

Plymouth LINK Stewardship Group's response to proposals contained in the Consultation *Liberating the NHS: An Information Revolution*

Plymouth LINK supports the need for an Information Revolution and improved information and communication between patients and services.

Specifically, we would like to comment on the following points:

Question 7: *As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?*

LINK feedback highlights that patients do not experience services which are flexible enough to meet their information and treatment needs. Methods of communication will need to be varied to meet the cultural, access and language needs of different groups; patients should have choice of methods of communication – for example, not everyone can read / write so written information is not always appropriate. Services should not assume what patients want.

Question 9: *What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?*

information should be responsive to what the patient is asking for. At a time when patients are stressed or anxious, barriers of language, poor communication and time need to be addressed. LINK feedback shows that these are common experiences.

Question 11 : *What additional information would be helpful for specific groups - eg.*

- users of maternity and children's health services;
- disabled people;
- people using mental health or learning disabilities services;
- the elderly;
- others?

Patients themselves are best placed to identify additional information. Specific groups should be consulted on the information needed (for example, wheelchair users will be able to tell you what is important to them – if you are not in a wheelchair, then it might not occur to you).

Question 12: *What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?*

LINK feedback highlights existing difficulties carers find in getting information about their cared-for ones and in being involved in decision making. Carers need to be seen as partners in care and involved in communication about the cared-for (not just told).

Question 16: *How can the benefits of seamless and joined up information be realised across the many different organisations (NHS and non-NHS) a service user may encounter?*

LINK feedback shows that health and social care are not working together as effectively as they need to and services quote systems as a key barrier to this happening. Current services often work in isolation and do not have information/communication/ understanding of the constraints and challenges of other services. Where there is a potential interface, services should be communicating to share patient information and work together to overcome their own issues. Transition between services should be monitored (and penalised where failing) as part of the regulation of services.

Question 20: *What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?*

Services should work more closely with independent groups (such as LINKs) to help gather views. Independence often encourages a more honest response.

Question 21: *What are the key changes in behaviour, systems and incentives required to make the NHS and adult social care services genuinely responsive to feedback and how can these be achieved?*

Targets around gathering of patient feedback, evidencing work with LINKs/HealthWatch, response to feedback, should form part of services' monitoring and assessment and part of their regulation. 'Mystery shopping' should form part of a regular cycle of checking services.

In the private sector customer satisfaction guarantees business. Health and social care services need to be thinking in the same way. Patients' ability to vote with their feet will be an incentive for services to work in a more patient-centred way.

Question 22: *Which questions, if asked consistently, would provide useful information to help you compare and choose services?*

Patients need to evaluate services by asking the following kinds of questions:

- would you use this service again?
- rating services in relation to:
 - staff attitudes;
 - patients' involvement in their own care;
 - whether they were listened to;
 - quality of information;
 - accessibility of service:
- where would you go next time?

Question 23: *What will help ensure that information systems - and the data they collect - are appropriate to support good commissioning at different levels, including decisions by individual patients, GP practices, GP consortia, service providers, local authorities and the NHS Commissioning Board?*

Information from patients about the following will help inform future commissioning:
unmet needs (what service did they want but not receive?);
waiting lists (indicating the need to increase service provision);
evaluation of the service provided.

Question 31: *How can a health and social care information revolution benefit everyone, including those who need care most but may not have direct access to or know how to use information technology? This might include those who do not have access to a computer or are remote and can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.*

No two people are the same and one size does not fit all, therefore we need a wider range of information opportunities that are developed after a mapping of the information needs of people, communities and groups in an area. A communication strategy should think wider than a website or leaflet and use different routes to access information, i.e. 'community champions', community venues, use of community and voluntary sector, clubs that meet, etc..