Online map reveals true picture of schizophrenia

Choosing Well? data* suggests regional variation in management of schizophrenia across England

London, [date] November 2010 – A new interactive map launched today at www.ChoosingWell.co.uk highlights key differences in the way schizophrenia is managed in England. For the first time the Choosing Well? initiative, supported by Janssen in association with leading mental health charities Rethink and SANE, has brought together a comprehensive range of statistics providing the broadest picture yet of how schizophrenia is managed in England. The initiative aims to highlight the importance of choice in helping people with schizophrenia to stay well and explores the apparent local and regional disparities in the choices people receive regarding their care, as well as showcasing best practice.

The map reveals the postcode lottery of schizophrenia management:

- The extent of choice of medication and psychological therapies that people are being offered appears to differ throughout the country
- When an individual’s mental health declines the data suggests there are clear differences in the percentage of people being admitted to hospital as emergency cases and/or being formally detained across the country (between 0.27% and 75.65% of people admitted as inpatients)*
- The average (median) length of inpatient stay varies between 10 and 148 days*
- In some primary care trusts (PCTs) as few as 40% of people with schizophrenia feel they are involved as much as they would like to be in decisions about their care and treatment*
- There is variation in the amount of prescribing of injectable antipsychotic medication across England*

*The data collected by Choosing Well? is complex and there are significant limitations associated with the interpretation and comparison of such a large number of distinct data sets. When comparing distinct data sets we need to be mindful that the collation methodology will vary and there may be differences in the way information is recorded, which may contribute to some of the variation observed.
With all public services being asked to make efficiency savings, there is no doubt that mental health services will need to respond to the challenge by learning from areas of best practice to deliver a cost-effective joined up package of care, tailored to individual needs.

“The data in Choosing Well? highlights that there is still work to be done to help the hundreds of thousands of people with schizophrenia get a choice in their treatment and care, both when well and at the earliest opportunity should their mental health decline. There is no doubt that services will come under scrutiny as budgets tighten and GP commissioning starts to make an impact but this should not be at the expense of patient care. We need to avoid as far as possible situations where all choice is taken away as this can have a negative impact on an individual’s chances of recovering and their family’s wellbeing” commented Jane Harris, Deputy Director of External Affairs, Rethink.

While there is clear evidence to suggest that appropriate access to the right medication and psychological therapies can help people stay well for longer, the Choosing Well? data indicates that there is currently widespread regional variation in the way schizophrenia services are provided across England. More needs to be done to help ensure all people with schizophrenia have access to the best possible, most clinically effective and outcome based care, including real choice, to help them maintain a good quality of life and ultimately stay well for longer.

“It is important that people with schizophrenia are able to discuss and choose a package of care suited to their individual needs including medication, psychological and other therapies and treatment in hospital if needed during an acute episode” concluded Marjorie Wallace, Chief Executive of SANE “This spotlight on schizophrenia care reveals a disturbingly wide variation in what treatment is offered, depending on the trust which provides mental health services. There has been a succession of reports showing that patients are not given the time from professionals essential to their understanding of their treatment, or consistent support in learning how to manage their symptoms and prevent relapse. This is why the research portraying this ‘true picture’ is timely to ensure that future patients are not forced to play the service user lottery”

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Notes to Editors

For further information on Choosing Well? and the management of schizophrenia in England, including best practice case studies, please visit www.ChoosingWell.co.uk.

For further information, please contact:

David Keown  
Senior Communications Manager  
Janssen-Cilag Ltd  
Tel: 01494 567 498  
Email: dkeown@ITS.JNJ.com

Victoria Boswell-Smith  
Senior Account Manager  
Virgo HEALTH  
Tel: 020 8939 2458  
Email: victoria.boswell-smith@virgohealth.com

Neha Desai  
Senior Account executive  
Virgo HEALTH  
Tel: 020 8939 2485  
Email: neha.desai@virgohealth.com

About Choosing Well?

Choosing Well? has for the first time brought together key data from multiple organisations and sources, to provide the broadest picture yet of how schizophrenia is currently being managed in England. These sources include data from the Mental Health Register\(^6\), population and deprivation measurements\(^7\), Hospital Episode Statistics (HES), the Mental Health Minimum Data Set (MHMDS), data from the Care Quality Commission (CQC)\(^3,8,9,10\) life expectancy data\(^11\), data from the Quality and Outcomes Framework (QOF)\(^12,13\) and antipsychotic medication prescribing data. Choosing Well? consolidates these data sources into an easy-to-navigate map of the country [www.ChoosingWell.co.uk], which can be viewed at Strategic Health Authority (SHA), Mental Health Trust (MHT) and Primary Care Trust (PCT) levels.

About Rethink

Rethink, is a leading national mental health membership charity that works to help everyone affected by severe mental illness recover a better quality of life.

Founded over 30 years ago to give a voice to people affected by severe mental illness and today, with over 10,200 members, they remain determined that this voice will continue to be heard. Rethink helps over 52,000 people every year through their services, support groups and by providing information on mental health problems and their website receives over 500,000 visitors every year.

Rethink’s aim is to make a practical and positive difference by providing hope and empowerment through effective services, information and support to all those who need them. People who use Rethink’s services and their carers are at the heart of their vision and they believe that all those who experience severe mental illness are entitled to be treated with respect and as equal citizens. Rethink carry out research which informs both their own and national mental health policy and actively campaign for change through greater awareness and understanding. They are dedicated to creating a world where prejudice and discrimination are eliminated.
About SANE

SANE is a UK-wide mental health charity established in 1986 with three objectives:

- To raise awareness and combat stigma about mental illness, educating and campaigning to improve mental health services
- To provide care and support for people with mental health problems, their families and carers as well as information for other organisations and the public
- To initiate research into the causes and treatments of serious mental illness such as schizophrenia and depression and the psychological and social impact of mental illness

The charity campaigns to combat stigma and ignorance and improve care through media activity and participation in government and professional initiatives.

SANE Services provide emotional support and information to anyone affected by mental illness, including families, friends and carers. This support is provided on a one-to-one basis through its helpline and e-mail services, while peer support is provided through its Discussion Board.

About Schizophrenia

What is Schizophrenia?

- Schizophrenia can be thought of as experiencing episodes during which reality is perceived differently. The symptoms of schizophrenia can be divided into two groups:
  - Positive symptoms: This might mean hallucinating; seeing or hearing things that other do not, or having delusions; erroneous beliefs that usually involve a misinterpretation of perception or experience
  - Negative symptoms: These are symptoms that involve loss of experience. In some cases, especially with hindsight, families may realise that their relative's behaviour has been changing over a period of time in subtle ways. They may for instance have become slower to think, talk and move, and may have become indifferent to social contact, their sleeping patterns may have changed so that they prefer to remain up all night and sleep all day

Who is affected by schizophrenia?

- Schizophrenia is relatively common and the prevalence is similar around the world; one person in every 100 will develop schizophrenia at some point in their life
- Symptoms can start at any age, but most commonly occur in the late teens or early twenties and if not managed properly can affect the course a person’s life takes

Schizophrenia management

- Treatment for schizophrenia should ideally involve a combination of antipsychotic medicines and psychological therapies
- There are two main types of antipsychotics:
  - Typical antipsychotics - the first generation of antipsychotics that were developed during the 1950s, and
o atypical antipsychotics - a newer generation of antipsychotics that were developed during the 1990s with the aim of reducing the neuromuscular side effects associated with the older drugs

- Atypical antipsychotics are often recommended because they are less likely to cause intolerable side effects. However, they may not be suitable or effective for everyone
- Antipsychotics can be taken orally (as a pill) or given as an injection. Several ‘slow release’ (long-acting) antipsychotics are available whereby patients only need to have one injection every two to six weeks
- Research suggests that mental health service users are more likely to remain well for longer when they are able to make shared decisions with their clinician about their treatment plan

About Janssen

Janssen Pharmaceutical Companies of Johnson & Johnson are dedicated to addressing and solving the most important unmet medical needs of our time, including oncology (e.g. multiple myeloma and prostate cancer), immunology (e.g. psoriasis), neuroscience (e.g. schizophrenia, dementia and pain), infectious disease (e.g. HIV/AIDS, Hepatitis C and tuberculosis), and cardiovascular and metabolic diseases (e.g. diabetes).

Driven by our commitment to patients, we develop sustainable, integrated healthcare solutions by working side-by-side with healthcare stakeholders, based on partnerships of trust and transparency.

More information can be found at www.janssen.co.uk

References: