

# 12.060 firme per il decalogo....e ora?

DECALOGO PER I DIRITTI DEI PAZIENTI ANTICOAGULATI

aiutaci a raggiungere

**12000** *firme*

change.org

COME SOTTOPORRE ALLE ISTITUZIONI LE ISTANZE DEI PAZIENTI ANTICOAGULATI

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**Il 22 gennaio 2016 a Bologna viene presentato alle AIPA il progetto ideato dal Prof. Gualtiero Palareti**



3° CONVEGNO DI ANTICOAGULAZIONE.it

ANTICOAGULAZIONE | Attualità cliniche e di laboratorio. Aspetti sociali

BOLOGNA 25-26 GENNAIO 2018 Savoia Hotel Regency - Via del Pilastro 2, 40127 Bologna



## Il progetto

1. Elaborare un decalogo con le nostre richieste
2. Raccolta firme: prima 10.000, poi 12.000...
3. Presentazione alle Istituzioni



## DECALOGO E RACCOLTA FIRME

- Divulgazione tramite inserto centrale del giornale AIPA NEWS
- Raccolta digitale tramite sito [change.org](http://change.org) (1.326) con supporto: [federaipa.com](http://federaipa.com), [anticoagulazione.it](http://anticoagulazione.it) e [cittadinanzattiva](http://cittadinanzattiva)
- Raccolta cartacea in tutta Italia (10.734)
- Tradotto in inglese e francese
- Presentato a Bruxelles nel 2016 giornata europea del malato

DECALOGO PER I DIRITTI DEI PAZIENTI ANTICOAGULATI		
Luogo	Firme raccolte	%
Lombardia	5299	45,0%
Emilia Romagna	2337	19,9%
Puglia	1456	12,4%
Toscana	606	5,2%
Campania	570	4,8%
Sardegna	411	3,5%
Lazio	380	3,2%
Veneto	218	1,9%
Friuli - Venezia Giulia	147	1,3%
Calabria	137	1,2%
Trentino - Alto Adige	64	0,5%
Liguria	56	0,5%
Sicilia	29	0,3%
Umbria	20	0,2%
Piemonte	13	0,1%
Marche	9	0,1%
Abruzzo	6	0,1%
Basilicata	3	0,0%
Molise	2	0,0%
Inghilterra	2	0,0%
Belgio	2	0,0%
Svizzera	1	0,0%
Germania	1	0,0%



- 1. Increase the quality of the Oral Anticoagulation Therapy access points**  
Citizens in anticoagulation therapy are over one million, with a upward trend. This therapy is life-saving and can currently make use of different drugs. Whenever the drug used, anticoagulation presents risks of bleeding and reduced protection. The risks increase if the therapy is conducted poorly and if it lacks healthcare services and medical performance needed for its quality.
- 2. Adjust the frequency of patient's INR measurements**  
Until a few years ago, the vitamin K antagonist (VKA, Coumadin and Sintrom in Italy) have been the only oral anticoagulant drug available and they are still the most used. The VKA oral anticoagulants require frequent laboratory monitoring and a consequent suitable adjustment of the daily dose. Insufficient quality of this monitoring activity (low level of time spent in the desired therapeutic range) reduces the efficiency and increases the risk of anticoagulation; therefore, patients are exposed to more thrombotic or bleeding complications.
- 3. Improve patients' and family caregivers' quality of life**  
Health services must provide to make available periodic test (essential for VKA) with modalities of access that favors the patients' quality of life (and of their relatives) and with suitable quality of execution (laboratory or portable instruments, subjected to quality control) reducing as much as possible the need of patient displacements (and of their relatives) and providing appropriate services to patients with limited mobility.
- 4. Ensuring periodic education and services network for anticoagulated patient**  
Proper adjustment daily dose of AVK drug is critical for safety and effectiveness of the therapy. This requires training and experience. Specialized medical centers, dedicated to the control of anticoagulated, are particularly suitable for this purpose. General Practitioners can play this activity after adequate specific training, with the use of computer tools to help in establishing dosages, and connection / collaboration with specialized medical centers, territorially organized (network of services for anticoagulated patients).
- 5. Ensure the anticoagulated patient's right of choice**  
Citizens in anticoagulation therapy with VKA should be given the right to choose who to entrust the monitoring and management of their own therapy. Patients have a right to require the retention of data relating to the Oral Anticoagulated Therapy requirements, at specialized medical centers. In this case, the Oral Anticoagulated Therapy must be registered in a database and specialized medical centers may be authorized by patients to monitor network data and interact with prescribers/Doctors according to well-defined protocols (in respect of privacy provisions).
- 6. Specialized Centers: reference points for training and information**  
Specialized centers must be established territorially, as a reference for doctors and patients in situations that require special expertise and experience (management of possible complications or in anticipation of surgery and invasive maneuvers). The Centers will also play employment and training function (related to anticoagulation) for healthcare professionals and patients.
- 7. Training and information for each anticoagulant therapy**  
For some years now are employed in clinical practice new oral anticoagulant drugs (NOA), for completely different action to VKA. In our country their prescription is governed. There is entirely insufficient attention to the necessary training of health personnel to manage these drugs and to provide the essential information of the patients. These drugs do not require periodic monitoring, but they are however, essential services protection of the treated patients.
- 8. Network services for anticoagulated patients**  
The network of services for anticoagulated patient (collaboration among expert centers, doctors General practitioners and specialists prescribers) should help to inform patients treated with NOA, (indispensable to obtain the appropriate level of adherence to therapy) and ensure the necessary Clinical and laboratory skills if they are to address various situations that may occur during treatment.
- 9. Expected time and clear objectives for the Regions Two management plans**  
Patient Associations Anticoagulation demanding that Health Services Regional make explicit, in a defined period of time, a general plan on how to organize the services for anticoagulated patients (behavior the drug employed) and that such plans are presented and discussed with representatives Associations.
- 10. Involvement of patient organizations**  
Patient Associations Anticoagulation Companies are demanding that Territorial health make explicit the organizational design of Services referring to implement for anticoagulated in their territory of competence, including and appropriately reorganizing existing resources and expertise. The organizational plan must be presented and discussed with the patient organizations (local or regional).

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LES DROITS DU PATIENT SOIGNÉ AUX ANTICOAGULANTS.  
Le Decalogue

- 1. Les patients soignés aux anticoagulants sont plus d'un million.**  
Le thérapeute anticoagulant a pour but d'apporter une information actualisée sur le niveau d'utilisation des médicaments sur les principaux risques et sur les règles de bon usage permettant d'optimiser leur bénéfice/risque.
- 2. Action d'information aux patients soignés aux anticoagulants. Prise en compte des risques d'effets indésirés et conduite à tenir.**  
Les médicaments anticoagulants AVK font l'objet d'une surveillance particulièrement renforcée au niveau national pour le risque d'hémorragie. L'INR permet une nouvelle évaluation régulière de la tolérance et de l'efficacité des médicaments. Une bonne adhésion des patients avec une coordination optimale du procureur de soins associé à l'utilisation de ces médicaments peut éviter le risque d'hémorragie.
- 3. Il faut améliorer la qualité de la vie des patients et du Caregiver de leur famille.**  
Une surveillance clinique appropriée est recommandée pendant toute la durée du traitement anticoagulant.
- 4. Action d'information.**  
Prise en compte des risques d'effets indésirés et conduite à tenir.
- 5. Accompagnement de la sécurité thérapeutique des médicaments et des produits de santé, respect de l'indication des doses prescrites, de contre-indications et les modalités d'administration.**  
Le patient soigné aux anticoagulants AVK a le droit de choisir un laboratoire pour l'INR. L'indice qui évalue l'action de l'AVK sur le fluide du sang. Le laboratoire utilisera un Carrel et les médecins spécialistes de laboratoire en contact direct avec le médecin traitant auront la possibilité de suivre le patient, pour le bon usage des produits de santé.
- 6. Le laboratoire, localisé sur le territoire, centre indispensable pour la formation et l'information.**  
Ces laboratoires sont très importants pour les médecins et les patients.
- 7. La formation et l'information appropriées à chaque thérapie anticoagulante.**  
Les traitements anticoagulants ont, au cours des dernières années, fait l'objet d'une attention particulière. Il y a des anticoagulants qui sont différents des anticoagulants AVK. Ces médicaments sont destinés pour une large population, souvent fragile. Ils font leur prescription est réglementée. Pour le bon usage des produits de santé il faut respecter l'importance de l'accompagnement à la fois des patients dans leur traitement mais aussi des médecins qui prescrivent le traitement. Ces derniers afin de favoriser le bon usage de ces médicaments anticoagulants doivent établir des Cartes de suivi et des cartes de surveillance pour les patients et des guides de prescription pour le médecin.
- 8. La collaboration des Services pour les patients.**  
Le médecin traitant de médecine générale doit travailler en collaboration pour une évaluation de la gestion du traitement par le patient de la nature des difficultés pratiques liées au traitement et de leurs conséquences.
- 9. Plan de gestion de TAO et organisation dans les Régions.**  
L'Association des Patients soignés aux anticoagulants demande aux Services de santé des Régions un projet général pour l'organisation des services pour les patients soignés aux anticoagulants pour en discuter et il faut discuter une proposition de loi.
- 10. La continuité d'un plan d'action et l'implication du patient.**  
Les Associations des Patients soignés aux anticoagulants ont pour but la présentation d'un projet sanitaire sur le territoire régional, pour en discuter avec les Associations et les Patients.

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## E ORA?

- Divulgazione Decalogo sintetizzato in 3 punti
- Inviata richiesta di incontro a n. 5 REGIONI e.p.c. al Ministero della Salute
- Modifiche ai Disegni di Legge Senato e Camera



## DECALOGO DEI DIRITTI DEL PAZIENTE ANTICOAGULATO in TRE PUNTI...

1. Individuare Centri Esperti (CE) sull'anticoagulazione e attivare **RETE TERRITORIALE SERVIZI**;
2. Vogliamo essere **informati ed educati alle Terapie anticoagulanti orali** e garantire la formazione permanente per personale sanitario;
3. Dispositivi POC rimborsabili al 100% e controllo decentrato in **RETE con CE**;



GRAZIE PER L'ATTENZIONE..  
DOMANDE?



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