

Empowering Patients as Data Owners and Partners for Research and Innovation

Kathi Apostolidis

President - Hellenic Cancer Federation – ELL.O.K.

Vice President ECPC-European Cancer Patient Coalition

Who we are

- ELLOK has 32 member organizations from all over Greece
- Representing all cancers, common and rare
- Member of ECPC – European Cancer Patient Organisation
- Close collaboration with the Greek and European medical oncology and research organisations and participation even if indirectly to several European Institutions
- ELLOK works for equality, where all cancer patients have timely and affordable access to the best treatment and care available, throughout their life.
- ELLOK believes that cancer patients are the most important partners in the fight against cancer and against all the cancer-related issues affecting our society.



- Patients have unique knowledge, perspectives and experiences
- Enhance health services and strengthen the link between research and practice
- Understanding the diverse needs and preferences of patients
- Optimal research, policy, and care
- ELLQK advocates for patients to be acknowledged as equal partners
- Need to work alongside researchers, policy-makers, and health professionals

Policy



Patients & patient organisations must be involved in developing policies **both on the national & European level** that result in improved survival and quality of life for people with cancer

Real world data



- Research and public health policies will increasingly be based on real world data.
- Patients are being recognised the owners of their own data, and as active partners in research.
- It is vital to design informed consent and data sharing procedures that strike a balance between encouraging research and ensuring patient privacy

Patients as data owners

- The Hellenic Cancer Federation advocates for truly informed consent.
 - Patients should have the right to access their own data, and to share with third parties.
 - Patients should be informed about the scientific discoveries that emerge from studies conducted with their data.



Patients as research partners

Partners in research

vs

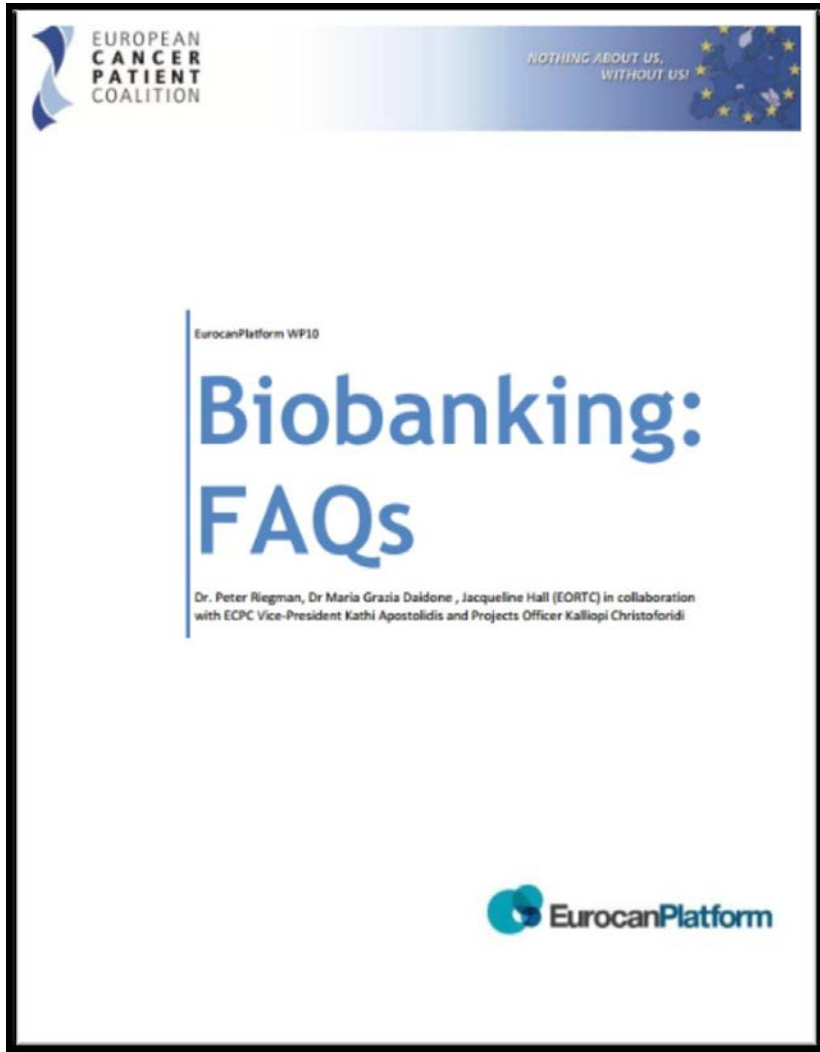
Subjects of research



- Patient organisations should be involved in the drafting of informed consent forms
- Linking health data sources and using them in an appropriate way may improve health outcomes for patients.
- It may help to improve the development of medicines and techniques to treat patients in a more personalised manner.

Biobanks

- Biobanks are a type of biorepository that stores human fluid and tissue samples for use in research
 - Biobanks will become increasingly important
 - The scientific community has to establish a dialogue to inform and empower people with cancer on the advantages related to the donation



Risks of the Data Protection Regulation

Risks of the new EU Data protection regulation: an ESMO position paper endorsed by the European oncology community

recommendations

In summary, patients should have the right to 'donate' their data and tissues to health research. Patient consent for use of data or tissue for health research should be a fully informed, withdrawable, more or less broad, 'one-time' process, which truly implements the patients' rights, rather than creating burdensome, possibly harmful consequences to the patients' community. The patient shall retain access to the tissue and data donated, hence ensuring him/her to obtain relevant information related to his/her condition. On the contrary, denial of this right would make patients less free, because they would be denied a civil right, i.e. to contribute to research, which advances knowledge and leads to new ways of improving their health and that of other patients. There need to be put in place legal provisions to protect data confidentiality, reviewing mechanisms to oversee retrospective researches and biobanks, and a system allowing full transparency of research processes and storage of patient tissue in biobanks. Cancer registries should be able to register cancer cases and patient data without the requirement of patient consent, in order to provide society and health administrators with exhaustive health data for public health policy decisions.

The European cancer community urges all EU decision makers to save research, as well as to protect the right of patients to donate their data and tissues to advance research and find cures. EU decision makers are urged to change the European Parliament Amendments 191 and 194 to Articles 81 and 83, as they would impair public health research within and across EU Member States. A balance between the right to privacy and the right to health can be achieved by reasonably addressing all concerns, while fully complying with those relating to confidentiality and ethical use of personal health data.

endorsements

This ESMO position paper on the EU General Data Protection Regulation is endorsed by the following organisations, and under review for endorsement by additional organisations:



- Position paper coordinated by ESMO in 2014
- It represented the voice of the cancer community
- ESMO, ECCO, EORTC, ESSO, SIOPE, EMEA Society for Biopreservation and Biobanking
- Broad consent
- Anonymization and use for historic record
- ECPC had important role, bringing the voice of cancer patients

Result:

ECPC's demands were integrated in final version of GDPR

Clinical trials

- People with cancer must have access to clinical trials that may be beneficial
- The European Cancer Patient Coalition has worked with Lilly to produce the innovative Clinical Trials Search Engine
- User friendly interface to search ClinicalTrials.gov for nearby relevant clinical trials that are recruiting patients

The screenshot shows the ECPC Immunology Portal website. The header includes the ECPC logo, a search bar, and navigation links: Αρχική σελίδα, Σχετικά με την, Πρόσβαση, Πόροι, Γλωσσάριο, and Ecpc.org. The main content area is titled 'Κλινικές μελέτες' (Clinical Trials) and contains text about the Trials4Me application, which is a user-friendly interface for searching clinical trials. The text mentions that the application is developed by Lilly and provides information on how to use it to find relevant trials.

Κλινικές μελέτες

Ο ECPC είναι στην ευχάριστη θέση να σας παρουσιάζει το **Trials4Me**, μια διαδικτυακή εφαρμογή που δημιούργησε η **LillyCOI**.

Η εφαρμογή Trials4Me εμφανίζει κλινικές δοκιμές, αντίστοιχες τοποθεσίες σε ένα χάρτη, με βάση τα κριτήρια του χρήστη και την καθορισμένη γεωγραφική τοποθεσία, καθώς και διάφορες επιλογές φιλτραρίσματος.

Στον χάρτη των αποτελεσμάτων αναζήτησης, μπορεί κανείς να επιλέξει μια καθορισμένη τοποθεσία και να αποκτήσει πρόσβαση σε μια συγκεκριμένη δοκιμή για να προβάλει έναν Επιθεωρητή δοκιμής που θα εμφανίσει πλήρεις λεπτομέρειες της δοκιμής και ευκρινώς παρουσιασμένα κριτήρια τοποθεσίας και ένταξης/αποκλεισμού, συν ένα σύνδεσμο στη μελέτη clinicaltrials.gov για περαιτέρω πληροφορίες.

Η Lilly προσέγγισε προληπτικά τον ECPC για να ελέγξει αυτήν τη νέα υπηρεσία. Πιστεύουμε πραγματικά στη δύναμη και τις δυνατότητες των διαδικτυακών λύσεων που βοηθούν στην εύρεση των καλύτερων κλινικών δοκιμών. Πιστεύουμε ότι αυτή η μηχανή αναζήτησης μπορεί να σας βοηθήσει να βρείτε περισσότερες επιλογές.

Εντούτοις, ο ECPC δεν αναλαμβάνει την ευθύνη για το περιεχόμενο της διαδικτυακής εφαρμογής. Ο ECPC σας καλεί επιτακτικά να ελέγξετε τις πληροφορίες που βρίσκετε με τον ογκολόγο σας.

WEBSITE: www.ellok.org

Mail: kathi.apostolidis@ellok.org
info@ellok.org

Facebook: Ελληνική Ομοσπονδία Καρκίνου
@EllokGR

Address: 1, Santaroza St. – Athens 1 - 10567
tel .0030 210-771-0335