



# Cystic Fibrosis Research News

## **Title:**

Insights into the cystic fibrosis care in Eastern Europe: results of survey

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## **What was your research question?**

The study was carried out to map the system and organization of CF care in Eastern European countries.

## **Why is this important?**

Contrary to the well described situation in Western Europe, we lack a detailed view of the framework of CF care in Eastern Europe. There is scarce information about the level of centralized care, presence of dedicated CF staff and overall implementation of standards of care that have been summarized by the European CF Society.

## **What did you do?**

We developed an online questionnaire and asked one CF physician and one patient representative from each Eastern European country to complete it. The questions were about the availability of CF centres for children and adults, structure of the CF healthcare team, CF centre facilities, infection control policy, support of CF care by the government and by hospital officials, financial resources and the access to conventional and novel CF therapy.

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## What did you find?

We received answers from 16 CF doctors and 17 CF patient representatives (Figure shows a map view of participating countries). Twelve out of 16 Eastern European countries reported the existence of CF centres, but only half of them had additional adult only CF centres. Some members of the core healthcare team were missing in many CF centres including a specialised CF nurse (not present in 4 of 12 countries with CF centres). Responses revealed that patients were significantly more critical of the organisation of the different aspects of CF care than physicians, especially in the Balkans.

## What does this mean and reasons for caution?

We understood that the organization and level of CF care across Eastern Europe is hugely variable, and some of its critical elements are lacking in many countries. More concerns were expressed by patients than by physicians which implies that the perception of the care by both groups is not necessarily equivalent. The results of the survey were based on a single respondent per country, therefore it may not reflect total reality of CF care.

## What's next?

The survey aimed to raise awareness of the inequality in CF care across Europe and promote the focus on Eastern Europe. Additional local, national and international activities are urgently needed to improve CF services in this European region.

## Figure. Countries participating in the survey.

Completed questionnaires from CF physician and patient representative were received from following countries (dotted): Bosnia and Herzegovina, Bulgaria, Czech Republic, Estonia, Hungary, Latvia, Macedonia, Moldova, Poland, Romania, Russia, Serbia, Slovakia, Slovenia, Ukraine; a single questionnaire returned from countries (striped): a CF physician from Croatia, patient representatives from Albania and Montenegro.

## Original manuscript citation in PubMed

<https://www.ncbi.nlm.nih.gov/pubmed/?term=Insights+into+the+cystic+fibrosis+care+in+Eastern+Europe%3A+results+of+survey>

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