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It's All About the Patients: Developing Advocacy

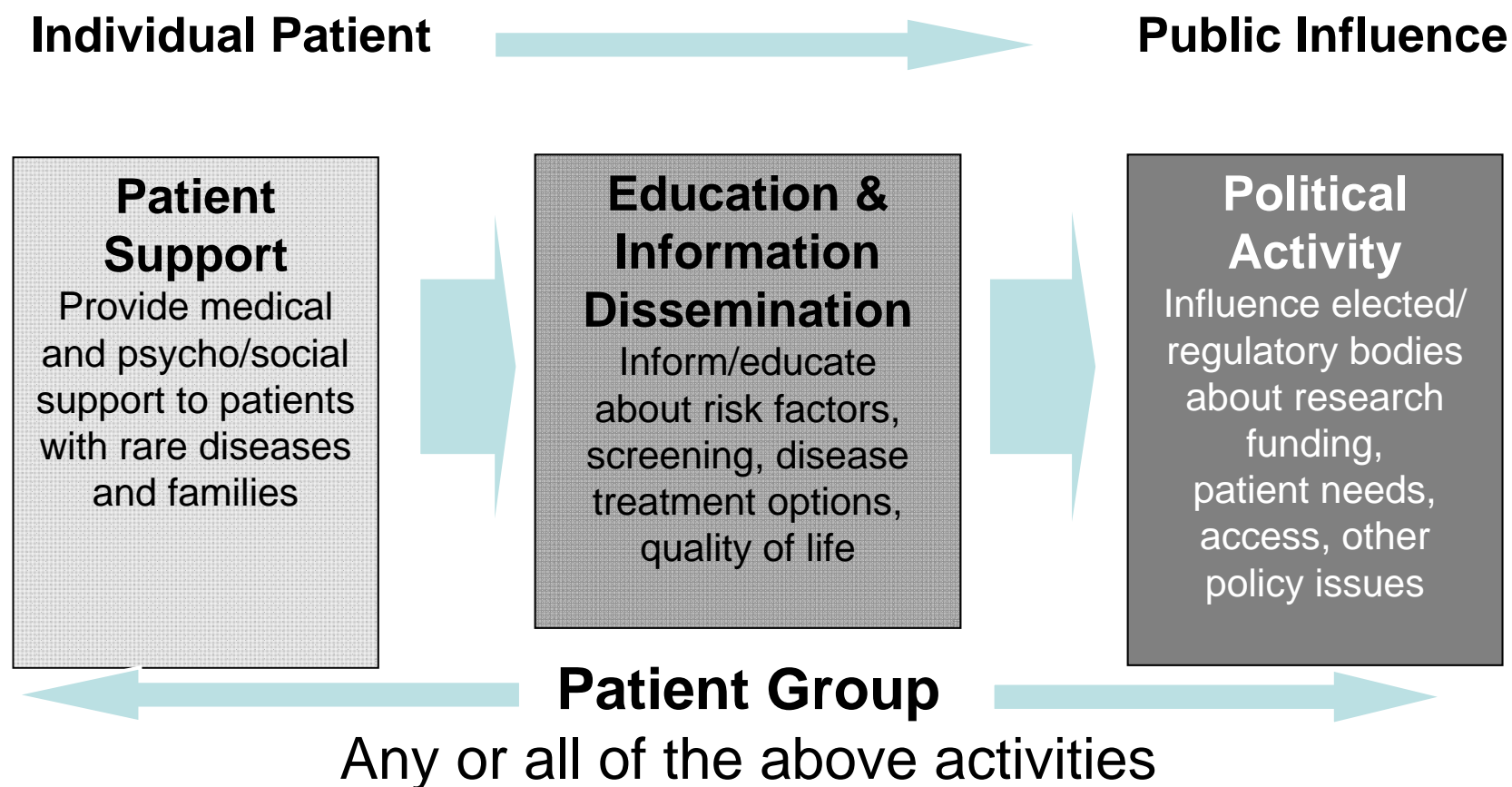
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Disclosure

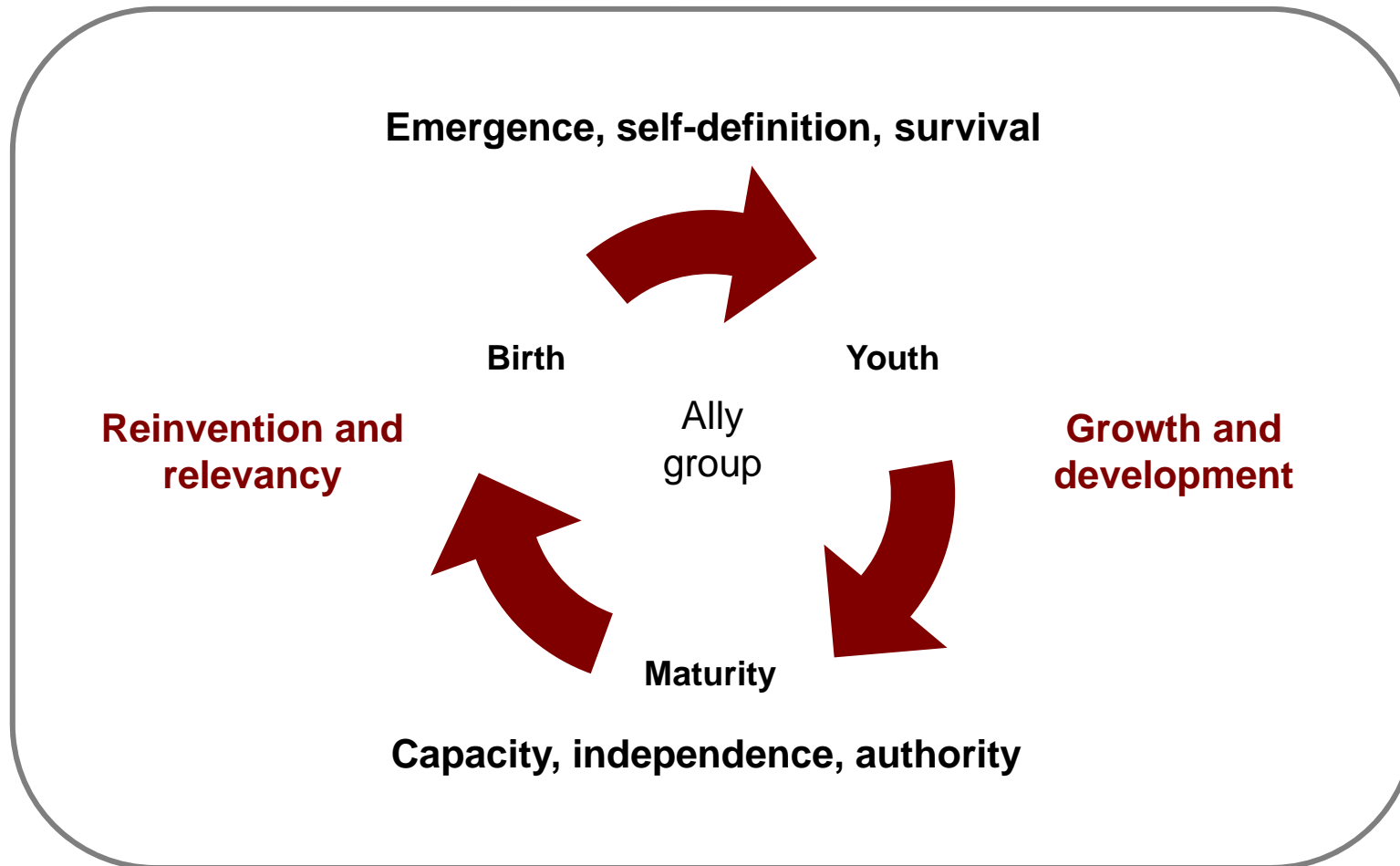
- Shareholder N
- Grant/research support N
- Consultant Y
- Employee Y
- Paid instructor Y
- Speakers' bureau Y



Continuum of patient groups: From patient support to healthcare politics



Patient group life cycle



The concept of advocacy



Information

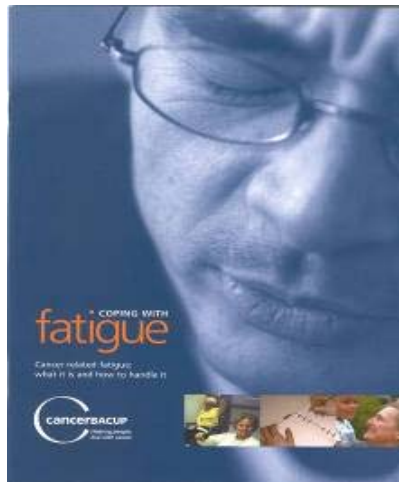
Helps individual patients understand what is happening

Continuum



Advocacy

Individuals and groups use information to press for better care



One in three authorities in breach of cancer guidelines

ONE IN THREE health authorities has failed to commit itself to paying for the best treatment for ovarian cancer, in contravention of official guidelines.

Research commissioned by the cancer charity Cancerbucup shows that the authorities have not included Taxol, a drug originally derived from the Pacific yew tree, for all women who could benefit from it in their cancer plans.

Taxol has been shown to improve survival in women with advanced ovarian cancer by a year but many health authorities have refused to pay the £10,000 per head annual cost of the drug until more evidence is available. This led to a flurry of reports of "postcode prescribing" with patients in one health authority provided with the

BY JEREMY LAURANCE
Health Editor

drug while those in neighbouring ones were denied it.

Guidance from the National Cancer Guidelines Steering Group issued last July recommended that paclitaxel (Taxol) combined with platinum should be the first-line treatment for ovarian cancer. The research by Cancerbucup found all health authorities were aware of the guidelines but only two-thirds were following them. The National Institute for Clinical Excellence, the government body responsible for issuing advice on new treatments, is due to report on Taxol and the other taxanes in the spring.

Jean Massman, chief executive of Cancerbucup, said:

"Official guidelines and recommendations must be updated and implemented quickly to avoid delays in access to innovative treatments. The difficulties NHS patients have experienced in getting paclitaxel, or in the provision of advanced radiotherapy for lung cancer, typify the problems that may otherwise occur in the future."

Professor Peter Selby, director of clinical research at the Imperial Cancer Research Fund, said: "We are pleased to see that the Government has made some commitments, but cancer services need new money to make a real difference. We must have high-quality care available for all cancer patients and that will, without doubt, cost more than we are currently spending."

Patient groups can shape policy



- They understand what people with rare diseases and their families want
- They know how to communicate with key stakeholders
- They have good relationships with clinicians, policy makers, and the media
- They can disseminate information broadly and quickly