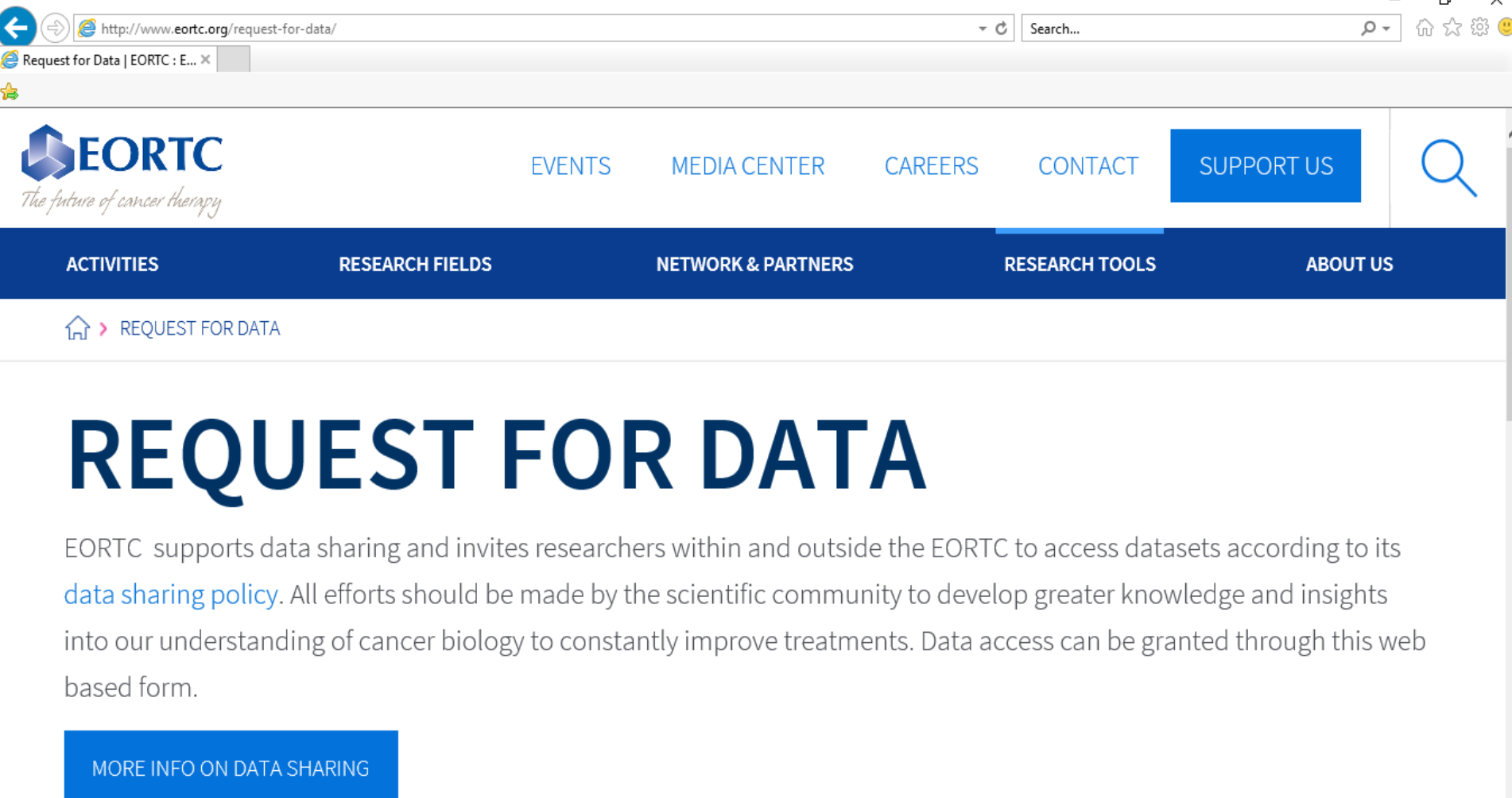


Data Sharing at EORTC

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Yes
we do share our data!

EORTC Data Sharing Policy (POL008) effective since October 2001



The screenshot shows a web browser window with the URL <http://www.eortc.org/request-for-data/>. The browser's address bar and tabs are visible. The EORTC logo, featuring a blue cube and the text 'EORTC The future of cancer therapy', is in the top left. The navigation menu includes 'EVENTS', 'MEDIA CENTER', 'CAREERS', 'CONTACT', and a blue 'SUPPORT US' button. A secondary menu below contains 'ACTIVITIES', 'RESEARCH FIELDS', 'NETWORK & PARTNERS', 'RESEARCH TOOLS' (which is highlighted with a blue underline), and 'ABOUT US'. A breadcrumb trail shows a home icon followed by 'REQUEST FOR DATA'. The main heading 'REQUEST FOR DATA' is in large, bold, dark blue letters. Below it, a paragraph states: 'EORTC supports data sharing and invites researchers within and outside the EORTC to access datasets according to its [data sharing policy](#). All efforts should be made by the scientific community to develop greater knowledge and insights into our understanding of cancer biology to constantly improve treatments. Data access can be granted through this web based form.' At the bottom left, there is a blue button with the text 'MORE INFO ON DATA SHARING'.

Request for Data | EORTC: E... x

EORTC
The future of cancer therapy

EVENTS MEDIA CENTER CAREERS CONTACT SUPPORT US

ACTIVITIES RESEARCH FIELDS NETWORK & PARTNERS RESEARCH TOOLS ABOUT US

REQUEST FOR DATA

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MORE INFO ON DATA SHARING

How we are willing to share data

- **Collaboration model**

- Clinical trials are complex
 - Study protocol and amendments
 - Data coding conventions
 - Updates since final publication
 - Statistical analysis plan
- We want our data to be used for good research
 - Close collaboration is needed to ensure that the data are well understood
 - There are so many ways of making the data speak...



How we share the data technically

- The data are ***de-identified***
- A copy of the database is **physically sent to the researcher via a secure password protected portal (eg. Filebox)**
- We follow-up the projects closely to avoid
 - further dissemination of copies of the data
 - uncontrolled use of our data



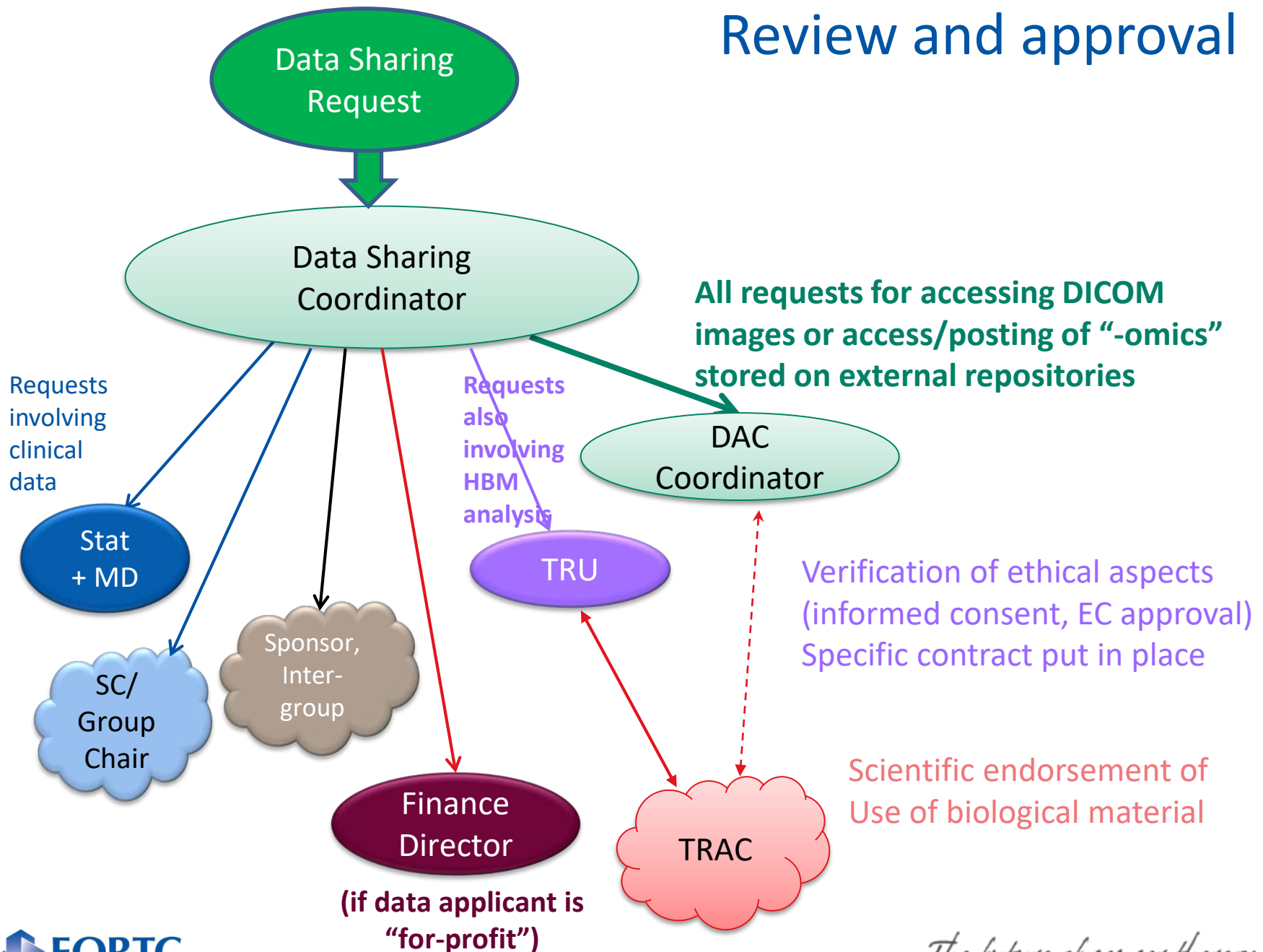
Data sharing at EORTC

Studies are available AFTER primary publication

Formal data request (online form)

- Description of the research
- Brief statistical analysis plan (SAP) and/or research protocol
- Curriculum Vitae of the methodologist in charge
- Publication plan
- **Terms of use (contract)** agreed and signed
 - Data to be used solely for the purpose of the defined project
 - Publications sent to EORTC prior to submission
 - Acknowledgement to EORTC
 - Protection of the confidentiality of the data!!
 - **Contract** if request of tissue/images/sensitive data
- So far at no cost if academic applicant

Review and approval



Terms related to authorship

At time of request, declare

- Publication and posting plan
- Whether the publication will be **published on behalf of EORTC and/or co-authored by an EORTC staff** (depending on level of involvement)

→
NO

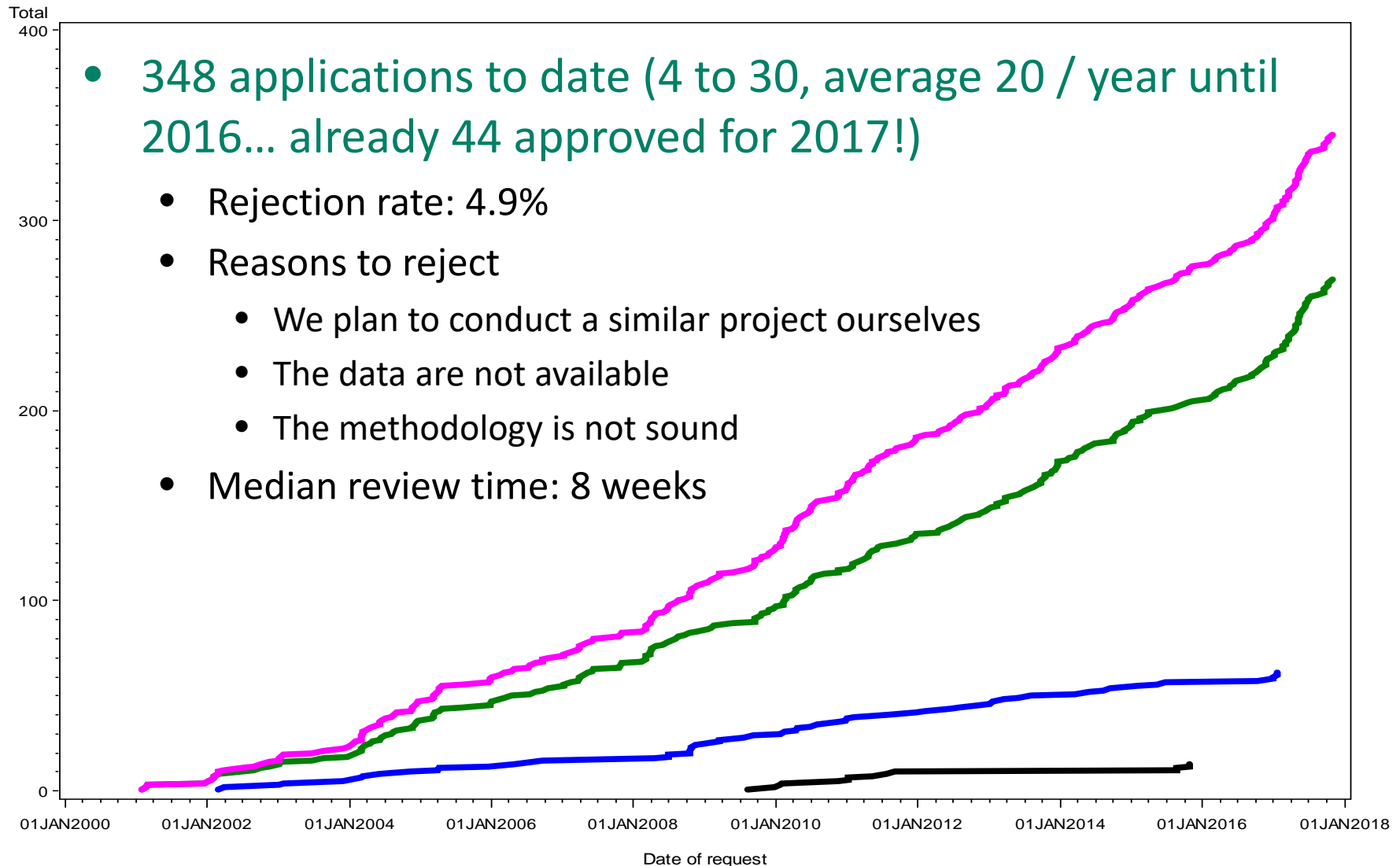
Triggers terms of use with respect to inclusion of disclaimers that work not done at EORTC and does not reflect official view of EORTC (If not)
+ follow-up to publication
+ HQ review of the draft prior to publication

→
YES

Publication follows standard path of EORTC publications (EORTC POL009)

- Changes to the declared plan require additional approval

16 years of data sharing at EORTC



- 348 applications to date (4 to 30, average 20 / year until 2016... already 44 approved for 2017!)

- Rejection rate: 4.9%
- Reasons to reject
 - We plan to conduct a similar project ourselves
 - The data are not available
 - The methodology is not sound
- Median review time: 8 weeks

What is done with the data?

- 30% were shared for meta-analyses
- 10% were shared with universities to test new statistical methods
- The rest is for secondary use of the data, alone (40%) or with biomarker results from bio-sample analyses (20%).
- None is to reproduce main study results

Publication

- 97% of the completed projects resulted in publications
- 25% of the ongoing projects already led to some publication
- We co-author 87% of the publications, reflecting collaborative work

Data Sharing at EORTC (summary)

- The process is in place and functions well
 - We are faster than many other organisations
 - Fosters collaboration
 - Increases the number of publications
- Few instances of data abuse to date
- The process has a cost:
 - Logistics of reviews, administrative support needed
 - Involves of several departments (notably contracts)
 - Burden of data sharing increases
 - Sharing of more sensitive data
 - Need to de-identify (may take up to 5 days for old studies)
 - Preparation on of data documentation

