

Bridging the equity gap in patient education: the biliary cancer Babel project

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INTRODUCTION

Patient education is a fundamental pillar of quality cancer care. Providing patients with adequate information about cancer and its treatment is essential to ensure shared decision-making and to enhance therapeutic compliance, psychological well-being, and quality of life.¹ However, despite strongly recommended and legally required in several countries, information provision is still an unmet need for many patients and is particularly challenging in resource-limited settings. Interventions aimed at overcoming global barriers in patient education are much needed to close the equity gap in cancer care and to improve patient outcomes.

GOAL

The European Cooperation in Science and Technology (COST) Action 18122 (EURO-CHOLANGIO-NET), as part of the European Network for the Study of Cholangiocarcinoma, has recognised this need and has launched the BABEL project, which aims to generate a packet of informational material for patients with biliary cancer who require chemotherapy and to make this material available in several languages. Additional aims of this initiative are to provide the global oncology community with standardised, high-quality, free, and easily accessible resources to facilitate communication between the patient and their care provider regarding this neglected tumour type, and to help as many as patients as possible, particularly those who live in lower-middle income countries and immigrants facing language barriers.

METHODS

Leaflets for the chemotherapeutic regimens currently approved for biliary cancers (capecitabine, gemcitabine, cisplatin - gemcitabine, folfox, capecitabine - oxaliplatin) were generated in English language by a panel of medical oncologists, nurses and patient representatives, and approved by the EURO-CHOLANGIO-NET BABEL working group.



Capecitabine for biliary tract cancers

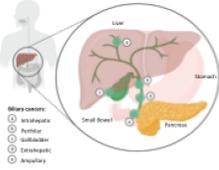
If your doctor recommended capecitabine to treat your cancer, here is some important information about this medication and some aspects related to it.

Biliary tract cancer
Cancers of the biliary tract develop from cells (called cholangiocytes) that normally make up the lining of the biliary system (depicted in green in the picture below). Biliary ducts are small tubes that carry the bile, which is used to digest food, from the liver and gallbladder into the small bowel.

Biliary tract cancers are cholangiocarcinoma, gallbladder cancer and ampullary cancer:

- **Cholangiocarcinoma** - which is also known as bile duct cancer. This cancer is categorised in three types, depending on where within the bile ducts it develops:
 - **intrahepatic cholangiocarcinoma** - when the cancer develops in the ducts inside the liver
 - **perihilar cholangiocarcinoma** - when it develops in the ducts just outside the liver
 - **distal/extrahepatic cholangiocarcinoma** - when it develops in the ducts further away from the liver
- **Gallbladder cancer** - arises from the gallbladder lining
- **Ampullary cancer** - arises from the join between the bile ducts and the small bowel

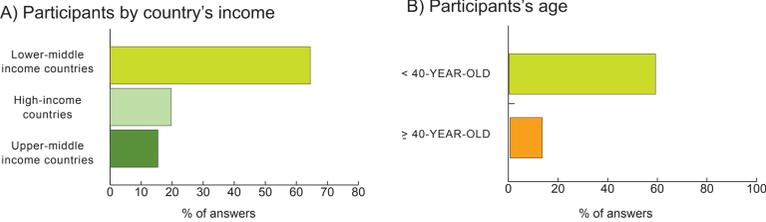
You have been given this leaflet because you have been diagnosed with a biliary tract cancer. Your oncologist can discuss with you which biliary tract cancer you have and how extended it is.



The documents included the anatomical illustration and description of different tumours of the biliary tract, detailed explanation of treatment, potential side effects, and advice on their management.

RESULTS

A total of 83 participants from 21 countries joined the initiative. The majority of them were young oncologists and from lower-middle income countries.

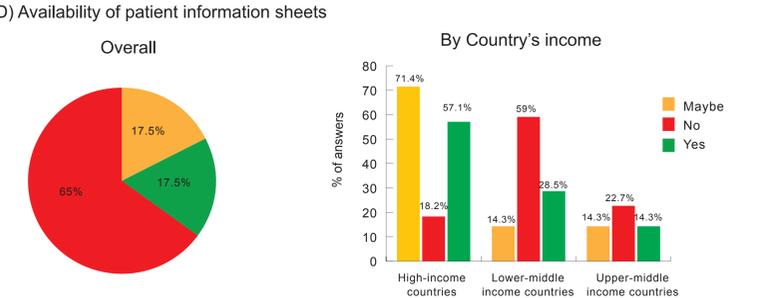


From October 2021 to January 2022 patient information sheets have been translated into 31 languages, including the top ten most spoken languages worldwide, covering a total of 208 countries.



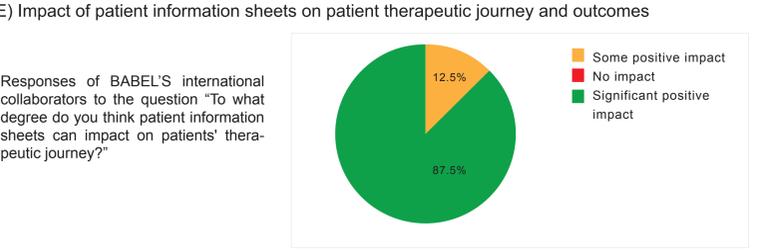
The 32 languages in which patient information sheets for biliary cancers have been made available through the BABEL project, including the combined number of native and second-language speakers of each language, and the 208 countries (coloured in green) in which at least one of these 32 languages is the first or second language.

The 65% of BABEL's collaborators reported no availability of patient information sheets in their country, with a substantial gap between high-income and lower-middle income settings.

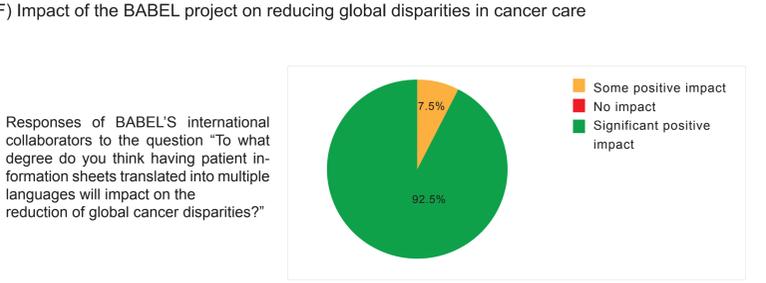


Responses of BABEL'S international collaborators to the question "Do you currently have patient information sheets on chemotherapy available in your country?"

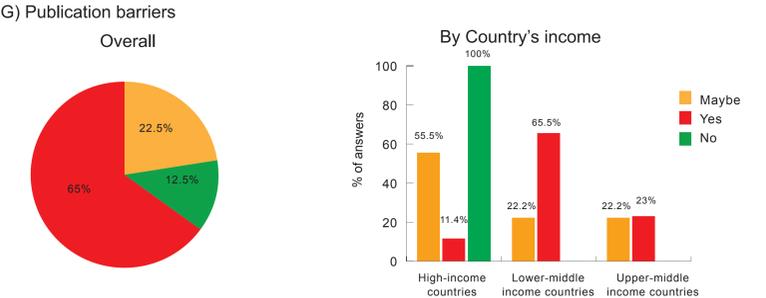
Most participants felt that patient information sheets would have a "significant positive impact" on patients' therapeutic journeys and outcomes.



Most participants was convinced of the significant positive impact of having leaflets in multiple languages in reducing global disparities in cancer care.



Barriers to publish in high ranked scientific journals were commonly reported by the BABEL's participants with substantial difference between high-income and lower-middle income settings.



Responses of BABEL'S international collaborators to the question "Are you experiencing any barriers in publishing scientific papers in leading medical journals?"

CONCLUSIONS

The BABEL project is a successful example of a global oncology approach that can contribute to bridging the equity gap in patient education and reducing disparities in cancer care.

It has the potential to disseminate information material for patients with biliary cancers on a global scale thus addressing the unmet need of patient education worldwide, particularly in resource-limited settings where these resources are much needed.

The opportunity to have information leaflets in multiple languages will also assist clinicians and interpreters in communicating with immigrant patients living in high-income countries who face health disparities due to language barriers, which represents a critical and growing challenge in cancer care.

By involving young collaborators from less privileged countries in this project we also illustrate how inclusive strategies may help early-career clinicians from resource-limited settings to advance their career through connections, education, networking, and publication opportunities.

AKNOWLEDGMENTS

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Secondly, volunteers interested in translating the leaflets into their native languages were recruited among members of our scientific societies. A questionnaire was administered to participants to evaluate the potential impact of this initiative.