Author’s response to reviews

Title: A data infrastructure for the assessment of health care performance: lessons from the BRIDGE-Health project

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Author’s response to reviews:

Dear Reviewer,

Thank you for your constructive review. Your valuable comments have definitively contributed to improve our manuscript. Please, see below our responses [in-line] with your comments, in a case-by-case basis. Some extra English copy-editing has been carried out as well

Reviewer’s comments and replies:

1. A good overview of some major efforts in international comparative HSPA research with a focus on data related issues and requirements for the future.

[Thank you for your kind appreciation]

2. Although the importance of investigating the variability of Healthcare outcomes among different settings is recognized, the paper could do with some more indications of the specific importance over the international dimension of such comparisons over, for instance, performance comparisons between hospitals in one region.

[Indeed, the added value of EwB is the international dimension and we (inadequately) took it for granted. In accordance with the reviewer’s suggestion we have redrafted the paragraphs in the Abstract and Background sections to highlight and enhance this perspective. As follows:

There are some countrywide examples where national health institutions have implemented actions meant to use health information systems in the evaluation of health systems performance. Although less frequent, there are also some pre-eminent international efforts on cross-country comparisons. Notably, the OECD is regularly producing the Health at a Glance report or numerous outlets from its Healthcare Quality Indicators project, and, the European Commission has set up an expert group on health systems performance assessment (HSPA) whose agenda is led for the exchange of HSPA experiences, the definition of HSPA priority areas and the support]
to national policy-makers on HSPA methods. Lastly, different EU research programs have fostered the development of research initiatives aiming the cross-country analysis of health systems performance. [An extensive review of those research projects can be found at http://www.euroreach.net/compendium]. A commonality between these initiatives is the use (reuse) of routinely collected data, in particular, administrative data.

One of those projects has been ECHO (European Collaboration of Healthcare Optimization) an international effort to access and link administrative health data sources from several European countries with a view to set the basis for cross-country health systems performance assessment. ECHO accessed and reused individual-level data from hospital admissions and, demographic, socioeconomic and supply information to analyse and report on a number of health system performance (HSP) dimensions (e.g., utilisation of low-value procedures, equity of access to effective care, or quality and efficiency), at meaningful levels of analysis (either hospitals or geographic healthcare areas).[quote]. (See more details at www.echo-health.eu). Later on, integrated within the context of the BRIDGE-Health project (www.bridge-health.eu), ECHO methods and achievements have been revisited with the aim to contribute to the design and development of a sustainable European infrastructure on public health research and monitoring.]

3. The storyline is interesting but rather elaborate on the one hand, but logical and fluent on the other. However, at a certain moment (P7, 29-30) the text says: ....the case study will use......At this point a reader gets the impression that he or she is reading a research proposal in stead of an essay on research outcomes. This may need some rewriting or clarification.

[Your remark is pertinent as in the section ‘Challenges on building a health information system based on routine health data’ we had given singularity and pre-eminence to the empirical case study on AMI mortality when, in fact, there are other examples to illustrate the arguments that were not highlighted in the description of the study aims, misleading to the readers. In accordance, we have taken off the last clause (page 4, lines 19-22), and redraft the corresponding paragraph in page 7, lines 30-31, as follows:

[…] A concise example on in-hospital case-fatality rates in the admission for an acute myocardial infarction (AMI-IM) is provided to have a hint on how to systematically analyse information flaws in the dataset. For that purpose, data from Slovenia and Spain, a total of 65 million episodes (5 million a year in Spain and half a million a year in Slovenia, from 2002 to 2014) have been analysed and discussed hereinafter. […]

4. As the research and data addressed in this paper involved mainly (only?) hospital data some reference should be made, e.g. in the discussion (and in the introduction as well) that the outcomes and conclusions of this research only cover and refer to a theoretically small part of a full European health information system. A full system will need to cover all Healthcare settings as well as information on health status, determinants of health and contextual information involving data from other sources, i.e. from surveys and/or statistical sources (demographic and mortality data, economic Healthcare data), which by linking to the data discussed her could further enrich this data, but might also put more and different restraints or prerequisites on the
ideal data models as proposed here. This does not contradict with the conclusions in this paper, but sets a much broader perspective, when talking about health information systems.

[Although the EwB data model includes both hospital data and contextual information covering demographic (i.e., socioeconomic data of the regions, health care areas, etc.) and hospital supply data (i.e., infrastructure and economic data on the hospital providers) further enriching the information on the hospitalization episodes [see page ‘Background’ page 3, lines 21-22], we agree that a ‘full system’ will need to cover all healthcare settings as well as information on health (i.e., electronic health records, health status, etc.), therefore we reflected on that necessity by concluding that ‘it might be recommendable a different type of logic data model (i.e., to facilitate the development of multi-cohort multi-intervention studies)” [page 11]. The MCD could potentially be expanded depending on the scope of the HSPA analysis to cover any health care setting, as well as other information on health from other data sources.

Nevertheless, to reflect more specifically this point we have added the following paragraph as part of the discussion section (page 10, lines 7 to 12), as follows:

EwB is confined though to the secondary use of hospital administrative data (enriched with some extra administrative data sources) aimed at specifically analysing health care performance, which may not be the only type of data sources (nor the only aim) in an eventual European Research Infrastructure. Nevertheless, the challenges addressed along this paper are not specific to hospital data, so should be quite the same for any other data source]

5. Another issue not discussed in much detail is the fact that the perspective of this paper is mainly research oriented, i.e. using data to answer specific complex questions on quality, accessibility and effectiveness of care. A major question remains on how to regularly repeat this type of data collection and analysis in a cost-effective way, that would allow for producing regular indicators for monitoring and quality assessment at the national and regional and possibly institutional (hospital) level. This poses the question of whether our largely different and constantly changing national health care systems in the EU would allow for such enormous repeated data efforts to produce reliable and useful outcomes for policy makers at all these levels.

[The reviewer raises a concern that we also share. However, there are two different issues in there: one, in the data collection side (in-countries effort) and another one, in the central data infrastructure (data processing and analysis efforts). In the former, as the data used in the infrastructure are regularly collected by data authorities and health providers upon normative provisions the effort is just confined to data sharing (i.e., collection should not be a problem while legislation supports the process).

On the latter, the data model and the processes to feed the data infrastructure should be responsive to changes in the health care systems (for example, hospitals splits or mergers, population re-allocation to providers, etc.) or to the coding systems. The EwB logic data model has been designed to enable that process although, logically, data management and data analysis efforts should be put in place. This has been specifically set in page 10, lines 15 to 25.]
In order to address the concern on data collection, a new paragraph has been added in the description of the EwB properties, as follows: As EwB builds on administrative data (i.e., data regularly collected by health or statistic authorities upon the compliance of normative provisions) it benefits of stability over time, irrespective of in-country health care reforms.

6. Who would pay and who would get the benefits? Or will it be enough to have a common language, common standards and procedures and a common conceptual framework and then be able to draw the full fruit of international comparisons, benchmarks for drawing tailor made conclusions for national and regional policy makers? Another question is how to get countries and/or professional groups and institutions (hospitals) to implement the needed additional common standards and operating procedures to be able to release their data timely and in a legally accepted and privacy protected way into central databases. This will not happen unless the actual data providers will see a real benefit for themselves.

[We do guess that the reviewer is not suggesting including any particular comment on this point, as is far beyond the scope of our paper (i.e. the data infrastructure is a mean not an end). On these lines, we much agree that the development of a well thought data infrastructure, even a distributed one (so, under the strict control of data and health authorities), fully respectful with national and European legislation on data protection issues, and sophisticated reporting systems are not sufficient conditions to let decision makers see their benefits (and positive externalities) and prompt them to pay for it. However all those elements are necessary conditions for the other ones to happen].

7. Regionality (NUTS or other levels) is another problem to concern as certain Healthcare types are organised at different levels in different countries where the NUTS-level division is unfortunately not useful. How to solve these types of problems is a question for further research, I think.

[Yes, this is a crucial point as geographic comparisons are highly dependent on how homogeneous are the units of analysis in terms of population size. This problem is concomitant with the need to attribute and report performance at meaningful decision units, as we want the indicators to foster policy action (i.e., NUTS are not necessarily linked to the organization of health care).

Indeed, we addressed this issue (building homogeneous areas with health policy relevance) during the development of the ECHO project (you might want to see Lau C. Thygesen, Cristobal Baixauli-Pérez, Julián Librero-López, Natalia Martínez-Lizaga, Manuel Ridao-López, Enrique Bernal-Delgado, on behalf of the ECHO Consortium; Comparing variation across European countries: building geographical areas to provide sounder estimates, European Journal of Public Health, Volume 25, Issue suppl_1, 1 February 2015, Pages 8–14, https://doi.org/10.1093/eurpub/cku229).
The data model developed in EwB has implemented the prescriptions coming out of this paper. A mention to this hospital-catchment areas has been included in page 5, line 14, and the reference to this paper has been added.]

8. Some of the above issues are in part addressed in P 9 and 10, where important conclusions and discussion issues are listed in a long list. Some of these conclusions may be even more valuable when added to the abstract and the long list of these conclusions may need some structuring in terms of new potential identified and pitfalls still to tackle (or some other logical set of categories).

[As a discursive essay, our aim has not been formally discussing pros and cons of each of the reflections listed out, nor ending up in a set of final conclusions or recommendations. We have just aimed at posing under the heading of ‘Developing HSPA with administrative data in an EU Health Information Infrastructure’ those elements that should play a role in the public discussion -each of those points might be subject of a specific paper. To better frame our intention, we have included an extra paragraph at the beginning of this section as follows:

EwB has developed a central relational data infrastructure that stores administrative data from different data sources from various countries, with a view to carry out health systems performance research and monitoring. Might this data infrastructure be taken as a reference in the context of an eventual EU health information infrastructure? Along the following paragraphs, we reflect on those elements that should be taken into consideration in the public debate on the development of such an infrastructure at EU level.

We have also reworded some of the sentences accordingly and added to the abstract a final clause, as follows The deployment of a distributed infrastructure based on semantic interoperability, where individual data remain in-country and open-access scripts for data management and analysis travel around the hubs composing the infrastructure, might be a sensible way forward.]

9. Some structuring and focusing of messages and conclusions will enhance the readability for less technically schooled readers, who still need to be convinced of the importance is this type of research.

[Thank you for you final remark. We do hope that the new drafting (more explicit and enriched) reads better for people with less technical expertise].