality, morbidity, or health economics. Measurability and the related data availability are further criteria which inform the selection of a topic as national health target. So, while national health targets depend on data from health monitoring and health reporting to measure change, there is no process established to ensure that the topic selection for national health monitoring activities considers indicators relevant to national health targets.

B. Data collection

Policy Delphi survey

Several methodological options were considered for this study, including focus groups, face-to-face meetings, interviews or a survey. Our aim was to explore and document HI prioritization processes in as many EU MS and associated countries as possible. This could

best be achieved by conducting an online survey. The Delphi approach, through its design in several rounds, matched our need to initially collect full-text information from experts which would then be translated into closed questions and submitted for a second-round ranking. The Delphi method also offers an anonymous forum for the exchange of ideas and opinions among survey participants which we anticipated could increase the willingness of participants to contribute also critical opinions.

We selected the Policy Delphi survey approach as the appropriate scoping survey format for several reasons. The Policy Delphi is a variation of an 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 [8]. In a Policy Delphi, participants are not a numerical sample of a given population of experts, but a sample of available expertise. Purposive sampling is needed for depth and specificity of expertise [9]. Heterogeneity of the panel is of benefit, as it minimizes the risk of overlooking obvious aspects of a question [10], while homogeneity of the level of expertise is a decisive factor for the validity of a Delphi survey's outcome [11]. For a Policy Delphi, topics under discussion are ranked by degree of desirability, feasibility, importance and confidence (see Table 1, below). Since our study aimed to explore and rank options for HI prioritization processes, rather than, at this stage, aim for consensus about good practices, we considered the Policy Delphi to be the adequate tool.

Table 1: Categories and ratings in a Policy Delphi

Table reproduced from [8]

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 (research and development) 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
Importance (Priority or Relevance)	
Very Important	<ul style="list-style-type: none"> - a most relevant point - first-order priority - has direct bearing on major issues - must be resolved, dealt with, or treated
Important	<ul style="list-style-type: none"> - is relevant to the issue - second-order priority - significant impact but not until other items are treated - does not have to be fully resolved
Slightly Important	<ul style="list-style-type: none"> - insignificantly relevant - third-order priority - has little importance - not a determining factor to major issue
Unimportant	<ul style="list-style-type: none"> - no priority - no relevance - no measurable effect - should be dropped as an item to consider
Confidence (In Validity of Argument or Premise)	
Certain	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - substantial risk of being wrong - not willing to make a decision based on this alone - many incorrect inferences can be drawn
Unreliable	<ul style="list-style-type: none"> - great risk of being wrong - of no use as a decision basis

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. For the analysis of full-text responses from our first round and their development into closed questions for the second round, we selected the iterative reading and category development process outlined in the text-sorting technique by Beywl and Schepp-Winter [12].

The number of rounds in a Delphi survey depends on the goal of the survey and on the definition of its endpoint [13]. The endpoint of the Policy Delphi on HI prioritization was to obtain experts' ranking of options for national prioritization processes. By limiting the survey to two rounds, we also anticipated to minimize the risk for attrition, which increases with each round.

a) Survey implementation

Participants for the HI prioritization exercise were recruited using the network of the InfAct partners. InfAct partners were encouraged to participate in the survey, and to inform the research team of names of additional experts who would possibly also be interested in participating. Participants' affiliation was to include, but not limited to national public health institutes, national statistics offices, national health targets or related strategic processes, policy making, or health monitoring and reporting. All potential participants received 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.

The first round of the survey (Annex 3) contained mainly open questions. Topics for the first round of the Delphi were:

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

Information from the first round was presented in closed question format for the second round (Annex 4). Main topics were overall organization of HI prioritization at national level, involvement of stakeholders, use of and basis for criteria, format for cooperation and approaches to good practices.

The survey was 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. Data protection approval was obtained from the Data Protection Officer at the RKI prior to implementing the survey. A pre-test was conducted in three countries to identify issues of comprehensibility and technical implementation. Participants to the actual survey received an email introduction and accessed the survey through an online link. Prior to accessing the questionnaire, potential participants had to give their informed consent. Participants were allowed to suspend and resume survey participation at will, until the survey submission deadline.

b) Analysis Plan

By ranking methods, processes and criteria, we aimed to highlight good practice-approaches for national HI prioritization. To this end, full-text replies to the first round were analyzed by the research team, using the text-sorting technique (TST) by Beywl & Schepp-Winter [12], for simple content analysis. From the anonymous complete Excel export of results, we extracted the full-text replies and saved them in a separate Excel file, with one sheet for each question. Column headings were *Varname*Value/response*Category*New question.

Figure 3: Organization of qualitative data for category development

Varname	Value/response	Category	New question
e.g. STAKEHOLDER_LIST_PRIORITIZATION	Full-text reply	000	...

Through a process of iterative reading and identification of similarities and in-vivo-codes, three-digit categories with short descriptions were developed, and each full-text reply was assigned to a category. Some responses were assigned to a subcategory (e.g. 200=National

government, 210=Ministry of Health, 220=Ministry of Finance). Depending on the heterogeneity of the replies, the number of categories ranged from two (very homogenous or very polarized responses) to ten categories with four subcategories (very heterogeneous responses). As aggregates of the individual responses, the category descriptions formed the new response options for the closed questions in the second round of the survey. Three researchers were involved in the process: One suggested the initial categories which were then reviewed independently by the other two. The team of three consented on the final version.

Further to the new questionnaire, participants in the second round received the quantitative results and a complete list of full-text responses from the first round for consideration. The full-text list was cleaned of any information which could reveal authorship of the respondents. Participants were asked to rank the closed questions according to degree of 'desirability', 'feasibility', 'importance' and 'confidence'. The ranking (Table 1 below) was based on the Policy Delphi Survey methodology by Turoff (2002) [8].

Instead of an additional neutral position on the rating scale, participants were given a fifth option to choose, labelled 'no judgement'. This option enabled the participants to actively indicate that they did not wish to express an opinion on an item. Adding this category may help to distinguish between active non-replies and missing values, and reduce the number of missing values.

IV. Results

a) *Response*

The Voxco software, which was used for the online survey, groups participants into four categories:

Completed: Filled out to the last question
Interrupted: Actively interrupted (interrupt button) and never resumed
Drop Outs: Closed the questionnaire / browser window without completing
Screened out: Participation actively denied (informed consent button)

The first round was launched on September 16, 2019, when we contacted 119 experts (100%) affiliated with the InfAct network. Two reminders were sent out and the deadline was extended twice. The first round closed in mid-October 2019.

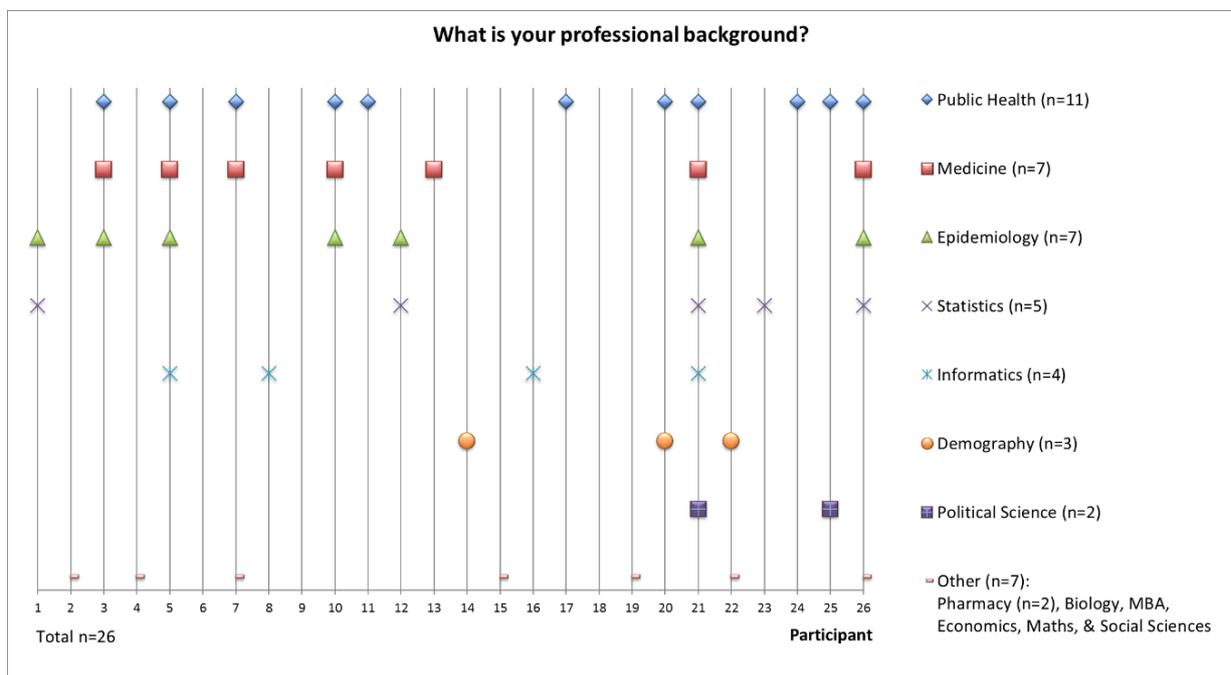
Of the 119 experts contacted, 17 participants (14%) fully and an additional 11 participants (9%) partially completed the questionnaire. 86 invited experts (72%) were registered by the system as drop outs and 2 (2%) actively denied participation by selecting 'no' on the Informed Consent-Page. To benefit from the total number of replies, frequency distributions include fully as well as partially completed questionnaires, with valid n calculated for each questionnaire item.

At the end of the questionnaire for the first round, respondents were asked to indicate their willingness to participate in the second round. 17 respondents agreed and provided their email for secured storing. The invitation for the second round was mailed on March 24, 2020. Following two reminder emails, the survey was closed by the end of May, 2020. Participation in the second round was n=6.

b) Background information on survey participants

Since the survey was conducted under the rule of anonymity, information about country affiliation of the respondents is not available. In the first round of the survey, we asked participants to provide information on their professional background and their professional affiliation. For professional backgrounds, multiple responses were possible. Experts were asked to select one or more items from a drop-down list including public health, medicine, epidemiology, statistics, informatics, demography and political science or add their professional background as full-text if it was not listed. As shown in Figure 4 below, 26 participants answered this question: 11 respondents had a professional background in public health, 7 in medicine and in epidemiology each, 5 in statistics, 4 in informatics, 3 in demography and 2 in political science. A total of 7 respondents chose the 'other' option and added their backgrounds, which included life sciences as well as economics, mathematics and social sciences.

Figure 4: Professional background of participants (Multiple responses possible)



As illustrated in Figure 5 below, at an institutional level, 11 (48%) participants were affiliated with a national public health institute while 5 (22%) respondents were working at the ministry of health. One participant each was affiliated with the national statistics office and with the ministry of research. 5 (22%) respondents were involved in another

institute related to a ministry of health or worked in academia or in the area of health research and HI.

Of particular interest for the study was the participants' self-rated degree of involvement in HI development (Figure 5 below). Indeed, the majority of the respondents, 16 participants, rated their degree of involvement as very high (n=6/23; 26%) or high (n=10/23; 44%). 7 respondents stated that their involvement was medium (n=4/23; 17%) or even low (n=3/23; 13%).

Figure 5: Current institutional affiliation of participants

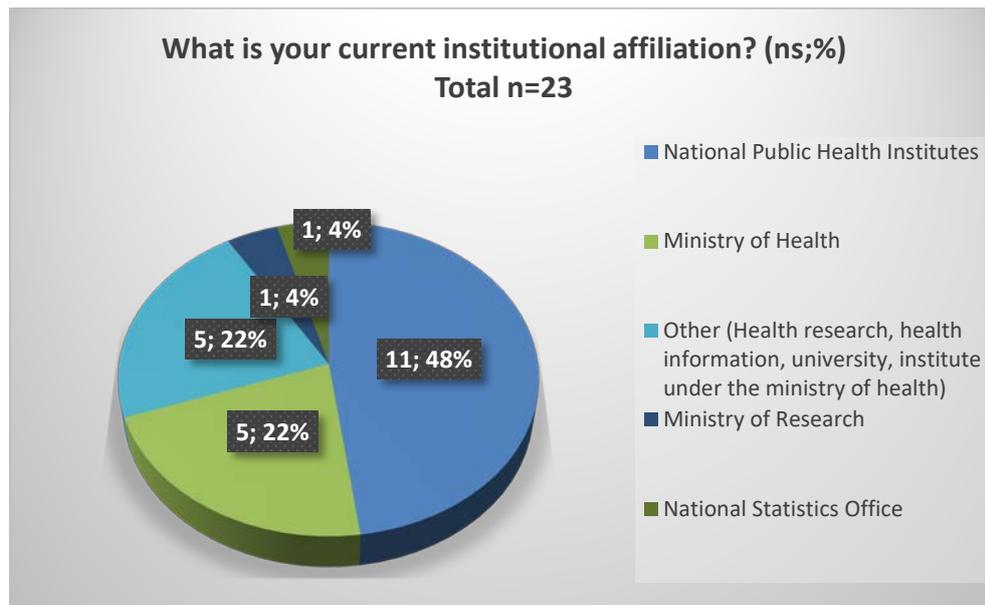
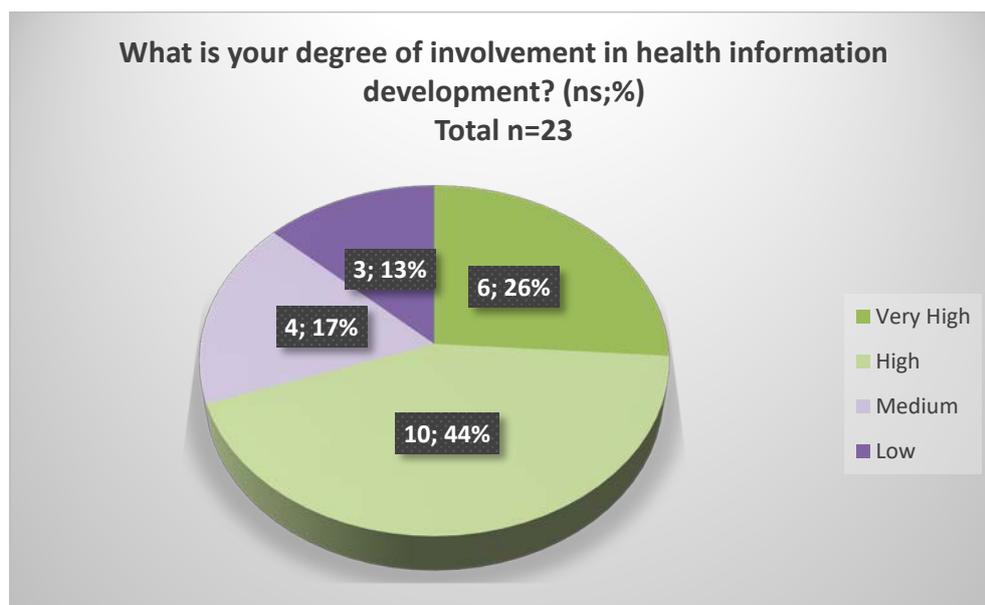


Figure 6: Participants' degree of involvement in health information development



c) Health information prioritization

In the first round of the survey, participants were given both structured and semi-structured questions. Replies to the latter were analyzed, and developed into closed questions for ranking in the second round (Figure 7).

Figure 7: From full-text (round 1) to closed questions (round 2)

Round 1	Round 2 Ranking of:
Structured prioritization processes?	<ul style="list-style-type: none"> • Approaches to national health information development
Stakeholder involvement in prioritization of Health Information?	<ul style="list-style-type: none"> • Potential stakeholders • Preferences for stakeholder coordination
Criteria used in prioritization of Health Information?	<ul style="list-style-type: none"> • Options for actors, methods and guiding frameworks
Good practice approaches?	<ul style="list-style-type: none"> • Approaches to good practices of Health Information prioritization • Approaches for promoting good practices

The following paragraphs provide an overview of the results of the first and the second round of the survey. Replies will be shown not separated by round, but in thematic blocks for both rounds. For the purpose of this report, we chose to visualize and discuss respondents' replies to the categories 'desirability' and 'feasibility' in the second round, as these convey the most relevant information for our research question. Frequencies for all categories (desirability, feasibility, importance, confidence) can be found in Fehler! Verweisquelle konnte nicht gefunden werden..

Structured processes - Round 1

In the first round of the survey, we explored where HI prioritization and development followed systematic procedures. Participants who answered 'yes' to this question for their country were asked to describe any structured methodologies, including whether these processes were documented or published. Participants who stated that no structured processes existed in their countries were asked to describe their national processes for HI prioritization and to indicate whether they considered the current approach supportive or a barrier to effective functioning of their health system.

A little over half (n=15/26; 58%) of the participants confirmed the existence of structured HI prioritization processes in their countries (Figure 8). 73% of these (n=11/15) stated that they are documented or published (Figure 9). 42% (n=11/26) reported that no structured processes existed in their country.

Figure 8: Existence of structured prioritization processes

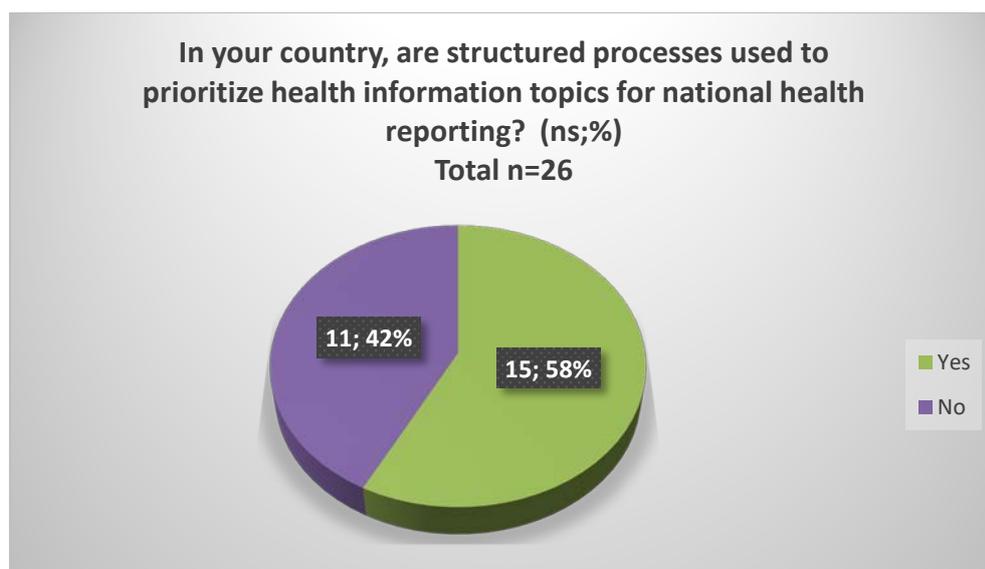
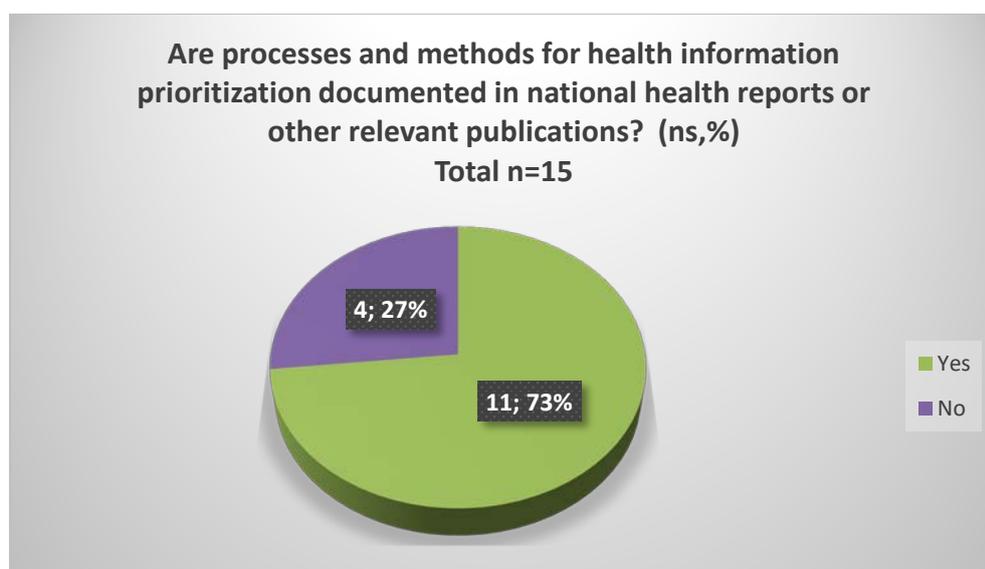
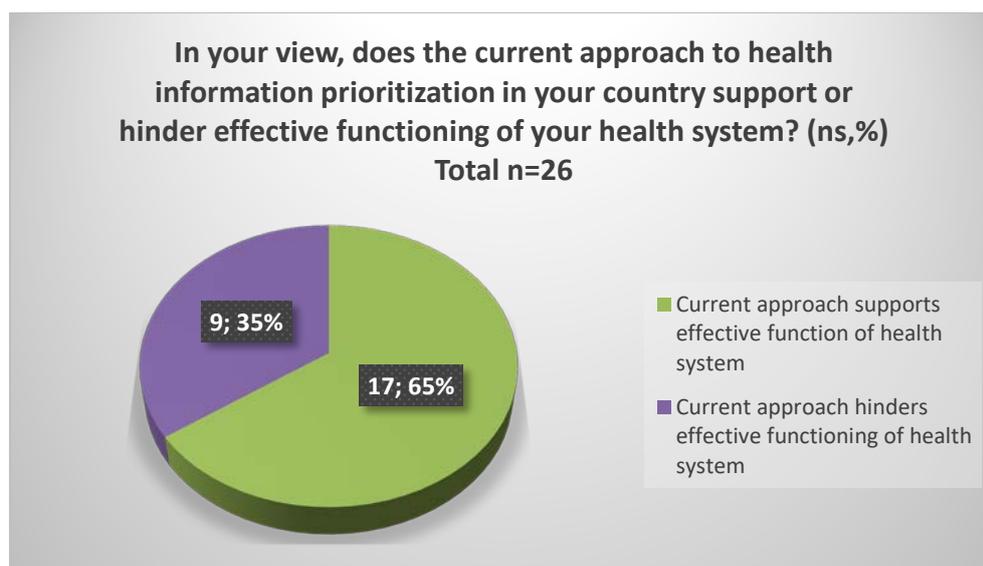


Figure 9: Documentation of structured prioritization processes



Participants were subsequently asked in the first round to state whether the current approach to HI prioritization in their country supported or hindered effective functioning of the health system. 65% (n=17/26) of the respondents stated that the current approach supports the effective functioning of health systems, whereas 35% (n=9/26) believed that their approach hinders an effective functioning of the respective health system (Figure 10).

Figure 10: Impact of current approach to prioritization on functioning of health system



Approaches to health information prioritization - Round 2

For the second round of the survey, full-text descriptions of processes used to prioritize HI were summarized into five approaches. Participants were first and foremost asked to rate these according to their desirability and feasibility.

As illustrated in Figure 11 and Figure 12, two approaches, i.e. a formal horizontal approach and a formal top-down approach, received positive ratings both for their desirability as well as for their feasibility. Minor variations could be observed within the scales for both categories. As regards desirability, respondents showed a preference for the formal horizontal approach, which includes experts and stakeholders in the prioritization process. On the other hand, the top-down approach, where governments set priorities, was considered more feasible.

Approaches relying on external influences to guide prioritization, such as the media, as well as informal, decentralized approaches, where priorities are developed on an ad-hoc basis, were not rated 'very desirable' by the respondents. Also, externally influenced approaches were the only ones that received votes for being definitely unfeasible.

Figure 11: Desirability of approaches to prioritization

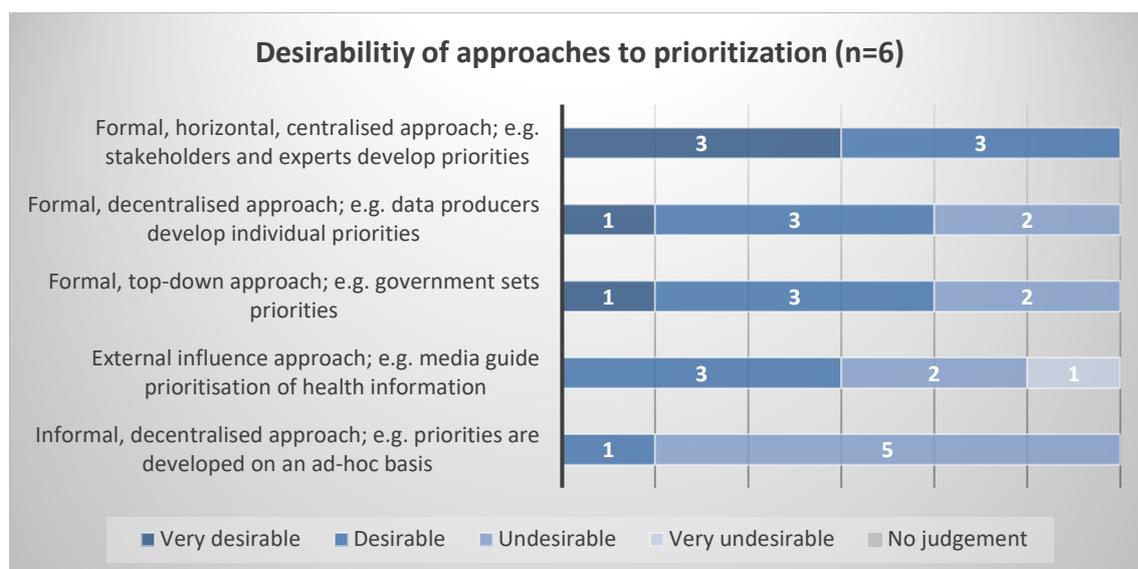
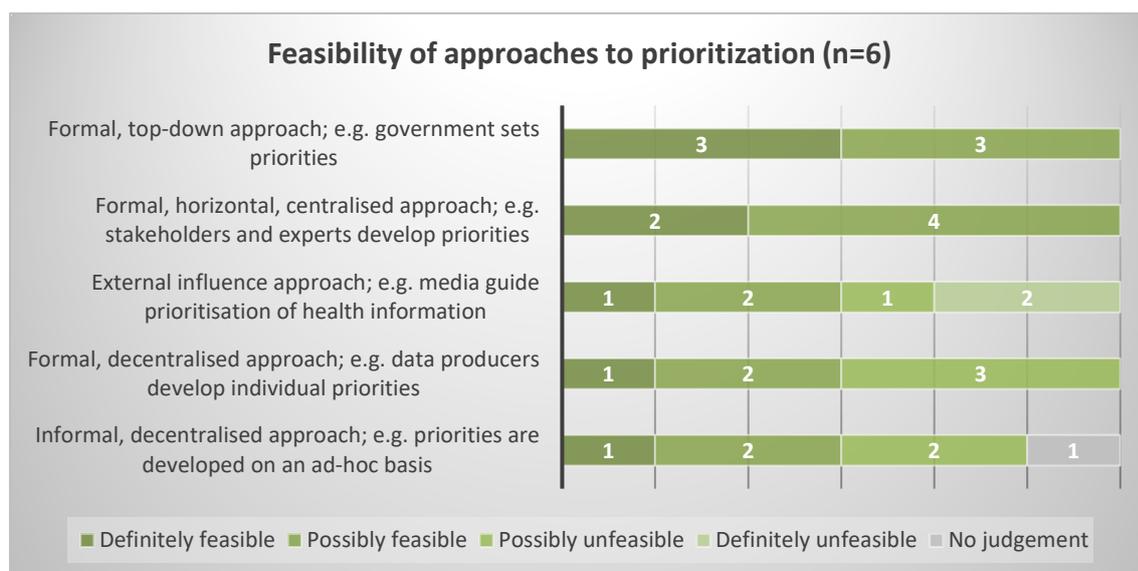


Figure 12: Feasibility of approaches to prioritization



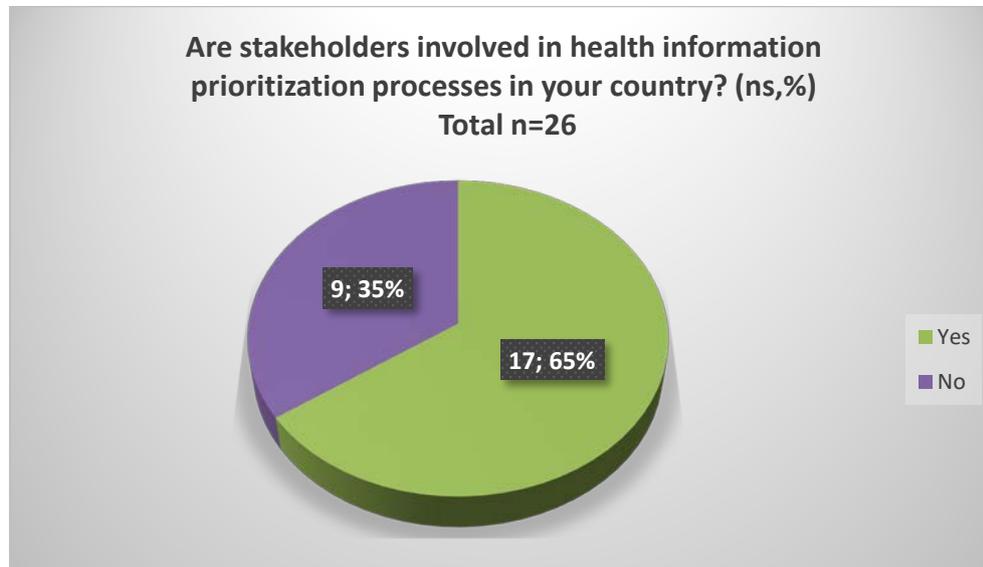
Stakeholder involvement in health information prioritization - Round 1

A crucial question in HI prioritization is the involvement of the stakeholder community. We therefore asked participants, whether stakeholders are involved in such processes in their countries, which stakeholders are involved and who carries out a coordinating function for stakeholder participation.

In response to the first question in round 1, about two third of the respondents (n=17/26; 65%) confirmed that stakeholders are involved in HI prioritization processes. Respondents

added a list of stakeholders which are involved in their country, and stated who coordinated stakeholder involvement. This information was structured and included in the second round.

Figure 13: Stakeholder involvement in health information prioritization



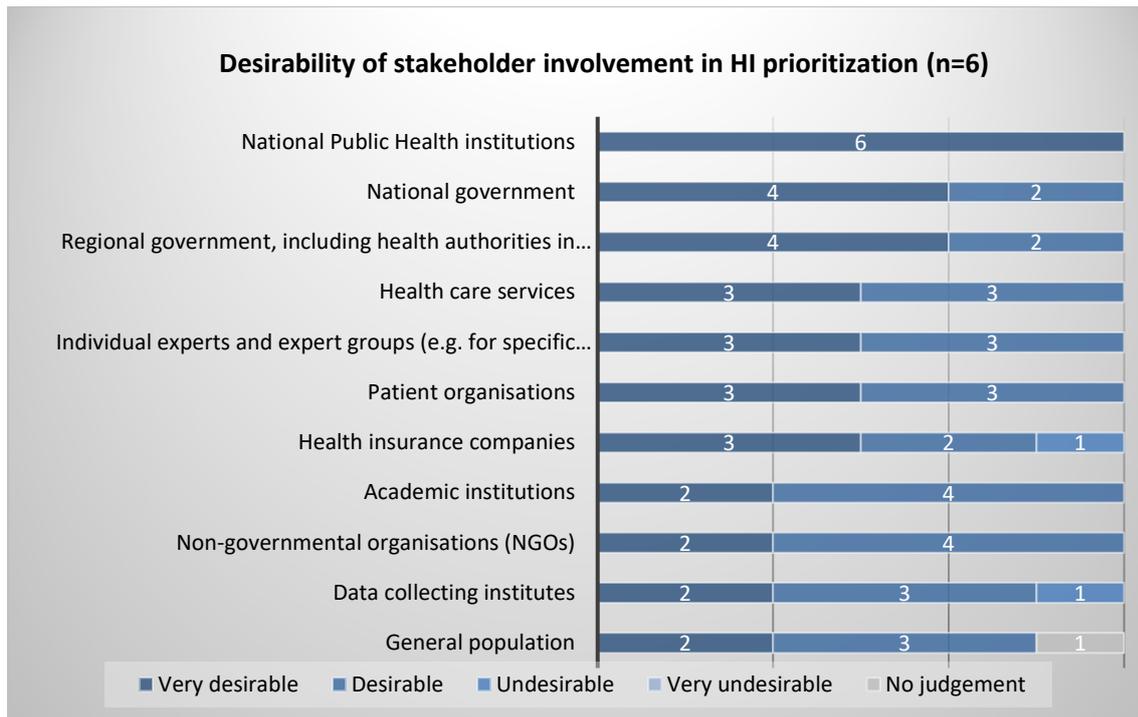
Stakeholder involvement in health information prioritization - Round 2

In the second round, using the list of potential stakeholders which respondents provided in the first round, we asked the participants about the desirability and feasibility of their involvement in national HI prioritization, and about preferences for stakeholder coordination.

National public health institutions were considered to be the most desirable and most feasible stakeholders for the HI priority setting process (Figure 14; Figure 15). Involving policy-makers was also rated as a (very) desirable option, with respect to both national and regional governments. As regards feasibility, an equal number of respondents rated the involvement of national governments to be definitely or possibly feasible. Regional governments' involvement also received a positive overall rating; however, none of the respondents considered it definitely feasible.

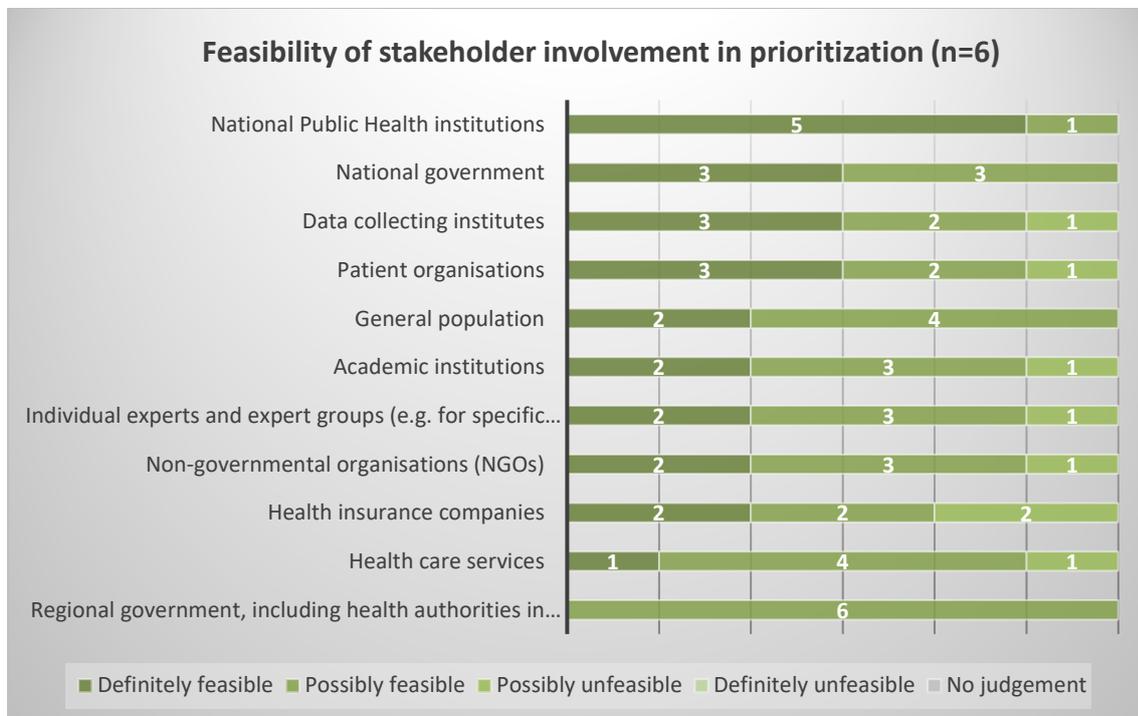
When asked to specify the most desirable organ of the national government, all (n=6/6) of the respondents indicated the Ministry of Health; 3 (n=3/6) also referred to other government branches (please refer to Annex 5 for further specifications).

Figure 14: Desirability of stakeholder involvement in health information prioritization



Please refer to Annex 4 for the full text of the presented options

Figure 15: Feasibility of stakeholder involvement in health information prioritization

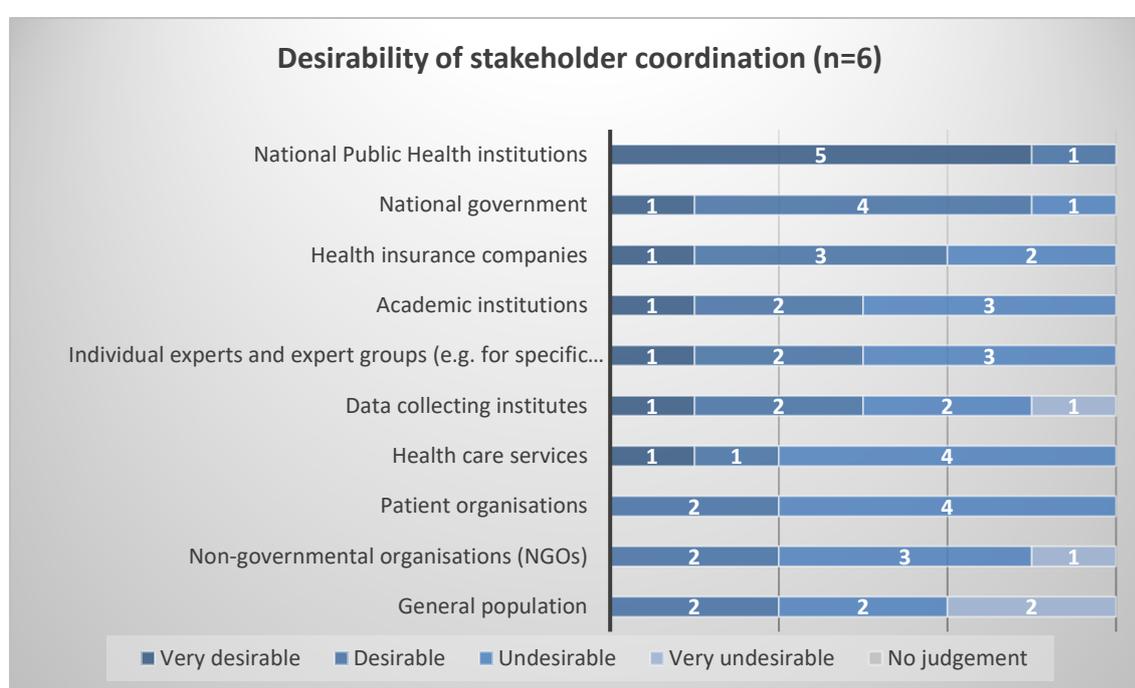


Please refer to Annex 4 for the full text of the presented options

Stakeholder coordination - Round 2

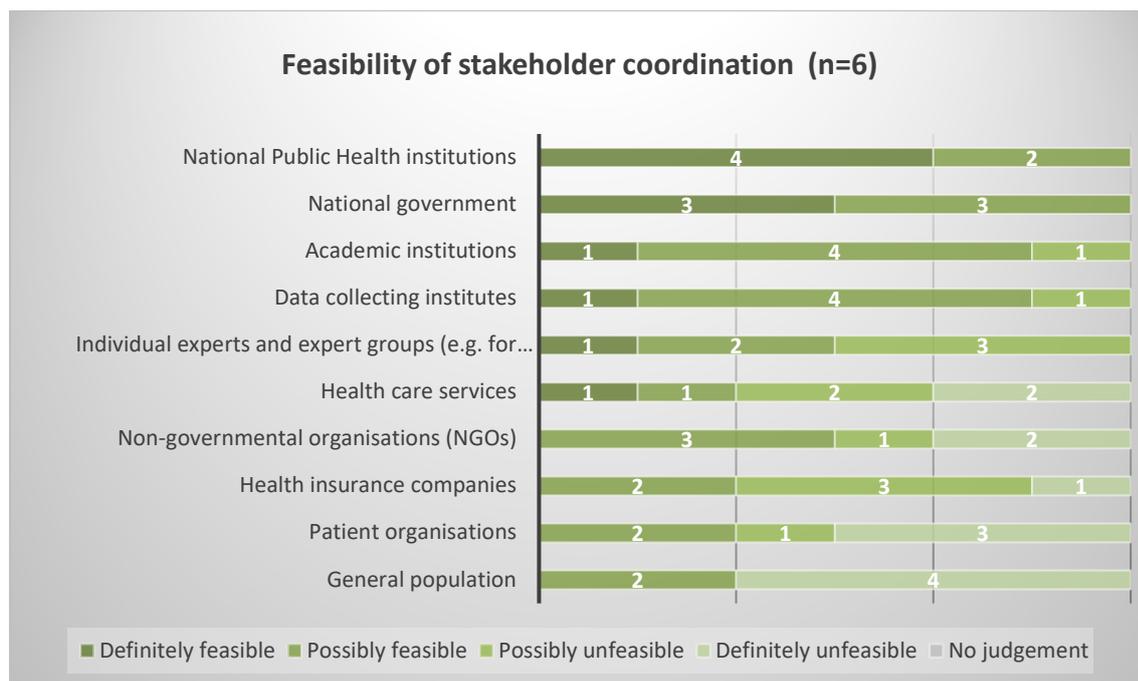
As illustrated in Figure 16 below, national public health institutes and national governments were the actors with the highest ratings for desirability and feasibility for stakeholder coordination whereby national public health institutes received higher rating for definite feasibility. Five stakeholders, i.e. patient organizations, non-governmental organizations (NGOs), health insurance companies, the general population, and health care services were considered as definitely unfeasible actors by some respondents for stakeholder coordination (Figure 17). Academic institutions as well as data collecting institutes were rated very desirable or desirable by 3 respondents and definitely/possibly feasible actors to coordinate stakeholders by 4 respondents.

Figure 16: Desirability of stakeholder coordination



Please refer to Annex 4 for the full text of the presented options

Figure 17: Feasibility of stakeholder coordination

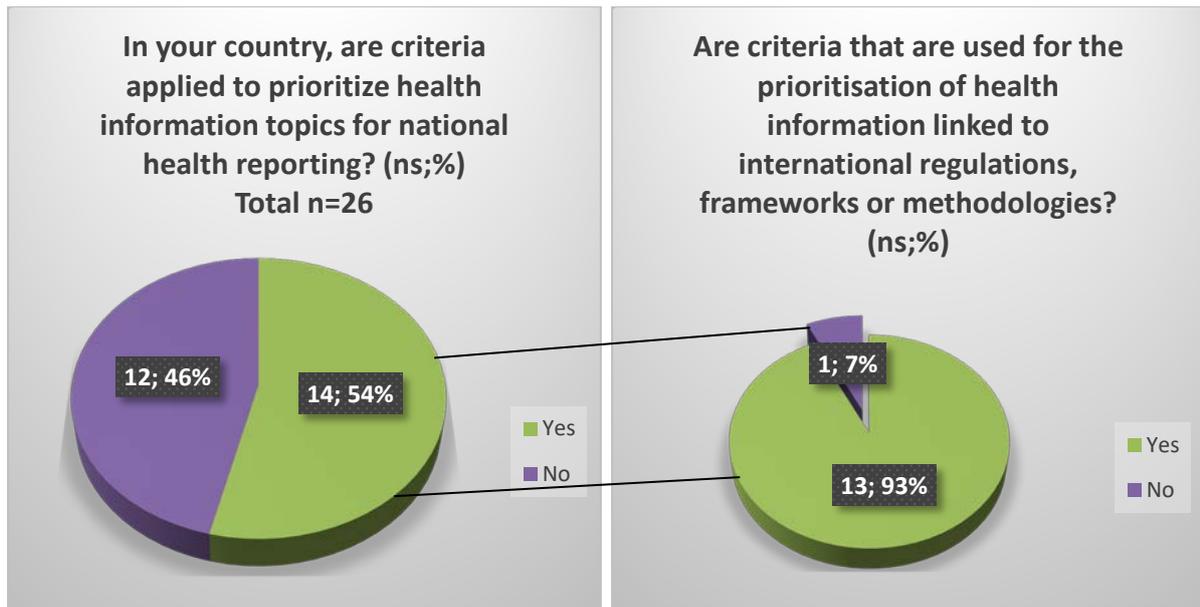


Please refer to Annex 4 for the full text of the presented options

Criteria application to health information prioritization - Round 1 and 2

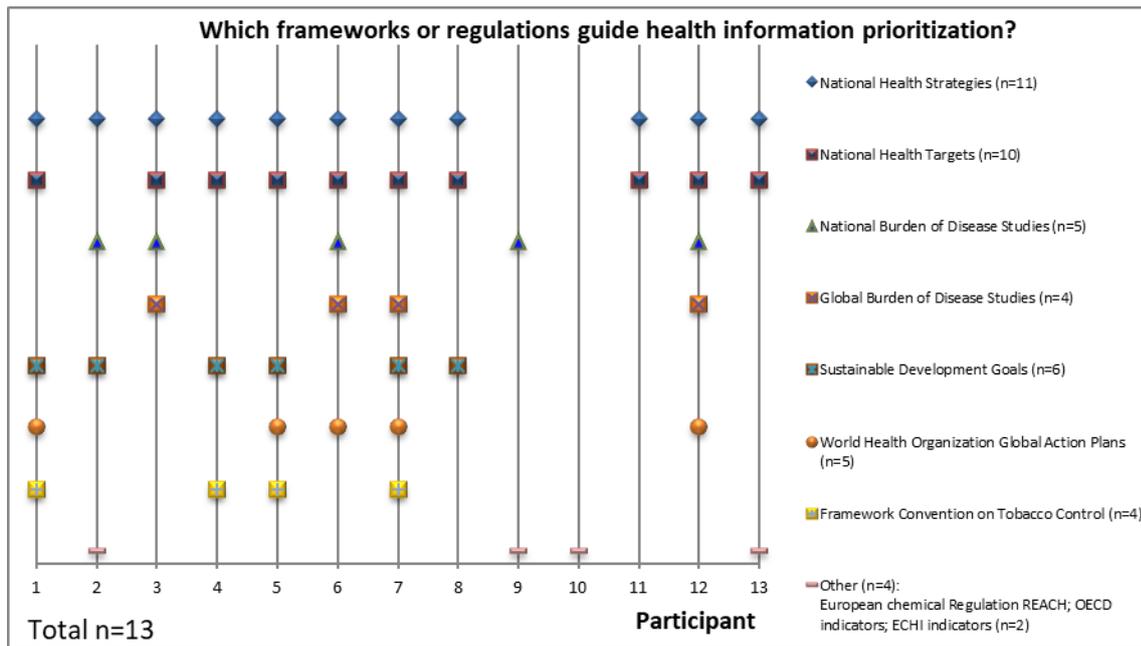
With our survey, we aimed to gather information not only on processes, but also on methods for HI prioritization. We therefore asked participants whether, in their countries, criteria are applied to prioritize HI. In the first round, around half of the participants (n=14/26; 54%) affirmed the use of criteria, and most of these (n=13/14; 93%) stated that criteria are linked to international frameworks (Figure 18). Those respondents who affirmed the use of criteria in HI prioritization in the first round (n=14) were also encouraged to describe who in their countries developed criteria and how cooperation around development was organized.

Figure 18: Application of criteria to HI prioritization and guiding documents



Also, in the first round, participants were asked to select from a drop-down list which frameworks guide their criteria development; full-text fields were provided for additional frameworks or regulations not listed. As shown in Figure 19 below, criteria development for HI prioritization was most often linked to national health strategies and national health targets. 6 of the 13 respondents referred to the Sustainable Development Goals (SDGs), 5 selected national burden of disease-studies and WHO Action Plans, while 4 chose Global Burden of Disease Studies and the Framework Conventions on Tobacco Control. OECD and ECHI indicators were added by participants, as well as specific regulations (EU Chemical Regulation).

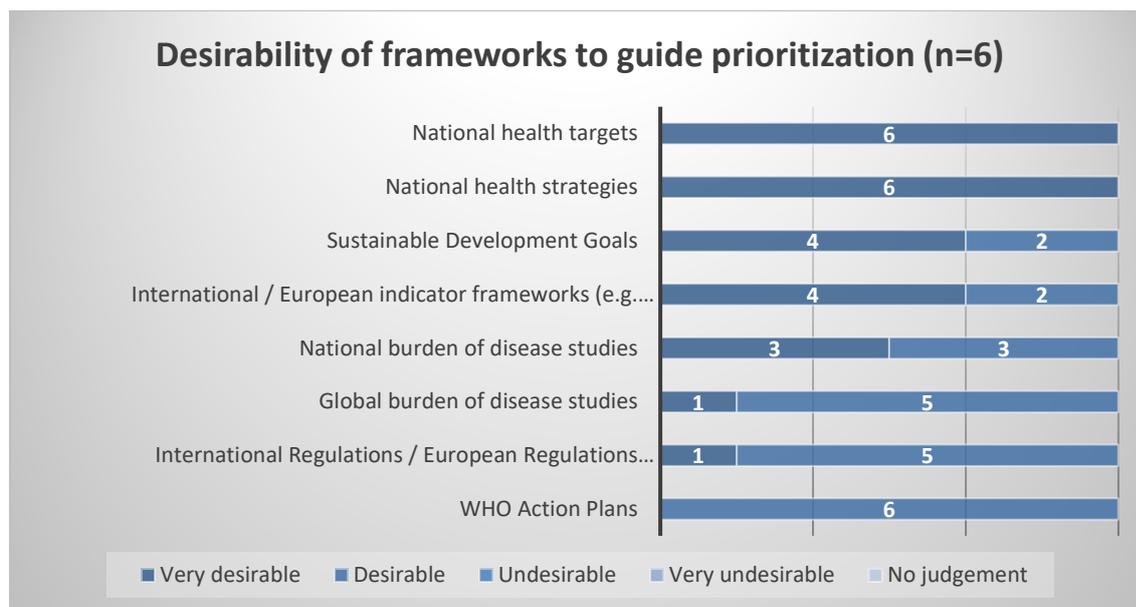
Figure 19: Guiding documents for health information prioritization (Multiple responses possible)



In the second round, respondents were then asked which of these frameworks they considered desirable and feasible to guide criteria development for HI prioritization.

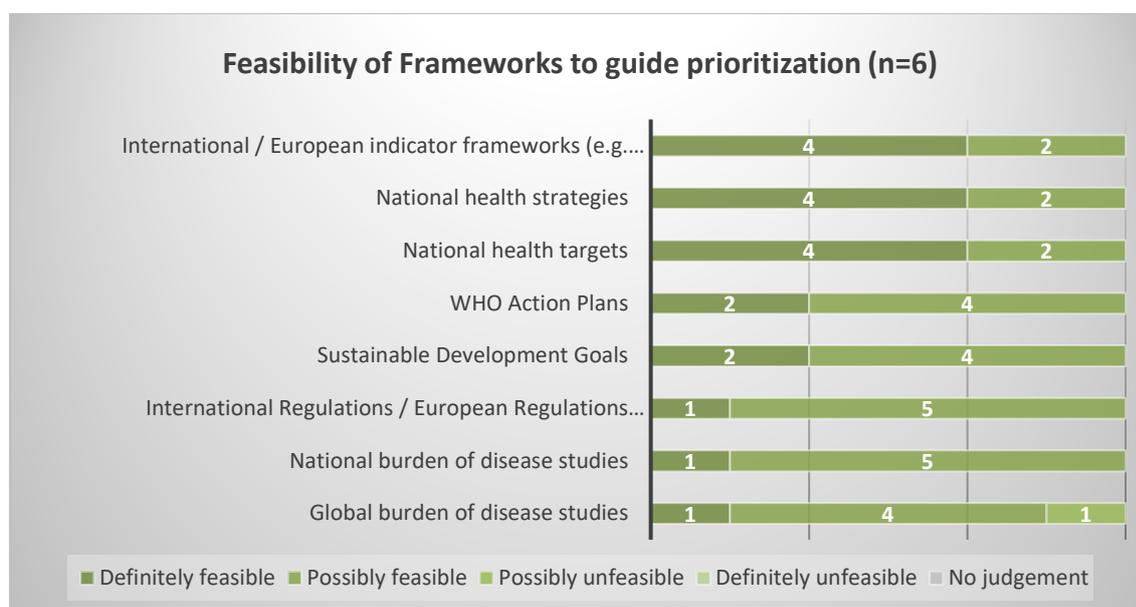
All participants considered national health strategies and national health targets to be a very desirable guidance for HI prioritization. None of the listed options was seen as (very) undesirable (Figure 20). As regards feasibility, 4 of the 6 participants considered international and European indicator frameworks as well as national health targets and national health strategies to be definitely feasible options for guiding HI prioritization (Figure 21). The third very desirable option, i.e. WHO Action Plans, was perceived as definitely feasible by 2 and possibly feasible by 4 of the 6 respondents. Of interest, one participant suggested that it was possibly unfeasible to use global burden of disease studies as guidance. This was the only negative judgment in both categories, desirability and feasibility.

Figure 20: Desirability of frameworks to guide prioritization



Please refer to Annex 4 for the full text of the presented options

Figure 21: Feasible frameworks to guide prioritization



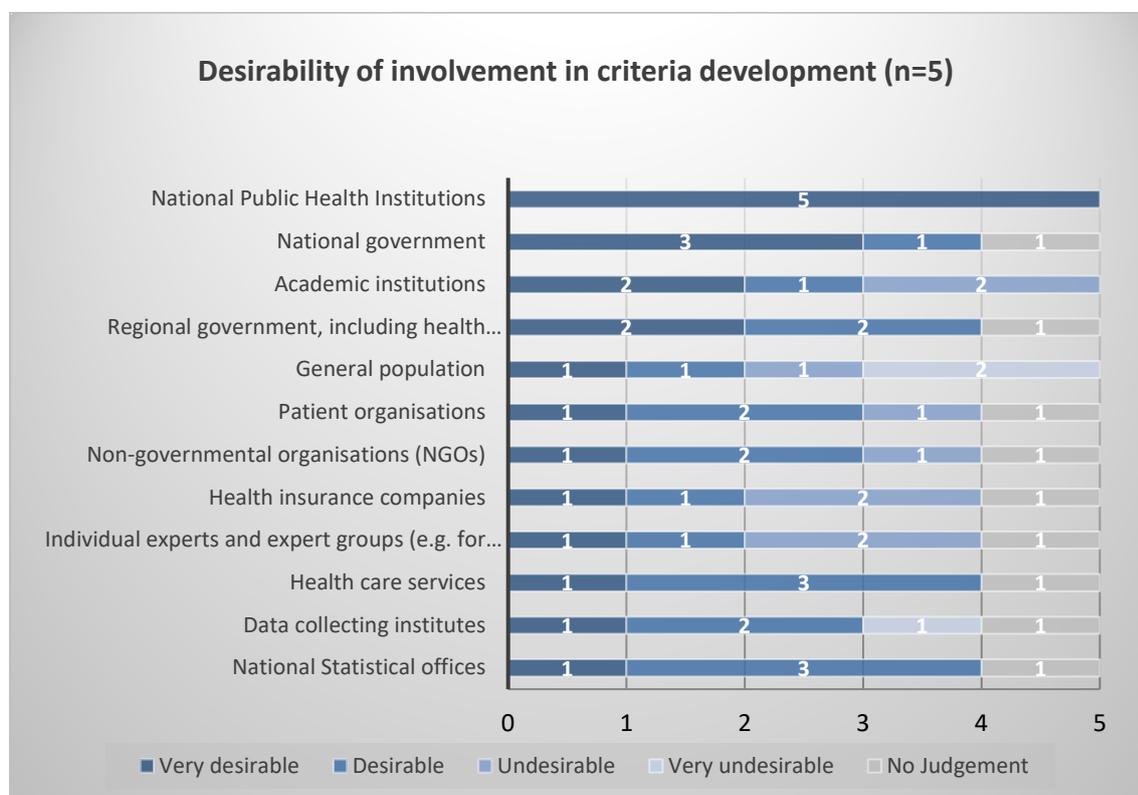
Please refer to Annex 4 for the full text of the presented options

As regards involvement in the development of criteria, again national public health institutions were rated as the most desirable option in round 2 (Figure 22). Attitudes of respondents towards the remainder of the actors on the list differed considerably. Least desirable as participants in criteria development, in terms of aggregate counts for undesirable/very undesirable, were the general population (n=3, with 2 very undesirable), academic institutions (n=2 undesirable), health insurance companies (n=2 undesirable) and

individual experts and expert groups (n=2 undesirable). One participant considered data collecting institutes to be a very undesirable stakeholder in criteria development. Of note, not all participants had a clear opinion on this question; for the first time in this study, respondents repeatedly selected the option 'no judgement'.

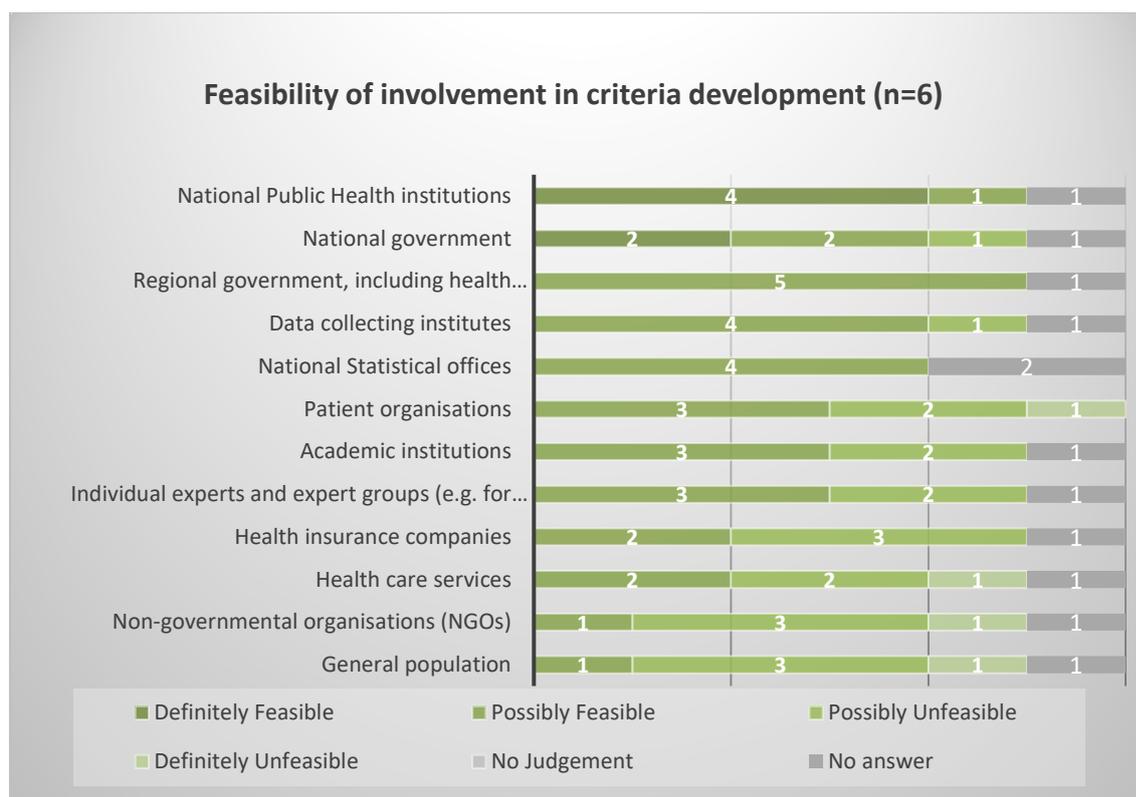
National public health institutions received the highest number of ratings as definitely feasible stakeholder to be involved in criteria development, followed by national governments (Figure 23). Indeed, these 2 stakeholders were the only ones that received a rating for 'definitely feasible'. On the other end of the feasibility scale, one respondent each considered the involvement of the general population, of patient organizations, NGOs and health care services to be definitely unfeasible. Overall, the majority of respondents seemed cautious about this question; most replies were given for 'possible feasibly' and 'possibly unfeasible'.

Figure 22: Desirability of involvement in criteria development



Please refer to Annex 4 for the full text of the presented options

Figure 23: Feasibility of involvement in criteria development



Please refer to Annex 4 for the full text of the presented options

Following the questions on stakeholder involvement and coordination, we asked the participants about the organization of stakeholder cooperation. The first-round questionnaire contained full-text fields for participants to describe processes in their countries. The full-text fields were analyzed and organized in the 8 categories, shown in Figure 24 below. These categories were again to be ranked according to desirability and feasibility.

Mixed meetings, in which researchers and policy-makers come together, were unanimously ranked to be the most desirable approach of cooperation, closely followed by expert meetings (Figure 24). Literature reviews, web-based surveys and face-to-face expert meetings also received only positive ratings on their desirability; web-based public consultations and data analyses received at least one negative rating for desirability by the participants (Figure 25). Two approaches were assessed as possibly unfeasible, which are mixed meetings and web-based public consultations.

Figure 24: Desirability of methods for criteria development

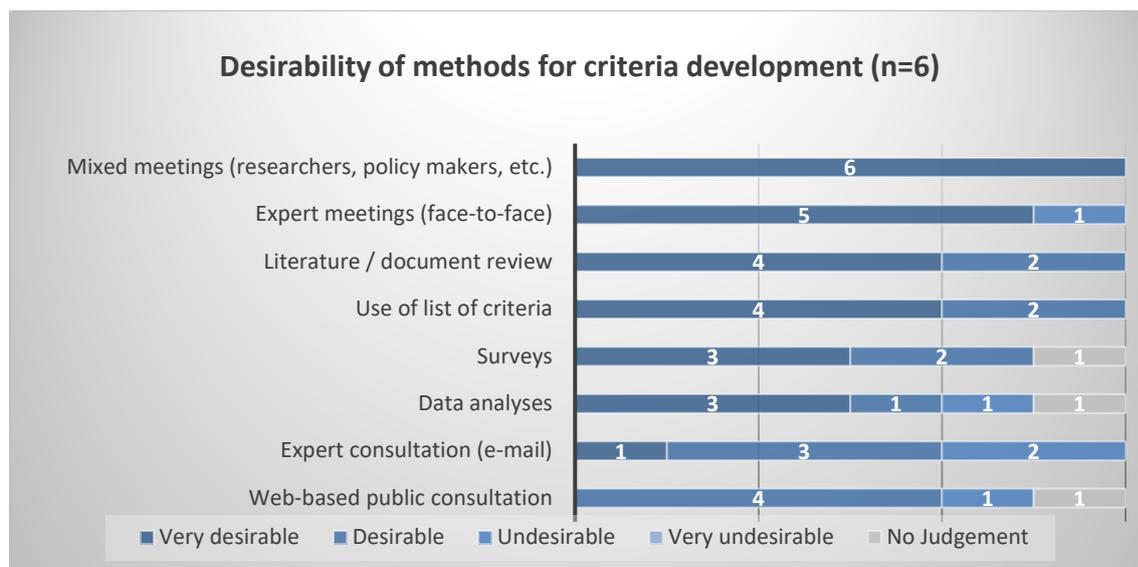
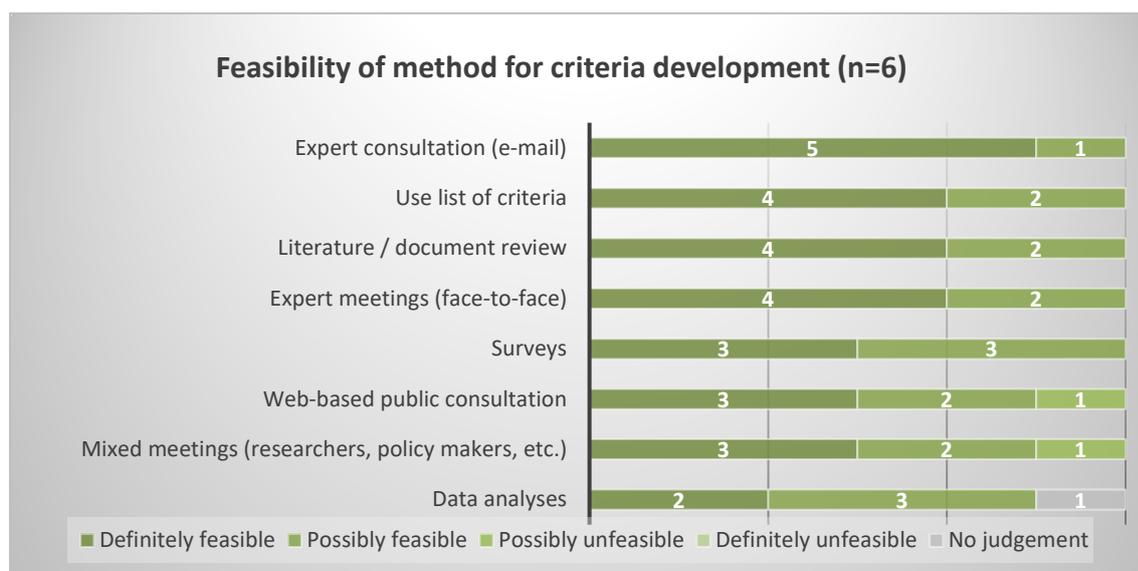


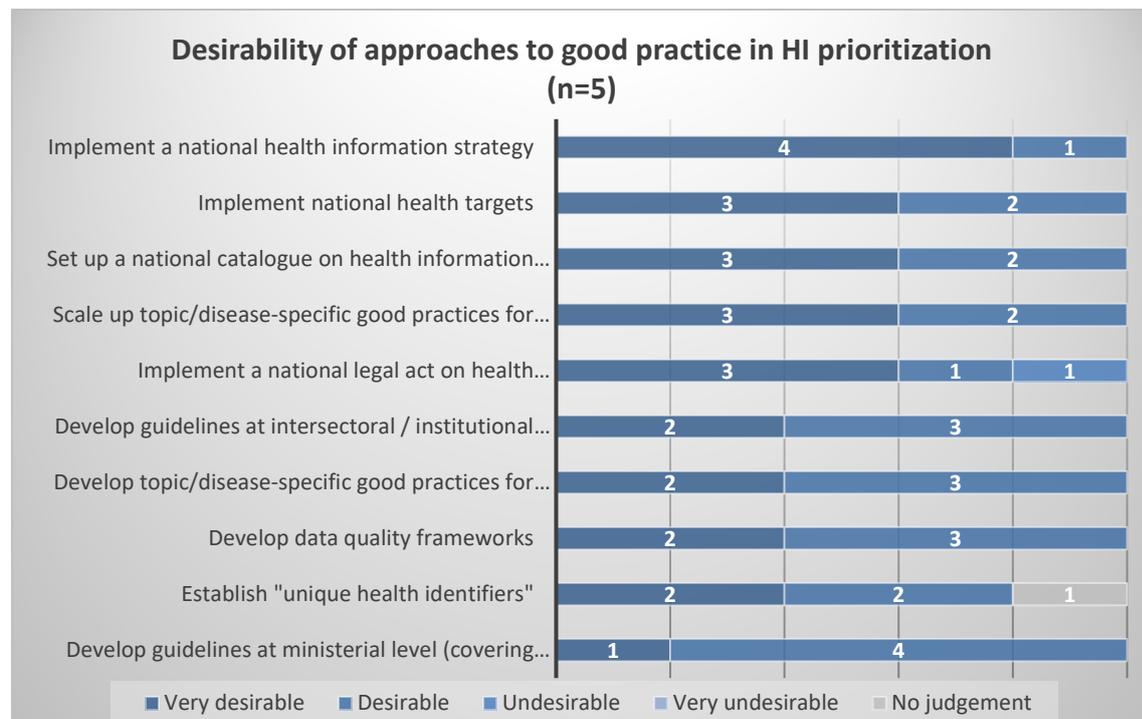
Figure 25: Feasibility of methods for criteria development



The questionnaire for the first round concluded with the question whether any national efforts existed in participants' countries to develop national good practices for prioritization of HI. We collected full-text replies, collated them into categories and asked participants in the second round to rate them. As shown in Figure 26 and Figure 27, the overall majority of the suggested approaches were considered either very desirable or desirable. Only one approach, i.e. to implement a HI law, received a negative rating from one participant; another respondent chose not to express an opinion on the 'unique health identifiers'. In contrast, the ratings for feasibility showed a more diverse assessment. National health targets were seen as a definitely feasible approach towards a good

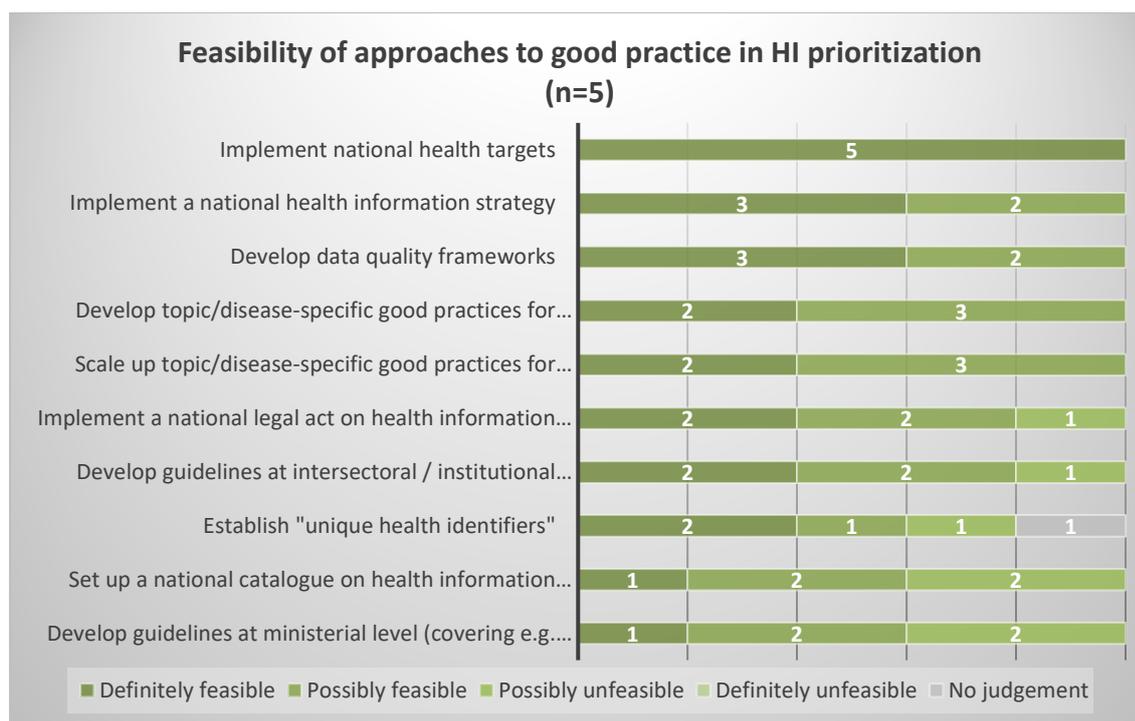
practice in HI prioritization; overall positive ratings were also received for a national HI strategy, for data quality frameworks, and for either developing or scaling up topic or disease-specific good practices. Interestingly, guidelines at intersectoral / institutional level received one feedback for being possible unfeasible; the same was true for the suggestions for a HI law. Guidelines at ministerial level and a comprehensive catalogue in HI were also considered possibly unfeasible by two participants.

Figure 26: Desirability of approaches to good practice



Please refer to Annex 4 for the full text of the presented options

Figure 27: Feasibility of approaches to good practice



Please refer to Annex 4 for the full text of the presented options

V. Implications and limitations

The desired implications of this study are that it will initiate and promote a debate among HI experts in EU-MS about good practices in HI prioritization for health reporting. While the literature search revealed little published research on HI prioritization, we learned that a majority of participating countries applied structured processes to HI prioritization; furthermore, if such processes were mentioned, they were often documented in health reports or other relevant publications. To follow-up on our study, a systematic review of such documented processes in countries' health reports could be done, with the objective of comparing and contrasting relevant processes and to identify those that may - irrespective of the underlying country-specific health information system - be identified as good practice. The respondents described very different approaches and degrees of systematization as regards HI prioritization, ranging from decentralized ad-hoc processes, sometimes triggered by media impulses, to very stringent and centralized processes, headed by ministries of health and relying on organized involvement of relevant stakeholders. From the description provided by the respondents, we developed broad categories of approaches to HI prioritization. Before applying these categories to a guidance on health information prioritization, they need to be refined.

We also learned that the majority of respondents involved stakeholders in HI prioritization. Suggestions for stakeholder involvements ranged from - highly desirable and highly feasible - national public health institutes to the general public. For some stakeholders, e.g. regional governments, that were deemed desirable partners in HI prioritization, respondents doubted the feasibility of their involvement. Here, potential

roadblocks would need to be identified, and ideally removed, to increase feasibility of involvement.

As regards the methodological approach we chose for our study, we consider the Policy Delphi an adequate instrument for our research question. The information especially about desirability and feasibility, was a valuable output which can guide next steps towards a draft guidance on HI prioritization. Based on the results, experts may discuss examples of overcoming barriers to the involvement of stakeholders or develop recommendations regarding the development and application of defined criteria to HI prioritization. Retrospectively, it may even have sufficed for our research question to use the categories 'desirability' and 'feasibility', and apply the categories 'importance' and 'confidence' to a later, more expanded study.

Using the list of contacts for the InfAct partners, we approached 119 experts affiliated with the project. We had hoped to receive a higher response to our survey. Indeed, our study suffered from a low participation rate, especially in the second round which focused on the assessment of previously gathered options. On the other hand, the project partners who did participate contributed fully and very valuable to this survey. In our letter of invitation, we encouraged recipients to forward the information about the survey to any colleagues for whom it could be of interest so that these could contact the research team to receive the link to the questionnaire. It may also well be that some recipients filled in the survey with competent colleagues at their institute. From the volume of contributions which we received we conclude that, despite the low response rate, the survey met with considerable interest in the InfAct community, and fulfilled its aim to establish a knowledge base on HI prioritization to be developed and used for further expert exchange. We are particularly grateful to the participants of the second round of the survey for their efforts, since the implementation of this round from March to May 2020, with several extension, coincided with the SARS-CoV-2 outbreak and its extraordinary burden on the public health community, also in the InfAct network.

VI. Conclusions and recommendations

The process of developing health information can be described as ranging from the selection of topics to the delivery of health reports which shall be based on carefully defined indicators with underlying quality data. Quality standards are attached to selected steps in this development process, e.g. to indicator development, data availability or health reporting. Despite the existence of structured processes to prioritize health information at the very early stage of the development process, very little information can be found in literature about HI prioritization methods or standards. Respondents to our survey indicated that ad-hoc approaches to selecting topics is not a desirable option. Wider preference was given to structured approaches, such as a health information strategy or health targets, either coordinated by ministries or enabling cooperation among experts and stakeholders more horizontally.

To further promote science-base, transparency and comprehension of HI prioritization, we recommend to use the project results presented here, together with international guidance on priority setting in health and on the development of national health

strategies, to initiate a process among EU MS to develop a guidance for 'Good Practice HI Prioritization'. Such guidance could complement any 'Good Practice Health Reporting' at the very opposite end of the HI development process. A guidance for 'Good Practice HI Prioritization' could include the following topics:

- Criteria for HI prioritization, which may include burden of disease, data availability, reporting obligations, national or international health policy agendas, actionability, social or economic impacts.
- Stakeholders in HI prioritization, which may include lead/coordination of stakeholders, selection and procedures for involvement of stakeholders (considering conflicts of interest), degree of involvement.
- Development of sustainable national frameworks for HI prioritization, e.g. a national health information strategy, which connects processes such as national health targets, national health monitoring, national public health strategies for mutual benefit and support.
- From national frameworks, explore the development of a European framework for HI prioritization, which shall facilitate decision-making processes for pan-European data collections.

We are hopeful that this study will contribute to national and European processes aimed at transparent and comprehensible selection and prioritization of HI for the benefit of adequate provision of health promotion, prevention and care. To this end, we would be glad if the results can be discussed in bodies, such as National Nodes for HI established under InfAct or Europe-wide HI working groups, to be set up in a future sustainable European HI system. We also aim to deepen the analysis and to further disseminate it in appropriate formats and venues.

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Annex 1: Letter of Invitation for Survey Participants

Dear Colleague,

What do we want to know about health in the European Union, and why do we want to know it?

This is the question we are addressing in a dual-round Delphi survey for which we are kindly asking your participation. For more details on our project, please open the pdf-Project Summary which we have attached to this Email.

We are contacting health information experts from a variety of professional backgrounds and institutional affiliations, including National Public Health Institutes, National Statistics Offices, Ministries of Health, Parliaments, Ministries of Research, Institutions developing national health targets, or individuals involved in the creation of national health reports. In case you feel that you are not the right person to answer the survey, or if there are other experts in your country whom you think we may also contact for the survey, please forward this Email to them so that they may contact the RKI team. We will gladly send them an invitation to participate in the survey.

The aim of our survey is to compile and assess processes and methods which are used to prioritize health information at national level in the EU. A particular focus is on information 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 first round of the survey is open until September 27, 2019. It can be accessed through this link:

<https://befragungen.rki.de/...> [Link truncated]

The questionnaire of the first round contains 36 questions. Participants can pause while taking the survey and resume the survey at any time. During pre-testing, participants finished the survey within 20 minutes.

We are conducting a survey with identifiable data. Data analysis will be performed anonymously and only at Robert Koch-Institute. The survey data will not be forwarded, and results will be reported in aggregate form only.

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. The exercise is part of the EU-funded Joint Action on Health Information (*InfAct*). *InfAct* is a 3-year project (2018-2021), involving 40 partners in 28 European countries. The aim of *InfAct* is to build a sustainable European health information infrastructure. Read more about the project here: www.inf-act.eu

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



Thank you for your time and contribution.

With best regards,

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Annex 2: Project Summary for Survey Participants

Delphi Survey on Prioritization of Health Information for National Health Reporting -Project Summary for Survey Participants-

Background

This survey is being implemented 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/.

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.

Our project addresses 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)?
 - Are defined methods or structured processes being used to prioritize health information? How can such processes be described?
 - Which other, less structured processes and sources, influence health information prioritization?
 - Which stakeholders are involved in health information prioritization?
 - Does health information prioritization follow defined criteria? If yes, how and by whom are they developed and applied? Are they linked to international regulations, laws or priorities?
- b)
 - 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?

Method

In order to answer the above questions, we are conducting a Policy Delphi survey among *InfAct* project partners and other stakeholders from EU-Member States (MS) and associated countries. The survey is conceptualized as an online Delphi survey in two rounds. The 1st round questionnaire will include discrete, (mainly) open-ended questions. Information from the 1st round will be presented in closed question format for the 2nd round.



Participants to the 1st round will then be asked to rank the collected methods, processes and criteria. 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. A third and final round will inform participants of the results of the survey.

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

We are conducting a survey with identifiable data. Data analysis will be performed anonymously and only at Robert Koch-Institute. The survey data will not be forwarded, and results will be reported in aggregate form only. Participants' identities will not, at any time during the analysis and publication of data, be visible to other survey participants, to the research team, or be linked to survey results.

Timeline

Implementation of the 1st round of the Policy Delphi will be in September 2019 for the first round and in October 2019 for the 2nd round. Final feedback is expected to be sent to participants in November 2019.

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Annex 3: Informed Consent and Questionnaire - Delphi Round 1

a) *Informed Consent - Delphi Round 1*

Statement regarding Informed Consent:

We are conducting a survey with identifiable data. Data analysis will be performed anonymously and only at Robert Koch-Institute. The survey data will not be forwarded, and results will be reported in aggregate form only.

Participation in this survey is voluntary. If you choose not to participate, there will be no negative consequences. You can stop and resume the survey at any time; 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 anonymity of the data analysis, please do not include any personal details in your response to survey questions. No details will be removed from survey responses, once submitted.

In the context of participating in the survey, please note that these are your rights under the EU General Data Protection Regulation (GDPR):

'I have the following rights pursuant to Art. 15-20 & 77 (1) GDPR:

- The right to demand information about the categories of data which have been processed concerning me, and to demand rectification, completion, deletion or restriction of processing of inaccurate personal data as well as the right to receive the personal data concerning me in a structured, commonly used and machine-readable format.
I can exercise these rights as long as I am identifiable by these data.
- The right to withdraw my consent, with effect for the future, at any time without giving any reason, and to prematurely end my participation in the survey without any detrimental consequences for me.
- The right to lodge a complaint with the data protection officer at the Robert Koch-Institute (Dr. Jörg Lekschas, Nordufer 20, 13353 Berlin, +49 (0)30 187543594) or with the supervisory authority (Der Bundesbeauftragte für den Datenschutz und die Informationsfreiheit (BfDI)/ Federal Commissioner for Data Protection and Freedom of Information, Husarenstr. 30 - 53117 Bonn, +49 (0)228-997799-0)

Do you want to participate in this survey?

- Yes
- No

b) Questionnaire - Delphi Round 1

For easier reading, this word version does not show the formatting of the original online questionnaire.

Questionnaire Round 1

Prioritization of Health Information for National Health Reporting

Definitions:

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.

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.

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).

As you continue the survey, you will find four sections with questions which will help us understand how health information 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.

Please note: text boxes for open-ended questions contain a field at the lower right corner allowing you to expand the writing space so you can write and read various response lengths comfortably.

Thank you again, for your time!

I. Structured 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

1.1 *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 process?*

- Free text box: _____

- Refusal
- Do not know

1.2 *Are processes and methods for health information prioritization documented in national health reports or other relevant publications?*

- Yes
- No

1.3 *Please provide the URL link or document title of any relevant reports or publications.*

- Free text box: _____
- Refusal
- Do not know

1.4 *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.

- Free text box: _____
- Refusal
- Do not know

II. Stakeholder Involvement in Prioritization of Health Information

2. *Are stakeholders involved in health information prioritization processes in your country?*

Stakeholders may include experts from the healthcare sector, from academia, patient groups, etc.

- Yes
- No

2.1 *Which stakeholders are involved?*

- Free text box: _____
- Refusal
- Do not know

2.2 *Who initiates, coordinates and / or leads stakeholder involvement?*

- Free text box: _____
- Refusal
- Do not know

III. Criteria Used in Prioritization of Health Information

3. *In your country, are criteria applied to prioritize health information topics for national health reporting?*

- Yes
- No

3.1 *Who is involved in developing the criteria?*

- Free text box: _____
- Refusal

- Do not know

3.2 *What methodologies (e.g. expert meetings, consultation, and consensus processes) are used to develop the criteria?*

- Free text box: _____
- Refusal
- Do not know

3.3 *In your country, who applies criteria for health information prioritization (e.g. stakeholders or experts)?*

- Free text box: _____
- Refusal
- Do not know

3.4 *Are criteria that are used for the prioritization of health information linked to international regulations, frameworks or methodologies?*

- Yes
- No

3.5 *Which international regulations, frameworks or methodologies are they linked to?*

- National health targets
- National health strategies
- Global Burden of Disease studies
- National Burden of Diseases studies
- Sustainable Development Goals (SDGs)
- WHO Global Action Plans
- Framework Convention on Tobacco Control
- Others: _____

IV. Role of Health Information Prioritization in Health Systems Functioning

4.1 *In your view, does the current approach to health information prioritization in your country support or hinder effective functioning of your health system?*

- The current approach to health information prioritization supports effective functioning of our health system.
- The current approach to health information prioritization hinders effective functioning of our health system.

4.1.a *Please explain.*

- Free text box: _____
- Refusal
- Do not know

4.2 *Which improvements to your national health information system would benefit health information users and policy makers in your country?*

Improvements may include continual indicator alignment with population health needs, data quality improvements, or improvements in dissemination (including access or formats used).

- Free text box: _____
- Refusal

- Do not know

V. Good Practices

5.1 *Please describe any national efforts to develop a set of national good practices for prioritization of health information, including whether structured process for establishment of national health information prioritization good practices were used.*

- Free text box: _____
- Refusal
- Do not know

5.2 *Did stakeholders evaluate a range of prioritization processes before establishing their current methodology? Please describe their decision process.*

- Free text box: _____
- Not Applicable
- Refusal
- Do not know

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

- Free text box: _____
- Refusal
- Do not know

VI. Additional Comments

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

- Free text box: _____
- Refusal
- Do not know

VII. Participant Background Details

You have completed the questionnaire. Before submitting the survey, please provide information about your professional affiliation, background, and expertise.

7.1 *What is your current institutional affiliation?*

- Ministry of Health
- Ministry of Research
- National Public Health Institute
- National Statistics Office
- Other

7.1a *You have selected 'Other', please specify your answer.*

- Free text box: _____
- Not Applicable
- Refusal
- Do not know

7.2 *What is your professional background?*

- Medicine
- Epidemiology
- Public Health
- Statistics
- Political Science
- Demography
- Informatics
- Other

7.2a *You have selected 'Other', please specify your answer.*

- Free text box: _____
- Not Applicable
- Refusal
- Do not know

7.3 *What is your level of involvement in health information (HI) development?*

- Very high (e.g. in charge of HI development)
- High (e.g. represent key stakeholder in HI development)
- Medium (e.g. participant or consultant in HI development, on an irregular basis)
- Low (e.g. observer to HI development process, user of health information)
- Not applicable, Refusal, Do not know

Thank you for participating in the 1st round of this Delphi survey. Would you like to participate in the 2nd (and last) round of the survey?

- Yes
- No

Please enter your Email address in the box below.

Your Email address will solely be used to send you the questionnaire for the second round of the Delphi survey; it will not be disclosed to any third parties. Your Email address will be treated as strictly confidential. Only staff involved in the survey has access to it. It will be stored separately from survey data, and it cannot be linked to your survey replies.

- Email: _____

Thank you for contributing to our research project. The results of this survey will be presented in the context of the InfAct-project.

Annex 4: Informed Consent and Questionnaire - Delphi Round 2

a) *Informed Consent - Delphi Round 2*

The wording of the Informed Consent in the second round of the Delphi survey was identical to that of the first round (Annex 3a: Informed Consent - Delphi Round 1).

b) *Questionnaire - Delphi Round 2*

In the second round of the Delphi survey, participants were asked to rank the presented options to their degree of 'desirability', 'feasibility', 'importance' and 'confidence':

Desirability (effectiveness or benefits):

Very desirable, Desirable, Undesirable, Very undesirable, No Judgement

Feasibility (practicality):

Definitely feasible, Possibly feasible, Possibly unfeasible, Definitely unfeasible, No Judgement

Importance (priority or relevance):

Very important, Important, Slightly important, Unimportant, No Judgement

Confidence (in validity of argument or premise):

Certain, Reliable, Risky Unreliable, No Judgement

For easier reading, this word version does not show the formatting of the original online questionnaire. Please also refer to the results tables in Annex 5 for an overview of the survey questions, presented options and rating categories.

Questionnaire Round 2

1. Approaches to prioritisation of health information

Different approaches are taken at national level to prioritise health information for national health reporting. From the perspective of your country, please rank the following options according to desirability (effectiveness or benefits), feasibility (practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- Formal, top-down approach; e.g. government sets priorities
- Formal, horizontal, centralised approach; e.g. stakeholders and experts develop priorities
- Formal, decentralised approach; e.g. data producers develop individual priorities
- Informal, decentralised approach; e.g. priorities are developed on an ad-hoc basis
- External influence approach; e.g. media guide prioritisation of health information

2. Stakeholder involvement in prioritisation of health information

2.1 Stakeholder Involvement

Health information is often developed by or in cooperation with a variety of stakeholders. From the point of view of your country, which stakeholders should be involved in prioritising health information for national health reporting? Please rank the following options according to desirability (effectiveness or benefits), feasibility

(practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- National government
- Regional government, including health authorities in (autonomous) regions
- National Public Health institutions
- Data collecting institutes
- Academic institutions
- Health care services
- Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)
- Health insurance companies
- Non-governmental organisations (NGOs)
- Patient organisations
- General population

Filter Question: *You have selected 'National government', please specify your answer:*

- Ministry of Health
- Ministry of Finance
- Other government branches: _____

2.2 Coordination of stakeholder involvement

Stakeholder involvement may be coordinated by a variety of actors. From the point of view of your country, which actor, or actors, should coordinate stakeholder involvement? Please rank the following options according to desirability (effectiveness or benefits), feasibility (practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- National government
- National Public Health institutions
- Data collecting institutes
- Academic institutions
- Health care services
- Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)
- Health insurance companies
- Non-governmental organisations (NGOs)
- Patient organisations
- General population

Filter Question: *You have selected 'National government', please specify your answer:*

- Ministry of Health
- Ministry of Finance
- Other government branches: _____

3. Criteria development in prioritisation of health information

From the point of view of your country, who should be involved in developing criteria for prioritising health information for national health reporting? Please rank the following

options according to desirability (effectiveness or benefits), feasibility (practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- National government
- Regional government, including health authorities in (autonomous) regions
- National Public Health institutions
- National Statistical offices
- Data collecting institutes
- Academic institutions
- Health care services
- Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)
- Health insurance companies
- Non-governmental organisations (NGOs)
- Patient organisations
- General population

Filter Question: *You have selected 'National government', please specify your answer:*

- Ministry of Health
- Ministry of Finance
- Other government branches: _____

4. Methods for criteria development in prioritisation of health information

Different methods are applied to develop criteria for the prioritisation of health information for national health reporting. From the point of view of your country, please rank the following options according to desirability (effectiveness or benefits), feasibility (practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- Expert meetings (face-to-face)
- Expert consultation (e-mail)
- Mixed meetings (researchers, policy makers, etc.)
- Web-based public consultation
- Surveys
- Data analyses
- Literature / document review
- Use of list of criteria

5. Frameworks to guide prioritisation of health information

From the point of view of your country, which frameworks should guide prioritisation of health information for national health reporting? Please rank the following options according to desirability (effectiveness or benefits), feasibility (practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- National health targets
- National health strategies
- Global burden of disease studies
- National burden of disease studies
- Sustainable Development Goals
- WHO Action Plans

- International Regulations / European Regulations (e.g. Framework Convention on Tobacco Control; European chemical Regulation REACH for exposure burden from environmental substances)
- International / European indicator frameworks (e.g. ECHI, OECD indicators)

6. Good practices in prioritisation of health information

Some countries strive to develop, or have already developed, sets of national good practices in health information prioritisation for national health reporting. From the point of view of your country, please rank the following approaches according to desirability (effectiveness or benefits), feasibility (practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- Implement a national health information strategy
- Implement national health targets
- Implement a national legal act on health information (covering e.g. data standards, health information systems, e-health, infrastructure)
- Set up a national catalogue on health information (including e.g. organisation, processes and standards around health care and health indicators)
- Develop guidelines at ministerial level (covering e.g. prevention, diagnostics and therapy)
- Develop guidelines at intersectoral / institutional level for health information and / or health reporting
- Develop topic/disease-specific good practices for health information and indicator development
- Scale up topic/disease-specific good practices for health information and indicator development
- Develop data quality frameworks
- Establish 'unique health identifiers'

7. Promotion of good practices at EU and national level

7.1 In your view, what processes can promote good practices in health information prioritisation at EU level (e.g. for European surveys)? Please rank the following options according to desirability (effectiveness or benefits), feasibility (practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- Cooperate at the level of supranational organisations (EU, OECD, WHO) to develop joint health information methodologies and good practices

7.2 In your view, what processes can promote good practices in health information prioritisation at national level across EU and associated countries? Please rank the following options according to desirability (effectiveness or benefits), feasibility (practicality), importance (priority or relevance) and confidence (in validity of argument or premise).

- Implement an EU-wide guidance on a minimum indicator set, data transparency, access to data, standards for health reporting
- Engage in structures peer-to-peer processes, e.g. twinning
- Develop, pilot and evaluate good practices at national level
- Establish a network for knowledge exchange, preferably a sustainable and coordinating initiative

- Implement exchange of experts at national and European level
- Promote the development of national health targets
- Learn from regional networks exchanging good practices

8. Additional Comments

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

- Yes
- No

Filter Question: *You have selected 'Yes', please specify your answer.*

9. Participant Background Details

You have completed the questionnaire. Before submitting the survey, please provide information about your professional affiliation, background, and expertise.

9.1 What is your current institutional affiliation?

- Ministry of Health
- Ministry of Research
- National Public Health Institute
- National Statistics Office
- Other: _____

Filter Question: *You have selected 'Other', please specify your answer.*

9.2 What is your professional background?

- Medicine
- Epidemiology
- Public Health
- Statistics
- Political Science
- Demography
- Informatics
- Other: _____

Filter Question: *You have selected 'Other', please specify your answer.*

9.3 What is your level of involvement in health information (HI) development?

- Very high (e.g. in charge of HI development)
- High (e.g. represent key stakeholder in HI development)
- Medium (e.g. participant or consultant in HI development, on an irregular basis)
- Low (e.g. observer to HI development process, user of health information)
- Not applicable, Refusal, Do not know

Thank you for participating in the 2nd round of this Delphi survey. Would you like to receive the final feedback of the survey and information on the next steps?

- Yes

- No

Please enter your Email address in the box below. Your Email address will solely be used to send you the final feedback of the Delphi survey and information of the next steps; it will not be disclosed to any third parties.

- Email: _____

Thank you for contributing to our research project. The results of this survey will be presented in the context of the InfAct-project. Please press the Submit-Button to finish the session.

Annex 5: Result Tables - Delphi Round 2

Desirability		Very desirable	Desirable	Undesirable	Very undesirable	No judgement	Total
		n	n	n	n	n	n
1. Approaches to prioritisation of health information: <i>Different approaches are taken at national level to prioritise health information for national health reporting. From the perspective of your country, please rank the following options according to desirability (effectiveness or benefits).</i>	Formal, top-down approach; e.g. government sets priorities	1	3	2	0	0	6
	Formal, horizontal, centralised approach; e.g. stakeholders and experts develop priorities	3	3	0	0	0	6
	Formal, decentralised approach; e.g. data producers develop individual priorities	1	3	2	0	0	6
	Informal, decentralised approach; e.g. priorities are developed on an ad-hoc basis	0	1	5	0	0	6
	External influence approach; e.g. media guide prioritisation of health information	0	3	2	1	0	6
2.1. Stakeholder involvement in prioritisation of health information: <i>Health information is often developed by or in cooperation with a variety of stakeholders. From the point of view of your country, which stakeholders should be involved in prioritising health information for national health reporting? Please rank the following options according to desirability (effectiveness or benefits).</i>	National government	4	2	0	0	0	6
	Regional government, including health authorities in (autonomous) regions	4	2	0	0	0	6
	National Public Health institutions	6	0	0	0	0	6
	Data collecting institutes	2	3	1	0	0	6
	Academic institutions	2	4	0	0	0	6
	Health care services	3	3	0	0	0	6
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	3	3	0	0	0	6
	Health insurance companies	3	2	1	0	0	6
	Non-governmental organisations (NGOs)	2	4	0	0	0	6
	Patient organisations	3	3	0	0	0	6
	General population	2	3	0	0	1	6
→ 2.1. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	6
	Ministry of Finance	–	–	–	–	–	0
	Other government branches ²	–	–	–	–	–	3
2.2. Coordination of stakeholder involvement: <i>Stakeholder involvement may be coordinated by a variety of actors. From the point of view of your country, which actor, or actors, should coordinate stakeholder involvement? Please rank the following options according to desirability (effectiveness</i>	National government	1	4	1	0	0	6
	National Public Health institutions	5	1	0	0	0	6
	Data collecting institutes	1	2	2	1	0	6
	Academic institutions	1	2	3	0	0	6
	Health care services	1	1	4	0	0	6
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	1	2	3	0	0	6
	Health insurance companies	0	1	3	2	0	6
	Non-governmental organisations (NGOs)	0	2	3	1	0	6

² Free text answers: In the spirit of Health in all policies, all ministries that have a significant influence on shaping the health-related living conditions of the population should be included (n=1); Dependent on the subject (e.g. work, environmental health) (n=1); Department of food safety, sanitation (n=1)

Desirability		Very desirable	Desirable	Undesirable	Very undesirable	No judgement	Total
		n	n	n	n	n	n
	<i>or benefits).</i>						
	Patient organisations	0	2	4	0	0	6
	General population	0	2	2	2	0	6
→ 2.2. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	4
	Ministry of Finance	–	–	–	–	–	0
	Other government branches	–	–	–	–	–	0
3. Criteria development in prioritisation of health information: <i>From the point of view of your country, who should be involved in developing criteria for prioritising Health Information for national health reporting? Please rank the following options according to desirability (effectiveness or benefits).</i>	National government	3	1	0	0	1	5
	Regional government, including health authorities in (autonomous) regions	2	2	0	0	1	5
	National Public Health institutions	5	0	0	0	0	5
	National Statistical offices	1	3	0	0	1	5
	Data collecting institutes	1	2	0	1	1	5
	Academic institutions	2	1	2	0	0	5
	Health care services	1	3	0	0	1	5
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	1	1	2	0	1	5
	Health insurance companies	1	1	2	0	1	5
	Non-governmental organisations (NGOs)	1	2	1	0	1	5
	Patient organisations	1	2	1	0	1	5
	General population	1	1	1	0	2	5
→ 3. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	4
	Ministry of Finance	–	–	–	–	–	0
	Other government branches ³	–	–	–	–	–	1
4. Methods for criteria development in prioritisation of health information: <i>Different methods are applied to develop criteria for the prioritisation of health information for national health reporting. From the point of view of your country, please rank the following options according to desirability (effectiveness or benefits).</i>	Expert meetings (face-to-face)	5	0	1	0	0	6
	Expert consultation (e-mail)	1	3	2	0	0	6
	Mixed meetings (researchers, policy makers, etc.)	6	0	0	0	0	6
	Web-based public consultation	0	4	1	0	1	6
	Surveys	3	2	0	0	1	6
	Data analyses	3	1	1	0	1	6
	Literature / document review	4	2	0	0	0	6
	Use of list of criteria	4	2	0	0	0	6
5. Frameworks to guide prioritisation of health information: <i>From the point of view of your country, which frameworks should guide</i>	National health targets	6	0	0	0	0	6
	National health strategies	6	0	0	0	0	6
	Global burden of disease studies	1	5	0	0	0	6
	National burden of disease studies	3	3	0	0	0	6
	Sustainable Development Goals	4	2	0	0	0	6

³ Free text answer: In the spirit of health in all policies (n=1)

Desirability		Very desirable	Desirable	Undesirable	Very undesirable	No judgement	Total
		n	n	n	n	n	n
<i>prioritisation of Health Information for national health reporting? Please rank the following options according to desirability (effectiveness or benefits).</i>	WHO Action Plans	0	6	0	0	0	6
	International Regulations / European Regulations (e.g. Framework Convention on Tobacco Control; European chemical Regulation REACH for exposure burden from environmental substances)	1	5	0	0	0	6
	International / European indicator frameworks (e.g. ECHI, OECD indicators)	4	2	0	0	0	6
6. Good practices in prioritisation of health information: <i>Some countries strive to develop, or have already developed, sets of national good practices in Health Information prioritisation for national health reporting. From the point of view of your country, please rank the following approaches according to desirability (effectiveness or benefits).</i>	Implement a national health information strategy	4	1	0	0	0	5
	Implement national health targets	3	2	0	0	0	5
	Implement a national legal act on health information (covering e.g. data standards, health information systems, e-health, infrastructure)	3	1	1	0	0	5
	Set up a national catalogue on health information (including e.g. organisation, processes and standards around health care and health indicators)	3	2	0	0	0	5
	Develop guidelines at ministerial level (covering e.g. prevention, diagnostics and therapy)	1	4	0	0	0	5
	Develop guidelines at intersectoral / institutional level for health information and / or health reporting	2	3	0	0	0	5
	Develop topic/disease-specific good practices for health information and indicator development	2	3	0	0	0	5
	Scale up topic/disease-specific good practices for health information and indicator development	3	2	0	0	0	5
	Develop data quality frameworks	2	3	0	0	0	5
	Establish 'unique health identifiers'	2	2	0	0	1	5
7.1. Promotion of good practices at EU level: <i>In your view, what processes can promote good practices in health information prioritisation at EU level (e.g. for European surveys)? Please rank the following options according to desirability (effectiveness or benefits).</i>	Cooperate at the level of supranational organisations (EU, OECD, WHO) to develop joint health information methodologies and good practices	4	1	0	0	0	5
7.2. Promotion of good practices at national level: <i>In your view, what processes can promote good practices in health information prioritisation at national level across EU and associated countries? Please rank the following options according to desirability (effectiveness or benefits).</i>	Implement an EU-wide guidance on a minimum indicator set, data transparency, access to data, standards for health reporting	4	1	0	0	0	5
	Engage in structures peer-to-peer processes, e.g. twinning	1	4	0	0	0	5
	Develop, pilot and evaluate good practices at national level	4	2	0	0	0	6
	Establish a network for knowledge exchange, preferably a sustainable and coordinating initiative	5	0	0	0	0	5
	Implement exchange of experts at national and European level	5	0	0	0	0	5
	Promote the development of national health targets	3	2	0	0	0	5
	Learn from regional networks exchanging good practices	3	2	0	0	0	5

Feasibility		Definitely feasible	Possibly feasible	Possibly unfeasible	Definitely unfeasible	No judgement	Total
		n	n	n	n	n	n
1. Approaches to prioritisation of health information: <i>Different approaches are taken at national level to prioritise health information for national health reporting. From the perspective of your country, please rank the following options according to feasibility (practicality).</i>	Formal, top-down approach; e.g. government sets priorities	3	3	0	0	0	6
	Formal, horizontal, centralised approach; e.g. stakeholders and experts develop priorities	2	4	0	0	0	6
	Formal, decentralised approach; e.g. data producers develop individual priorities	1	2	3	0	0	6
	Informal, decentralised approach; e.g. priorities are developed on an ad-hoc basis	1	2	2	0	1	6
	External influence approach; e.g. media guide prioritisation of health information	1	2	1	2	0	6
2.1. Stakeholder involvement in prioritisation of health information: <i>Health information is often developed by or in cooperation with a variety of stakeholders. From the point of view of your country, which stakeholders should be involved in prioritising Health Information for national health reporting? Please rank the following options according to feasibility (practicality).</i>	National government	3	3	0	0	0	6
	Regional government, including health authorities in (autonomous) regions	0	6	0	0	0	6
	National Public Health institutions	5	1	0	0	0	6
	Data collecting institutes	3	2	1	0	0	6
	Academic institutions	2	3	1	0	0	6
	Health care services	1	4	1	0	0	6
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	2	3	1	0	0	6
	Health insurance companies	2	2	2	0	0	6
	Non-governmental organisations (NGOs)	2	3	1	0	0	6
	Patient organisations	3	2	1	0	0	6
	General population	2	4	0	0	0	6
→ 2.1. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	6
	Ministry of Finance	–	–	–	–	–	0
	Other government branches ⁴	–	–	–	–	–	2
2.2. Coordination of stakeholder involvement <i>Stakeholder involvement may be coordinated by a variety of actors. From the point of view of your country, which actor, or actors, should coordinate stakeholder involvement? Please rank the following options according to feasibility (practicality).</i>	National government	3	3	0	0	0	6
	National Public Health institutions	4	2	0	0	0	6
	Data collecting institutes	1	4	0	1	0	6
	Academic institutions	1	4	0	1	0	6
	Health care services	1	1	2	2	0	6
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	1	2	3	0	0	6
	Health insurance companies	0	2	3	3	1	6
	Non-governmental organisations (NGOs)	0	3	1	2	0	6
	Patient organisations	0	2	2	3	0	6
General population	0	2	0	4	0	6	

⁴ Free text answers: In the spirit of Health in all policies, all ministries that have a significant influence on shaping the health-related living conditions of the population should be included (n=1); no specification (n=1)

Feasibility		Definitely feasible	Possibly feasible	Possibly unfeasible	Definitely unfeasible	No judgement	Total
		n	n	n	n	n	n
→ 2.2. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	6
	Ministry of Finance	–	–	–	–	–	0
	Other government branches	–	–	–	–	–	0
3. Criteria development in prioritisation of health information: <i>From the point of view of your country, who should be involved in developing criteria for prioritising Health Information for national health reporting? Please rank the following options according to feasibility (practicality).</i>	National government	2	2	1	0	0	5
	Regional government, including health authorities in (autonomous) regions	0	5	0	0	0	5
	National Public Health institutions	4	1	0	0	0	5
	National Statistical offices	0	4	0	0	0	4
	Data collecting institutes	0	4	1	0	0	5
	Academic institutions	0	3	2	0	0	5
	Health care services	0	2	2	1	0	5
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	0	3	2	0	0	5
	Health insurance companies	0	2	3	0	0	5
	Non-governmental organisations (NGOs)	0	1	3	1	0	5
	Patient organisations	0	3	2	1	0	6
	General population	0	1	3	1	0	5
→ 3. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	4
	Ministry of Finance	–	–	–	–	–	0
	Other government branches ⁵	–	–	–	–	–	1
4. Methods for criteria development in prioritisation of health information: <i>Different methods are applied to develop criteria for the prioritisation of health information for national health reporting. From the point of view of your country, please rank the following options according to feasibility (practicality).</i>	Expert meetings (face-to-face)	4	2	0	0	0	6
	Expert consultation (e-mail)	5	1	0	0	0	6
	Mixed meetings (researchers, policy makers, etc.)	3	2	1	0	0	6
	Web-based public consultation	3	2	1	0	0	6
	Surveys	3	3	0	0	0	6
	Data analyses	2	3	0	0	1	6
	Literature / document review	4	2	0	0	0	6
	Use of list of criteria	4	2	0	0	0	6
5. Frameworks to guide prioritisation of health information: <i>From the point of view of your country, which frameworks should guide prioritisation of Health Information for national</i>	National health targets	4	2	0	0	0	6
	National health strategies	4	2	0	0	0	6
	Global burden of disease studies	1	4	1	0	0	6
	National burden of disease studies	1	5	0	0	0	6
	Sustainable Development Goals	2	4	0	0	0	6
	WHO Action Plans	2	4	0	0	0	6

⁵ Free text answer: In the spirit of Health in all policies (n=1)

Feasibility		Definitely feasible	Possibly feasible	Possibly unfeasible	Definitely unfeasible	No judgement	Total
		n	n	n	n	n	n
<i>health reporting? Please rank the following options according to feasibility (practicality).</i>	International Regulations / European Regulations (e.g. Framework Convention on Tobacco Control; European chemical Regulation REACH for exposure burden from environmental substances)	1	5	0	0	0	6
	International / European indicator frameworks (e.g. ECHI, OECD indicators)	4	2	0	0	0	6
6. Good practices in prioritisation of health information: <i>Some countries strive to develop, or have already developed, sets of national good practices in Health Information prioritisation for national health reporting. From the point of view of your country, please rank the following approaches according to feasibility (practicality).</i>	Implement a national health information strategy	3	2	0	0	0	5
	Implement national health targets	5	0	0	0	0	5
	Implement a national legal act on health information (covering e.g. data standards, health information systems, e-health, infrastructure)	2	2	1	0	0	5
	Set up a national catalogue on health information (including e.g. organisation, processes and standards around health care and health indicators)	1	2	2	0	0	5
	Develop guidelines at ministerial level (covering e.g. prevention, diagnostics and therapy)	1	2	2	0	0	5
	Develop guidelines at intersectoral / institutional level for health information and / or health reporting	2	2	1	0	0	5
	Develop topic/disease-specific good practices for health information and indicator development	2	3	0	0	0	5
	Scale up topic/disease-specific good practices for health information and indicator development	2	3	0	0	0	5
	Develop data quality frameworks	3	2	0	0	0	5
	Establish 'unique health identifiers'	2	1	1	0	1	5
7.1. Promotion of good practices at EU level: <i>In your view, what processes can promote good practices in health information prioritisation at EU level (e.g. for European surveys)? Please rank the following options according to feasibility (practicality).</i>	Cooperate at the level of supranational organisations (EU, OECD, WHO) to develop joint health information methodologies and good practices	2	3	0	0	0	5
7.2. Promotion of good practices at national level: <i>In your view, what processes can promote good practices in health information prioritisation at national level across EU and associated countries? Please rank the following options according to feasibility (practicality).</i>	Implement an EU-wide guidance on a minimum indicator set, data transparency, access to data, standards for health reporting	2	2	1	0	0	5
	Engage in structures peer-to-peer processes, e.g. twinning	1	3	1	0	0	5
	Develop, pilot and evaluate good practices at national level	2	2	1	0	0	5
	Establish a network for knowledge exchange, preferably a sustainable and coordinating initiative	3	2	0	0	0	5
	Implement exchange of experts at national and European level	4	1	0	0	0	5
	Promote the development of national health targets	2	3	0	0	0	5
	Learn from regional networks exchanging good practices	2	2	1	0	0	5

Importance		Very important	Important	Slightly important	Unimportant	No judgement	Total
		n	n	n	n	n	n
1. Approaches to prioritisation of health information: <i>Different approaches are taken at national level to prioritise health information for national health reporting. From the perspective of your country, please rank the following options according to importance (priority or relevance).</i>	Formal, top-down approach; e.g. government sets priorities	1	4	1	0	0	6
	Formal, horizontal, centralised approach; e.g. stakeholders and experts develop priorities	4	2	0	0	0	6
	Formal, decentralised approach; e.g. data producers develop individual priorities	0	3	3	0	0	6
	Informal, decentralised approach; e.g. priorities are developed on an ad-hoc basis	0	1	4	1	0	6
	External influence approach; e.g. media guide prioritisation of health information	1	1	3	1	0	6
2.1. Stakeholder involvement in prioritisation of health information: <i>Health information is often developed by or in cooperation with a variety of stakeholders. From the point of view of your country, which stakeholders should be involved in prioritising health information for national health reporting? Please rank the following options according to importance (priority or relevance).</i>	National government	2	4	0	0	0	6
	Regional government, including health authorities in (autonomous) regions	1	5	0	0	0	6
	National Public Health institutions	5	1	0	0	0	6
	Data collecting institutes	1	4	1	0	0	6
	Academic institutions	1	3	1	1	0	6
	Health care services	2	2	1	1	0	6
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	2	3	1	0	0	6
	Health insurance companies	1	1	3	0	1	6
	Non-governmental organisations (NGOs)	1	3	1	1	0	6
	Patient organisations	1	5	0	0	0	6
	General population	1	3	2	0	0	6
→ 2.1. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	6
	Ministry of Finance	–	–	–	–	–	0
	Other government branches ⁶	–	–	–	–	–	2
2.2. Coordination of stakeholder involvement <i>Stakeholder involvement may be coordinated by a variety of actors. From the point of view of your country, which actor, or actors, should coordinate stakeholder involvement? Please rank the following options according to importance (priority or relevance).</i>	National government	1	4	1	0	0	6
	National Public Health institutions	5	1	0	0	0	6
	Data collecting institutes	1	3	1	1	0	6
	Academic institutions	1	3	1	1	0	6
	Health care services	1	3	2	0	0	6
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	1	2	3	0	0	6
	Health insurance companies	0	1	3	2	0	6
	Non-governmental organisations (NGOs)	1	1	2	2	0	6
	Patient organisations	1	2	1	2	0	6
	General population	1	1	1	3	0	6

⁶ Free text answers: In the spirit of Health in all policies, all ministries that have a significant influence on shaping the health-related living conditions of the population should be included (n=1); no specification (n=1)

Importance		Very important	Important	Slightly important	Unimportant	No judgement	Total
		n	n	n	n	n	n
→ 2.2. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	5
	Ministry of Finance	–	–	–	–	–	0
	Other government branches	–	–	–	–	–	0
3. Criteria development in prioritisation of health information: <i>From the point of view of your country, who should be involved in developing criteria for prioritising health information for national health reporting? Please rank the following options according to importance (priority or relevance).</i>	National government	3	1	0	0	1	5
	Regional government, including health authorities in (autonomous) regions	1	3	0	0	1	5
	National Public Health institutions	4	1	0	0	0	5
	National Statistical offices	0	3	1	0	1	5
	Data collecting institutes	0	1	3	1	0	5
	Academic institutions	1	1	2	1	0	5
	Health care services	0	2	2	0	1	5
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	1	1	3	0	0	5
	Health insurance companies	0	2	2	0	1	5
	Non-governmental organisations (NGOs)	0	1	2	1	1	5
	Patient organisations	0	2	1	1	1	5
General population	0	1	2	0	2	5	
→3. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	4
	Ministry of Finance	–	–	–	–	–	0
	Other government branches ⁷	–	–	–	–	–	1
4. Methods for criteria development in prioritisation of health information: <i>Different methods are applied to develop criteria for the prioritisation of health information for national health reporting. From the point of view of your country, please rank the following options according to importance (priority or relevance).</i>	Expert meetings (face-to-face)	4	1	1	0	0	6
	Expert consultation (e-mail)	1	4	1	0	0	6
	Mixed meetings (researchers, policy makers, etc.)	5	1	0	0	0	6
	Web-based public consultation	0	4	1	0	1	6
	Surveys	1	3	1	0	1	6
	Data analyses	3	1	1	0	1	6
	Literature / document review	4	2	0	0	0	6
	Use of list of criteria	4	2	0	0	0	6
5. Frameworks to guide prioritisation of health information: <i>From the point of view of your country, which frameworks should guide prioritisation of health information for national</i>	National health targets	5	1	0	0	0	6
	National health strategies	4	2	0	0	0	6
	Global burden of disease studies	2	3	1	0	0	6
	National burden of disease studies	2	4	0	0	0	6
	Sustainable Development Goals	4	2	0	0	0	6
	WHO Action Plans	1	5	0	0	0	6

⁷ Free text answer: In the spirit of health in all policies (n=1)

Importance		Very important	Important	Slightly important	Unimportant	No judgement	Total
		n	n	n	n	n	n
<i>health reporting? Please rank the following options according to importance (priority or relevance).</i>	International Regulations / European Regulations (e.g. Framework Convention on Tobacco Control; European chemical Regulation REACH for exposure burden from environmental substances)	1	5	0	0	0	6
	International / European indicator frameworks (e.g. ECHI, OECD indicators)	4	2	0	0	0	6
6. Good practices in prioritisation of health information: <i>Some countries strive to develop, or have already developed, sets of national good practices in health information prioritisation for national health reporting. From the point of view of your country, please rank the following approaches according to importance (priority or relevance).</i>	Implement a national health information strategy	4	1	0	0	0	5
	Implement national health targets	4	1	0	0	0	5
	Implement a national legal act on health information (covering e.g. data standards, health information systems, e-health, infrastructure)	3	2	1	0	0	6
	Set up a national catalogue on health information (including e.g. organisation, processes and standards around health care and health indicators)	2	3	0	0	0	5
	Develop guidelines at ministerial level (covering e.g. prevention, diagnostics and therapy)	1	4	0	0	0	5
	Develop guidelines at intersectoral / institutional level for health information and / or health reporting	3	2	0	0	0	5
	Develop topic/disease-specific good practices for health information and indicator development	1	4	0	0	0	5
	Scale up topic/disease-specific good practices for health information and indicator development	2	3	0	0	0	5
	Develop data quality frameworks	3	2	0	0	0	5
	Establish 'unique health identifiers'	3	0	1	0	1	5
7.1. Promotion of good practices at EU level: <i>In your view, what processes can promote good practices in health information prioritisation at EU level (e.g. for European surveys)? Please rank the following options according to importance (priority or relevance).</i>	Cooperate at the level of supranational organisations (EU, OECD, WHO) to develop joint health information methodologies and good practices	3	2	0	0	0	5
7.2. Promotion of good practices at national level: <i>In your view, what processes can promote good practices in health information prioritisation at national level across EU and associated countries? Please rank the following options according to importance (priority or relevance).</i>	Implement an EU-wide guidance on a minimum indicator set, data transparency, access to data, standards for health reporting	1	3	1	0	0	5
	Engage in structures peer-to-peer processes, e.g. twinning	3	1	1	0	0	5
	Develop, pilot and evaluate good practices at national level	4	1	0	0	0	5
	Establish a network for knowledge exchange, preferably a sustainable and coordinating initiative	5	0	0	0	0	5
	Implement exchange of experts at national and European level	3	1	1	0	0	5
	Promote the development of national health targets	4	0	1	0	0	5
	Learn from regional networks exchanging good practices	3	2	0	0	0	5

Confidence		Certain	Reliable	Risky	Unreliable	No judgement	Total
		n	n	n	n	n	n
1. Approaches to prioritisation of health information: <i>Different approaches are taken at national level to prioritise health information for national health reporting. From the perspective of your country, please rank the following options according to confidence (in validity of argument or premise).</i>	Formal, top-down approach; e.g. government sets priorities	1	3	2	0	0	6
	Formal, horizontal, centralised approach; e.g. stakeholders and experts develop priorities	0	6	0	0	0	6
	Formal, decentralised approach; e.g. data producers develop individual priorities	0	2	3	1	0	6
	Informal, decentralised approach; e.g. priorities are developed on an ad-hoc basis	0	1	5	0	0	6
	External influence approach; e.g. media guide prioritisation of health information	0	1	2	3	0	6
2.1. Stakeholder involvement in prioritisation of health information: <i>Health information is often developed by or in cooperation with a variety of stakeholders. From the point of view of your country, which stakeholders should be involved in prioritising health information for national health reporting? Please rank the following options according to confidence (in validity of argument or premise).</i>	National government	3	2	1	0	0	6
	Regional government, including health authorities in (autonomous) regions	2	3	1	0	0	6
	National Public Health institutions	5	1	0	0	0	6
	Data collecting institutes	3	2	1	0	0	6
	Academic institutions	1	4	1	0	0	6
	Health care services	2	3	1	0	0	6
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	3	2	1	0	0	6
	Health insurance companies	1	1	3	1	0	6
	Non-governmental organisations (NGOs)	0	2	4	0	0	6
	Patient organisations	0	3	3	0	0	6
	General population	0	1	4	0	1	6
→ 2.1. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	5
	Ministry of Finance	–	–	–	–	–	0
	Other government branches ⁸	–	–	–	–	–	1
2.2. Coordination of stakeholder involvement <i>Stakeholder involvement may be coordinated by a variety of actors. From the point of view of your country, which actor, or actors, should coordinate stakeholder involvement? Please rank the following options according to confidence (in validity of argument or premise).</i>	National government	2	4	0	0	0	6
	National Public Health institutions	5	1	0	0	0	6
	Data collecting institutes	2	2	2	0	0	6
	Academic institutions	2	1	3	0	0	6
	Health care services	1	3	1	1	0	6
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	1	2	2	0	1	6
	Health insurance companies	0	3	1	2	0	6
	Non-governmental organisations (NGOs)	0	2	3	1	0	6
	Patient organisations	0	2	3	1	0	6
	General population	0	1	2	2	1	6

⁸ Free text answer: In the spirit of Health in all policies, all ministries that have a significant influence on shaping the health-related living conditions of the population should be included (n=1)

Confidence		Certain	Reliable	Risky	Unreliable	No judgement	Total
		n	n	n	n	n	n
→ 2.2. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	6
	Ministry of Finance	–	–	–	–	–	0
	Other government branches	–	–	–	–	–	0
3. Criteria development in prioritisation of health information: <i>From the point of view of your country, who should be involved in developing criteria for prioritising health information for national health reporting? Please rank the following options according to confidence (in validity of argument or premise).</i>	National government	1	3	1	0	0	5
	Regional government, including health authorities in (autonomous) regions	0	4	1	0	0	5
	National Public Health institutions	4	1	0	0	0	5
	National Statistical offices	1	3	1	0	0	5
	Data collecting institutes	1	2	2	0	0	5
	Academic institutions	2	1	2	0	0	5
	Health care services	0	3	2	0	0	5
	Individual experts and expert groups (e.g. for specific diseases or activities, such as health promotion, infectious disease surveillance or vaccination)	1	2	2	0	0	5
	Health insurance companies	0	2	3	0	0	5
	Non-governmental organisations (NGOs)	0	1	4	0	0	5
	Patient organisations	0	1	4	0	0	5
	General population	0	1	3	0	1	5
→ 3. Filter question: <i>You have selected National government, please specify your answer.</i>	Ministry of Health	–	–	–	–	–	4
	Ministry of Finance	–	–	–	–	–	0
	Other government branches ⁹	–	–	–	–	–	1
4. Methods for criteria development in prioritisation of health information: <i>Different methods are applied to develop criteria for the prioritisation of health information for national health reporting. From the point of view of your country, please rank the following options according to confidence (in validity of argument or premise).</i>	Expert meetings (face-to-face)	3	2	1	0	0	6
	Expert consultation (e-mail)	1	3	2	0	0	6
	Mixed meetings (researchers, policy makers, etc.)	3	3	0	0	0	6
	Web-based public consultation	0	2	3	0	1	6
	Surveys	0	4	1	0	1	6
	Data analyses	2	3	0	0	1	6
	Literature / document review	1	5	0	0	0	6
	Use of list of criteria	2	3	1	0	0	6
5. Frameworks to guide prioritisation of health information: <i>From the point of view of your country, which frameworks should guide prioritisation of health information for national</i>	National health targets	3	3	0	0	0	6
	National health strategies	2	4	0	0	0	6
	Global burden of disease studies	1	5	0	0	0	6
	National burden of disease studies	1	5	0	0	0	6
	Sustainable Development Goals	1	5	0	0	0	6
	WHO Action Plans	1	5	0	0	0	6

⁹ Free text answer: In the spirit of health in all policies (n=1)

Confidence		Certain	Reliable	Risky	Unreliable	No judgement	Total
		n	n	n	n	n	n
<i>health reporting? Please rank the following options according to confidence (in validity of argument or premise).</i>	International Regulations / European Regulations (e.g. Framework Convention on Tobacco Control; European chemical Regulation REACH for exposure burden from environmental substances)	1	4	1	0	0	6
	International / European indicator frameworks (e.g. ECHI, OECD indicators)	2	4	0	0	0	6
6. Good practices in prioritisation of health information: <i>Some countries strive to develop, or have already developed, sets of national good practices in health information prioritisation for national health reporting. From the point of view of your country, please rank the following approaches according to confidence (in validity of argument or premise).</i>	Implement a national health information strategy	3	2	0	0	0	5
	Implement national health targets	2	3	0	0	0	5
	Implement a national legal act on health information (covering e.g. data standards, health information systems, e-health, infrastructure)	3	2	0	0	0	5
	Set up a national catalogue on health information (including e.g. organisation, processes and standards around health care and health indicators)	1	4	0	0	0	5
	Develop guidelines at ministerial level (covering e.g. prevention, diagnostics and therapy)	1	4	0	0	0	5
	Develop guidelines at intersectoral / institutional level for health information and / or health reporting	1	3	1	0	0	5
	Develop topic/disease-specific good practices for health information and indicator development	1	4	0	0	0	5
	Scale up topic/disease-specific good practices for health information and indicator development	1	3	1	0	0	5
	Develop data quality frameworks	1	4	0	0	0	5
	Establish 'unique health identifiers'	2	1	1	0	1	5
7.1. Promotion of good practices at EU level: <i>In your view, what processes can promote good practices in health information prioritisation at EU level (e.g. for European surveys)? Please rank the following options according to confidence (in validity of argument or premise).</i>	Cooperate at the level of supranational organisations (EU, OECD, WHO) to develop joint health information methodologies and good practices	1	4	0	0	0	5
7.2. Promotion of good practices at national level: <i>In your view, what processes can promote good practices in health information prioritisation at national level across EU and associated countries? Please rank the following options according to confidence (in validity of argument or premise).</i>	Implement an EU-wide guidance on a minimum indicator set, data transparency, access to data, standards for health reporting	1	3	1	0	0	5
	Engage in structures peer-to-peer processes, e.g. twinning	1	2	2	0	0	5
	Develop, pilot and evaluate good practices at national level	1	4	0	0	0	5
	Establish a network for knowledge exchange, preferably a sustainable and coordinating initiative	0	5	0	0	0	5
	Implement exchange of experts at national and European level	0	5	0	0	0	5
	Promote the development of national health targets	1	3	1	0	0	5
	Learn from regional networks exchanging good practices	1	3	1	0	0	5

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