

# Instant messaging systems as grassroots healthcare infrastructures. The case of an expert opinion service for breast cancer via WhatsApp

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**Abstract.** ‘Healthcare infrastructures’ is often associated with large, complex and costly technical solutions made available by institutions. The widespread use of smart devices made possible the development of information exchange building on general purpose communication technologies. Through the analysis of an expert opinion service for breast cancer via WhatsApp, we illustrate the process of setting up the service, the challenges and the ramifications of health information exchange taking place through non-institutional channels. We introduce the concept of ‘grassroot infrastructures’ to indicate socio-technical systems created and managed by lower-ranked organizational actors, invisible to rationalized representations of work.

## Instant messaging systems as grassroots health infrastructures

The notion of healthcare infrastructure, far from being a mere analytical construct, possesses a significant evocative power. The design, testing and implementation of information systems and infrastructures in the clinical practice has traditionally required the involvement of national or regional governments, standardization authorities, professional bodies, technology assessment experts, healthcare managers and the list could easily go on. The naïve enthusiasm of the early days of

medical informatics has been soon flanked by the acknowledgement of the complexity in coordinating different professional visions, funding the implementation and maintenance of systems, coordinating different local practices, not to mention the increasing building on the installed base and taking into account legacy systems. Each system is, at least partially, an *ad hoc* technology tailored to fit the needs of a specific context.

Alongside the traditional information infrastructures and systems, however, the adoption of personal communication devices by the vast majority of the population has created the opportunity to develop new forms of information exchange building on freely available general purpose communication technologies. Mobile phones, SMS, e-mail have allowed providers to create new forms of minimal healthcare services delivery bypassing the formal communication systems provided by institutions (Brooks and Menachemi, 2006). The use of such communication systems in the clinical practice has been accompanied by the fear of work overload and difficulties to define reimbursement schemes.

Despite these issues, the rise of instant messaging system (such as Whatsapp or Telegram) has increased the possibility to set up grassroot services such as remote monitoring schemes (Petruzzi and De Benedittis, 2016), doctor-to-doctor communication (Gulacti et al., 2016) or in clinical practice in general (Mars and Scott, 2016). In the present paper we document one of such systems, namely an informal second opinion service for breast cancer activated in northern Italy based on short messaging communication via a WhatsApp group chat used by 24 clinical oncologists. Drawing on our research (still ongoing) we illustrate the process of setting up the service, the challenges and the ramifications of health information exchange taking place through non-institutional channels.

## Theoretical framework

Here we propose to look at the process of creating such a grassroot infrastructure as a practice. Expert opinion is a practice, a set of specific patterned activities that are meaningful to those involved and as well as to researchers. Following Silvia Gherardi, we define a practice as “a mode, relatively stable in time and socially recognized, of ordering heterogeneous items into a coherent set” (Gherardi, 2006, p. 34). Seen through the conceptual lens of practice, organised activities are sustained by a shared understanding among practitioners that allows their replication in a more or less institutionalised way. Practitioners do not act according to a rigid script; rather, they share a “feel for the game”, the logic of practice (Bourdieu, 1990), which allows a “repetition without repetition” (Clot and Béguin, 2004). The recursiveness of the organised activities, their regularities and the (at least partially) shared meaning attributed to them both by those who practice and those who observe from the outside allow consideration of a given practice as an emic unit of analysis of a social phenomenon. In a socially informed perspective,

there is no clear-cut distinction between knowing and practicing. Pre-existing knowledge (e.g. a guideline) is mobilised and put-in-practice, thus becoming a resource for collective action. Knowing is practicing and participating.

We consider the practice of ‘expert opinion’ as an ‘infrastructuring practice’. Drawing on Karasti and Baker we consider infrastructuring as “an ongoing design process that highlights participation and co-construction, as well as the complex relationships between the long-term, data, participants, collaborations, information systems, and infrastructures” (Karasti and Baker 2004). As we shall see in the next pages, practitioners create the new practice practicing it, learning and defining as they proceed how to become competent practitioners. In doing so, they shape the infrastructure that sustain their interaction, creating a set of relations among each other, the data shared and the technology.

## Methodology

The process of setting up of the expert opinion on breast cancer has been studied analysing the messages exchanged in the WhatsApp chat exchanged between March 2017 and August 2018. The log file contains all the messages (texts and emoticons) plus information about actions performed on the group (e.g. new people invited).

The research was performed through a structured content analysis of the messages with the objective to identify patterns of interaction, language style and rules regarding the use/misuse of the chat, content different from request/offering of expert opinion. Access to the field was negotiated having being invited to the first (and only) two-days face-to-face meeting held in 2019. In this occasion it was possible to perform a quick-and-dirty participant observation and to discuss with participants about their involvement in the project. In the next phases of the research we will interview a sample of the participant to investigate in depth the history of the service, the use in the daily practice, the rules of engagement, and the relation between this service and other information systems or infrastructures.

## The case

Clinical oncology has evolved over the years into a highly formalized discipline (Band 2010) with several subspecialties (e.g. Albritton et al. 2009) each of them with a specific set of guidelines and protocols. The fast-paced innovation in pharmacology and the continuous clinical research has led to a significant standardization of each subdiscipline. As a consequence, however, the specialization of each subdiscipline has created a partial incommunicability among oncologists with different subspecialty. In most clinical setting it is rare for a physician to have an expert opinion since only large oncological department hire

more than one oncologist for each subspecialty. While guidelines and protocol offer a clear pathway to follow in most cases, in some cases several therapeutic options are equally possible. According to doctors involved case described, undecidability affects the 20% of all cases of breast cancer. While this is more a rule of thumb rather than accurate figure, it suggest that in one case out of five oncologist dealing with breast cancer believe that guidelines and protocols would need to be complemented by a second opinion which is often impossible to have.

Donna Rosa (trans. Pink Lady, but in Italian it also can be considered as a proper noun) is an expert opinion service for breast cancer set up in March 2017 by two breast cancer specialist with “*the objective of sharing ideas, doubts, questions and therapeutic strategies on the most controversial breast cancer cases addressed in daily clinical practice*” (A.A.V.V. 2019, p.3). At present 24 breast cancer specialists have been admitted to the group and some more required to join.

The preliminary analysis reveals that some participants are very active in providing opinions while others tend to keep a lower profile. The style of communication is in line with the personal conversations taking place in instant messaging platforms: short sentences, little or no attention to form (punctuation, capitalization, spaces between words), use of emphatic tone (e.g. emoticons, exclamation marks), colloquial tone.

## Expert opinion

The expert opinion is offered by peers in a WhatsApp group. All oncologists admitted to the network can post their clinical case and receive an opinion by a colleague. Each interaction follows a similar pattern. The doctor initiating the conversation presents a case in short sentence, providing only the information deemed necessary to describe it and she poses a question to the group. Data is anonymized and presented making use of the jargon well understood by specialist.

As a general rule, the question should not introduce a bias as in the following case.

Hi! Women born in 1976, QIE to dcis (3mm) g1 E100%,P100%. What would you do?thanks (Doctor 1)

At times, however, the request is to confirm the correctness of a decision or to decide among given alternatives. The different ways to phrase the questions depend on what doctors require to the community, whether a suggestion or a reassurance.

Women, 64 years, invasive ductal c., pT1a (4mm)N0M0, G1, ki 67 9%, ER 100, P2%, her 2 neg. how many of you would do Ot? Thanks (Doctor 2)

60 years. Pt1b 9mm er 95 PgR 60 ki 67 15 her 2 pos 3 pos. Antra yes or APT study? (Doctor 3)

Presenting their decision and asking for confirmation is consistent with one of the declared objectives of the service that is to provide reassurance about a difficult clinical decision. While the final responsibility is on the designated provider, “*having at disposal a service less fallible than one own’s personal experience offer a significant professional comfort*” (A.A.V.V., 2019). For each case presented, there are five/six opinions on average. The responses are mostly very short to the point that when a simple confirmation is asked the usual reply is a series of dry ‘yes’ or ‘no’.

Only in few cases there is a debate among different positions. In these cases, the short discussion offers not merely a range of opinions but also it allows to catch a glimpse of the clinical reasoning of colleagues, the different local practices in different settings or professional opinions about a still controversial study.

I agree with Michael. Here [in our department] too we do test to manage follow ups not for platinum (Doctor 5)

Yes, because here I have colleagues great at immunotherapy. (Doctor 6)

There are huge controversies about this among radiotherapists! There is a random [randomized] study in Pat dcis small g1/2 that shows preferability of rt (Doctor 4)

Each conversation, while focused on an expert opinion regarding a specific clinical case, holds the potential to offer more information about how the profession is practiced in different contexts.

In some cases, the expert opinion can even open up to offer new therapeutic services to patient. Some doctors of the network may be aware of some ongoing or soon-to-start experimental protocols in which the patient could be enrolled. In such cases, all participants to the chat are informed about studies and may have privileged access to them.

If you need, just let me know the name and I will enrol her. I only need her consent and the histologic material, the lady will still be cared for by the oncologist who send her to me, obviously. Contact me if you need!! (Doctor 2)

## Beyond expert opinion

As noted above, the discussion of a clinical case can trigger the sharing of additional information. In some cases the WhatsApp chat is used to deliver information relevant to the community. We identified different contents that go beyond the expert opinion about a clinical case.

The first is what could be considered as an expert opinion not regarding a single case but a protocol or guideline. The discipline advances rapidly and new protocols may not be adopted at the same time in all clinical setting or there could be different approaches still under discussion. In these occasion the chat allows to have a quick idea about how new or contested protocols have been adopted.

Sorry but I'm at Evento Era in Rome and they discuss about premenopause and ot! Here experts say that women intermediate-high risk should do lhrh and exe independently from their age. None starts with lhrh and tam but that is considered a shift only in case of collateral effect from lhrh and exe! Is that what you do?

Similarly, the chat can be used to share information regarding administrative requirements and regulations or other not strictly clinical matters.

Has anyone already started to implement the new directives ("oncology visit with handing over of oral drugs"..) and if yes, did you understand the financial implications?

At times the chat is used to spread news or requiring collaboration in projects. In the period under analysis, several times participants provided information about clinical trial offering colleagues the possibility to join if interested. Enrolling patients can be a burdening task and collaboration with colleagues is of the only viable option to fulfil the requirements of the clinical protocol.

Girls/boys I take the opportunity of this group to ask if someone is interested in a first line study of brca mutata triple negative patients that will be treated with carbo e pembrolizumab until PD. It's my study and I need to enrol 53 patients in two years: without networking I'll never make it... I'll share the feasibility form if interested. Bye

While the tone of the conversation is colloquial and some not strictly clinical information is shared among participants, the community has drawn a line between admissible and not-admissible content. In one significant case, for instance, one doctor share a joke on immigration and someone responded with emoticons. Later that day, one of the founding members of the chat contacted him/her privately to ask to stick to professional contents.

## Discussion and conclusions

The case presented allows to reflect on the complexities and ramifications of what we have termed as 'grassroot infrastructures'. The label evokes the shop-floor level process stemming from the voluntary work of healthcare professional through the use of personal resources. The term also suggests the tinkering and bricoleur-like

activities of using raw materials to create unique combination that fits a particular need (Barret 1998).

We refer to infrastructuring to describe the process of setting up the expert opinion service as it emerges from practicing it among participants. The process observed bears only partial resemblance to the most common processes usually observed in the healthcare domain. The main difference is that the technology is pre-existing and not modifiable by users, which do not have access to designer nor are furnished with tools to customize it. The relationships among participants cannot not be inscribed in the artefact itself rather they are defined through the interaction. While interaction cannot be structured by design (e.g. imposing limits to text, defining undesirable contents), the repetition without repetition of conversations (Clot and Béguin 2004) allows participants to develop a shared understanding of the ‘correct’ way to perform the practice.

With no institutional involvement or any form of organizational rewards implied, the practice of expert opinion is sustained by the commitment of participants to the group. This reveals the fragile and ephemeral nature of grassroots infrastructures. However, analysis reveals how over time the group develops a sense of communality and a feeling of belonging to a professional community which creates the premises for the resiliency of the infrastructural arrangements and the continuation of the service. Under this light, what is shared besides the mere ‘expert opinion’ proves to be highly relevant to understand why participation to the group is appreciated. By creating connections among dispersed professionals with limited possibilities to have a significant discussion with peers in their daily routines, the expert opinion offers a solution to an unmet need of connectedness and sense of professionals of a subdiscipline. The information needs in complex clinical cases, reassurance and sense of belonging are inextricably intertwined and they are all to be taken into account.

On a separate note, it is worth noting how the ‘grassroot infrastructure’ identified as no connection, at least from a purely technical standpoint, to the existing infrastructures and systems in place and currently used by oncologist in their work routines (for example, systems described in Galligioni et al. 2015, Passardi et al. 2017). While this may provide some flexibility and no dependency on legacy systems, further research is needed to explore if the lack of communication with systems that are obligatory passage points in key organizational processes may weaken and lead to the abandonment of grassroots infrastructures in the long run.

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