



share and move to face nasty bugs

Comunicazione e partecipazione dei cittadini
per una migliore gestione delle emergenze:
l'esperienza delle consultazioni europee in ASSET

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L'epidemiologia oggi:

evidenze, comunicazione e partecipazione

PARALLELA 1.3: PARTECIPAZIONE IN EPIDEMIOLOGIA

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www.asset-scienceinsociety.eu



Il contesto





«In the next influenza pandemic, be it now or in the future, be the virus mild or virulent, the single most important weapon against the disease will be a VACCINE but the second will be COMMUNICATION»



John Barry. The Great Influenza; Nature, 2009





Country	% Informed (°)		% Distrust in information sources (°)				
	'Well'	'Not well'	Health professionals	National health authorities	European authorities	Media (TV, radio, newspapers)	Internet
Slovenia	91	8	26.7	35.0	39.6	56.3	39.6
Norway	87	12	10.7	13.2	17.4	69.6	44.8
Switzerland	87	13	13.3	24.9	36.6	69.1	51.9
Finland	87	13	7.4	14.2	24.8	39.6	43.6
Portugal	84	15	10.1	19.8	16.9	46.2	33.2
Malta	85	15	6.0	14.9	14.6	41.2	33.3
Luxembourg	84	15	14.0	31.0	37.3	68.4	56.1
United Kingdom	83	16	8.1	18.3	36.4	65.1	44.5
Iceland	83	16	3.5	6.6	20.4	54.2	43.3
HU: Hungary	83	17	29.0	43.4	33.7	70.7	40.2
IE: Ireland	83	17	7.1	22.1	21.2	49.6	43.5
Belgium	82	17	7.7	21.4	24.3	64.4	55.8
Sweden	82	17	11.0	14.9	23.2	72.8	47.7
Denmark	81	19	7.8	10.6	17.1	56.3	38.3
Netherlands	80	20	8.7	16.0	22.4	64.3	48.9
France	77	22	19.5	48.1	48.0	73.7	59.0
Austria	77	22	15.5	29.7	42.9	66.6	48.6
Germany	75	25	17.2	36.1	45.8	65.8	47.8
Italy	75	25	23.1	42.9	40.5	66.7	48.9
Cyprus	72	29	19.7	24.6	24.0	49.7	33.4
Slovakia	71	28	18.6	24.3	26.8	44.2	36.4
Bulgaria	70	29	21.1	35.6	25.5	39.8	21.2
Spain	69	30	12.8	41.7	38.7	62.3	48.9
Greece	67	33	26.5	43.1	36.8	74.1	35.4
Czech Rep.	66	34	15.3	25.8	32.3	42.4	37.9
Romania	66	34	15.0	34.9	29.4	44.5	31.0
Poland	66	35	23.6	52.0	44.3	57.5	44.5
Estonia	57	42	16.2	24.7	24.4	45.0	34.9
Latvia	51	48	27.4	56.4	48.5	53.8	42.3
Lithuania	43	54	25.4	36.5	39.3	39.3	27.4
EU-27	75	24	16.6	35.5	38.2	62.8	46.3

INFORMAZIONE E SFIDUCIA NEI CITTADINI EUROPEI, PANDEMIA 2009

Table 1: Percentages of perceived information level across European countries, and percentages of distrust responses in five information categories (Data adapted from Eurobarometer No 287)

INFORMATION
How well informed do you feel about the pandemic H1N1 flu

DISTRUST
How much do you trust each of the following sources to inform you about the pandemic (H1N1) flu

H1N1 Expert Group. *Science, H1N1 and society: Towards a more pandemic-resilient society*. Brussels, 2011





COMUNICAZIONE PANDEMICA

Eur J Public Health. 2015 Feb;25(1):135-9. doi: 10.1093/eurpub/cku131. Epub 2014 Aug 14.

'By failing to prepare you are preparing to fail': lessons from the 2009 H1N1 'swine flu' pandemic.

Crosier A¹, McVey D², French J³.

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Abstract

BACKGROUND: Pandemic influenza has the potential to cause widespread death and destruction. Communications with the public have a vital role in the prevention of pandemic influenza by promoting the effective uptake of behaviours that can delay the spread of infection. This study explored the development and implementation of communications in the pandemic influenza outbreak of H1N1 ('swine flu') in 2009 in three European countries.

METHODS: In-depth interviews were conducted with senior policy and communication officials involved in the planning and delivery of communications programmes in England, Italy and Hungary.

RESULTS: The study found a lack of planning and a low value attached to the skills required to produce effective communications. In all case study countries there was a dearth of good quality audience research to inform the development of communications. Little thought had been given to the tone, targeting or channelling of messages. Instead, communications were characterized by a 'one size fits all' and a 'top down', expert-led response. There was also little effort to evaluate the impact of communications, but where this was done, very low levels of public compliance and engagement with key behavioural messages were found.

CONCLUSIONS: Policy makers should prioritize investment in the skills and expertise required to achieve desired behaviour changes. Audience research should be conducted throughout the planning cycle to inform national communications strategies. This should include insights to inform the segmentation of public audiences, targeting of messages and consideration of content and emotional tone most likely to achieve desired behavioural outcomes.

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DECISIONS

DECISION No 1082/2013/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL

of 22 October 2013

on serious cross-border threats to health and repealing Decision No 2119/98/EC

(Text with EEA relevance)

THE EUROPEAN PARLIAMENT AND THE COUNCIL OF THE EUROPEAN UNION,

among themselves their policies and programmes in the areas covered by Union action in the field of public health.

Having regard to the Treaty on the Functioning of the European Union, and in particular Article 168(5) thereof,

- (2) Pursuant to Decision No 2119/98/EC of the European Parliament and of the Council^(?) a network for the epidemiological surveillance and control of communicable diseases in the Community was set up.

Having regard to the proposal from the European Commission,

- **La Decisione europea 1082/2013** riconosce la comunicazione del rischio quale elemento essenziale nella gestione di emergenze internazionali di salute pubblica (PHEIC), come epidemie e pandemie.





Decision 1082/2013/EU



Article 4

Member States and the Commission shall consult each other (...) with a view to coordinating their efforts to develop, strengthen and maintain their capacities for the monitoring, early warning and assessment of, and response to, serious cross-border threats to health.

That consultation shall be aimed at:

- (a) **sharing best practice and experience** in preparedness and response planning;
- (b) **promoting the interoperability** of national preparedness planning;
- (c) addressing the **intersectoral dimension** of preparedness and response planning at Union level; and
- (d) supporting the **implementation of core capacity** (...) of the **IHR**.





Il programma ASSET





14 ENTI PARTNER da 11 PAESI

1. Forskninginstitutt - FFI
2. The International Emergency Management Society - TIEMS
3. Forsvarets Fonden Teknologiradet - DBT
4. European Institute of Women's Health - EIWH
5. VITAMIB
6. LYONBIOPOLE
7. International Prevention Research Institut - IPRI
8. Datamining International - DMI
9. Universitatea de Medicina si Farmacie «Carol Davila» din Bucuresti - UMFDB
10. ZADIG SRL
11. Istituto Superiore di Sanità - ISS
12. National Center of Infectious and Parasitic Diseases - NCIPD
13. Institute of Preventive Medicine Environmental and Occupational Health - PROLEPSIS
14. University of Haifa - HU





- Il progetto europeo **ASSET** (*Action plan in Science in Society in Epidemics and Total pandemics; 2014-2017*)
 - per il disegno di strategie efficaci di preparazione e risposta a emergenze sanitarie
 - secondo un approccio partecipato, *multistakeholder*
 - mettendo la partecipazione e l'inclusione al centro.





- **PAROLE CHIAVE**

- Scienza in Società – SiS
- Ricerca e Innovazione Responsabili – RRI
- Mobilisation and Mutual Learning Action Plan – MMLAP





GOVERNANCE OF PANDEMICS AND EPIDEMICS



ETHICS, LAW AND FUNDAMENTAL RIGHTS IN PANDEMICS AND EPIDEMICS



ENGAGEMENT FOR INTENTIONALLY CAUSED OUTBREAKS



OPEN ACCESS TO SCIENCE OUTCOMES UNSOLVED SCIENTIFIC QUESTIONS RELATED TO PANDEMICS AND EPIDEMICS



GENDER ISSUES IN PANDEMICS AND EPIDEMICS



PARTICIPATORY GOVERNANCE IN CRISIS MANAGEMENT





STRATEGIE DI RICERCA PARTECIPATIVA IMPLICANO IL COINVOLGIMENTO DELLA POPOLAZIONE FIN DALLA DEFINIZIONE DELL'AGENDA DI RICERCA

Ann Ist Super Sanità 2017 | Vol. 53, No. 1: 3-5
DOI: 10.4415/ANN_17_01_02

EDITORIAL Knowledge and participation. Moving towards scientific citizenship

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The scientific and technological progress of the first modernity developed through the centralization of intelligence, power and risk control, which was concentrated in technical structures comprising technicians, specialist, decision makers. The relationship between science and society has progressively evolved establishing a net separation between the experts who, through the use of the usual investigative methodologies, are able to reach an excellent level of analytical understanding of the issues that need resolving, and the public authorities. In this sense, the institutions are to be considered the client that ordered the investigations and also the users of these results, which then are transformed into some form of operative function in policy making. In this way, a mechanism has been generated in which collective will is flanked by the desires of policy makers, which are released from democratic procedures but which in their turn are legitimated due to the availability of a surplus of knowledge which determines the attribution of representative ability. In the words of Antonio Gramsci in the *Quaderni dal carcere*: "The popular element 'hears' but does not always understand or knows; the intellectual element 'knows' but does not always understand and especially 'hears'. If the relationship between intellectuals and population-nation, between directors and subordinates, and between the governors and the governed - is based on a form of participation in which sentiment-passion becomes understanding and therefore knowledge (not mechanically but actively), only then can the relationship be considered representation with an exchange of individual elements between the governed and governors, between the subordinates and directors. In other words, only shared life represents social power" [1].

This is a surprisingly up to date statement if one compares it to the current historical period, characterized by a rapid transition towards a knowledgeable society in which new forms of social relationship are evolving based on the ability to look for, elaborate and gain knowledge, which becomes the parameter in determining the levels of freedom, self-realization and independence of each person. In this sense, it is important to remember that knowledge is a more advanced and refined style of elaboration, because it requires the capacity to create links between people and disciplines. This

means that it can gain value if it is considered a relational asset and not simply as static and limited goods. This prospective is based on the idea that knowledge is, ever more, a cooperative asset and this means it is necessary to modify the structures and forms of representation and inclusion of science, the economy, law and politics [2].

This series of theoretical questions is closely linked to the need to define social strategies and public policies that are able to favour a balanced and rational management of the risks and benefits that are present in the interaction between science and society. Science has become one of the main organizational instruments of a multitude of individual and collective actors and is positioned between the influence of some subjects and forces that are often opposing and which amplify the role of general politics [3]. This new dimension of scientific enterprise means having to increase and diversify the responsibilities of scientists, who must make a broader evaluation of transparency, communication and the use of the results of their research. Identifying the elements that condition the work of scientists and highlighting incongruences does not mean making accusations against science and the cultural patrimony it is based on, but, on the contrary, it simply means posing the question regarding a more serene evaluation of its importance and therefore of the responsibility of science in contemporary society. In order to express the contents and realize the potential of a knowledge-based society, it is becoming ever more important to make a correct evaluation of the conditions of the general background to understand the possible alternatives between risk and benefit. The importance of bearing in mind this intricate network of relations was evidenced by the transformation that has taken place in an extremely delicate sector, namely communication and the public management of risk [4]. The crisis today regards the model which is based on what could be considered as a form of technocratic protection of policies founded on an untouchable "hierarchy of knowledge", which in cases of doubt "determine knowledge". However, who is it that decides in those situations of "mixing knowing and not knowing what must and must not be considered as proof?" [5]. As Stuart Kauffman so often reminds us, the combination of all biological and technological func-

3

EDITORIAL





Le Consultazioni multicentriche





Obiettivi

- Consultare gruppi di cittadini di 8 paesi europei su:
 - Libertà personale e sicurezza per la salute pubblica;
 - Comunicazione tra cittadini e autorità sanitarie;
 - Trasparenza in salute pubblica;
 - Accesso alle informazioni.





Metodi 1

- 24 Settembre 2016;
- in simultanea in 8 città europee:
Copenaghen, Bucarest, Dublino, Ginevra, Lione, Oslo, Roma, Sofia;
- protocollo operativo standard;
- materiali e strumenti elaborati dai coordinatori danesi, tradotti poi nella lingua nazionale dai partner.





Metodi 2

Selezione dei gruppi di cittadini

- **Numerosità per paese**

- 2500 cittadini invitati con lettera
- 125 effettivamente iscritti
- 70 scelti come titolari + supplementari (20)
- 50* numero minimo per cui, pur senza una rappresentatività statistica, si potesse fornire un quadro realistico delle tendenze quantitative.

* non eleggibili medici o operatori sanitari

- **Criteria rispetto alla distribuzione demografica della popolazione generale**

- età (>18)
- genere
- zona geografica di residenza
- livello di istruzione
- occupazione
- eventuali criteri a rilevanza nazionale.





Metodi 3

- **Conduzione consultazioni**

- Invio materiale propedeutico prima delle consultazioni
- Cittadini suddivisi in gruppi (10x7) con un facilitatore ciascuno
- Proiezione di video tematico (4 sessioni)
- Discussioni parallele in ogni gruppo
- Somministrazione di questionari di sessione (4)
- Restituzione e inserimento contestuale degli input.

- **Elaborazione dati**

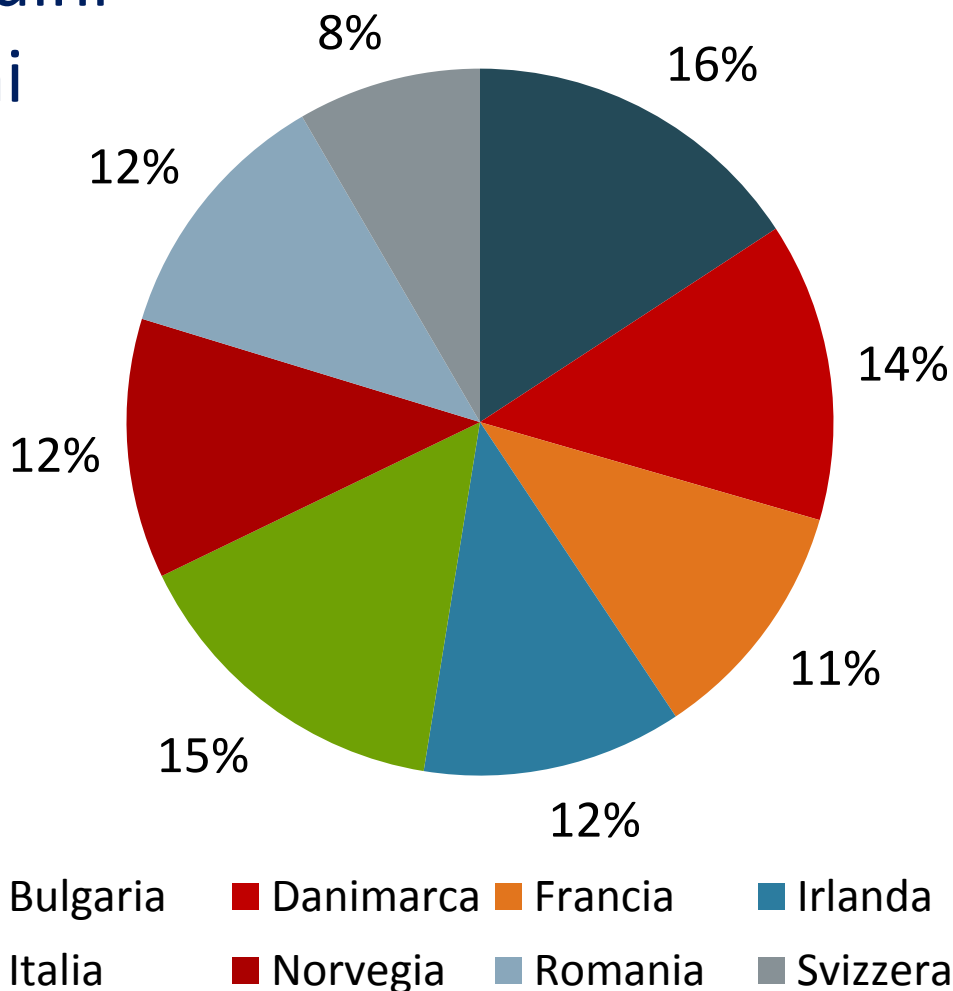
- In tempo reale, centralmente da strumento web automatico.
- Successivamente, analisi con EpiInfo7.





Partecipazione

- 430 cittadini
- 66 italiani





Età e sesso

Età

non risponde

1%

65+

14%

45-64

33%

25-44

42%

<24

10%

Sesso

non risponde

1%

uomini

44%

donne

55%

Totale rispondenti: 424

0%

20%

40%

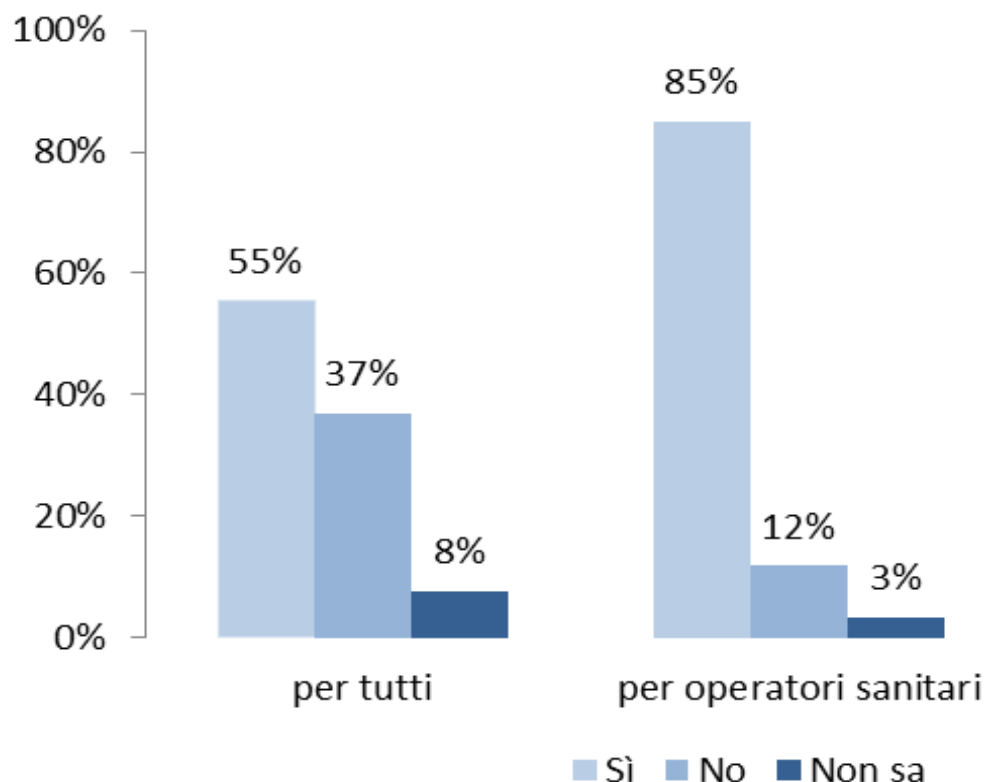
60%





Risultati 1

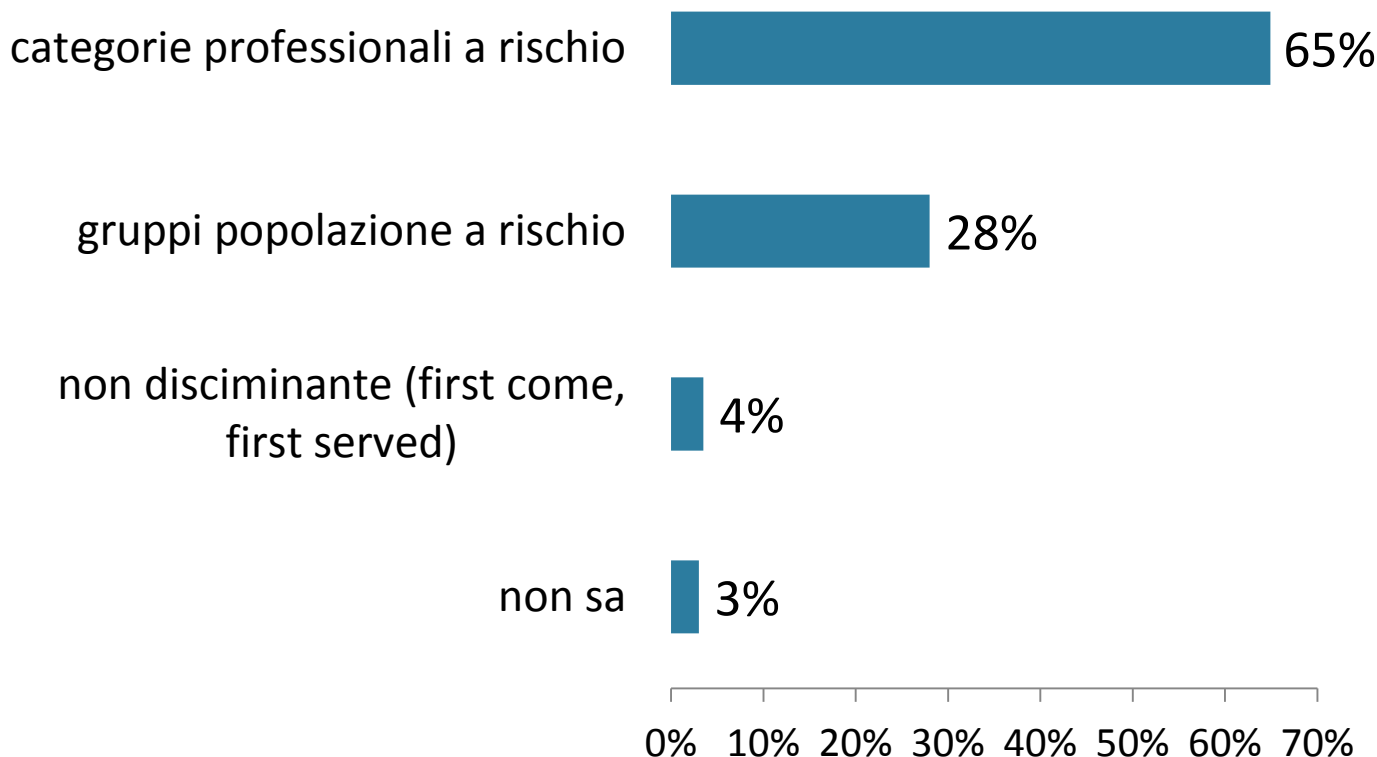
- In caso di rischio pandemico o epidemico le autorità sanitarie dovrebbero rendere obbligatoria la vaccinazione





Risultati 2

- In caso di epidemie o pandemie, quale dovrebbe essere la priorità per il principio di distribuzione dei vaccini





Risultati 3

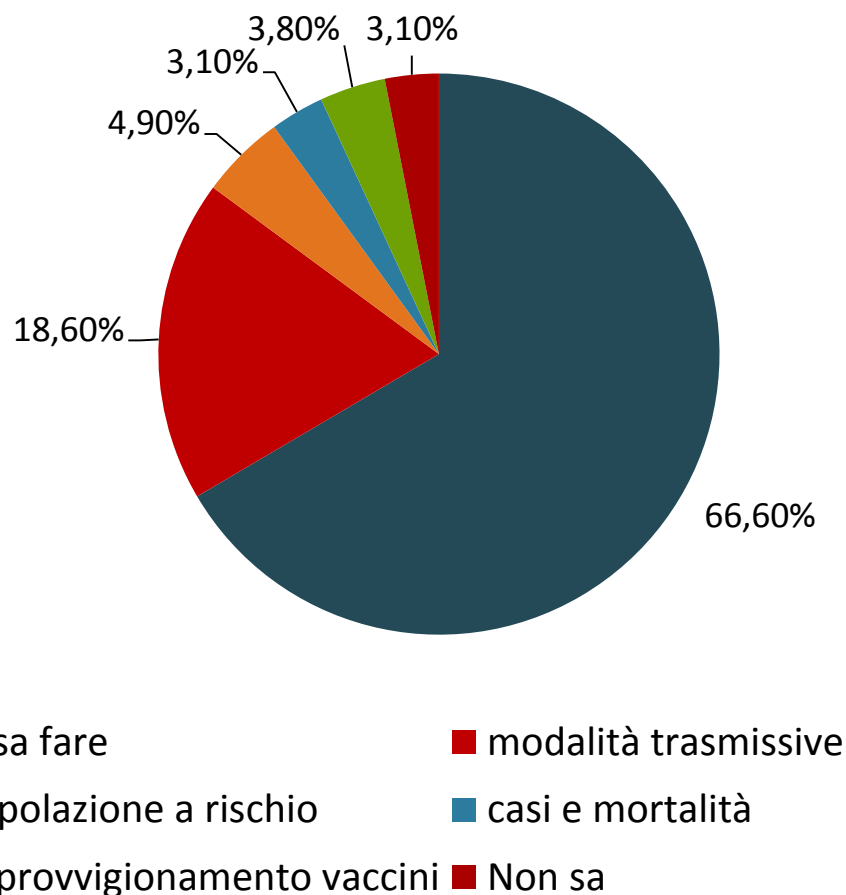
In caso di epidemia o pandemia, quale fonte di informazione dovrebbe essere utilizzata preferibilmente dalle autorità sanitarie	%	IC 95%
Radio	8,7%	6,3-11,9
Social media	10,4%	7,7-13,7
Media pubblici	29,9%	25,6-34,5
TV	27,3%	23,2-31,8
Siti web istituzionali	14,6%	11,4-18,4
Nessuna delle precedenti	4,0%	2,4-6,5
Non sa	5,2%	3,3-7,9





Risultati 4

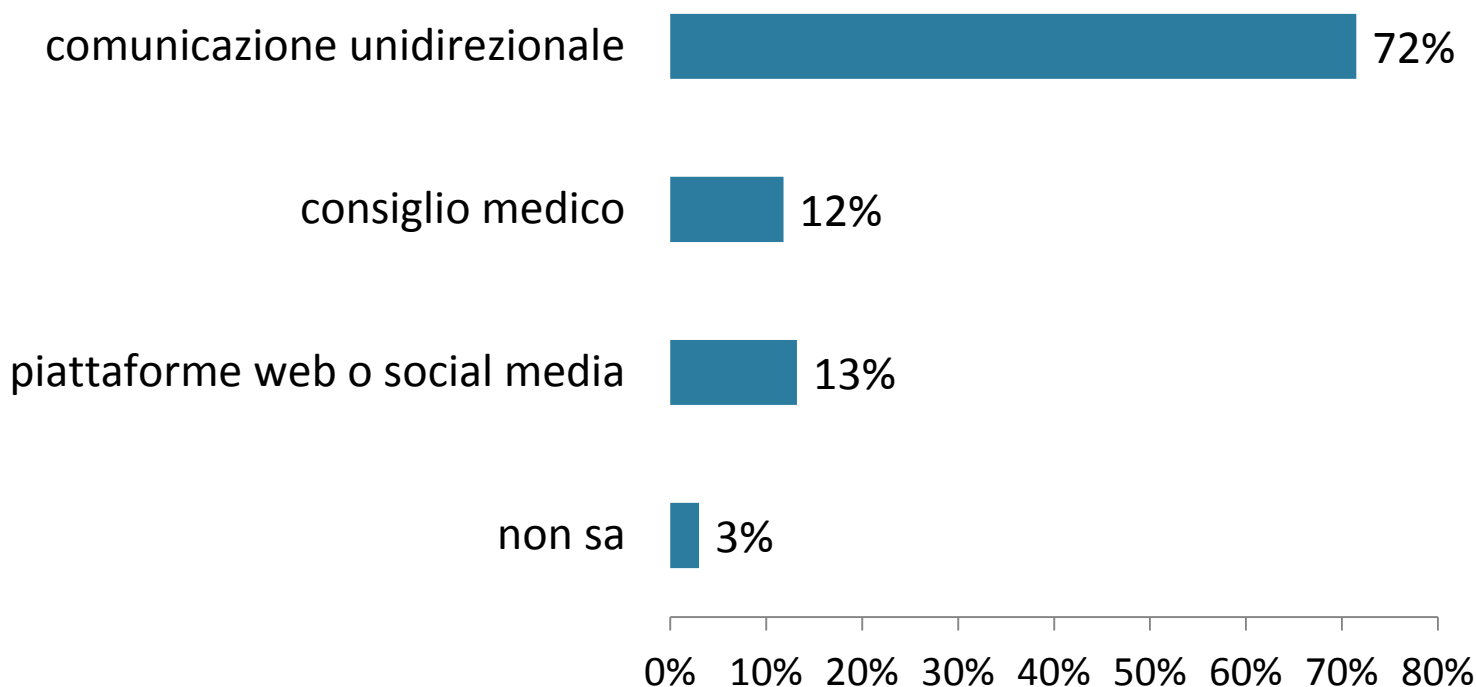
- Informazioni che le autorità sanitarie dovrebbero fornire in caso di epidemie o pandemie





Risultati 5

- In caso di epidemie/pandemie, i cittadini chiedono informazioni chiare e univoche



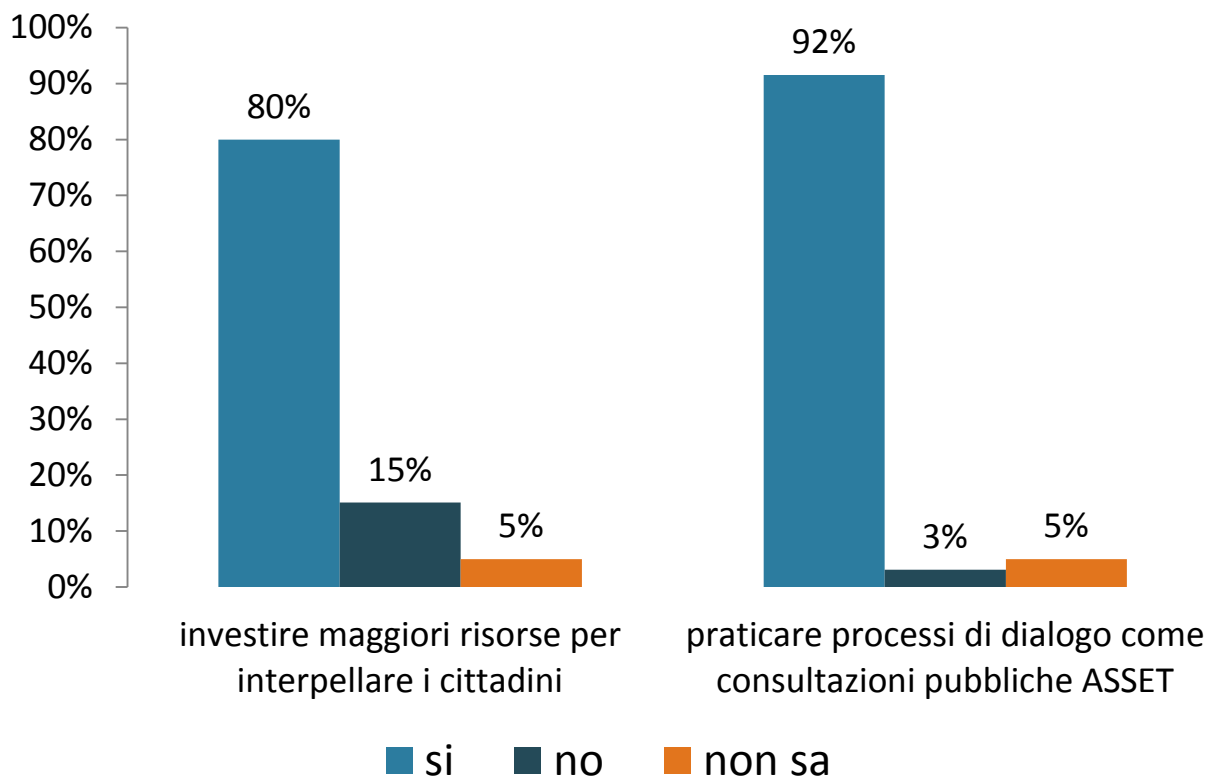


Risultati 6

• I cittadini europei consultati credono che:

– le autorità sanitarie debbano raccogliere sistematicamente informazioni dai cittadini in corso di pandemie

– percorsi simili a quelli realizzati in ASSET debbano essere realizzati per la preparazione e risposta a epidemie





Discussione

- Con riferimento a emergenze di salute pubblica quali epidemie e pandemie, le persone
 - reputano prioritaria la vaccinazione degli operatori sanitari (in termini di obbligatorietà a vaccinarsi e distribuzione dei vaccini);
 - ricorrono ai media tradizionali in misura maggiore rispetto a quelli di più recente generazione (social networks);
 - richiedono alle autorità competenti informazioni chiare e concrete;
 - ritengono che si dovrebbe investire maggiormente in processi di consultazione pubblica.





Conclusioni

- Le questioni cruciali per informare correttamente le politiche di preparazione e risposta alle minacce per la salute pubblica:
 - **fiducia** nelle istituzioni,
 - **trasparenza** nella comunicazione,
 - **coinvolgimento** della popolazione.





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GRAZIE PER L'ATTENZIONE!



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