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The art of drawing numbers and stories in the air: epidemiology, information, emotion and action

Rafael Cofiño,¹ Miguel Prieto,¹ Oscar Suárez,¹ Kristen Malecki²

The impulse to paint comes neither from observation nor from the soul (which is probably blind) but from an encounter: the encounter between painter and model: even if the model is a mountain or a shelf of empty medicine bottles

John Berger, The Shape of a Pocket

How do we transmit epidemiological information? How do we transmit the information to guide public health and community health? Do we have stories to be told? How do we tell the stories about health and disease situation in our population? Do we know how to tell stories about 'numbers'? Are we using the same graphic designs as those used 30 years ago? Do we consider presentation of the data as important as collecting the information and analysing it? Is that collected information useful to improve the health of our population?

BRIDGING GAPS BETWEEN EPIDEMIOLOGY AND COMMUNITY HEALTH PROMOTION

Epidemiological information has the power to be transformative and promote action that is both effective and efficient, but these actions are not possible without forging bridges between disciplines and thoughtful collaborations including researchers, practitioners, people and communities. Translating epidemiological findings into meaningful results and action is a challenge because of the miscommunication and lack of a common language between those who are generating the data and those who need this data and information to make decisions. We propose that this translation of epidemiological findings, particularly in a community setting, could benefit from the art of

storytelling and the contribution of new data visualisation approaches.

STORYTELLING MAY PROVIDE AN IMPORTANT FRAMEWORK TO SUPPORT THIS TRANSLATION AND COMMUNITY ACTION

In 2009, the United Nations launched a series of guides called 'Making Data Meaningful'.¹ The first one emphasises the importance of the statistical story: "First and foremost, you need a story to tell. You should think in terms of issues or themes, rather than a description of data. Specifically, you need to find meaning in the statistics. A technical report is not a story, nor is there a story in conducting a survey. A story tells the reader briefly what you found and why it is important to the reader. Focus on how the findings affect people. If readers are able to relate the information to important events in their life, your article becomes a lot more interesting." Something that is so obvious in some pedagogical processes sometimes is forgotten and not employed in the transmission of epidemiological information: it is necessary to relate the information with people's life events.

narrative called The technique 'Storytelling' is currently on the rise. Storytelling uses information about experiences and actions of people and communities, to visualise and capture, beyond the statistics, the meaning embodied within the data.² This process is thought to promote the use of data to create knowledge. This knowledge builds community capacity for generating effective and meaningful change. The foundations of storytelling date back to the early 20th century as a tool developed by American marketing and advertising theorists; since then its applications have been widely adopted by different fields, ranging from the business environment to policy.

This paradigm of storytelling is often counterintuitive for academic minds that are trained to not make up stories and just simply present the evidence without distortion and as exact as possible. This can be a critical point: storytelling can be useful but we should always have an academic perspective avoiding rough data simplifications or manipulations.³

INFORM AND COMMUNICATE: THE ART OF DRAWING NUMBER AND STORIES IN THE AIR

The process of communicating information to help in decision-making is a complex process, although we try to represent it as a linear one. Community-based translational research aims to use evidence to support priority setting, future goals and programme design. Data can support these objectives if they are communicated to stakeholders in a clear way. Data from observational epidemiological studies may not be community or population specific and often tell one part of a larger story. Unfortunately, often times, the different data from these studies are not pulled together in a systematic way that tells a meaningful story.

Thygesen and Sundgren systematise the steps needed to communicate the information: generate data, view them, generate a story and disseminate them to the media (classic and current ones).^{4 5} They insist on some key elements such as supporting policies for open data access, the role of the intermediate agents beyond the statistician or epidemiologist (programmers, designers, communicators) to facilitate data visualisation and dissemination of the information. Elements of data visualisation that help to tell stories are maps or graphic interactive tools that take data and information and provide some spatial context and relevance for the decisionmakers. The final process requires the integration of all of these elements into a story (or a video) that generates knowledge and stirs emotions. Stories can then be used as a foundation to motivate individuals, communities or policymakers into action: either to stop an adverse action or promote future action.

Some experiences, where some of the aforementioned elements are combined, are shown in table 1. Looking at some of these projects—for example, the Better Life Index created and design by Moritz Stefaner *et al*—we should ask ourselves: How much art do their jobs have? What points in common exist between data visualisation and contemporary art? Are they epidemiological projects and data visualisation or pieces of art?

Back from Eyeo Festival in 2011, Gemignani,⁶ member of Juice Analytics, makes a reflection about visualisers work with a great artistic component and others who mainly want the information to be understood. In his opinion, the first, the

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Table 1 Some examples about data visualis

Examples	Link	Visualisation tools	Description
Gapminder	http://www.gapminder.org/	Web interactive graphics, videos and offline interactive graphics	Statistical information about development and achievement of the United Nations Millennium Development Goals
OECD eXplorer	http://stats.oecd.org/ OECDregionalstatistics/#	Web application	This application enables the statistics visualisation of socioeconomic information at national or detailed territorial level
María's story: Health Center is not (the only) center of the health	http://bit.ly/1qCVhQz	Storytelling through web interactive 360° pictures	Narrative visual project showing information about social determinants of health and inequalities in a neighborhood and a primary care health setting
BetterLifeIndex	http://www. oecdbetterlifeindex.org/	Web interactive tools	Showing information about some key factors that contribute to well-being in OECD countries.
London Health Observatory	http://www.lho.org.uk/	Web interactive maps and graphics	Statistics and epidemiological information at territorial level
County Health Rankings	http://www. countyhealthrankings.org/	Web interactive maps and graphics, videos	Benchmarking epidemiological information about health determinants and outcomes in the United States counties
Asturias Health Observatory	http://www.obsaludasturias. com/ http://bit.ly/1oWxJGC	Web interactive maps, smartphone apps and videos	Benchmarking epidemiological data and health promotion/ health assets maps
The 99 وتس <i>يعو</i> ن التس <i>يعة</i> al-tisa'a wa tisaun ¹⁴	http://www.the99.org/	Web, comics books and movies	A comic book featuring a team of superheroes based on Islamic culture and promoting social justice, peace, multicultural education and

OECD, Organisation for Economic Co-operation and Development.

artists, are looking for an emotional 'wow', whereas the latter are looking for a 'aha' moment that implies that the person who is looking at the information learns something that can lead to a change.

Presentation of epidemiological data should invoke a response to public and community health information that is a combination of 'wow' and 'aha'. Goals and how information is presented will depend on who the intended audiences are and if it is more necessary to create an emotional effect or a rational one, always trying to motivate the audience (individuals, community leaders or other decision-makers) to ask themselves "and now, what can I do about this?" once the information is presented.

HOW DO WE TRANSFORM INFORMATION INTO ACTION?

We present three examples to illustrate how storytelling, deliberate analyses and data visualisation have turned information and data into action.

The first example looks explicitly at how deliberate data transformation and storytelling were used to influence implementation of actions linked to human rights and the latter explore evaluation of these approaches. Tactical Technologic Collective (TTC)⁷ is a non-governmental organisation created in 2003 whose mission is to improve strategies for the use of information and social media as critical tools to help the most vulnerable social sectors to understand data and to develop political, social and environmental changes. One of the most outstanding TTC projects is '10 tactics: transforming the information into action'. On its website, you can see a series of materials in which 10 tactics are described that can be used in the development of humanitarian actions and the defence of human rights. Besides, these descriptions are real examples of some of these actions and the importance of social networks and new technologies in the visibility or dissemination of them.

The Health Observatory, developed by Asturian Public Health Directorate (a region in the north of Spain), is based on the conceptual model of the County Health Rankings and the Take Action program of the Population Health Institute at the University of Wisconsin.⁸ The Observatory tries to represent information on health deficits of the different Asturian municipalities (through a benchmarking model based on rankings indicators) and also provide information on community health actions that are being developed. This information (from a model of health determinants, outcomes and health assets) is especially aimed at local health officials working at the municipal level with the purpose of launching policies and programmes to support public and community health action.

A study evaluation published this year,⁹ based on a similar one about the use of the County Health Rankings,¹⁰ attempts to establish the degree of utilisation of the Observatory social media tools (twitter, web and facebook) and the knowledge and use of it by the professionals.

This kind of evaluation is a key element, although the sequence presented by Thygesen and Sundgren explains well the process to transfer the information into knowledge, it would be necessary to take a step forward and ask ourselves if this knowledge is truly creating any action.

Another example is from a communityacademic partnership in Milwaukee, Wisconsin. Individuals at the Walnut Way Conservation Corp and in partnership with the Lindsay Heights Neighbourhood Health Alliance have been using storytelling to develop a quality of life plan or vision for future work in their community for the past 10 years.¹¹ In 2011, a household-based survey was conducted by the University of Wisconsin, Madison, The quality of life plan provided a platform to weave together data in the form of charts, graphs and pictures along with the stories being told by the community. Contextualising the complex survey data using the community's vision for change increased the accessibility of the statistics and a common platform that built community capacity and facilitated community planning and programme development. Hawe's theory of health promotion through capacity building argues the act of partnership building, linking organisations and fostering communication between them, will have a multiplying effect on the efficacy of health promotion and prevention activities.12 13

At the time of big data and open data, the connection between 'data specialists', programmers, designers and community health workers is essential. The art of storytelling through innovate data visualisation is one such approach to bridging communication gaps, creating a common language, moving forward towards community health promotion, and in a shortmedium-long term it has to be able to improve the health of the populations in which we work. This leads to the need for the inevitable meeting described by Berger between the painter and the model, the public health professionals and the population that they work with.

This text is based on a series of articles published in the blog 'Salud Comunitaria' by Rafael Cofiño from 2011 to 2014, in the section called 'El arte de dibujar números e historias en el aire' (Art of drawing numbers and stories in the air). The original articles can be viewed at the following link http://saludcomunitaria. wordpress.com/category/art-of-drawingnumbers-on-the-air/

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