

Adult Learning Disability Survey for Acute Hospital Trusts

Picker institute Europe have developed and piloted a short survey to ask adults with a learning disability about their recent hospital care. The survey is relevant to inpatients who have recently received care in an acute hospital trust.

Background

The Mencap '*Death by Indifference: 74 deaths and counting*' report 2013 highlighted the lack of progress in addressing the health inequalities experienced by people with a learning disability. The report recommended that:

- Standards of health services for people with learning disabilities should be monitored to ensure they are receiving care appropriate to their needs;
- NHS organisations should involve and consult patients (and carers of patients) with a learning disability, to plan and develop services based on their views and interest.

The Department of Health established and funded the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Findings show that people with learning disabilities continue to have poor experience and outcomes compared to people without a learning disability. The Government response in July 2013 made 18 recommendations, two of which are:

- Clear identification of people with learning disabilities on the NHS central registration system in all healthcare record systems
- Reasonable adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.

The Picker Institute's Learning Disability Survey supports the above recommendations, since it relies on Trusts recording patients with a learning disability, and asking them to comment on their hospital experiences to ensure that the service is being delivered in a manner suitable to their needs.

About the survey

The adult Inpatient Learning Disability survey was developed by Picker Institute Europe on behalf of the Leeds Teaching Hospitals NHS Trust in 2012. The survey has been thoroughly tested with acute inpatients who have a learning disability to check for comprehension and recall. It is in easy read format, and has been reviewed by a learning disability charity and their members.

The questionnaire includes twelve key experience questions regarding a recent hospital inpatient episode. The survey asks about:

- Communication with doctors and nurses
- Pain control
- Information about operations
- Discharge information
- Overall impression

Two open-ended questions at the end of the survey ask whether the patient has anything else to say (positive or negative) about their hospital visit.

2. Did you **understand** what doctors and nurses said to you?

1 Yes

2 Sort of

3 No

4 Not sure



What the survey provides

The survey allows acute NHS Trusts to:

- Gather feedback about experiences of learning disability inpatients in a manner appropriate to their needs and abilities
- Identify where there is room for improvement
- Benchmark against other participating NHS Trusts (if running at the same time)
- Monitor performance over time (if the survey is repeated in the future)

How to take part in the survey

It is likely that we will offer the learning disability survey to all acute NHS Trusts in 2014 using a mail-out methodology, and it will run if we get sufficient interest. **Please note** that participation is dependent on Trusts being able to identify recently discharged inpatients that have a learning disability who are eligible to participate. Costs will vary according to throughput of inpatients with a learning disability. The Picker Institute would oversee all aspects of the survey fieldwork (printing and mailing of questionnaires, with reminders to non-responders), data entry, full reporting, additional analysis upon request, and an on-site presentation of key survey findings. Full details are available upon request.

Further information

If you would like further information about the learning disability inpatient survey, please contact Amy Tallett on 01865 208115 or email amy.tallett@pickereurope.ac.uk.

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