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A User Study to Assess the Situated Social Value of Open Data in Healthcare

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Abstract

In this paper, we propose an original methodology by which to assess the construct of the *situated social value* of open data and we apply it to the healthcare domain in regard to information by which hospitals can be ranked to compare service providers. Our methodology encompasses a questionnaire-based user study and a method by which to rank information items by their perceived social value in situated scenarios. While the social component of the construct is addressed traditionally, the main asset of our contribution is to ground the assessment of information value on a multidimensional space of potential situations where that information can be perceived as valuable, and to inquiry the respondents of the user study about their empathized perceptions in daily life scenarios, which are defined to cover the dimensional space properly. The findings of the user study are reported and the implications on the construct assessment discussed in the aim to enable IS benchmarking and more focused interventions of data quality improvement.

1. Introduction and Motivations

That we are living in times of "big data" is a common place that scholarly research is trying to go beyond to understand what this really means. When a partition of this big amount of data is made available to the Public, the

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"open data" phrase is used, especially when the data regard public institutions. Open data would allow citizens to be informed of how certain organizations perform: this, especially for the publicly funded bodies, means greater transparency towards the taxpayers, but also the pragmatic ability to compare their performances and hence choose their services consequently, especially in regard to welfare, security and healthcare. However, just making data openly available is not enough, if their potential consumers can hardly access, understand, appreciate and exploit the data to fulfill their needs, reach their goals and, in short, add value to their daily life experiences.

Assessing whether open data fulfill this general requirement, which justifies the efforts and expenses they require, is related to assessing their social value. In this paper, we focus on the social value of the information that health institutions share with the citizenship and potential consumers of their services, especially to enable benchmarking, quality comparison and the informed choice of the service provider.

To this respect, we define the social value (of a dataset from which information can be extracted that is deemed valuable by more than one non-professional person) the extent to which such a dataset is perceived important, worthy and useful within a community. As plain and straightforward this definition might be, we are aware of the many pitfalls it conceals. First of all, it is not obvious how to define what a community is: yet, for our aims and scope we will not separate too much from the common sense definition to mean the people living in the catchment area of the healthcare facilities that are mentioned in the dataset. The same holds for the concept of value: in this regard, we purposely adopt a standard meaning that refers to the extent to which a person can leverage data to positively inform (i.e., affect, shape) her thought, knowledge, decision making and, hence, action; in this light, information is equated to a commodity that enables the consumers to satisfy their needs or wants, and its value is related to the extent to which it can be exploited to that aim (in short, the idea of "value-in-use" in the classical political economy connotation [1]). Putting this concept into the social dimension could be facilitated by borrowing the well know intuition of the utilitarian philosopher Jeremy Bentham (1776) and hence by conceiving of the "social value" (of anything) in terms of "the greatest utility for the greatest number" of people.

That said, as natural as the concept of "social value" might look, we want to address three related questions that we find are still fundamentally under-researched so far. Can the social value of a dataset be measured? If so, how can it be measured? Of course, measuring the social value should not be seen as a futile task but rather connected to quality improvement cycles where something must be monitored over time and improvement interventions planned and enacted to see if these are effective and worth the hassle. Thus, as a last matter of concern, we also wonder how the social value of a dataset can be improved, so that the efforts and investments to make data open and publicly available to the general public can return in terms of a greater value for the taxpayers and the institutions that provide it.

In our research, we want to address all of these questions, and in this paper we focus on the former two ones regarding social value assessment. In particular, we propose to assess it by binding it to the use of information in concrete situations of daily life; this is because we speak of *situated social value*, which in the rest of the paper we simply denote as social value. Our focus on situativity is justified by a short digression: as for anything that is abstract enough to be resistant to any endeavor of strict definition, let alone assessment (e.g., happiness, utility), also for "value" two main attitudes can be outlined. On the one hand, an approach that can be traced back to Jeremy Bentham, who claimed such a thing to be "quantifiable, [and] something that both could and should be the subject of measurement, of reckoning, of calculation" [2]; on the other hand, a second approach, which is a refinement of the former, than can be traced back to Bentham's pupil, John Stuart Mill, who claimed that the experience of value by human beings do not only differ on a quantitative scale but also in qualitative ways, and "only those who have experienced [value] of both sorts are competent judges of their relative quality." [3].

2. Method

In the strand of Stuart Mill's intuition, we propose an original methodology to assess the social value of information that encompasses these main phases:
1) dataset search and analysis;
2) information item definition;
3) definition of situated scenarios and questionnaire-based user study;
4) social value assessment of information items and ranking;

5)   social value assessment of datasets (possibly with a composite score).

This paper mainly covers steps 3 and 4. Steps 1 and 2 have been presented in [*blinded*], while step 5 is still under research. Social value assessment is usually done by aggregating the single perceptions of large sets of either actual or potential users/consumers of that information with statistical techniques [4], so that these sets of respondents can be taken as representative of a target population within a specific margin of error. Actual users are usually addressed as soon as they have retained an information, with questions like "Have you found this information useful? Comprehensive? Clear?" and so forth. Single perceptions are then summarized in terms of average scores (e.g., means, medians). On the other hand, potential users can be challenged either with abstract questions on the conceptual value of some class of information, or conversely with questions that refer to daily situations which the respondents could have likely experienced in their life or expect to experience directly sooner or later.

So far, so good. However, user multiplicity by sampling covers the social dimension only, while the value-in-use dimension is usually disregarded. For this reason we chose to adopt the latter approach of inquiring the users in step 3, which we dub "situated" or, more prosaically, "scenario-based". We use the term "situated" to hint at the impossibility to decouple value appraisal from concrete situations of use, as any actual use of information is necessarily bound to a specific situation in which some need emerges and which gives human actions a context where to reach some goal [5]. This calls for a second kind of multiplicity to be considered, that is of situations.

2.1. The definition of situated scenarios

Given the infinity of situations in which any data consumer can be, we consider prototypical cases of relevant situations, exemplified to the respondents in terms of scenarios. We detected four dimensions that the scenarios must exhibit to represent as many potential situations as possible: *criticality, likelihood, urgency* and *connection*. *Criticality* regards the extent to which a situation is serious in regard to either the health need to receive hospital care, the related condition or the health problem: levels could be estimated as a composition of the likelihood of negative outcome (like death and permanent impairment) and normalized treatment costs (on the basis of e.g., the Diagnosis Related Groups – DGR – taxonomy), as well as in a qualitative expert-driven fashion. *Likelihood* regards the probability (estimated, e.g., on a frequentist basis on epidemiological data) of a health condition or of the emergence of the related need. These two latter dimensions could be composed together to represent the meta-dimension of the social impact. *Connection* regards the degree of emotional engagement that the respondent reading the scenario could feel with respect to the health condition: "myself" and offspring being the highest levels of connection, acquaintances and strangers the lowest one, and dears like relatives and close friends the intermediate levels on which to appraise scenarios on this dimension. *Urgency* relates to the need for a fast intervention, and hence for a fast retrieval of the related information to get the intervention done. The idea is that each scenario must exhibit all of the dimensions at different degrees of intensity (four levels could be considered enough as a first approximation) so that the whole set of scenarios covers the dimensions as comprehensively as possible. See Figure 1 for the result of this step in the reference user study: our conjecture here is that combining multiple scenarios that cover all the relevant levels of these dimensions allows for the evaluation of specific information items, both comprehensively and in a relatively affordable manner.

Table 1. The three scenarios each representing a context and the related needs.

Dear's Stroke :: One of your dears is showing symptoms of a sudden stroke. You propose her to call for an ambulance, but she replies that she is not so ill and asks if you could personally take her to the best hospital instead.

Your Back Pain :: You have suffered for a back pain for years. You still suffer for it to the point that doing certain movements is extremely difficult for you. Based on some medical examination you did in the past, the diagnosis of your orthopaedist is slipped disc, and the treatment of choice is surgery to be scheduled soon.

Your Child Fever :: Your 1-year-old daughter is sick and she has got high fever. As it is late night you cannot take her to the paediatrician, so you decide to take her to one of the city hospitals.

Table 2. The information items selected to rank and characterize sets of hospitals.

Q1 – (Ranked list of all of the hospitals) by their reaching time from one's place;
Q2 – (") by no. of admissions for the pathology of interest;
Q3 – (") by percentage of patients that have been discharged without having had any complication;
Q4 – (") by percentage of patients that, within six months since discharge, have not been admitted again to the hospital for the same pathology;
Q5 – ("), grouped by physician, that reports the percentage of patients that have been discharged without complications;
Q6 – ("), grouped by physician, that reports the percentage of patients that, within six months from discharge, have not been admitted again to the hospital for the same pathology;
Q7a – (") by level of satisfaction for the quality of the care treatment perceived by patients treated for the pathology of interest;
Q7b – (") by level of satisfaction for the quality of the care treatment perceived by all the hospitalized patients;
Q8a – (") by level of satisfaction for the quality of the care treatment perceived by patients' relatives and friends for the pathology of interest;
Q8b – (") by level of satisfaction for the quality of the care treatment perceived by all the patients' relatives and friends;
Q9 – (") by average wait time for the pathology of interest (e.g., since the arrival at the emergency department to the ward admission, and since the service reservation to the service provision);

2.2. The conception of the questionnaire-based user study

In step 3, we also developed a questionnaire including the information items defined in step 2 according to the review performed in step 1: these regard place-related matters (Q1), time-related matters (Q9), competence (Q2) and excellence, both in terms of outcome (Q4, Q5, Q6) and satisfaction (Q7a, Q7b, Q8a, Q8b). For the user study presented here, we have selected the items of interest on the basis of a survey of the main open datasets available online in the hospital domain that we carried out following the methodology presented in [*blinded*]. Table 2 reports the long descriptions of the items, each representing a piece of information that is accessible in, or easily extractable from, the analyzed datasets.

In order to find a trade-off between keeping the user questionnaire short and produce a sound proof-of-concept of the situated approach, we conceived only three scenarios, whose characteristics are summarized in Figure 1 and whose integral text is reported in Table 1[†].

We then developed an online multi-page questionnaire that would present only one of these scenarios to each respondent on a random basis. The idea was that, by involving a sufficiently large sample, a good number of respondents would have considered each scenario; consequently, the aggregated value at sample level would be representative of the "case mix" for the typical needs of hospital-related information. In so doing, the larger the potential sample of respondents, the more the scenarios that can be considered, the length of the questionnaire being equal. In presenting the scenario, we asked the respondents to imagine themselves as people involved in it, and even more than that, to identify themselves with one of the *personas* involved therein, and fancy to need to use some piece of information to reach the goal implied in the scenario. After that, each item identified in the phase of item definition (see Table 2) was associated with an ordinal six-value scale of perceived value (from 1, not useful at all, to 6, very useful). In the last page of the questionnaire, we also collected information on gender, age and the frequency by which the respondent had ever looked for hospital-related information or had assessed hospital quality on the basis of the information thus retrieved: this latter item was considered a proxy of the familiarity with the task of assessment.

2.3. User study analysis for the social value assessment and ranking of the information items

In the analysis of the user study results, in step 4 the method requires to focus on three null hypotheses, denoted as

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[†] The reader should notice that we deliberatively avoided to define an urgent scenario where the most natural action would be calling 911, because this would have made the task of information retrieval unlikely.

H_{01}, H_{02}, H_{03} respectively, and to look for significant evidence to reject any of them. In what follows p-value is (by well-known definition) the probability to collect the actually collected values assuming the H_0s as true. Rejecting a null hypothesis will be based on low p-values, that is p-values under the conventional threshold of 5% (p-value<0.05), which is associated with a confidence level of 95%. The three null hypotheses are the following ones:

1) H_{01}: the respondent sample did not express clearly polarized indications with respect to the value attached to the information items proposed in Table 2.
2) H_{02}: there are no significant correlations between the social values of the information items.
3) H_{03}: responses do not show significant differences between strata (i.e. groups) of respondents.

In step 4, also the item rankings are produced. This is done with an original procedure, implemented by a Python script that derives a relative ranking from absolute evaluations, which is reasonable for the ordinal nature of the scale employed, and then generates a collective item ranking according to all of the individual rankings.
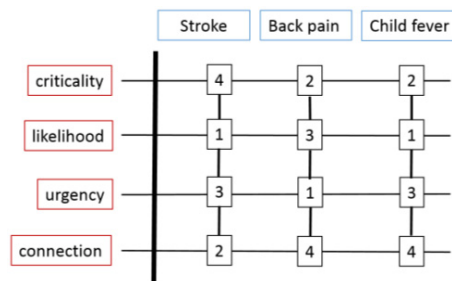

Fig. 1. The situation-oriented dimensions of the three scenarios conceived for the user study. In each column, degrees do not repeat.

3. Results

In step 3, we sent an invitation to fill in the questionnaire to three target populations: personal friends and acquaintances; all of the colleagues of our university department; and the students of two master classes from the same university. The questionnaire was left accessible for three weeks and one reminder was sent after two weeks to recall the invitation. At the end of the survey, we had collected 129 complete questionnaires. For the relevant presence of students with young age and low task familiarity, we weighted the response set by age according to the 2014 census, so that the response distribution was representative of the national population along these dimensions.

To address the hypotheses mentioned above, we performed non-parametric tests with IBM SPSS (v. 21). We adopted non-parametric techniques for two main reasons: first, because responses were to be expressed on ordinal scales where the assumptions of scale continuity and of measurement on equal intervals do not hold; second, because also the assumption of normality had to be rejected (tested with the Kolmogorov-Smirnov test). In what follows, statistical results are reported by adopting the APA style [6].

3.1. Assessing collective value perception

For the first hypothesis, we undertook a binomial test, where conventionally the first proportion relates to negative answers, and the second proportion relates to the positive answers.

Clear positive tendencies have been detected for four items: Q1 (proportions=.38 vs. .62, p = .030) Q2 (proportions=.04 vs. .96, p = .000); Q7a (proportions= .22 vs. .78, p = .000); and Q9 (proportions=.27 vs. .73, p=.000). Conversely, clear negative tendencies were detected for items: Q7b (proportions=.62 vs. .38, p=.033); Q8a (proportions=.73 vs. .27, p=.000) and Q8b (proportions=.80 vs. .20, p=.000). For the other items (Q3-Q6) respondents did not express any clear tendency and we cannot reject H_{01}.

3.2. Correlations between the information items

In regard to H_{02} (inter-item bivariate correlations), we performed a Spearman test and found the following correlations (p-values are all below .000; in what follows we consider only either moderate or strong correlations, that is correlations with the Spearman rho greater than .50).

- Q1 and Q6 are inversely and moderately correlated (r=-.50);
- Q3 is moderately correlated with Q4 (r=.72), Q5 (r=.63), Q6 (r=.53), and Q7a (r=.50);
- Q4 is moderately correlated with Q5 (r=.70) and strongly correlated with Q6 (r=.81);
- Q5 is strongly correlated with Q6 (r=.87);
- Q7a is moderately correlated with Q7b (r=.50);
- Q7b is moderately correlated with Q8a, Q8b and Q9 (r=.53, r=.62 and r=.57, respectively);
- Q8a is very strongly correlated with Q8b (r=.90);
- Q8b is moderately correlated with Q9 (r=.56);

3.3. Differences according to the respondent profile

In regard to H_{03} (inter-strata differences), we performed a Mann-Whitney test on dichotomous strata by gender, by age and by past behaviors in looking for hospital-related information on line, in short by previous experience and familiarity with the scenarios proposed. In regard to gender differences, we found significantly different perceptions for almost half of the items proposed. More specifically, on average, male respondents valued information of item Q1 more than the female ones (U(93)=598, p=.006). On the contrary, on average, females value information higher than males in regard to items Q3, Q4, Q5 and Q6 (namely, U(91)=498, p=.001 for Q3, U(91)=434, p=.000 for Q4, U(91)=364, p=.000 for Q5, U(90)=424, p=.000 for Q6). This is also confirmed by the correlative analysis.

In regard to familiarity, on average the information of item Q2 is considered more important for who has sometime looked for hospital data online (U(91)=636, p=.032). On the other hand, items Q3, Q8a, Q8b, and Q9 are deemed as more valuable information for who has never looked for hospital data online before (U(90)=590, p=.041 for Q3, U(90)=370, p=.000 for Q8a, U(90)=442 , p=.003 for Q8b, U(90)=522, p=.016 for Q9).

In regard to age, on average item Q2 is considered more valuable for people older than 30 (U(93)=807, p=.019). The correlative analysis suggests that the younger the respondents, the higher the value of Q1 (r=.32, p=.002).

We also performed a Kruskal-Wallis H Test to detect any difference between the different scenarios that we defined to "mix" cases of different criticality and urgency. Indeed, this test showed that for item Q1 there was a statistically significant inter-scenario difference in perceived value, ($\chi^2(2, 94) = 46$, p =.000), with a mean rank of 65.9 for the potential stroke scenario, 23.2 for back pain and 49.4 for the child-fever scenario. The same holds for:

- Q3 ($\chi^2(2, 93 = 27$, p =.000), with a mean rank of 33.8 for the potential stroke scenario, 65.6 for back pain and 41.5 for child-fever scenario.
- Q4 ($\chi^2(2, 92) = 41$, p =.000), with a mean rank of 33 for the potential stroke scenario, 70.5 for back pain and 35.1 for child-fever scenario.
- Q5 ($\chi^2(2, 92) = 32$, p =.000), with a mean rank of 30.6 for the potential stroke scenario, 65.8 for back pain and 47.4 for child-fever scenario.
- Q6 ($\chi^2(2, 90) = 38$, p =.000), with a mean rank of 30.7 for the potential stroke scenario, 67.6 for back pain and 38.3 for child-fever scenario.
- Q7a ($\chi^2(2, 90) = 11$, p =.004), with a mean rank of 36.1 for the potential stroke scenario, 56.1 for back pain and 46.4 for child-fever scenario.
- Q7b ($\chi^2(2, 90) = 7$, p =.031), with a mean rank of 37.4 for the potential stroke scenario, 49.9 for back pain and 53.8 for child-fever scenario.

3.4. The item ranking by social value

On the basis of the ordinal responses collected for each item, in step 4 we also produced two rankings with the method outlined in the Method Section: ranking results are reported in Table 3. Our method provides two item rankings: see columns "Rank" and "Level of Social Value" in Table 3. The former ranking is a fine-grained one,

where each item is associated with a position; the latter one is a level-based ranking, which is constructed by means of a test on the null hypothesis that all items are at the same level of social value. The former ranking is intended to be of easy comprehensibility and great conciseness, and to result informative without the need of lengthy explanations; however, its precision is sensitive to sampling error, i.e., different samples taken from the reference population could yield different rankings, although slightly so (cf. e.g., Q7a in Table 3). In the latter ranking conversely, each item is associated with a category (or level) of value, but more items can be associated with the same level to mean that it is hard (or useless) to distinguish between them in terms of value and relevance. For the "Level of Social Value" we distinguish 2 categories and 4 levels: two *value levels,* with which we can associate items with statistical significance (that is being confident that association is stronger than any sampling error); and two *buffer levels,* where we put items when no significance was reached (i.e., we cannot exclude that different surveys would yield different results). Namely: "high value" with statistical significance at a conventional confidence level, ("significantly high" in Table 3), high value with no statistical significance ("probably high" in Table 3); low level with no statistical significance ("probably low" in Table 3), "low value" with statistical significance ("significantly low" in Table 3). As we will hint at the end of the paper, rank positions (see column Rank in Table 3) can be used to weight a linear combination of items, so that in step 5 (which we do not cover explicitly), an *overall social value score* can be calculated for a single dataset, on the basis of what information items it allows to extract and on their single value, as a simple weighted summation.

Table 3. Items considered in the user study and summary of the main results.

Information Item	Rank	Level of Social Value	Collective Value Perception	Median Value
Q1 – (ranking) by hospital distance;	4th	Significantly High (*)	Significantly positive	5
Q2 – (") grouped by hospital pathologies;	1st	Significantly High (***)	Significantly positive	6
Q3 – (") by no of complication discharges;	6th	Significantly Low (**)	Not significant	4
Q4 – (") by no of readmissions within 6 months;	8th	Significantly Low (***)	Not significant	4
Q5 – (") by no of complication discharges, by physician;	5th	Significantly Low (**)	Not significant	4
Q6 – (") by no of readmissions, by physician;	7th	Significantly Low (**)	Not significant	4
Q7a – (") by satisfaction of patients by pathology;	3rd	Probably Low	Significantly positive	5
Q7b – (") by satisfaction of all patients;	9th	Significantly Low (***)	Significantly negative	3
Q8a – (") by satisfaction of patients' dears by pathology;	10th	Significantly Low (***)	Significantly negative	3
Q8b – (") by satisfaction of all patients' dears;	11th	Significantly Low (***)	Significantly negative	2
Q9 – (") by average wait time;	2nd	Significantly High (*)	Significantly positive	5

4. Discussion and Conclusions

The statistically significant differences that we found in the perceived social value in regard to 7 items out of 11 according to the different scenarios confirms *empirically* the importance of the concept of fitness for use [7] to evaluate the quality of information (in terms of impact and utility). In particular, we can draw a qualitative relationship between information items and situation-oriented dimensions for two reasons: first, each scenario is characterized by a composition of situation-related dimensions where one or two dimensions are the predominant ones; for instance, criticality and urgency in the stroke scenario, proximity and likelihood in the back pain scenario, urgency and the proximity in the child-fever scenario (see Figure 1). Second, it is possible, by performing a series of test pairs (Mann Whitney and Kruskal Wallis), to understand what scenario (if any) has contributed more to the positive/negative appraisal of the item; for instance, the stroke scenario for location-based ranking, back pain scenario for the rankings related to occurrence of complications, either in the short or mid-long term. This relationship suggests interesting indications that could help make open data fitter to user profiles: for instance womanhood moderately correlates with information items related to complications after recovery, readmission and the items related to who actually provides care (items Q4, Q5 and Q6). Manhood slightly correlates with map-based hospital distance (item Q1). This could mean that women value more about the process of care, while men are more intrigued by map-based decision, which are also those to be taken more frequently in emergencies. This qualitative analysis supports the idea that the social value of information items is not only situated but also mediated by other factors, especially gender-related factors. Furthermore, the detection of 38 statistically significant correlations between single items, out of a potential of 55 (69%), suggests that even in simple scenarios users need to get a

comprehensive picture by composing heterogeneous items to make their decision choices; however, rho scores were never above 90% indicating complementarity rather than redundancy or overlap.

In this paper, we have outlined a methodology to assess the social value of open data, exemplifying it in the domain of healthcare domain. Assessing the social value of the information based on the datasets that an Information System (IS) allows to extract is also a way to assess its impact on a community of potential consumers, and hence a way to prioritize resource consumption on what data to manage and publish. The rankings shown in Table 3 indicate that, by averaging both subjectivity and situativity and, most notably, *irrespective of the sample of respondents involved*, few items are certainly *valuable socially*, perhaps not surprisingly: our finding is that, in order to look for the hospital where to receive healthcare services (in varying situations), people esteem valuable to know: whether the hospital treats the condition of interest (Q2 in Table 3), how far the hospital is from them (Q1 in Table 3); and how long they are supposed to wait to be seen (Q9 in Table 3). This is a clear indication that can inform prioritization of investments for hospitals to make those information items available in their Web sites before any other, perhaps more expensive to extract and manage, and less valued by potential consumers. Furthermore, the priming effect seems to have been negligible [8] because we did not present items in random order but always in the same order to respondents and the last one (Q9) was ranked very high. We focused on steps 3 and 4, which regard the user study by which to collect value perceptions, and the analysis of the results to compose both a relative and an absolute ranking of the value of the information items that the ISs make openly available.

Next work will be devoted in the composition of an overall score at dataset level (and also at IS level), to be obtained through the weighted summation of the single social values for each information item made available. In this paper, the social values have been indicated both in qualitative terms (positive/negative) and quantitatively (in terms of medians), but also other indicators can be extracted from the user study with standard procedures (e.g., means). The weights could be defined either on the basis of the perceived rankings with the formula *(n-k+1)/n* (with *n* number of items considered, *k* the position in the ranking); for instance, in this case Q1 would be weighted the most (e.g., 1), Q8b the least (e.g., 1/11); by considering the social impact (see above); by other measures, or lastly by a combination of these methods. With this assessment, health facilities can understand how to extract from their ISs and make public datasets that maximize perceived social value and hence their reputation within a community. In this line, further research should be addressed on how social value can be improved by means of specific techniques of data visualization, tailored information retrieval and presentation, and how (if) this value correlates with other subjective dimensions of visual representations, like *intuitiveness*, *clarity*, *informativity* and *aesthetic appearance*, just to mention the main ones. This is because we believe any effort of assessment is properly justified if intended to be part and parcel of a comprehensive quality monitoring and improvement program.

Acknowledgements

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