



Registered Charity No. 292157

## **E-Bulletin from the National Association for Patient Participation Issue Number 55 September 2011**

### **1. Getting the most from your GP practice**

A “one stop shop” guide to help patients get the most from their GP practice is launched by the Royal College of General Practitioners (RCGP).

[It's Your Practice: A Patient Guide to GP Services](#) is available free of charge and gives patients a diverse range of useful information - from choosing and registering with a surgery and understanding the different services that are available, through to making appointments and getting the most from your consultation.

### **2. Online survey aims to improve NICE guidance for patients and the public**

NICE, the [National Institute for Health and Clinical Excellence](#) is gathering the opinions of patients and the public to help develop and improve the ways it presents its guidance. They have launched a [short online questionnaire](#), asking about your knowledge and experience of using our clinical guidelines, is a mixture of multiple choice questions and opportunities to provide more detailed replies.

The [survey](#), which should continue running throughout September forms part of a larger study called [DECIDE](#), which is a five-year collaborative project funded by the European Commission's Seventh Framework Programme and is designed to research and improve the way healthcare evidence and recommendations are presented in clinical guidelines.

### **3. New films to raise awareness of self directed support for people living with dementia**

The Mental Health Foundation has launched a suite of films aimed at raising awareness about dementia and the use of self directed support in helping people with dementia, their families, carers and social care professionals.

The [films](#) are part of a range of resources launched in response to the findings of [Dementia Choices](#), a two year project which found that people with dementia, their carers and social care workers are in need of more practical information about how self-directed support (including direct payments and personal budgets) can help improve their care

### **4. A stronger voice for patients**

75 Local HealthWatch pathfinders, introduced as part of the Government's plans to modernise the NHS, were announced early in August. These new learning networks will champion patients' views and experiences, promote the integration of local services and improve choice for patients through advice and access to information.

Local HealthWatch will provide a collective voice for patients and carers, and advise the new clinical commissioning groups on the shape of local services to ensure they are informed by the views of the local community. To view the details, click [here](#)

## 5. Scotland SIGN Awareness Volunteers

The Scottish Intercollegiate Guidelines Network (SIGN) develops evidence-based clinical practice guidelines for the NHS in Scotland, using systematic reviews of scientific literature. The guidelines are designed to accelerate the translation of new knowledge into action with the aim of reducing variations in practice, and improving patient-important outcome.

**SIGN develops evidence-based national clinical practice guidelines for NHS Scotland, providing guidelines to:**

- help NHS staff and patients understand medical evidence and use it to make decisions about healthcare
- make sure patients get the best care available, no matter where they live
- improve healthcare across Scotland

SIGN at present is recruiting **Awareness Volunteers** to help with dissemination. More information on how to get involved at <http://www.sign.ac.uk/patients/index.html>

## 6. The Patient Information Forum

Founded in 1997, the Patient Information Forum (PIF), is the UK organisation for people who work in consumer health information. It aims to improve the quality and availability of health information for patients and the public. High quality information was starting to be recognised as a key element in the successful management of any health condition, particularly long-term medical conditions, and the prevention of ill health. For further information about the Patient Information Forum, please go to <http://www.pifonline.org.uk/>

The first **Scottish** Patient Information Forum Conference '**The Rise of Consumer Health Information in Scotland**' in Glasgow on 4<sup>th</sup> October 2011 looks at the challenges and opportunities these changes bring for information producers and providers. Click [here](#) for information, the conference brochure and programme.

## 7. Cross-border inequalities in access to cancer treatments in England, Wales and Scotland.

A report by the charity Rarer Cancers Foundation (RCF) suggests that patients in Wales are five times less likely to gain access to newer cancer drugs than those in England. In Scotland, the likelihood is three times less than English patients.

The RCF offers advice and information to people with rare or less common cancers and to their families and friends, facilitates supportive networking, raises awareness of these cancers and works to ensure that people with rarer cancers have access to the best possible services. Between 30% and 50% of cancers are classified as 'rarer', either because it affects an unusual site in the body, because it is of an unusual type, or requires special treatment.

As part of its public policy programme, the RCF has conducted research into the processes used by NHS organisations in determining where patients with rarer or less common cancers gain access to the treatments their clinicians wish to prescribe. To learn about RCF and to read the report, see [more information ...](#).

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