NALD
NATIONAL AUDIT OF
LEARNING DISABILITIES
CCQI

Report on the National Audit of Learning Disabilities Feasibility Study (NALD-FS)

RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

RCGP Royal College of General Practitioners

HQIP
Healthcare Quality Improvement Partnership

Executive summary

Background and aims

Concerns have repeatedly been expressed about the quality of healthcare that people with learning disabilities receive in the NHS. Clinical audit can be an effective method for improving the quality of healthcare especially when existing standards are poor. This feasibility study for a national audit of learning disabilities examined the acceptability of data collection methods and the role that audit data could play in raising the standard of care provided. The audit team used these results to recommend how a future national audit should be conducted, including recommendations for standards, recruiting services, data collection methods, and helping services use audit data to improve the quality of care they provide.

Participation and data received

Primary care data were extracted for 794 people with learning disabilities from 12 primary care practices. In secondary care nine acute general hospitals and seven mental health services participated. 176 case notes were audited and each secondary care service provided information on systems used to flag people with learning disabilities, use of reasonable adjustments, liaison with specialist staff, and staff training. These data were supplemented with 614 staff and 141 patient and carer surveys.

Feedback from stakeholders

Commissioners, providers and service users who reviewed the study's findings supported investment in a future national audit of learning disabilities and saw potential to drive much needed change in this area. Feedback from study sites indicated that a national audit is feasible and valuable. Primary care sites highlighted their need for contextual information to help interpret the data. Some study sites shared ways they were using audit data to help improve their service. All secondary care study sites, and those primary care sites that received support to review their data, said that they would be willing to participate in a future audit of learning disabilities.

Findings and recommendations

Results of the study confirm that the quality of care for people with learning disabilities falls below recommended standards. Variation in practice across study sites suggests that it is possible to improve the quality of care people receive.

Primary care standards in a national audit should address whether physical and mental health monitoring is adequate for people with learning disabilities. Based on stakeholder feedback, the audit should also collect information about interventions associated with these standards. Audit data should be reported to individual practices as well as at a commissioning level, to maximise engagement with quality improvement.

A national audit of secondary care should include acute and mental health providers, as well as specialist learning disability services. Private providers commissioned for NHS patients should also be included within the audit's remit. Standards in secondary care should be centred on physical and mental health monitoring, staff training, reasonable adjustments and delivery of person-centred care. There should be a core set of standards applying to all types of service, and a subset developed to audit priority issues specific to each service. Experience measures for staff, carers, and patients are necessary.

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Rationale and potential impact of a future audit

This feasibility study aimed to answer two questions: (1) would a national clinical audit be able to generate reliable data about the quality of care provided by healthcare organisations to people with learning disabilities, and (2) is a national clinical audit an effective way of driving improvement within NHS organisations? The findings of this study and feedback collected from study sites and stakeholders indicate that the answer to both questions is yes.

Need for an audit

There are over 1.5 million people with a learning disability in the United Kingdom[i]. We know inequalities exist in the provision of healthcare to people with learning disabilities; numerous reports[4,6,11,12] have revealed a high level of unmet need. This has resulted in less effective treatment and in some instances to premature death[6]. A poor overall level of care and variation in practice were found in the feasibility study. In primary care the low uptake of annual health checks mirrored the current national levels, there was unsatisfactory physical health monitoring and health promotion, and substandard recording of health action plans. Secondary care services were found to have difficulty identifying people with learning disabilities and making the reasonable adjustments that people needed. Learning disability was not included in mandatory training programmes and some staff reported feeling out of their depth when caring for this patient group.

Support from stakeholders

Study sites

> ***"For all trust boards to sit up and treat learning disabilities as a priority, we need a national audit to stare them in the face."*** – Audit lead, secondary care study site.

Primary care sites said that benchmarking information was useful as it allowed them to reflect on the data which led to discussions about implementing quality improvement. Practices that had the data presented and discussed at a clinical meeting said they would be willing to take part in a national audit. Secondary care study sites commented that the workload for this audit was manageable and in line with other national audits. They were receptive to the audit findings and all secondary care sites said they would be willing to take part in a national audit.

People with learning disabilities and carers

> ***"This audit you're talking about is long, long overdue...what we're talking about here could have been said 10, 15, 20 years ago and the fact that your findings show so little change in all that time just demonstrates to me that we've not been pushing it hard enough."*** – Carer of a person with a learning disability.

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[i] http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/

The audit team consulted people with learning disabilities and carers, who agreed that the feasibility study was in line with their priorities and supported a national audit in this area. People with learning disabilities expressed frustration at being patronised and ignored by health professionals, and carers voiced their anger at having to constantly fight for adequate care.

Other stakeholders

> ***"I can't think of a more important national clinical audit in mental health that isn't already being done. We've got one for psychological therapies, one for dementia and one for schizophrenia, so this absolutely is the top priority."*** – Special Policy Lead and Lead for Mental Health, Care Quality Commission.

Overall, stakeholders recognised the usefulness of audit and how feedback to providers could be used for quality improvement. Stakeholders' suggestions for improving the audit have informed the recommendations for a future audit.

Impact of an audit

Clinical audit offers providers the opportunity to evaluate their own practice against evidence-based standards, and encourages alignment with established best practice and national guidelines. Not only does clinical audit allow services to reflect on their compliance with best practice standards, it also allows them to compare their performance against other services. The value of this was confirmed by participating study sites, who reported finding such benchmarking helpful.

> ***It's helpful to know how we are doing as a practice compared to others in our locality and certainly made us think about certain aspects of care we provide"*** – GP, primary care study site.
>
> ***"The national average benchmark and findings give us enough evidence to see where we are in relation to others. If other hospitals are doing well it gives us leverage to say if that hospital has this, why don't we?" -*** Audit lead from an acute hospital.

A national audit would need to complement existing or upcoming quality improvement initiatives in the learning disability field. The strength of using audit as a method for promoting quality improvement in tandem with such initiatives lies in its ability to generate widespread learning, while supporting individual services to prioritise areas for improvement specific to them. As clinical audit is cyclic, the focus is not just on quality improvement, but also sustaining that improvement over two or more rounds of audit. Providers would be able to evidence any improvement, and this is particularly illustrative when the views of clinicians, service users and carers are embedded in the clinical audit process.

Challenges

Engaging primary care services

Limited time and competing priorities are challenges that cut across all of primary care. Currently there is no obligation or financial incentive for primary care sites to participate in a national audit. This places it at a disadvantage against other national programmes. Despite this, once study sites were provided the right information in the right way, practices were keen to participate.

Primary care services need to be engaged throughout an audit cycle; firstly to ensure they sign up and allow access and sharing of their data; and secondly to ensure they understand and use their data for ongoing quality improvement. Engagement at the practice and commissioning level would be crucial to ensure success as there are different levers, motivations and opportunities at both levels.

Identifying patients in secondary care services

Many hospitals do not have a systematic way of flagging people with learning disabilities using their service[6,12] and only a minority of acute and mental health services in the feasibility study had an electronic flagging system. Without this, it is difficult to keep track of this patient group and monitor whether appropriate reasonable adjustments are being made across the care pathway.

Each secondary care service was required to identify 15 eligible patients for the case note audit. Some found this difficult because without a flagging system they had to rely on community teams, learning disability liaison nurses and ICD-10 coding to identify eligible patients. In the absence of an electronic flagging system, the bias of using specialist staff to identify patients would need to be considered. It may not provide a fair representation of people with learning disabilities using health services, but it would generate a bigger patient sample.

Alignment with national priorities

The feasibility study focussed on the mental and physical care of people with learning disabilities. This complements the Mental Health Strategy for England[7], and the ‘parity of esteem’ agenda[15]. All providers of health services to people with learning disabilities should consider the relationship between physical and mental health by adopting a holistic approach to care. A future audit of learning disabilities should consider both physical and mental health irrespective of the care setting, as was the case in the feasibility study.

The NHS Mandate[9] highlights the key priorities of the English NHS over the next two years. Efforts to provide safer, more effective and more compassionate care for people with learning disabilities lie at the core of this report's proposal and would assist services in meeting several principles in the Mandate including: preventing people from dying prematurely; enhancing quality of life for people with long-term conditions; protecting people from avoidable harm; and ensuring that people have a positive experience of care. NHS Wales aims to improve the experiences and outcomes of people with learning disabilities when they access general hospital services by encouraging better integration, information sharing, and communication between general hospital and specialist services. NHS Wales' *1000 Lives report*[13] on improving hospital care for people with learning disabilities highlights the need to systematically identify people with learning disabilities, improve communication, deliver person-centred care, and improve discharge planning, as priority areas.

The feasibility study also reflects the Care Quality Commission's Essentials Standards of Quality and Safety[3]. This includes the importance of: (a) involving service users and carers in decisions about care and treatment, (b) delivering person-centred care, treatment and support, and (c) ensuring staff have the appropriate training and experience to deliver high quality care.

Further development

The audit team propose a national audit of learning disabilities be undertaken in primary and secondary care services. In secondary care this should include acute and mental health providers, and specialist learning disability services. This is because people with learning disabilities are at a higher risk of developing physical and mental health problems, compared to the general population[ii]. Private providers should also be considered for inclusion as otherwise the audit will overlook some services that have been known to provide poor care to NHS patients (for instance Winterbourne View Hospital[8]). Once an audit in these sectors is established, a future audit of learning disabilities should aspire to track patients through primary, secondary and community care. To ensure that care is person-centred and continuous, it is vital that service users receive an integrated approach.

In primary care, lessons learnt from other primary care national audit models should be considered especially data collection and quality improvement methods used. In particular, the pilot of the National Clinical Audit and Quality Improvement Programme for Chronic Kidney Disease, in primary care.

A national secondary care audit should consider using a prospective case note study design and its impact on the size of local case note samples. Doing so would generate a more up to date picture of the care provided and allow a more integrated approach with other health providers, such as primary care.

[ii] http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187705/?view=Standard

The results of this study demonstrate that a future national audit is feasible and would generate information that commissioners and providers can use to drive improvements in the quality of primary and secondary care for people with learning disabilities. We have developed a series of recommendations for a future national audit of learning disabilities based on key learning from the study and feedback from participating study sites, patients and carers and other stakeholders.

Standards for a national audit

What we achieved in the feasibility study

The feasibility study demonstrates that audit standards can be used to measure the quality of care provided to people with learning disabilities in primary and secondary care settings. A total of 28 criteria were developed for primary care using a consensus process. A total of 21 standards were developed for secondary care. These were derived from a review of current literature and consultation with the audit's advisory group.

Next steps for a future audit

Primary care:

1. The primary care standards used in the feasibility study should be used as the basis for a primary care component of a future national audit of learning disabilities.
2. A future national audit should collect data on interventions and treatments, in addition to data on monitoring and screening.

Secondary care:

1. A core set of standards should be used for both mental health and acute hospitals, and additional subsets of standards developed specifically for each setting.
2. Consideration should be given to how services are meeting standards based on objective evidence. A future audit should require services to evidence what they actually provide to patients with learning disabilities.

Primary and secondary care:

1. Key Performance Indicators (KPIs) should be identified to support services in prioritising areas for action. They should be based on a small number of core standards that every participating service is expected to achieve. A developmental approach to KPIs is recommended.

Recruiting sites

What we achieved in the feasibility study

A total of 60 GP practices were approached about the feasibility study and 14 agreed to participate. Due to competing priority areas, some primary care services were reluctant to participate. 11 acute hospitals and eight mental health services were approached to participate in the feasibility study. In total, nine acute hospitals and seven mental health services participated. All secondary care services said they would be willing and able to participate in a future audit of learning disabilities.

Next steps for a future audit

Primary care:

1. Participation in a future audit would be influenced by the approved consent model adopted. Due consideration should be given to the impact an opt-in model may have when commissioning a national audit (e.g. timing, resources) and ability to report at a national level (e.g. potential for representative sample only).

Secondary care:

1. A future audit should include acute and mental health providers, as well as specialist learning disability services.
2. The secondary care component of the audit should be extended to include private sector services that are commissioned for NHS patients.

Methods to extract and collect data

What we achieved in the feasibility study

Data were successfully extracted from 12 primary care study sites. This involved a third-party organisation writing and extracting data via MIQUEST queries with minimal involvement from individual practices. All secondary care services submitted an organisational checklist and a total of 176 case notes were received. Staff, patient and carer questionnaires were also distributed - a total of 614 staff questionnaires and 141 carer and patient questionnaires were received. The main challenge for secondary care services was identifying patients for the case note audit as they needed to have a flagging system in place to identify people with learning disabilities. In the absence of a flagging system, services relied on community teams, learning disability liaison nurses and ICD-10 coding to identify eligible patients.

Next steps for a future audit

Primary care:

1. Different models of implementing a national audit and the likely success and challenges associated with each should be considered. Some models rely very little on practice engagement (e.g. National Diabetes Audit), whereas others plan to enable practices to access real-time audit data, and actively encourage services to undertake their own quality improvement activity (e.g. National Chronic Kidney Disease Audit).

Secondary care:

1. A retrospective case note audit should be used to provide information about the patient's journey through the service being audited, from admission to discharge. Each service should submit data on a consecutive sample of 50 people with learning disabilities. To be eligible, patients must be aged 18+, have a diagnosis of a learning disability, and have had at least one overnight stay in the service. Services should record how each patient has been identified for the audit e.g. flagging system, coding, or information from specialist staff.
2. Staff, patient and carer questionnaires should be used in a future audit of learning disabilities. Study sites found this information most useful, and welcomed local feedback even if based on a low number of survey returns.
3. A short organisational checklist should be used to examine systems that hospitals use to: (a) flag people with learning disability and the reasonable adjustments they need, (b) liaise with community teams, and (c) provide staff training. Data collected should include the number of people identified through the flagging system, numbers of staff trained, and copies of easy-read information sheets used.
4. Community learning disability teams are very well placed to give feedback on key aspects of the quality of care provided by local primary and secondary care services. Teams should be invited to give feedback on areas of good practice and areas of concern especially regarding services' ability to make reasonable adjustments, the quality of interaction between patients and staff, and the ability of staff to deliver person-centred care.

Disseminating local audit findings

What we achieved in the feasibility study

Both primary and secondary care study sites received a report showing their local data benchmarked against all data received. Study sites were asked to comment on the report and whether it could support them to change their practice. Primary care sites that received support in interpreting the findings found the reports useful and reported that they would be interested in participating in a national audit. Secondary care study sites also found their local reports useful, particularly in using it as evidence for the need for service improvement.

Next steps for a future audit

Primary care:

1. Reporting should occur at both a practice and Clinical Commissioning Group (CCG) level. This would be crucial to demonstrate the need for change, facilitate any structural or funding support, and continual engagement to encourage and bring about change. Engagement of commissioners and practices should be seen as key to the success of any future national audit and reporting should be tailored for both, therefore making a national audit more accessible to CCGs should be a priority.
2. Resources will be needed to engage primary care services in the audit and to act on results. This will be required at a CCG and practice level to provide contextual information as to why the data extracted are important and the implications for patient outcomes if this is not acted upon.

Secondary care:

1. All services should be benchmarked for the ‘core’ audit standards i.e. ones that apply to all types of health setting.
2. Data should be benchmarked across acute hospitals, mental health services, and specialist learning disability services in the NHS and private sector, according to ‘service-specific’ standards.

1.1. Developing standards

The first objective of the feasibility study was to develop a set of provisional standards for the healthcare of adults with learning disabilities, based on existing literature and evidence.

Two sets of standards were developed – for primary and secondary care. This section of the report describes how these were developed for the feasibility study, and presents the standards and criteria used.

1.1.1 Primary care

The criteria put forward for the consensus process are based on a similar process used to develop the Quality and Outcomes Framework (QOF) standards[5]. The National Institute for Health and Care Excellence suggested a review of standards. Further potential standards and criteria were identified through reports and a review of evidence published through the Public Health Observatory, which is now part of Public Health England.

Consensus process

Consensus techniques are increasingly used to combine available evidence with expert professional opinion, to develop standards where the available evidence is patchy or inconclusive.[2,10] Consensus techniques are democratic in that the rating of every panellist carries equal weight. A list of the experts who took part in the consensus process is provided in Appendix 3.

A modified consensus process using aspects of both the Delphi Technique and the RAND Appropriateness Method[1] was used. There were two rounds of rating. No audit standard was added or deleted between rounds. Both rounds were undertaken by email. Panellists were sent a summary report of the available evidence relating to each audit standard that they were asked to rate in round one. In this respect, panellists were asked to use three criteria when considering their ratings:

1) The summary of evidence accompanying the audit standard in round one.
2) Their own professional experience.
3) In addition, the feedback of ratings from round one.

Audit criteria were rated on integer scales of 1 to 9:

- 1 to 3 meant they thought the criteria are not necessary for high quality care;
- 4 to 6 meant the criteria are an uncertain measure of quality of care;
- 7 to 9 meant that they thought the criteria are a necessary measure of quality of care.

Necessary care (7 to 9) refers to care that has a reasonable likelihood of providing benefit to patients and improving patient outcomes, or that it would be improper not to provide the care.

Ratings of necessity and consensus

Within a consensus technique, there are two aspects to the rating process for each scale and for each audit criteria: (a) the overall panel median rating, and (b) the level of agreement within a panel's ratings for each audit criteria, defined according to the distribution of the panellists' ratings on the 9 point scale. The rating for each audit criteria therefore contains a number and a letter, as follows:

Rating of necessity

1-9: The number represents the overall panel median for that audit criteria. A criteria has to have an overall panel median rating ≥7 to be rated as necessary.

Rating of consensus

A: Agreement: ≥80% of the panellists' ratings within the same 3 point range on the 9 point scale as the overall median
D: Disagreement: 33% of ratings in the range of 1-3 and 33% of ratings in the 7-9 regions for the same criteria
Equivocal: Absence of agreement or disagreement

To be included in a final recommended set of necessary audit criteria, an audit criterion had to be rated ≥7 for necessity with agreement (see Appendix 5 for outcome of consensus process for those criterion that scored ≥7).

1.1.2 Secondary care

Before the feasibility study began in May 2013, the NALD advisory group (see Appendix 4) were asked to prioritise the main issues that audit standards should address and how these would be measured. Their advice was supplemented by a review of current legislation, inquiry reports, research papers and best practice guidelines[iii]. The literature review focussed on results, recommendations, guidelines and conclusions. This was used to develop standards with further consultation with the advisory group.

This process ensured that audit standards covered high-level issues, reflecting those highlighted in reports about the care and experiences of people with learning disabilities. Some key themes emerged:

- Making reasonable adjustments
- Physical health and recording of information
- Capacity and decision making
- Managing challenging behaviour
- Psychotropic medication
- Discharge processes
- Staff training

The literature review highlighted that the audit should not be limited to collecting information about the health of the person receiving care, but should also examine services' ability to meet the needs of people with learning disabilities, deliver person-centred care and involve the person and their carers/family in healthcare decisions. This helped determine which audit methods could feasibly be used. A common set of standards was developed for both acute and mental health care settings.

[iii] http://www.rcpsych.ac.uk/pdf/NALD%20Standards%202013.pdf

Primary care audit criteria

	Learning disability and recording of information
1	Patients receive an annual health check.
2	Patients who had an annual health check also had a Health Action Plan.
3	Patients under the age of 18 who have a learning disability (coded).
	Physical health and recording of information
	In the preceding 12 months:
4	patients had their BMI recorded
5	patients with an active diagnosis, and drug treatment of epilepsy, had their seizure frequency recorded
6	patients with an active diagnosis, and drug treatment for epilepsy, have been seizure-free
7	patients with Down's Syndrome had a record of blood TSH
8	patients with Down's Syndrome, on treatment for thyroid disorder, had a record of blood TSH within therapeutic level
	Patients with an annual health check in the preceding 12 months also had a:
9	vision assessment
10	swallowing assessment
11	hearing assessment
12	Patients had an influenza vaccination in the last flu campaign.
13	Patients in high risk groups (coronary heart disease , stroke or TIA, diabetes, DM18, COPD , All ≥ 65 years, chronic neurological disease, CKD, long stay care patients) had an influenza immunisation in the last flu campaign.
14	Women aged 25 - 64 had a cervical cancer screening test in the last five 5 years.
15	Women aged 50 – 70 had a breast cancer screening in the last 3 years.
	Psychotropic medication
	In the preceding 12 month patients on antipsychotic medication had a record of their:
16	smoking status
17	lifestyle advice for smoking cessation
18	lifestyle advice for safe alcohol consumption
19	lifestyle advice for a healthy diet
20	BMI
21	HbA1c
22	total cholesterol
23	blood pressure
	Mental health and recording of information
	In the preceding 12 months patients on the (QOF) mental health register had a record of their:
24	alcohol consumption
25	blood pressure
36	cholesterol
27	blood glucose
28	Patients with Down's Syndrome who had dementia recorded as a current active problem.

Secondary care audit standards

	Making reasonable adjustments
1	The service's healthcare system can identify people with learning disabilities and any reasonable adjustments they require.
2	Services make reasonable adjustments for people with learning disabilities, based on the individual needs of the patient.
3	The patient's health passport, or similar document, is used by the service to help them care for the patient.
4	The service has ready access to specialist learning disability services.
	Physical health and recording of information
5	The patient receives a comprehensive physical examination within 24 hours of admission. This includes blood pressure, pulse and temperature.
6	The patient receives high quality nutritional care, based on their individually assessed needs.
7	The patient's current mobility needs have been assessed and recorded.
8	Patients with epilepsy have a risk assessment in their notes.
9	Patients with epilepsy have a description of their seizures recorded in their notes, including type, frequency and duration.
10	An assessment of the patient's preferred method of communication is recorded and used.
	Capacity and decision making
11	Discussions about care involve the patient and their carer/family where relevant.
12	The patient's capacity is assessed and recorded, whenever decisions need to be made about their care.
13	If assessment of the patient shows that they lack capacity to make a decision about their care, a best interests meeting takes place and involves them and their carer/family where relevant.
	Managing challenging behaviour
14	If the patient presents challenging/aggressive behaviour, the reasons for this are investigated and documented.
15	If the patient presents challenging/aggressive behaviour, de-escalation is tried before use of physical restraint or pharmacological intervention.
	Psychotropic medication
16	If the patient is taking psychotropic medication, this is reviewed during their stay.
	Discharge processes
17	The discharge summary includes information about support and care needs the patient has following their stay at the service.
18	Discharge planning involves the person with learning disabilities and their carer/family where relevant.
19	Informal carers are signposted to an assessment of their current needs in advance of the patient's discharge.
	Staff training
20	All staff should receive training in learning disabilities.
21	Staff feel equipped to respond to the needs of people with learning disabilities.

1.2. Developing methods

An objective of the feasibility study was to develop methods for collecting data that are acceptable, feasible, and generate valid and reliable information about the quality of care provided by primary and secondary care services. The intention at the outset was to collect information about the experiences of people with learning disabilities and their carers.

This section of the report details the methods used in the primary and secondary care audit, and the processes undertaken to develop audit tools.

1.2.1 Primary care

Extraction of data from primary care record systems is an acceptable audit method of large scale data collection in primary care, as evidenced in the successful National Diabetes Audit[iv].

A high level analysis of a variety of data extraction methods was undertaken. Methods were discounted for the feasibility study due to:

- Limitations with availability (e.g. General Practice Extraction Service, GPES[v]).
- Development time and/or costs (such as the Health and Social Care Information Centre; in-practice based data collection system e.g. the GRASP tool [vi]).
- Limitations with accessing all of the data required (e.g. Calculating Quality Reporting Service, CQRS[vii]).
- Burden of data collection.

Based on this analysis, a decision was made to use MIQUEST queries to access the primary care data.

'MIQUEST is a methodology and an approach to common data access which enables enquirers to execute queries and extract data from different types of general medical practice computer systems using a common query language. It has been endorsed by the NHS Executive as the recommended method and therefore adopted as a standard, for this purpose.'[viii]

A third party organisation, PRIMIS, was brought in to write the MIQUEST queries and extract the data. Only data that can be extracted from the primary care record system were considered for this feasibility study due to resource limitations. Hence, information on the experiences of people with learning disabilities and their carers was not collected from primary care.

[iv] http://www.hscic.gov.uk/nda
[v] http://www.hscic.gov.uk/gpes
[vi] http://www.nottingham.ac.uk/primis/tools/audits/grasp-copd.aspx
[vii] http://systems.hscic.gov.uk/cqrs
[viii] http://www.connectingforhealth.nhs.uk/systemsandservices/data/miquest

1.2.2 Secondary care

One set of audit tools were developed to collect data from acute and mental health inpatient services which allowed for comparisons across both settings. These tools were:

- Organisational checklist
- Case note audit tool
- Staff questionnaire
- Patient questionnaire
- Carer questionnaire

Two additional audit tools were developed specifically for community learning disability teams (CLDTs), as the advisory group and audit team recognised their potential for providing professional opinion on the quality of local inpatient care. These tools were:

- CLDT feedback survey – this elicited community teams' views on how well local inpatient services (a) made reasonable adjustments for people with learning disabilities, and (b) involved community teams to ensure a positive patient experience.
- CLDT observation survey – community teams were asked to observe clients' visits to the inpatient services and rate how well secondary care staff communicated with them.
- CLDTs were also sent patient questionnaires to distribute to clients who were known to have had an inpatient stay during the data collection period.

Audit tools for secondary care services

Organisational checklist

The literature review highlighted the importance of services identifying (a) people with learning disabilities, (b) patients' needs for reasonable adjustments to be made, and (c) the extent of awareness training for staff. The effectiveness of an organisational checklist was considered, as the National Audit of Dementia[14] found despite reports that organisational structures and policies were in place, this was not always reflected in the actual care delivered to patients. The checklist was therefore limited to information about reasonable adjustments and provision of training, as this could be cross-checked against data generated by other audit tools. Each participating acute and mental health site was asked to complete the organisational checklist.

Case note audit

The development of this tool was a greater challenge as it needed to apply to acute and mental health inpatient services. The aim was to reduce the burden for audit leads, without compromising its ability to capture vital information about the care they provide.

Each participating study site was asked to audit 15 case notes of people with learning disabilities. The first three cases were re-audited so that a reliability analysis could be carried out (see Appendix 6).

Table 1: The eligibility criteria for the case note audit.

Eligibility criteria	Reasons for the criteria
Diagnosis of a learning disability	If patients with a *suspected* learning disability were included, further standards and questions in the case note audit tool relating to diagnosis would be necessary. To make standards and tools simple and fit-for-purpose, the advisory group agreed to restrict eligibility criteria to people with a diagnosed learning disability.
18 or over	The advisory group discussed the importance of care of children with learning disabilities and young adults in transition of services. Due to time and resource constraints, the focus of the study was restricted to people over the age of 18.
At least one overnight stay in the service	This was to allow for the experiences of people with learning disabilities using services for a short period of time (e.g. accident and emergency department, short stay units), as well as those admitted onto wards. A minimum of one overnight stay was required to allow standards to be measured on the discharge process.
Discharged between 1/08/12 and 31/07/13	The period was set to one year to allow services to identify notes for 15 patients who met the eligibility criteria. Ability to identify patients for the case note sample was expected to vary between services (due to size of the service, use of electronic flagging systems, employment of specialist learning disability staff etc). A snapshot sample of 15 case notes was decided as an appropriate number for a processed based feasibility study.

Staff questionnaire

A questionnaire for staff, including frontline staff (doctors, nurses, healthcare assistants) and non-clinical staff (receptionists, administrators) was developed. The questionnaire focussed on training in learning disabilities, staff views on caring for this patient group, and their perception of the quality of care provided to people with learning disabilities.

The questionnaire was designed to be simple and quick to complete. Five-point Likert scales were used to determine staff satisfaction and agreement with statements about meeting care needs of people with learning disabilities, training received, and support from the wider hospital. Staff could also provide free-text comments.

Acute study sites distributed the questionnaire to staff in their Accident and Emergency department and one medical and surgical/orthopaedic ward of their choice. Mental health study sites distributed it to the crisis resolution team and nominated two wards/units of their choice. The audit team recommended one should be a specialist learning disability service if there was one within the site. Each department/ward was given a target of completing 15 questionnaires each.

Patient questionnaire

The advisory group and audit team were keen to explore patient experience in the feasibility study. To collect as much patient feedback as possible within the data collection period, an easy-read questionnaire was developed.

The questionnaire focused on communication and information, and whether people were given sufficient support to discuss and decide what treatment they receive. Respondents had the option of providing free-text comments and were asked whether the questionnaire had been completed by the person with a learning disability alone or whether they had help from a carer or family/friend.

To evaluate the acceptability of the questionnaire and improve the content, the audit team met with a group of people with learning disabilities from the Carers Centre in Tower Hamlets, London. There were 34 people with a range of learning disabilities present, and six facilitators. The group were familiar with each other and the facilitators, and this environment encouraged open discussion. Most of the suggested changes related to language used and how the questionnaire could be further simplified. Suggestions were made about pictures that could be used alongside the questions asked. This version of the questionnaire was then sent to the Accessible Communications Support and Training Department at Mencap, who specialise in the production of easy-read documentation. A member of Mencap and a person with a learning disability commented on the questionnaire and suggested some further changes to simplify the language. These suggestions were incorporated.

Patient questionnaires were posted to people with learning disabilities identified from the case note audit tool. Acute and mental health study sites were also given questionnaires and self-addressed envelopes to distribute to people with learning disabilities receiving care in the service at the time of data collection (September – November 2013). CLDTs were also given patient questionnaires to distribute to people with learning disabilities who had recently stayed in any of the sites taking part in this study.

Carer questionnaire

The audit team developed a questionnaire for carers of people with learning disabilities. The aim of this was to explore carers' experiences of the quality of care provided and determine whether they were satisfied with their level of involvement in healthcare and treatment decisions for the person they cared for.

The carer questionnaire was developed specifically for the feasibility study. The audit team circulated the questionnaire to two national forums - UK Health and Learning Disability Network at the Foundation for People with Learning Disabilities and the National Valuing Families Forum from the Carers Trust. From this, comments and suggestions were received from professionals in the field and from carers of people with learning disabilities. This influenced the wording of questions, inclusion of questions about mental capacity, and a modified layout to improve the overall accessibility of the questionnaire.

Carer questionnaires were posted to people with learning disabilities identified from the case note audit tool. Acute and mental health study sites were also given questionnaires and self-addressed envelopes to distribute questionnaires to carers of people with learning disabilities who had received care in the service at the time of data collection (September – November 2013).

Audit tools for Community Learning Disability Teams (CLDTs)

Early discussion with the advisory group highlighted the importance of CLDTs, particularly their role in supporting people with learning disabilities when they access primary and secondary care services. CLDTs were recruited to (a) give their views on the performance of the acute and mental health study sites registered to take part in the study and (b) to observe visits to these services. This helped the audit team gain insight into the interaction and communication that takes place between staff and people with learning disabilities. The aim of this was to verify and quality check the self-reported information received from participating study sites.

The tools for CLDTs were developed in consultation with members of the advisory group who work in CLDTs in London.

CLDT feedback survey

The audit team asked participating acute and mental health study sites about their links with their local CLDT and also asked CLDTs about their working relationships with participating study sites. This helped the audit team to cross-check and validate information received from secondary care sites. The questionnaire was designed to be simple and quick to complete. Five-point Likert scales were used to determine staff satisfaction and agreement with statements about services' ability to make reasonable adjustments for people with learning disabilities, and the working relationship between the services and the CLDT.

Each CLDT was asked to complete a feedback survey for every participating acute and mental health study site that they worked with.

CLDT observation tool

It was recognised that CLDTs could capture information about health services that could potentially give useful context to how patients are treated from a professional perspective. This was important as it was anticipated that not many patient and carer questionnaires would be received. This would also give an idea about the extent to which reasonable adjustments were being made.

The development of this tool was influenced by a successful observation module used in the National Audit of Dementia[ix], managed by the Royal College of Psychiatrists' Centre for Quality Improvement, whereby ward staff in an acute hospital observe whether person-centred care was delivered to people with dementia by studying the interactions and the environment. This method is time and resource intensive, and so a short observation tool was developed for the feasibility study. This could be completed by a member of the CLDT when they accompanied a person to a participating study site during the data collection period (September – November 2013). Five-point Likert scales were used to determine staff satisfaction and agreement with statements about communication between staff and the person with a learning disability.

Each CLDT was asked to complete observation surveys each time a member of the team accompanied a person with a learning disability to a participating acute or mental health study site they work with. A minimum/maximum number was not set as it was not possible to predict how often this would occur.

[ix] http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/dementia/nationalauditofdementia/informationabouttheaudit/observationalmodule-pie.aspx

1.3. Recruiting study sites

The third objective of the feasibility study was to develop a strategy for recruiting services to a subsequent national audit, and engage and support them throughout their participation in the feasibility study.

This section of the report details how study sites were approached and recruited for the primary and secondary care audit. This section also reports why some services did not participate and the obstacles faced by the audit team during the recruitment phase.

1.3.1 Primary care

Establishing links with practices

A decision was made to collect primary care data from one geographical region due to resource limitations. As the primary care clinical lead was based in Lancashire, it was agreed that primary care data would be collected here.

60 general practices in Lancashire were contacted by letter in October 2013 and invited to participate in the study. They were given contact details for the primary care clinical lead, an overview of the study, the extent of their involvement, and a registration form to complete and return.

Table 2: A list of the 14 practices that agreed to participate in the study

Number	Practice name
1	Queen Square Medical Centre
2	Kiddrow Medical Centre
3	Pendle View Medical Centre
4	Station House Surgery
5	Harambee Surgery
6	Pendleside Medical Practice
7	Earby Surgery
8	Waterfront Group of Doctors
9	Padiham Medical Centre
10	Irwell Medical Practice
11	Whitefield Health Care
12	Drs Robb & Robb
13	Peel House Medical Practice
14	Colne Corner Surgery

Barriers to recruiting study sites

There were several factors that impacted on the recruitment of general practice sites for the study. The timing of registration was important. The deadline for registration in the audit coincided with a holiday period, which meant that those responsible for making the decision to participate were not often available. Despite the reassurance of the limited burden on the practice staff for data collection, there was a feeling of having too much to do and too many demands. No financial incentive or compensation for loss of time was offered to practices for taking part in the study. The data extraction process required minimal effort by practices, but the initial process for agreeing to take part required discussion and agreement amongst the partners at each practice. Consideration will need to be given to potential strategies for engaging with practices for a future national audit.

1.3.2 Secondary care

Establishing links with acute and mental health study sites

Advisory group members engaged with services to generate interest and promote the feasibility study. The members then provided contact details within each of the services, allowing the audit team to formally invite them to register for the feasibility study. This took place from August 2013, leading up to the launch of the data collection phase in early September. From the outset, the aim was to have a CLDT, an acute and a mental health site participating in each region – London, Nottinghamshire, Lancashire, and South Wales.

Table 3: Services that were approached and which registered to take part in the feasibility study

Speciality	Sites approached	Sites registered
	London	
Mental health	Camden and Islington Foundation Trust	✓
	East London NHS Foundation Trust	✓
Acute	University College London	✓
	The Royal Free London Hospital	✓
	The Whittington Hospital	✓
	Newham Hospital	✓
	Whipps Cross Hospital	✓
	Royal London Hospital	✓
CLDTs	Camden Learning Disability Service	✓
	Islington Learning Disability Service	✗
	East London Learning Disability Team	✓
	Nottinghamshire	
Mental health	Nottinghamshire Healthcare NHS Trust	✓
Acute	Queens Medical Centre	✗
CLDTs	Gedling Community Learning Disability Team	✓
	Lancashire	
Mental health	Lancashire Care NHS Foundation Trust	✓
Acute	Royal Blackburn Hospital	✓
CLDTs	Lancashire Learning Disability Team	✓
	South Wales	
Mental health	Abertawe Bro Morgannwg Health Board	✓
	Cwm Taf Health Board	✓
	Cardiff and Vale Health Board	✗
	Learning Disability Directorate *	✓
Acute	Morriston Hospital	✓
	University Hospital of Wales	✓
	Royal Glamorgan Hospital	✗
CLDTs	CLDT teams across south Wales	✓

* A learning disability inpatient service in South Wales was included in this study as it came to light that people with learning disabilities with mental health problems/those presenting challenging behaviour, would tend to receive care in this specialist service rather than the generic mental health beds within hospitals at Cwm Taf Health Board and Abertawe Bro Morgannwg Health Board. With this in mind, it was anticipated that Cwm Taf Health Board and Abertawe Bro Morgannwg Health Board may not achieve the required number of case notes (15), as the majority of patients would be directed to the specialist learning disability inpatient service to receive care.

The audit team achieved the aim of recruiting a CLDT, an acute and a mental health site in each region with the exception of Nottinghamshire, where an acute hospital was not recruited.

Table 4: The study sites registered to participate in the audit, by region

Region	Acute	Mental health
Lancashire	1	1
Nottinghamshire	0	1
South Wales	2	3
London	6	2
Total	**9**	**7**

Barriers to recruiting study sites

Local engagement

Medical Directors and members of Executive Boards were in the main very supportive of the feasibility study. Finding a clinician to lead the audit locally was time consuming for study sites. The study sites that did not register to participate in the feasibility study (a CLDT in London, acute sites in Nottinghamshire and South Wales, and a mental health site in South Wales) were unable to, due to a lack of resources and limited time to assign a team to take forward the piece of work.

Reservations about participating in an audit of learning disabilities

Some sites approached were initially reluctant to participate in the audit as they believed it to be beyond their remit. This was generally because they felt that small numbers of people with learning disabilities were being admitted to acute and mental health hospitals, meaning this group were a small minority of people they provide care to. Data from the Confidential Inquiry[6] and other reports were used to help explain the background and importance of the audit.

2. Data collection

Once standards and methods were finalised and sites recruited for the audit, data collection began.

This section of the report presents the number of data returns from each study site. In secondary care, it also presents information about the patients chosen for the case note audit tool and where staff questionnaires were returned from.

2.1 Primary care

The primary care data collection took place between 25 November and 6 December 2013. This two week time frame allowed for planned data collection at all 14 practices in the first week, with an additional week in case any errors occurred with data collection.

Errors occurred within three practices and data were successfully collected from one of those three practices in the second week. Due to the time frame the audit team could not collect data from the remaining two practices.

Data received

Data were successfully extracted from 12 general practices, which included a total of 794 patients with a learning disability. The tables below show some demographic information about the patients in the primary care sample.

Table 5: Information about patients in the primary care audit sample

	Patients with Down's Syndrome (N = 92)	Patients with learning disability on QOF register (N = 594)
% male / % female	59 / 41	59 / 41
Maximum age	66 years	87 years
Under 18 years / Over 18 years	32 / 60	75 / 519

2.2 Secondary care

Data collection took place between 9 September 2013 and 29 November 2013.

Data received

The table below shows the data received for each of the audit modules from acute and mental health study sites. Despite participation from two more acute sites than mental health sites, acute sites submitted a considerable amount more case note audits and staff questionnaires. Carer and patient questionnaire returns were also higher in acute sites.

Table 6: Data received from acute and mental health inpatient services

Audit module	Acute (N = 9)	Mental health (N = 7)
Organisational checklist	9 submitted	7 submitted
Case note audit	109 submitted	67 submitted
Staff questionnaires	440 submitted	174 submitted
Carer questionnaires	43 submitted	14 submitted
Patient questionnaires	64 submitted	20 submitted

Organisational checklist

All acute and mental health sites submitted an organisational checklist. The organisational checklist was not suitable for the specialist learning disability mental health study site in South Wales. This is because all their patients have a learning disability, therefore the checklist items about identifying patients, staff training and employing specialist staff, did not apply. The service completed a checklist, and as expected it scored positively on all questions. This data were excluded from the analyses to avoid biasing the organisational checklist results from other participating mental health study sites.

Case note audit

Four of the nine acute sites and one of the mental health sites submitted 15 case note audits. Two of the acute sites and three of the mental health sites submitted between 10 and 14 case note audits. One mental health site in Wales was unable to identify any eligible patients for the case note audit. Another mental health site in Wales identified only five eligible patients. This was anticipated as people with learning disabilities and mental health problems are generally referred to the specialist learning disability service in South Wales.

Table 8 presents information about the patients whose case notes were audited. The median length of stay in acute sites was significantly lower (8 days) compared to mental health sites (31 days). The patients who had the highest length of stay were receiving care in forensic settings. Approximately half of case notes from acute sites had no record of the severity of the learning disability. About a quarter of patients in the acute sample had a 'severe' learning disability. In the mental health sample over two thirds of patients had a 'mild' learning disability.

Table 7: Information about the patients in the case note audit sample

	Acute (N = 109)	Mental health (N = 67)
% male / % female	51 / 49	52 / 48
Median age	51 (range: 18 – 90)	35 (range: 18 – 70)
Median length of stay (days)	8 (range: 1 – 419)	31 (range: 1 – 1321)
% patients died during stay	6	0
% patients with record of extent of their learning disability:		
Mild	11	69
Moderate	6	21
Severe	25	3
Profound	7	0
Not indicated in the notes	51	8

The table below shows which ward patients had stayed in, in the acute and mental health sites. Most acute case notes were of patients who stayed in a general medical ward or a surgical/orthopaedic ward. In mental health sites, two thirds of case notes were of patients that had spent time in generic mental health wards.

Table 8: Type of ward patients in the case note sample stayed in for the majority of their admission

Type of ward	% of case notes
Acute (N = 109)	
General medical	48
Surgical / orthopaedic	26
Other e.g. short stay, respiratory, elderly, cardiac	26
Mental health (N = 67)	
General working-age acute	55
Learning disabilities	34
Other e.g. forensic, psychiatric intensive care, older people, supported recovery	11

Staff questionnaires

A substantial number of staff questionnaires were received (614 in total). 440 were from acute sites. All acute sites submitted 35 or more staff questionnaires. This seemed a more difficult module for mental health sites to complete – three sites were only able to submit between 5 and 14 questionnaires. Audit leads said it was a challenge to encourage staff to complete questionnaires across a whole trust as the wards were not always in the same location and ward managers were not always known by local audit leads.

Patient and carer questionnaires

Patient and carer questionnaires were distributed to patients identified in the case note audit. They were also distributed during the data collection period (September – November 2013) to people with learning disabilities receiving care in the acute or mental health sites. Patient questionnaires were also posted to CLDTs, requesting CLDTs distribute them to people with learning disabilities if they were known to have had an inpatient stay in one of the study sites during the data collection period.

The table below shows how many patient and carer questionnaires were received from acute and mental health sites, and by which method. Carer questionnaires were more likely to be completed and returned when they were directly posted by the study sites to the patients identified via the case note audit. This was the same for patient questionnaires in acute sites. However in mental health sites, patient questionnaires were more likely to be completed and returned when they were distributed to people with learning disabilities receiving care in the service during the time of data collection.

Table 9: Carer and patient questionnaires received from acute and mental health sites

Questionnaire distribution	% of questionnaires	
	Acute	Mental health
Carer questionnaires (Acute N = 43/Mental health N = 14)		
Patients identified in the case note audit	61	71
Distributed to patients receiving care during data collection	39	29
Patient questionnaires (Acute N = 64/Mental health N = 20)		
Patients identified in the case note audit	48	25
Distributed to patients receiving care during data collection	27	60
Distributed by community teams to people known to have had an inpatient stay during data collection	25	15

CLDT feedback survey

Most participating sites received a feedback survey from the CLDT in their area. Two London acute sites did not receive feedback because the CLDT recruited in this area did not work with these hospitals; as such the CLDT were not in a position to comment. CLDTs in South Wales were unable to complete feedback surveys for all participating sites, due to a lack of resources.

Table 10: CLDT feedback surveys received for acute and mental health sites

Geographical area	Acute	Mental health
London	4 / 6	2 / 2
Lancashire	1/1	0/1
Nottinghamshire	-	1/1
South Wales	0/2	2/3

CLDT observation survey

Completion of observation surveys varied across acute and mental health sites. From discussions with CLDTs, it appears that the variation may be due to commissioning and the remit of the team. The table below shows how many study sites in each of the regions had observations completed.

Table 11: CLDT observation surveys received for acute and mental health sites

Geographical area	Acute	Mental health
London	2 / 6	2 / 2
Lancashire	1/1	1/1
Nottinghamshire	-	0/1
South Wales	0/2	1/3

The number of observation surveys from each CLDT varied – with some sites receiving none or less than two, and some receiving up to 16 surveys.

3. Collecting feedback from stakeholders

Key stakeholders were invited to feedback on the feasibility of doing a national audit of learning disabilities and whether it has potential to generate useful information:

1. Study sites fed back on what it was like to take part in the audit and the usefulness of the end product i.e. their local report.
2. People with learning disabilities gave feedback on whether the audit addressed the issues that were most important to them.
3. Carers of people with learning disabilities also gave feedback on the audit findings.
4. Other stakeholders (such as commissioners, professional bodies, the CQC, voluntary sector providers, leaders in research and the confidential inquiry in learning disabilities) commented on the usefulness of the audit information, including its potential to drive quality improvement.

3.1.1 Primary care

Findings of the audit were sent to participating study sites in January 2014. The layout and structure of this report allowed study sites to see their practice's performance in the audit against all participating practices. Feedback was sought from practices in the following ways:

- Informal feedback – via email, telephone calls.
- Completing a feedback survey that was sent with the local reports – no responses were returned by practices using this format.
- Presentation of findings at four practices' clinical meetings was requested. At clinical meetings, all primary care staff involved in delivering care (e.g. GPs, nurses, trainees, healthcare assistants and managerial staff) are usually present. This proved to be the most useful way to obtain feedback from the practices.

Primary care study sites were asked to comment on: how useful they found the local reports; what information they found least useful; whether there was any information missing; and whether they could use this information to make changes to their service. Overall, study sites were receptive to their audit data. Practices found the benchmarking against other practices useful. Practices have many different ways of delivering healthcare, and joint meetings allowed practice teams to discuss reasons why there may be differences in particular aspects of the findings and potential changes necessary to improve care.

GPs need to understand the audit data

Study sites requested contextual information about the need for developing an audit and how standards were identified. This was important as providing results to individual practices, does not in itself lead to action. When presenting results, it was useful to compare local and national data.

Why criteria were used and what was the evidence base?

When practices were recruited to take part in this audit, they were given a report which outlined the evidence for each criterion being put forward. Despite this, individual criterion being evaluated as part of the audit did not always make sense to clinicians. It is not known how the report was shared or disseminated within the practice, but it was necessary to provide clinicians the evidence for each criterion at clinical meetings.

Quality Outcomes Framework (QOF) has already standardised the process for recording (Read coded) clinical data and has set standards for the quality of care for many conditions expected for the general population. Most criteria developed through the consensus process were based on previous reports to develop specific standards for learning disability within QOF. However QOF is a negotiated contract linked to a financial incentive, and as such many of the standards put forward were not negotiated into the QOF.

How would the results be used in the future?

Although some practices taking part in this audit are also participating in other national audits (data are extracted for the National Diabetes Audit from some practices but there is no formal quality improvement activity linked to this) there was uncertainty about how a national audit would work within primary care. Should there be a national audit for learning disability, those practices that had their results presented to them in a clinical meeting would be keen to take part.

The parameters made sense for some patients but not others

The results for breast screening and cervical screening generated a lot of discussion. Practices were uncertain of their role in improving uptake for breast screening or the clinical justification for undertaking cervical smear in some patients with severe learning disabilities. Similarly, there was uncertainty around screening for dementia in patients with Down's Syndrome (what age this should start, which screening tools should be used) and as no patients within the practices were identified as having dementia it was difficult to provide comparative data.

What study sites found useful

Practices found benchmarking against other practices useful. The clinical meeting allowed practices to reflect on the implications of the findings, and how the practice could potentially improve the quality of care delivered.

How the audit could be improved

Some practices said their staff felt burdened by requests for data and invitations to take part in different incentives and programmes, including competing clinical areas and even sometimes the same clinical area. Feedback indicated that a coordinated approach to data collection, reporting results, and processes for quality improvement, would make it much easier for general practices to be involved in a future national audit and any other existing incentives and programmes (e.g. Commissioning for Quality and Innovation, CQUIN).

The feasibility study has not tested the full cycle of an audit. It has tested the process of identifying standards, engagement with practices, data extraction and analysis, and some preliminary feedback activity. The audit team cannot under estimate the importance of quality improvement activity which engages with practices (either as a group or individually) around a specific topic such as a learning disability audit. This is the process being used for other national priorities, for example the 'Improving Access to General Practice', and there is significant funding for practices to do this.

3.1.2 Secondary care

Experiences of taking part in the audit

The audit team conducted phone interviews with study sites in London, Lancashire and Nottinghamshire and ran workshops for study sites in London and South Wales. The audit team spoke with a mixture of clinical staff (e.g. psychiatrists), specialist learning disability staff (e.g. liaison nurses), non-clinical staff (e.g. audit leads) and some higher-level management (e.g. training and workforce and operations managers). The aim of discussions was to determine how user-friendly and relevant the audit tools were, and what difficulties study sites encountered during data collection.

Audit modules evaluated as being easy to complete

Organisational checklist

Generally, study sites said the organisational checklist was easy to complete and the least time consuming of the audit tools. Some sites suggested that the questions should be more evidence-based to improve validity.

Staff questionnaire

Overall response rate for staff questionnaires was high and a large amount of data was generated. Mental health sites had much lower returns, possibly because trust participation made it more difficult to raise awareness of the audit and engage staff.

Challenging aspects

Identifying patients for case note audit

Almost all sites experienced difficulties in identifying patients with learning disabilities, particularly when they do not have a systematic way of flagging patients with learning disabilities. This meant that many study sites had to rely heavily on specialist learning disability staff, such as liaison nurses and CLDTs to identify patients.

The implications of solely auditing the case notes of patients known to specialist services were discussed at the workshop in South Wales. Some attendees were concerned that the quality of care may be worse for those unknown to specialist learning disability teams. A number of sites suggested that having a clear definition of what classified as a learning disability would have assisted them in the process of identifying patients.

Completing the case note audit

Many audit leads said the quality of case notes was extremely variable and often they had to trawl through mounds of information, using numerous systems to answer questions. Despite this, study sites mostly said questions were relevant, and time spent completing a set of case notes was reasonable and in line with other audits.

Some sites commented that certain questions in the case note audit tool were "subjective", as how they were answered often depended on the auditor being able to find the information and their interpretation of what was recorded in the notes. Some acute sites found the questions on capacity and best interest decisions difficult to answer. While some suggested that the questions on capacity were subjective, others suggested that the issue was documentation being unclear in the case notes.

Distributing patient and carer questionnaires

Patient and carer questionnaire returns were low across all sites. Study sites said the main barrier to distribution was the difficulty of identifying patients with learning disabilities in the first place. Some sites questioned the suitability of using questionnaires for this patient group and recommended speaking directly with people or asking ward nurses to support people to complete the questionnaire.

Usefulness of local reports

Findings of the audit were sent to participating sites in January 2014. The layout and structure of this report allowed the study sites to:

- Compare their service's performance in the audit against similar participating services (e.g. an acute hospital's data were benchmarked against data from all acute hospitals).
- See all data collected from different audit tools about a given theme (e.g. reasonable adjustments)
- Review six or seven "key messages" highlighted at the front of the report. Each was flagged red, amber or green according to the service's benchmarked performance. This made it clear for a service to see areas of good practice and areas in need of improvement.

When local reports were sent to study sites, a feedback form was also sent for audit leads to complete. This asked for their comments on: how useful they found the local reports; what information they found least useful; whether there was any information missing; and whether they could use this information to make changes to their service provision. Two workshops were held in London and South Wales, to discuss this information in more detail. Feedback from study sites was in the main positive, with all sites stating that they would be willing to participate in a future national audit of learning disabilities, should one be commissioned.

> ***"I think potentially audit is very powerful and could be massively useful in driving change."***– Audit lead from an acute hospital.

When speaking with audit leads, they felt the process of participating in the feasibility study had better informed them of how their services cares for people with learning disabilities, and they gained greater insight into the needs and challenges of people with learning disabilities.

Benchmarking performance

When meeting with study sites at the two workshops, many spoke of how constructive it was to see their service's performance shown against all other services. This helped them to make comparisons and identify where more timely action was needed. Benchmarking performance is a strong advantage of audit, as it can easily identify best/worst practice both at a national and local level. Some sites asked for the benchmarking to be more thorough.

> ***"A lot of national audits have anonymous benchmarking that might be good to include like a scoring ranking system. A league would be an opportunity to see where you are."*** *- Audit lead from an acute hospital.*

"Key messages" section

The one-page "key messages" section in local reports summarised a service's performance. The audit team selected and rated one item from each of the audit's main domains (e.g. 'identifying people with learning disabilities', 'staff training'): a green triangle indicated an item where the service was performing well against the benchmark set by all participating services; a red triangle where it was underperforming; and an amber triangle where it was performing above the benchmark, but improvement was still needed to meet agreed standards of good practice. On the whole, study sites were in favour of highlighting key messages at the front of the report.

> ***"The layout and format was good and easy to understand. It was easy for someone like me to see red and green." -*** *Audit lead from a specialist learning disability service.*

Some concern was expressed about how reflective the key messages section was of overall performance. Suggestions were made to select the same criteria for every participating site, so not to cherry-pick items based on data return.

Feedback from staff

Staff feedback was presented graphically in the local reports. One graph displayed staff views between the departments/wards that the individual site put forward for the audit, and the second graph displayed staff views from the whole site compared to all the staff surveyed in the audit. Comments made by staff were also presented in the local reports, and these were site specific.

Study sites valued being able to see comments that their staff had made about caring for people with learning disabilities and training they had received. Audit leads commented that the breakdown of staff feedback both locally and "nationally" gave them valuable insight. Many said that this was the information that they would use to drive local change in relation to training provision.

> ***"The staff feedback was really useful in terms of training….I think the staff comments were very good to highlight, very poignant."****- Audit lead from an acute hospital.*

Supporting quality improvement

On the whole, the study sites expressed certainty that their participation in the audit, and the information provided to them, could help them identify and make changes to their service. Whilst some audit leads commented that the report did not necessarily tell them anything that they did not already know, they were optimistic that having the information documented in such a way would provide a case for changes to be made to service provision and give learning disabilities some precedence.

> ***"Nothing in the report was a surprise as I am experiencing the issues daily in my work but having evidence is essential."*** *- Audit lead from an acute hospital.*

Main areas identified for action

When discussing the local reports with study sites and whether they could use this information to make improvements to their service, some reoccurring themes arose:

- Many sites raised concerns that they were not able to easily identify people with learning disabilities using their services – either at a trust level (i.e. a flagging system) or at a ward level (i.e. visual identifier, page in the notes). The study sites that do not have such systems in place tended to rely on CLDTs and learning disability liaison nurses to help them identify eligible patients for the case note audit.

- Nearly all sites mentioned staff training in learning disabilities as a priority area highlighted by their local report. A few sites specifically mentioned mental capacity training for staff and ensuring that learning disability training is incorporated into induction programmes.

- Some sites mentioned the appointment of a learning disability liaison nurse or champion, and even a review of how often they are available if there is already one in post. One audit lead had already used her hospital's local report to apply pressure to higher management to recruit such a role.

Suggestions to improve the audit

Carer and patient feedback

Most study sites that fed back on the audit, expressed their disappointment that carer and patient feedback was not presented at a local level in service reports. This decision was made because of low questionnaire return from both patients and carers, and to avoid information being misinterpreted if it were only based on a small number of returns. The consensus was that even if only one questionnaire was returned from a service user or a carer, this information would have been valuable to the service.

> ***"One of the areas we struggle with is getting feedback from our patients and carers and it feels as though we missed the opportunity to hear their voice. It is my view that without feedback from patients with learning disabilities and their parents/carers we cannot be sure that we are delivering a service which is fit for purpose."*** *- Audit lead from an acute hospital.*

Service-specific standards

Study sites questioned the applicability of some audit data items to their service. Some mental health sites queried particular questions on physical health monitoring, and some acute sites commented on the applicability of questions on psychotropic medication and managing challenging behaviour. The specialist learning disability service felt that many questions were too 'generic' and some issues in their service were not audited, such as delayed discharges. It was generally agreed that whilst all types of services should be providing a high standard of care across all audit themes, some themes were more applicable than others depending on the service. If standards and tools were to be revised, this should be taken into consideration.

Data returns

Some study sites were unable to identify 15 eligible patients to take part in the case note audit, and consequently they raised concerns about the validity of the findings. As some of the questions in the case note audit tool were routed, (some questions only asked based on answer given to a previous question) this also had an implication on the number of case notes.

As this was a feasibility study, study sites were given three months to identify eligible patients and submit case note audits. Sites were also given a one year period when the patients had to have received care. In a national audit the time frame could be wider and more time allocated to identify patients and submit data.

3.2. Feedback from people with learning disabilities

The audit team disseminated the findings of this study to two groups of people with learning disabilities to determine whether the study reflected their priorities. A short easy read document was developed with the themes: hospital information, training for hospital staff, and doctors and annual health checks.

"Have your say" group: This group had worked with the audit team to develop the easy read questionnaire for people with learning disabilities. It included 25 people with a diverse range of learning disabilities. They meet to discuss various issues affecting people with learning disabilities, but not specifically to discuss healthcare services. Not everyone had experience of staying in hospital or could recall going to their GP. People were familiar with the venue, the organisers and each other.

Self advocates group: The audit team ran a workshop at a self advocate conference in Blackpool. Self advocates are people with learning disabilities who are aware of their rights and take control of their lives by speaking about them. 18 people with learning disabilities attended the workshop. This group chose to attend because they had a specific interest in how healthcare organisations treat people with learning disabilities. More people in this group wanted to talk about their experiences of being in hospital or visiting their GP.

Key themes

Both groups gave valuable feedback on the themes discussed. When asked whether these were important to help improve the quality of care for people with learning disabilities, the majority agreed they were. The audit team were reassured to hear people sharing their own experience around topics discussed. Sadly, these experiences were almost entirely negative.

Hospital information

Both groups said they felt patronised and excluded from interactions with hospital staff as they would speak too fast, use medical jargon, avoid eye contact, and direct conversation to their carers.

> ***"Talk to me not my carer."*** – Person with a learning disability.

> ***"They use too much jargon they just talk to each other."*** – Person with a learning disability.

Both groups, particularly the self advocacy group, agreed that health passports were not being used widely enough in hospitals. People spoke about having to rely too much on their carers because they cannot understand the information given to them by hospitals. One person said they wanted to be able to attend hospital appointments without his carer and a health passport could help him to do this. People said that hospitals had to improve this, especially as some people do not have carers to explain things and remind them to stay healthy.

> ***"People with carers get reminders, not fair to people with no carer."*** – Person with a learning disability.

> ***"They don't use health passports even if you do have one. What's the point?"*** – Person with a learning disability.

The main issues identified (quality of communication, information and underuse of health passports) reflect the issues identified at an early stage in the study through a literature review, which highlights that these issues are ongoing and improvement is needed.

Staff training

Both groups were highly engaged in the discussion about staff training. People said it was "disgusting" that staff can work in a hospital without being trained in learning disabilities and many questioned the ability of staff to provide the right care and communicate effectively. People from the self advocacy group said that training should be delivered to staff face-to-face and involve people with learning disabilities. People from both groups said training should extend beyond doctors and nurses to all staff who work with people with learning disabilities. There was a strong consensus for the importance of staff to receive training and how unfair it is to staff and people with learning disabilities that many do not.

> ***"Staff should have training in learning disabilities – it is not right that they do not know things that they should."*** – Person with a learning disability.

> ***"Staff need to have more training in communicating with people with learning disabilities. Staff need to know about different ways people can talk."*** – Person with a learning disability.

A few people in the self advocacy group said there is an issue with staff attitudes towards people with learning disabilities. Two self advocates shared their experiences of delivering training to staff, with one commenting that many staff seemed disinterested in the training. A wider discussion took place in the self advocacy workshop about how staff culture needs to change.

> ***"Staff are afraid to treat people because they haven't had the right training."*** – Person with a learning disability.

GPs and annual health checks

The majority of people in the "Have your say" group did not know what an annual health check was but felt it was important that people receive one, once they did understand what it was. They discussed difficulties experienced when they went to their GP which were mostly centred on communication and waiting times. A few people said it was very hard to talk to doctors because doctors will only discuss one problem per appointment.

They said information doctors send could be better (e.g. easy read appointment letters). The self advocacy group said doctors need to get better at offering annual health checks to people with learning disabilities. They again spoke about relying on their carers to remind them to get annual health checks, and many were concerned about the health of those who did not have a carer.

> ***"Doctors don't always remind you if you need a health check – rely on carers, key workers"*** – Person with a learning disability.

An advantage of meeting an established group ("Have your Say") was that people were familiar with each other. This helped the initial flow of conversation. While the self advocates were more accustomed to attending these kinds of workshops it took a bit longer for people to warm up and feel comfortable talking amongst each other. The establishment of a service user and carer reference group for a national audit would make it much easier to obtain good quality input from people with learning disabilities and carers throughout the course of the audit.

The audit team ran a focus group for carers of people with learning disabilities to obtain feedback on the content and findings of the feasibility study, and whether this reflected their priorities. The Foundation for People with Learning Disabilities invited family carers to attend the focus group, through a number of networks. Interested carers contacted the audit team directly to request to attend the focus group, which was held in London.

The audit team encouraged carers to think critically and consider if the information could be used to help raise care standards in health services for people with learning disabilities, and if any important information was missing that carers would like included in a national audit. Twelve family carers attended the workshop. The group was made up of eight women and four men, and were geographically spread throughout England. All carers were parents of people with a range of learning disabilities and there was a good mix of younger and older generations. The 12 carers were very supportive of national audit. Some were surprised that it was not happening already while others said it was long overdue.

Key themes

Communication problems

Several carers expressed their frustration at how staff ignore the person they care for or speak inappropriately in their presence because they assume the person would not understand. Two carers said they were disappointed with health passports because staff do not routinely use them. One carer highlighted that a lot of NHS money has been wasted due to lack of joined up thinking amongst healthcare professionals and the absence of a liaison nurse to ensure continuity. Carers spoke about the importance of staff being able to communicate with patients with learning disabilities and suggested that if a couple of nurses on a ward knew basic Makaton (a programme using signs, symbols and speech to help people communicate) it would help to relieve some of the anxieties about being in hospital.

> ***"Why do we have to be the parent, the nurse, the physiotherapist, the doctor? Why can't we just enjoy our children? Why do we have to take on these roles? Why aren't people performing? Why do you have to fight for everything?"*** – Carer of a person with a learning disability.

Staff attitudes and training

Many carers said they suspect professionals are scared of having to treat people who have learning disabilities. Carers suspected that the quality of staff training is poor and recommended that a national audit should focus more on this.

Some carers said that staff having the right attitude is the most important change to be made. Carers were critical about GPs' knowledge and approach to treating people with learning disabilities. Some felt that GPs were not very good at treating people with mental health problems and presumed that they received very limited training in this area.

One carer said he was worried that ignorant attitudes about the quality of life of people with learning disabilities might result in a decision being made by a healthcare professional that his son's life is not worth saving.

> ***"My GP's petrified if I take my child there to be quite honest. She doesn't give her antibiotics, she doesn't give her anything that she needs, all she says is, take her to the hospital…I shouldn't have to take her 30 miles when my GP's less than a mile away."*** – Carer of a person with a learning disability.
>
> ***"My daughter went through hell that day [when she had a seizure at the neurology department] as did I and my older daughter because we ended up having to do all the sitting on her and holding her down...Because of that I said I'm not going back to that neurology mob, we went to the epilepsy hospital...I was astounded at how kind they are [in comparison]. I think the reason is because of course many people with learning disabilities have autism, have epilepsy as well, so they're used to it."*** – Carer of a person with a learning disability.

Carers are not taken seriously

Carers expressed considerable anger at not being taken seriously by healthcare professionals. Carers shared examples of being ignored by professionals to the detriment of their children and also the NHS as it resulted in wasted resources and missed appointments. Carers talked about being frustrated with expectations that they should conduct care duties that are the responsibility of healthcare professionals. Carers said they did not trust the healthcare system and had concerns about leaving their children unattended in hospitals. One older carer said he was worried about what kind of care his son would get when he dies, while some younger carers worried what would happen to their children if they became ill themselves.

The audit team are satisfied that the feasibility study's standards reflect the concerns of people with learning disabilities and carers. Carers made positive comments about the usefulness and relevance of the study's content and also shared personal experiences of poor care. They were supportive of a national audit. Carers advised the audit team to ask more evidence-based questions to ensure data generated is an accurate reflection of the quality of care.

The audit findings were shared with:

- NHS England: National Clinical Director of Learning Disabilities
- Welsh Government: Mental Health and Vulnerable Groups Division and Healthcare Quality Division
- Care Quality Commission: Special Policy Lead and Lead for Mental Health
- Public Health England: Consultant in Public Health
- Royal College of Nursing: Learning Disabilities and Criminal Justice Nursing Adviser
- Royal College of Physicians: Programme Manager for Respiratory Medicine
- Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD): Senior Research Fellow
- Institute of Psychiatric Medicine and Clinical Neurosciences: Professor of Learning Disability Psychiatry
- University of Hull: Programme Director/Reader in Clinical Psychology
- The Royal College of Psychiatrists' Faculty of Intellectual Disability: Learning Disability Psychiatrist
- The Royal College of General Practitioners: Clinical Expert in Learning Disability
- The Royal College of General Practitioners Intellectual Disability Professional Network

Stakeholders were invited to give feedback on whether the data generated by the feasibility study were useful; whether any important information was missing; and whether this sort of information could help raise standards of care for people with learning disabilities. This was discussed in further detail with the audit's advisory group.

Can audit data help raise standards of care?

All stakeholders recognised that the audit findings highlighted significant issues about the quality of care provided by health services to people with learning disabilities. Stakeholders described the various ways audit data could be used to plan and improve service provision and workforce training. A Learning Disability CCG Lead stated that the audit information provides *"guidance and evidence to further support plans for commissioning services that can tackle the health inequalities our LD populations suffer."* The findings were unsurprising to some stakeholders; however they felt the audit was useful for presenting information, and benchmarking was seen as a powerful driver of service improvement:

> ***"Inevitably if a CCG is below average in delivering a service, more pressure is both applied from outside but also from within that CCG to drive up standards. If there is nothing to compare against then no pressure occurs."*** – Commissioner.

Stakeholders acknowledged how audit data can support health services by identifying areas of good and poor practice, and challenging service providers at national and local levels. Targeting providers in a national audit was recognised as a strong advantage, particularly if they are able to use this as a lever to create positive change.

A member of the Royal College of General Practitioners' Intellectual Disability Professional Network saw this as an opportunity to use audit information as evidence for inequalities that need to be addressed and although an audit like this would not resolve all problems pertaining to integrated care *"nationalised audit data captured on a regular basis could complement and if acted upon raise the standards of care across health sectors."*

The Care Quality Commission offered a powerful endorsement of how clinical data could be used:

> ***"…any such audit data will help support the CQC regulatory activity in both primary care and secondary settings…If we had national data of the type that you've got in this report, that fed into the pre-inspection planning that we do for an acute trust and for primary care, and for mental health trusts, I think that would be extremely useful."*** – Special Policy Lead and Lead for Mental Health, Care Quality Commission.

Some stakeholders expressed concern about the self-reported nature of audit:

> ***"I think that an audit such as this can give us a hazy picture of what is happening – although I doubt that self-completion assessments by services bear much resemblance to reality 'on the shop floor'."*** – Senior Research Fellow, CIPOLD.

It was suggested that the audit should focus more on how providers are acting, rather than the processes in place for recording information:

> ***"It's not good enough just to document your incompetence as a clinician…that people would record poor health, and then not act on it…what interventions came as a result of that? That's the more interesting information."*** – National Clinical Director of Learning Disabilities, NHS England.

The aim of the feasibility study was to determine if it was possible to gather valuable information. The next step is to ensure that the information is as robust as possible, e.g. via method triangulation. In a future audit, the audit team propose focusing more on treatment and intervention so that the data reported to providers are meaningful, and have the potential to impact on service provision and the experiences of service users. We also propose asking services to provide evidence of good practice (see Recommendations).

How could the audit be improved?

The Welsh Government stated their satisfaction with the audit's *"usefulness and comparability"* and the *"design and scope".* Other stakeholders made recommendations for a future a national audit.

Table 12: Suggestions for a future audit of learning disabilities

Suggestions	Source
Focus on journey of people with learning disabilities from primary to secondary care to ensure continuity of care	Royal College of Physicians, Public Health England, Commissioners
Include the independent hospital sector	Care Quality Commission, NALD advisory group
Address readmission rates and out of area admissions. Look in more detail at length of time of psychotropic medication, use of sectioning, making best interest decisions and advocacy	Royal College of General Practitioners
Ask for evidence that a single consultant is taking the lead and coordinating a patient's care in secondary health services	CIPOLD
Incorporate community services – learning disability specific or not	Royal College of Psychiatrists' Faculty of Intellectual Disability
Audit standards should be more specific to people with learning disabilities	Royal College of Psychiatrists' Faculty of Intellectual Disability
Information on neuro-developmental disorders is absent Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder.	RCGP Intellectual Disability Professional Network
Quality and follow through of annual health checks and health actions plans.	CCG Lead
Improve reasonable adjustments made - look into roles like specialist primary care liaison nurses and health facilitators.	CCG Lead
Data needs to be presented simply with some key performance indicators or key areas that you want practices to start addressing first.	CCG Lead

Reservations about the role of a future audit of learning disabilities

Some of the feedback gathered raised questions about the role of a future national audit of learning disability, especially where it would sit alongside other approaches that could be used to collect data about the quality of care received by people with learning disabilities.

Learning disability register or a learning disability audit?

The Consultant in Public Health, Public Health England, suggested that a register of learning disabilities would be more effective than an audit, as it would identify every person with a known learning disability and establish whether they were receiving adequate standards of care.

Whilst the benefits of a learning disability register is recognised, the audit team and other stakeholders see standards of care being raised through clinical audit – it would give a national picture of health services for this patient group, but more importantly it would allow individual providers to see their performance and allow clinicians to reflect on and change their practice. Re-audit would then establish whether performance in the audit has improved, whether problems have been addressed, and consequently whether standards of care have improved.

Possible duplication of work

When sharing findings of the feasibility study, the extent to which this audit differed from other quality improvement programmes and data sets was questioned, including the Joint Health and Social Care Learning Disability Self Assessment Framework (JHSCSAF), minimum datasets, and a possible mortality register.

The audit team agree that service providers should not be asked to duplicate work by participating in more than one of the programmes collecting the same type of data. Where possible, the audit should be conducted in line with other data gathering, reporting and quality improvement processes that are ongoing or in development. When primary care study sites were questioned about the self assessment framework, they did not know what this was, and had not seen any results. Therefore, the audit team do not see this as a duplication of work as the findings are not disseminated beyond a commissioning level, whereas a future audit would report back to individual practices as well as CCG level.

Primary care participation

Concerns were raised about primary care participation in a national audit. In the feasibility study, practices were approached and sign-up was voluntary. The same approach would be adopted in a national audit, as there is no obligation for primary practices to participate and engage in national audits. Primary care engagement is essential at the stage of encouraging participation, and at supporting practices to understand the data once it is reported, to ensure action is taken and quality improvement occurs.

In an audit in primary care the focus would be on the performance of an individual practice and benchmarking against all other practices, as well as the performance of a CCG as a whole. Practice level data may reflect poorly due to aspects that only a CCG can correct e.g. structural issues. The success of both practice and CCG level engagement would rely on the audit team's ability to report data in a meaningful way.

Secondary care participation

A concern was raised about the resources needed for a full scale national audit. Whilst it was recognised that the primary care data could be extracted from GP systems, it was noted that the secondary care audit required more local engagement to collect and submit data.

The audit team see this as a strength of the secondary care audit. When there is local engagement and ownership of the audit, providers are more likely to reflect and act on their results. It is through this engagement process that secondary care has been able to provide a comprehensive picture of the quality of care from a patient and carer perspective, as well as eliciting staff views. Many study sites commented on the value of seeing this kind of data and how collecting data for audit helped them understand the needs of this patient group and reflect on the quality of the service they are currently providing.

Conclusion

The feasibility study has demonstrated that it is possible to collect data on healthcare that people with learning disabilities receive in both primary and secondary care. The findings of the study clearly demonstrate a need for services to improve the quality of care they provide to people with learning disabilities.

Feedback from stakeholders indicates that information generated from this study is meaningful and has already helped study sites identify priority areas in need of improvement. Study sites found benchmarking local and "national" performance extremely valuable and a driver for change in practice. The audit team sees this as a strength of audit, particularly how progress at a local and national level can be monitored over time.

People with learning disabilities and carers confirmed that the feasibility study addressed their priorities, and expressed concerns about some of the findings in particular: a lack of staff training, use of health passports, the quality of health checks and appropriate reasonable adjustments being offered and made. They felt that a national programme focusing on poor standards of care for people with learning disabilities was long overdue, and welcomed the opportunity to be involved and voice their experiences of GPs and hospitals.

If a future audit of learning disabilities is commissioned, it should focus on the need to change culture and practice at an organisational level, and at the level of individual healthcare practitioners. It should focus on measuring the experiences of people with learning disabilities, their carers, as well as the staff providing care. The most effective way of doing this is to involve service users, carers and staff in the audit, and elicit their views.

Appendices

In this section you can find:

1. Acknowledgements
2. References for this report
3. A list of members of the primary care consensus panel
4. A list of members of the audit's advisory group
5. Primary care criteria with scores ≥7
6. The test-rest analysis of the case note audit tool
7. Secondary care standards for a future audit

1. Acknowledgements

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1. Professor Jill Morrison, General Practice and Primary Care, University of Glasgow.
2. Professor Jill Rassmussen, GP, RCGP Clinical Champion for Dementia.
3. Professor Sally Ann Cooper, Professor of Learning Disabilities, University of Glasgow.
4. Professor Irwin Nazareth, Professor of Primary Care UCL.
5. Professor Eric Emerson, Professor of Disability & Health Research Centre for Disability Research Lancaster University, and Professor of Disability Population Health Centre for Disability Research and Policy University of Sydney Australia.
6. Professor Gyles Glover, Public Health England.
7. Mr Martin Bollard, Senior Lecturer, University of Coventry.
8. Dr Peter Lindsey, GP, Leeds and Member of the RCGP Intellectual Disability Professional Network.
9. Dr Ken Courtney, Consultant Psychiatrist.
10. Dominic Slowie, Chair North East & Cumbria Learning Disability Clinical Network NHS England.
11. Laurence Taggart, Lecturer, Institute of Nursing Research, School of Nursing, University of Ulster.

1. Dr Glyn Jones, Honorary Senior Lecturer, Cardiff University. Consultant Psychiatrist , Abertawe Bro Morgannwg University Health Board.
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5. Dr Ian Hall, Chair of the Faculty of the Psychiatry of Learning Disability, Royal College of Psychiatrists.
6. Dr Pauline Heslop, Senior Research Fellow, Norah Fry Research Centre, University of Bristol.
7. Dr Matt Hoghton, Royal College of General Practitioners, Clinical Expert in Learning Disability.
8. Allyson Kent, Chair of the Access to Acute Network.
9. Professor Mike Kerr, Professor of Learning Disability Psychiatry, Honorary Consultant in Neuropsychiatry, Cardiff University.
10. Megan Lanigan, Programme Manager Clinical Evidence and Effectiveness, Royal College of General Practitioners.
11. Anna Marriott, Research Associate, Norah Fry Research Centre, University of Bristol.
12. Ann Norman, Learning Disabilities and Criminal Justice Nurses Adviser, Royal College of Nursing.
13. Dr Peter Oakes, Programme Director/Reader in Clinical Psychology, University of Hull.
14. Lesley Russ, Learning Disability Nurse and Learning Disability Adviser, Bristol.
15. Navin Puri, Programme Manager for Respiratory Medicine (Asthma and Lung Cancer), Royal College of Physicians.

5. Primary care criteria with scores ≥7

Criteria Number	Wording	Rating
1	Percentage of patients with learning disability who have a positive experience of GP Services in the preceding 12 months	7E
3	Percentage of patients under the age of 18 identified and coded as having learning disability	8A
4	Percentage of patients 18 years and over on the LD register who have a record of annual health check in the preceding 12 months (April to March).	8E
8	Percentage of patients on the LD register with Downs' Syndrome over the age of 18 who have a record of blood TSH in the preceding 12 months.	9A
9	Percentage of patients with learning disability and Down's syndrome aged 18 years and over on treatment for thyroid disorder who have a record of blood TSH within therapeutic level within the preceding 12 months.	9A
10	Percentage of patients with learning disability aged 18 years and over who have record an Annual Health check in the preceding 12 months (March to April) which includes details of a Health Action Plan (HAP).	8E
11	Percentage of patients with learning disability aged 18 years and over who have record of an Annual Health check in the preceding 12 months (April to March) which includes assessment of hearing.	7E
12	Percentage of patients with learning disability aged 18 years and over who have record of an Annual Health check in the preceding 12 months (April to March) which includes assessment of vision.	7E
13	Percentage of patients with learning disability aged 18 years and over who have record of an Annual Health check in the preceding 12 months (April to March) which includes assessment of swallowing.	8A
14	Percentage patients with learning disability with a record of a BMI in the preceding 12 months.	7E
15	Percentage of patients with learning disability with an active diagnosis of epilepsy, on drug treatment for epilepsy and have a record of seizure frequency in the 12 months.	8A
16	Percentage of patients with learning disability with an active diagnosis of epilepsy, on drug treatment for epilepsy, who been seizure-free for the last 12 months.	8E
17	Percentage of patients with learning disability who have had influenza immunisation in the preceding 1 September to 31 March (Coronary Heart Disease , Stroke or TIA, Diabetes, DM18, COPD , All ≥ 65 years, chronic neurological disease, CKD, long stay care patients).	7A
18	Percentage of patients with learning disability on the mental health register (QOF) who have a record of (alcohol, BMI, blood pressure, cholesterol, blood glucose) in the preceding 12 months.	7E

19	Percentage of women 20 years or over and below the age of 65 with learning disability diagnosis and record of cervical cancer screening test in the 5 years to Reference Date.	7A
20	Percentage of women aged 43 or over and below the age of 73 with and without a recording of a potential or actual learning disability diagnosis and record of breast cancer screening in the last 3 years to Reference Date.	8A
21	Percentage of patients with learning disability on antipsychotic medication with smoking status recorded in past 12 months.	7E
22	Percentage of patients with learning disability on antipsychotic medication who are given lifestyle advice in the preceding 12 months for: smoking cessation, safe alcohol consumption and healthy diet.	8A
23	Percentage of patients with learning disability on antipsychotic medication with BMI recorded in the preceding 12 months (April to March).	8E
24	Percentage of patients with learning disability on antipsychotic medication with blood pressure recorded in the preceding 12 months.	7E
25	Percentage of patients with learning disability on antipsychotic medication with HbA1c recorded in the preceding 12 months (April to March).	7E
26	Percentage of patients with learning disability on antipsychotic medication with total cholesterol recorded in past 12 months.	7E
32	Percentage of patients with Down’s Syndrome and dementia recorded as a current active problem.	7E

Criteria 3 wording: ***Percentage of patients under the age of 18 identified and coded as having learning disability.***

Code Criteria	Qualifying diagnostic codes		Time criteria
	Read codes v2	*CTV3*	
Included	E3...% Eu7..% Eu814 Eu815 Eu816 Eu817 Eu81z 918e.	E3...% XaQZ4 XaQZ3 XaKYb XaREt XaREu Eu81z	*Latest < (REF_DAT)*
	(Learning disabilities codes) PJ0% PJ2..% PJ1..% PJyy2 ZV400		
Excluded			

Introduction

An audit of case notes was performed by secondary care study sites. In addition a selection of case notes were re-audited by a different person. The aim of the analysis was to examine the agreement between the audit and re-audit results.

Statistical methods

All the data analysed was categorical in nature, with each question having a finite number of distinct response categories. Due to the nature of the data, the agreement between the two sets of measurements was assessed using the kappa statistic. This method measures the agreement between the two sets of measurements over and above that which would be expected due to chance. Kappa is measured on a scale ranging up to a maximum agreement of 1, and an interpretation of kappa values is suggested in the subsequent table.

Value of Kappa	Strength of agreement
< 0.20	Poor
0.21 – 0.40	Fair
0.41 – 0.60	Moderate
0.61 – 0.80	Good
0.81 – 1.00	Very Good

In addition to the calculated kappa values, a corresponding confidence interval indicating the uncertainty in the result was also calculated.

No analysis was performed if there was insufficient data. Additionally, questions with a text variable with lots of different responses were also omitted from the analysis.

For some variables all of the responses fell into the same category for both the audit and re-audit data. In such instances it was not possible to calculate a kappa statistic. Additionally it was not always possible to calculate a confidence interval for kappa, when all values fell into one category for either the audit or the re-audit data.

Results

The agreement between audit and re-audit results was assessed, and the results are summarised in the next table. The figures presented are the number of case notes in each analysis, the estimated kappa value, and also corresponding confidence interval.

Kappa values below 0.50 have been highlighted in the table.

6. Test-retest analysis of the case note audit tool

QUESTION IN CASE NOTE AUDIT TOOL		N	KAPPA (95% CI)
Physical health of the patient			
	Is there evidence in the notes that the patient received the following physical examinations within 24 hours of admission:		
q1a	Blood pressure (Yes, No)	38	0.54 (0.23, 0.85)
q1b	Pulse (Yes, No)	38	-0.06 (-0.37, 0.24)
q1c	Temperature (Yes, No)	38	0.46 (0.15, 0.78)
q2	Is there evidence in the notes that the patient's mobility needs were assessed and recorded? (Yes, No, N/A)	38	0.38 (0.10, 0.67)
q3	Is there a record of the patient's BMI/weight? (Yes, No, N/A)	38	0.44 (0.20, 0.68)
q4	Is there evidence that food and drink intake were monitored? (Yes, No)	38	0.54 (0.23, 0.85)
q5	Did the patient receive a swallowing assessment? (Yes, No, N/A)	38	0.47 (0.24, 0.70)
q6	Did the patient have problems with eating and drinking? (Yes, No, Not recorded)	38	0.58 (0.35, 0.80)
q7	Did the patient have epilepsy? (Yes, No)	38	0.94 (0.62, 1.00)
q7a	Do the case notes include an epilepsy risk assessment? (Yes, No)	16	0.58 (0.09, 1.00)
	Has information been recorded in the case notes on:		
q7b1	Type of seizures (Yes, No)	16	0.75 (0.27, 1.00)
q7b2	Frequency of seizures (Yes, No)	16	0.75 (0.25, 1.00)
q7b3	Duration of seizures (Yes, No)	16	1.00 (0.50, 1.00)
Managing challenging behaviour			
q8	Do the notes indicate that the patient displayed challenging/ aggressive behaviour that was difficult for the staff to manage? (Yes, No)	38	0.87 (0.56, 1.00)
q8a	Is there evidence in the notes that the cause of behaviour was investigated? (Yes, No)	11	0.23 (-0.33, 0.80)
	Were any of the following interventions used to manage this behaviour?		
q8b1	Drug treatment (Yes, No)	7	0.00 (*)
q8b2	Physical restraint (Yes, No)	7	1.00 (0.25, 1.00)
q8b3	Other (Yes, No)	7	-0.23 (-0.91, 0.43)
q8b4	What was the drug treatment? (Antipsychotics, Benzodiazepines, Both, Other)	6	0.66 (-0.08, 1.00)
q8c	Is there evidence in the case notes that de-escalation interventions were tried before use of drugs or physical restraint? (Yes, No)	6	(†)
Psychotropic medication			
q9a	Was the patient taking psychotropic medication on admission? (Yes, No)	38	0.68 (0.37, 0.99)
q9b	Was this patient prescribed any new psychotropic medication during their stay? (Yes, No)	38	0.77 (0.45, 1.00)
q9c	Is there evidence in the notes that the necessity of this prescription was reviewed during their stay? (Yes, No)	20	0.85 (0.42, 1.00)
q9d	Is there evidence in the notes that the necessity of this prescription was reviewed on discharge? (Yes, No)	20	0.58 (0.15, 1.00)
q9e	Is there any record in the discharge notes that a prescription of psychotropic medication was being continued post discharge? (Yes, No)	20	0.68 (0.24, 1.00)
Communication with the patient and meeting their needs			
q10	Is there evidence in the case notes that a health passport, or similar document, was used? (Yes, No)	38	0.88 (0.56, 01.1)
	Is there any evidence in the notes that reasonable adjustments were made for this patient?		
q11a	Patient given information in alternative formats (Yes, No)	38	0.14 (-0.15, 0.43)
q11b	Patient allocated extra time (Yes, No)	38	0.37 (0.12, 0.62)
q11c	Use of appropriate tools to identify pain/distress (Yes, No)	38	0.47 (0.17, 0.77)
q11d	Other (Yes, No)	38	0.54 (0.24, 0.85)

q12	Is there a record of how best to communicate to the patient? (Yes, No)	38	0.65 (0.33, 0.96)
Communication with the patient and meeting their needs			
q13	Is there evidence in the case notes that the patient's capacity was assessed and recorded before this decision was made? (Yes, No)	38	0.73 (0.41, 1.00)
q13a	Did this patient lack capacity? (Yes, No)	15	0.46 (-0.04, 0.97)
q13b	Is there evidence in the case notes that a best interests meeting took place for this patient? (Yes, No)	6	1.00 (0.19, 1.00)
q13b1	Was the patient invited to the best interests meeting? (Yes, No, N/A)	4	(†)
q13b2	Was the carer/family invited to the best interests meeting? (Yes, No, N/A)	4	1.00 (0.01, 1.00)
q13b3	Was an advocacy service invited to the best interests meeting? (Yes, No)	4	(†)
q13b4	Was there any specialist learning disability input at the best interests meeting? (Yes, No)	4	1.00 (0.01, 1.00)
q13c1	Is there evidence in the notes that discussions about this decision involved the patient? (Yes, No, N/A)	5	1.00 (0.12, 1.00)
q13c2	Is there evidence in the notes that discussions about this decision involved the carer/family? (Yes, No, N/A)	5	1.00 (0.35, 1.00)
q13c3	Is there evidence in the notes that discussions about this decision involved advocacy services? (Yes, No)	5	(†)
q13c4	Is there evidence in the notes that discussions about this decision involved specialist learning disability input? (Yes, No)	5	1.00 (0.12, 1.00)
q14	Is there evidence in the notes that discussions about this decision involved the patient? (Yes, No, No further decisions were made/can be found)	38	0.32 (0.10, 0.54)
q15	Is there a 'do not resuscitate' order recorded in the patient's notes? (Yes, No)	38	1.00 (0.68, 1.00)
q15a	Was the patient involved in the 'do not resuscitate' decision (Yes, No, N/A)	6	(†)
q15b	Was the carer/family involved in the 'do not resuscitate' decision (Yes, No, N/A)	6	0.10 (-0.50, 0.70)
q15c	Was an advocacy service involved in the 'do not resuscitate' decision (Yes, No)	6	0.00 (*)
q15d	Was there any specialist learning disability input in the 'do not resuscitate' decision (Yes, No)	6	0.00 (*)
q16a	Is there evidence in the notes that discussions about discharge involved the patient (Yes/No)	35	0.58 (0.33, 0.83)
q16b	Is there evidence in the notes that discussions about discharge involved the carer/family? (Yes, No, N/A)	35	0.36 (0.11, 0.61)
q16c	Is there evidence in the notes that discussions about discharge involved advocacy services? (Yes, No)	35	0.43 (0.12, 0.75)
q16d	Is there evidence in the notes that discussions about discharge involved specialist learning disability input? (Yes, No, N/A)	35	0.70 (0.37, 1.00)
q17	Were the support and care needs of the patient recorded in the discharge summary? (Yes, No)	35	0.51 (0.17, 0.84)
q18	Is there evidence in the case notes that the patient's informal carer had been signposted to an assessment of their current needs in advance of discharge? (Yes, No, N/A)	35	0.50 (0.26, 0.74)

(*) Unable to calculate confidence interval for this outcome

(†) Not possible to calculate kappa, as all audit and re-audit values in a single category

The analyses suggested a range of results. For some questions there was very good, almost perfect, agreement (e.g. q7). On the other hand for other questions there was poor agreement (for example q1b). It should be noted that a number of the analyses are based on very small sample sizes. As a result the confidence intervals for the kappa values are very wide. In such instances the results should be interpreted with caution.

7. Secondary care standards for a future audit

Twenty-one secondary care standards were developed for the feasibility study. The proposed amendments to them, presented in the table below, are based on feedback received from stakeholders (see Section 3: Collecting feedback from stakeholders).

MAKING REASONABLE ADJUSTMENTS
1. The service can identify people with learning disabilities and any reasonable adjustments they require **REVISE:** This is a national priority and the feasibility study found variability between hospitals. The audit team propose asking services to provide information about the number of people with learning disabilities who used their service over the previous 12 months.
2. Services make reasonable adjustments for people with learning disabilities, based on the individual needs of the patient **REVISE:** The audit team were advised that some staff do not know what constitutes a 'reasonable adjustment'. The audit team propose asking staff direct questions about their awareness and use of reasonable adjustments.
3. The patient's health passport, or similar document, is used by the service to help them care for the patient **INCLUDE:** Recording of this in case notes is low in acute (32%) and mental health (12%) settings. There was good test-retest reliability for this question in the case note audit tool (see Appendix 6).
4. The service has ready access to specialist learning disability services **REVISE:** The audit team propose that in the organisational checklist, the service is required to provide information about their local community learning disability team and liaison nurses/champions (if applicable).
PHYSICAL HEALTH AND RECORDING OF INFORMATION
5. The patient receives a comprehensive physical examination within 24 hours of admission. This includes blood pressure, pulse and temperature **REVISE:** This is a particularly important issue for mental health services, but not acute services, so we propose applying it to the former only. The audit team found poor test-retest reliability on this item (Appendix 6). Suggested revision: *There is evidence that the patient received a comprehensive physical examination within 24 hours of admission*.
6. The patient receives high quality nutritional care, based on their individually assessed needs **REVISE:** This is an important standard and our results suggest that it is less likely to be recorded in mental health than in acute services. A 'not applicable' option was included in the feasibility study; we recommend removing this. As in the feasibility study, focus should be on swallowing as well as nutritional needs.
7. The patient's current mobility needs have been assessed and recorded **EXCLUDE:** This is an important issue, but does not apply to all people with a learning disability in hospital.

8. Patients with epilepsy have a risk assessment in their notes

9. Patients with epilepsy have a description of their seizures recorded in their notes, including type, frequency and duration

INCLUDE: A minority of people in the feasibility study sample had epilepsy, and the recording of information about this was poor. These items had good test-retest reliability (Appendix 6) and should be included in a future national audit. A future audit could ask further questions about risks in hospital, for example bathing.

10. An assessment of the patient's preferred method of communication is recorded and used

REVISE: Recording of this in case notes was low in acute (55%) and mental health (58%). This standard can be measured using more than one audit tool, which will allow for triangulation. This standard only applies to a proportion of patients, so the audit team propose revising the standard to: *Among those patients who have issues with communication (e.g. non-verbal, partial hearing) there is a record of their communication needs.*

CAPACITY AND DECISION MAKING

11. Discussions about care involve the patient and their carer/family where relevant

12. The patient's capacity is assessed and recorded, whenever decisions need to be made about their care

13. If assessment of the patient shows they lack the capacity to make a decision about their care, a best interests meeting takes place and involves them and their carer/family where relevant

REVISE: The number of instances where capacity issues were documented in case notes was marginal (particularly for 'Do Not Resuscitate' decisions). Acute sites suggested that this information was difficult to obtain from case notes. The audit team propose identifying one or more major clinical decisions during the admission and checking whether capacity was assessed appropriately, and if capacity was absent check that the requisite best interest consultation took place.

MANAGING CHALLENGING BEHAVIOUR

14. If the patient presents challenging/aggressive behaviour, the reasons for this are investigated and documented

15. If the patient presents challenging/aggressive behaviour, de-escalation is tried before use of physical restraint or pharmacological intervention

INCLUDE: Data for this were easily collected and there was consensus among study sites and other stakeholders that this is an important issue. Further questions could be asked in mental health services because the prevalence of challenging behaviour and use of drug treatment/restraint is higher than in acute services.

PSYCHOTROPIC MEDICATION

16. If the patient is taking psychotropic medication, this is reviewed during their stay

INCLUDE: Data were easily collected and the consensus was that this is an important issue. Further questions about this could be asked in mental health services because the prevalence of psychotropic medication use is comparatively high.

DISCHARGE PROCESSES

17. The discharge summary includes information about support and care needs the patient has following their stay at the service

INCLUDE: Recording of this in case notes is low in acute (61%) and mental health (72%) settings. This standard can also be measured using different audit tools, allowing for triangulation.

18. Discharge planning involves the person with learning disabilities and their carer/family where relevant

REVISE: Study sites fed back that determining whether this standard was met was too subjective (in case note audit). Appropriate involvement of patients and carers at discharge is best determined by patients and carers, so the audit team propose this revision to the standard: *Patients and carers feel they had appropriate information and notice of discharge*.

19. Informal carers are signposted to an assessment of their current needs in advance of the patient's discharge

INCLUDE: Recording of this in case notes is low in acute (45%) and mental health (24%) settings. This standard can be measured using multiple audit tools.

STAFF TRAINING

20. All staff should receive training in learning disabilities

REVISE: This item could be improved by requesting hospitals to report the percentage of staff who received learning disability training in the last 12 months, alongside evidence that staff receive training on induction.

21. Staff feel equipped to respond to the needs of people with learning disabilities

REVISE: A future staff questionnaire should capture information about individual practice and knowledge.

Areas to consider including in a secondary care audit:

- Unplanned vs. planned admissions and the monitoring of readmission rates
- Length of time on psychotropic medication
- Use of detention under Mental Health Act
- Continuity of care – more linkage between primary, secondary and community services
- Further investigation of risks in hospital e.g. when bathing

The feasibility study is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

This report was prepared by: Aarti Gandesha, Pamela Gallagher, Alan Quirk and Mike Crawford from the Royal College of Psychiatrists; and Megan Lanigan and Umesh Chauhan from the Royal College of General Practitioners.

For more information about the audit please contact the team:

Royal College of Psychiatrists' Centre for Quality Improvement
21 Prescot Street London E1 8BB

0203 701 2697
agandesha@rcpsych.ac.uk