

## **An Information Revolution**

### **A response from Counsel and Care**

#### **About Counsel and Care**

Counsel and Care is a national charity working with older people, their families and carers to get the best care and support. We work with older people and their carers to ensure they are aware of and receive their rights and entitlements, and promote choice and control in later life.

We operate a unique and personalised advice service, which deals with around 250,000 enquiries per year, through telephone calls, emails, letters and our website. The frequency of contact we have with older people and the issues raised through this service are used to inform our campaigning and lobbying work.

The advice service is an expanding part of the organisation as ever-increasing numbers of people are in need of advice and guidance about issues affecting older people, particularly on care and support. Enquiries are answered in detail and are followed up with a tailored letter, which emphasises the options available in each case, and provides a resource that people can revisit for guidance.

#### **Counsel and Care's standpoint**

Counsel and Care has considered, with great interest, the Department of Health Consultation 'Liberating the NHS: An Information Revolution'. In particular, we welcome the government's commitments to openness, transparency and comparability in data collection as well as providing access to joined-up systems of information and guidance. We are also pleased to hear that the NHS will support patients and service users to be active participants in their own care.

We would like to address the three points mentioned in 1.7: informing, engaging, and empowering. These best correspond to the mission of Counsel and Care and throughout this consultation document represent the most important and powerful tools with which to help older people who may otherwise be missed out of the complex health and social care system. However, these tools cannot be implemented

appropriately or with real success if there is not a systematic information gathering and sharing infrastructure on which service users can rely to gain valuable information.

### **Informing:**

The reliance of the NHS and adult social care services on information which is not comparable or easily accessed by patients leaves many older people as passive recipients of care, instead of being active and willing advocates for their own needs. This is particularly relevant in adult social care where multiple and sometimes conflicting needs are often not properly communicated between health and social care professionals and service users. This is due to a distinct lack of joined up working between the two sectors. Therefore, it is in the best interests of all professionals involved as well as the older person, their carer and/or family to have the best possible information available to them.

It is Counsel and Care's understanding that improving the way that information is shared between health and social care professionals would ameliorate a great deal of stress incurred when service users are not aware of their full rights, abilities and all of the options available to them. With appropriate statistical data gathering and specific and understandable personal patient reports, available to all relevant parties, patients will have the best possible chance of receiving high quality and consistent care that is in harmony with their needs and wishes. Health and social care agencies should utilise the NHS Caldicott Guardian manual 2010 to review and implement best practice around information sharing.

### **Engaging:**

Counsel and Care welcome the initiative to create one, comprehensive, record of a patient's entire health and social care history. However, there are some concerns that this will not be accomplished in a way that is transparent and available to the patient. What are the measures the Department of Health will be making to ensure that patients can verify and participate in their care recording? Publishing data in basic formats so that people can make meaningful choices about their care and support, particularly in light of the personalisation agenda being rolled out by the government, is of utmost importance in the goal to engage older people in their care.

Similarly, there are concerns about how such an information revolution will be accessed from the front line. Improvements in information technology have made it possible for older people to understand and receive care through technologies such as telecare, which may allow them to maintain independence for longer. However, this is in tandem with the very real concern that an over reliance on technical or computer based

programmes will disadvantage those service users who are not computer literate or do not have access to the internet. This may disproportionately affect older people and their carers, who may also be an older person themselves with health and social care needs.

### **Empowering:**

The goal of empowering people to take charge of and be participants in their care is an important one. The personalisation agenda, along with Liberating the NHS, could be seen as important tools in allowing older people to be managers of their own treatment. However, the availability of information is not sufficient to empower older people and will not make significant change if it is not disseminated properly. There are many older people who have health and social care needs which do not allow for them to be able to fully partake in the Information Revolution. They may need carers or family members to support them in order to keep their records and advocate for suitable care.

The document does not clarify how routine access to care records supports those people to understand or receive quality information and advice about what can be done with those records. Older people may become disempowered by a system with no clear framework for support. This is in addition to the necessity of a health and social care infrastructure with a robust complaints process. One in which patients, their carers, or families cannot just 'correct errors and see changes when they are made' but can assess, contest and address any issues they have when endeavouring to get the appropriate care.

### **Summary**

Improved joint working between health and social care is integral to making the Information Revolution work, together with an agenda that informs, engages and empowers to ensure better care for older people, who are the biggest users of health and social care services. This will not be possible if there is no clear framework for information sharing between the health and social care sectors. Not all people will be capable of participating in the Information Revolution and will need support to access information and guidance. This must be accounted for when building a data gathering infrastructure which relies on personal ability to maintain records and be one's own 'expert' or advocate. Counsel and Care is pleased to hear that the Department of Health is focussing on patient-centred outcomes and transparency in health reporting.

It is of the utmost importance that all patients and service users have consistent and quality advice and information in order to receive the best possible outcomes.

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