Now in our 20th year of supporting users to speak out

WILTSHIRE
& SWINDON
USERS'
NETWORK
1991 - 2011

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The Wiltshire & Swindon Users' Network (WSUN) Response to the "Equity & Excellence: Liberating the NHS - Consultation Questions on Information Strategy"

Foreword

The Wiltshire and Swindon Users' Network (WSUN) is a user-controlled organisation that meets the Department of Health "Design Criteria" for an established User Led Organisation (ULO). WSUN supports people who come with the experience of having physical or sensory impairments, using mental health services, being an older person, or having a range of learning difficulties. (Hereafter referred to as marginalised groups, which will also apply to the other 6 equality strands.) Our members are supported to become involved to develop ideas to shape Services, such as Health, Social Care, Community Partnerships with Wiltshire Police Equality Unit and through this contact WSUN supported a Disability Forum. WSUN has also taken a recent commission to set up Focus Groups to undertake Access Audits and scrutinise plans for Disability Access Issues.

We also host a very successful award winning Wiltshire Independent Travel Scheme (WITS).

WSUN believes, and is totally committed to the vision and values of social inclusion, (including Equality and Human Rights for all). Ensuring and promoting Dignity and Respect for all in our local communities. But all Local Authorities (with Social Care Responsibilities) need to ensure ULOs are supported appropriately with continual funding to ensure this vision becomes a "true reality for all," not just a few.

Patient Engagement & Good Accessible Information

One of the most positive aspects of the White Paper is its patient-centric feel and intent. Indeed, Andrew Lansley has said himself that “no decision about me, without me” is the very essence of the Government’s approach. Patients should have more choice, and to this end the White Paper has promised to scrap “top-down targets” in favour of measuring standards and performance through collecting information on patient health outcomes. The new NHS will be required to provide information based on key indicators such as hospital acquired infection and MRSA rates, whilst ensuring patients through the use of Patient Reported Outcome Measures (PROMS) are asked about the quality of their care.

Choose & Book Scheme

The “choose and book scheme” needs to expanded to include the new PROMS measures to ensure informed choices for patients, including hospital mortality rates

Do not assume everyone have access to the internet, to use “choose and book”. So other formats such as telephone, text and postage mail, need to be considered.

Also the website design needs to be reconsidered, in terms of accessibility, such as:-

- large “Click on” buttons
- large fonts
- Audio voice over
- BSL inset interpreter
- Peoples’ first language is not English
- Plain English and plain background

Whilst WSUN endorses the broad principle of empowerment of patient’s information GPs need to improve the way in which they present and explain peoples’ options, considering some of the following areas, where appropriate:-

- The Deaf community have told us GPs and acute Hospital services need to provide British Sign Language (BSL) interpreters for appointments, as they have strongly said, English is **not** our first Language, BSL is!
- Blind People have said they miss vital appointments because the GPs & NHS generally write to them, WSUN believes there is a general assumption people have daily support to read to them, this is **not** always the case.

WSUN's possible solution would be: with the permission of the patient, of course. On the front of everyone's file should be a section on - "Access Requirements". ***Fundamentally, covering what support the person needs to be involved in the "informed decision making" of our treatment*** which might include some of the following, but **not** exclusively:-

What is your preferred way of communicating with us?

- Plain English formats – Easy Read,
- Different languages formats (to include BSL)
- Do you need a professional advocate to support you, or is there a friend or family member, who we need to contact too?
- Would you like to be offered some emotional support, during your appointment? Please tell us who this would be?
- Would you like some counselling after a new diagnosis (Including; peer support of experienced people with the same condition?)
- Are there any Physical, Emotional barriers, Cultural, or Religious or lifestyle choices we need to take in to consideration when discussing your proposed course of treatment?

WSUN believes the Government needs to take another look at the implications of their proposals for mental health, specific learning difficulties, and long-term conditions. To consider whether commissioning these and other marginalised groups, specialist Health and Care services should be under the remit of the NHS Commissioning Board and have ULO and family carer organisations representatives as a mandatory requirement on these Boards. WSUN believes many GPs lack the expertise to commission some care services especially when it comes to certain conditions, and their proposed new powers could lead to a disparity in provision of good accessible information.

For example, the mental health charity Rethink found that only 31% of GPs felt equipped to take on the role of commissioning mental health services.

Quality and Outcomes

A substantial part of the White Paper is dedicated to outlining how the improvement of healthcare outcomes for all will be the primary purpose of the NHS. At a National level, the government believes that the focus and accountability should, as far as possible, be centred on the health and clinical outcomes. Locally, the structures and processes of care will need to be monitored and evaluated using Equality Impact Assessment (EIA).

WSUN, would strongly recommend that the processes of care are transparent and fully accessible in a variety of different formats to meet need and to be fully inclusive of all marginalised groups**.**

A new NHS Outcomes Framework will be the main mechanism for driving up quality and promoting equity and excellence across all services. This will provide an indication of the overall performance of the system within an international context. It will include a focused set of national outcome goals determined by the Secretary of State, against which the NHS Commissioning Board will be held to account, alongside overall improvements in the NHS.

Therefore WSUN believes the NHS Outcomes Framework should be credited for its declared focus. It is clear that the primary focus of any healthcare system should be placed on improving patient health outcomes. The patients "Experts by Experience" programme model should be expanded with ULOs leading on this to empower people, along with clinical input where appropriate. However, it will be crucial that the outcome framework is not too prescriptive and allows flexibility and choice and control for all patients, ensuring consortiums can still be innovative. In the recent evaluation of the Quality Outcomes Framework, evidence shows that one of its central flaws was that targets were set at national and central level not allowing local areas to prioritise their own local needs. It would be deeply regrettable if the Government were to transfer this flawed way of thinking to the new NHS framework.

The new framework must support the delicate balance of providing national leadership, but also allowing local consortia to innovate when considering patient, control and appropriate lifestyle decisions and appropriate information at the right time is the key to this being successful.