Briefing Paper: Learning Disabilities Mortality Review (LeDeR) Programme - Handover to CCGs in Wessex area

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1. Introduction

This paper will provide a handover summary to support the CCGs/TCPs going forward.

2. Background

The National LeDeR Programme has been established in response to the recommendations from the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD, 2013). The LeDeR programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and led by the Norah Fry Institute at the University of Bristol.

NHS England set up the Wessex LeDeR pilot on 1st August 2016 and has since moved to a successfully established programme of work in March 2017, well ahead of other sites that are at various stages of development across England.

In response to the Care Quality Commission's (CQC) review of deaths: *Learning, Candour and Accountability (December 2016)*, a letter was sent to all Medical Directors outlining recommendations and commitments for improving how the NHS learns from reviewing the care of patients who have died. This was followed by the *National Guidance on Learning from Deaths* (National Quality Board, March 2017) which stated that the LeDeR methodology should be used to review the deaths of all those with learning disabilities.

On 14th March 2017, a letter was sent from NHSE (South) Regional Chief Nurse and Transforming Care Lead (South) to all DCOs and DONs outlining the requirements for CCGs and provider Trusts;

- To support the roll out of the LeDeR programme
- To nominate a local leader – a Local Area Contact (LAC) - to co-ordinate and enable reviews of all deaths of people with a learning disability
- To support the recruitment of LeDeR reviewers

It was agreed that the operational process for LeDeR should be handed over to Transforming Care Partners (TCPs) / Clinical Commissioning Groups (CCGs) in the Wessex region from 1st October 2017. Embedding the process at a local level will enable the outcomes/learning/action plans from LeDeR reviews to be shared via the local established networks within TCPs/CCGs. It will ensure that any learning and improvements for the care of learning disabilities patients can be addressed by commissioner.

3. Wessex update

Table (1): below provides a summary of the total notifications of death received since the pilot start date 01/08/2016 to 30/09/2017, and progress with reviews:

LeDeR Case Summary	
Total no. of active notifications received 01.08.2016 - 30.09.2017	93
Total no. allocated for initial review	31
Total no. escalated to Multi-Agency review	4
No. of referrals on hold (under DHR / police / coroner/ safeguarding investigation)	20
No of initial reviews completed	11
No. of multi-agency reviews completed	3
No. of completed reviews waiting for Quality Assurance Panel	6
No. pending allocation	62

Table 1, shows that of the total number of notifications received to 30th September 2017 (93), 31 cases have been allocated for an initial review. An initial review should usually be completed **within 4 weeks** from allocation and cases that trigger a wider, multi-agency should be completed **within 12 weeks**. Data so far shows that 4 (out of 31 cases allocated) have progressed to a multi-agency review.

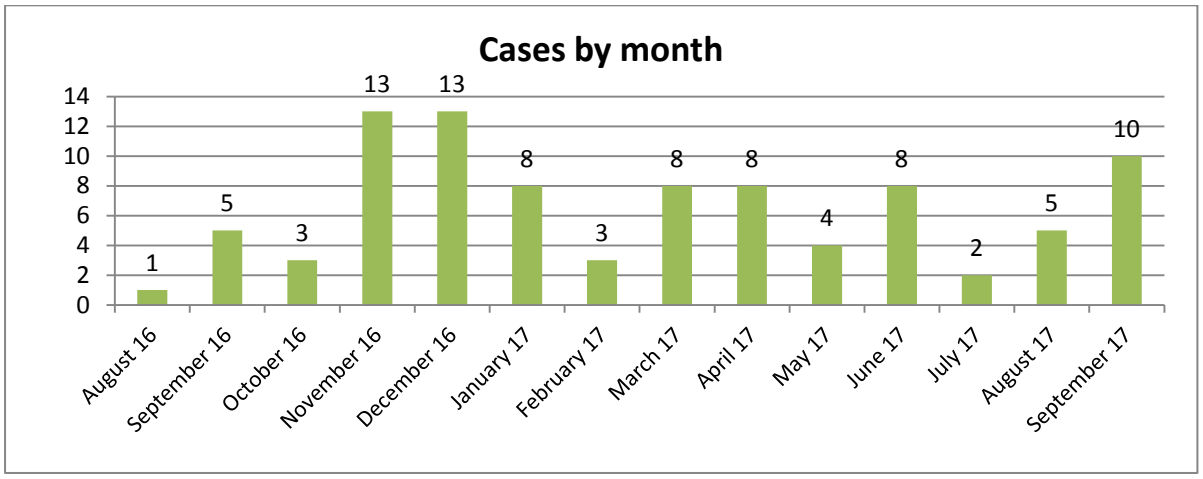
To date, there are 11 fully completed initial reviews and 3 completed multi-agency reviews. Once the initial review has been completed by the Reviewer it is passed to the Local Area Contact to check and then sent to the Quality Assurance Panel, LeDeR Team at the University of Bristol to approve. At the end of September 2017, there were 6 completed reviews pending approval by the QA Panel which will equate to 20 fully completed reviews.

There are 20 notifications on hold. These are notifications received which have identified that there are other review/investigation processes in progress (such as DHR, police, Coroner, safeguarding). The Local Area Contact will check with the relevant agency as to whether it is appropriate for a LeDeR review to be undertaken in accordance with the LeDeR guidance briefing paper:

5. Briefing paper - Working with other in

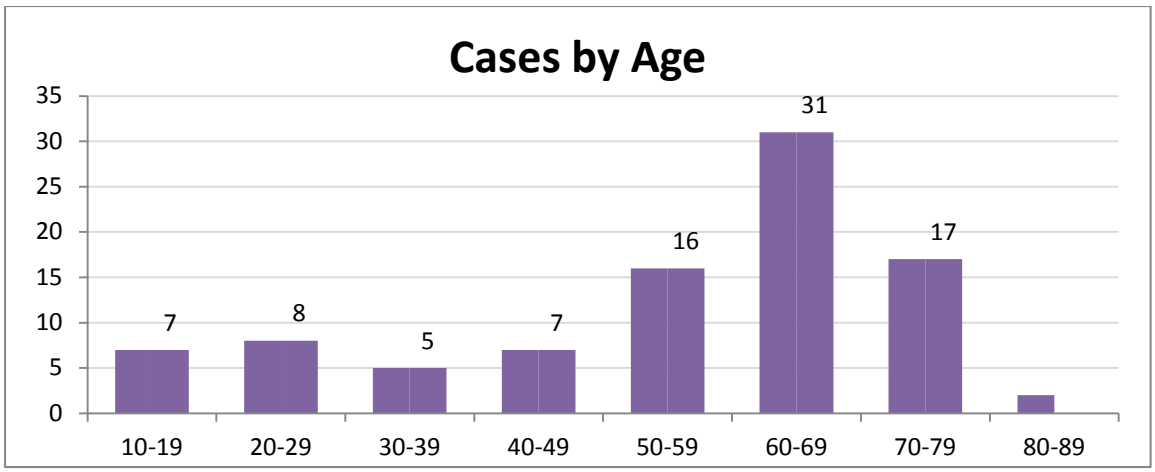
There are a number of reviews pending allocation; 62 at 30th September 2017. Reviews have been allocated in chronological order of receipt from 1st August 2016, with cases now being allocated that were notified in January 2017.

Table (2): shows the number of notifications per month from 01/08/2016 - 30/09/2017:



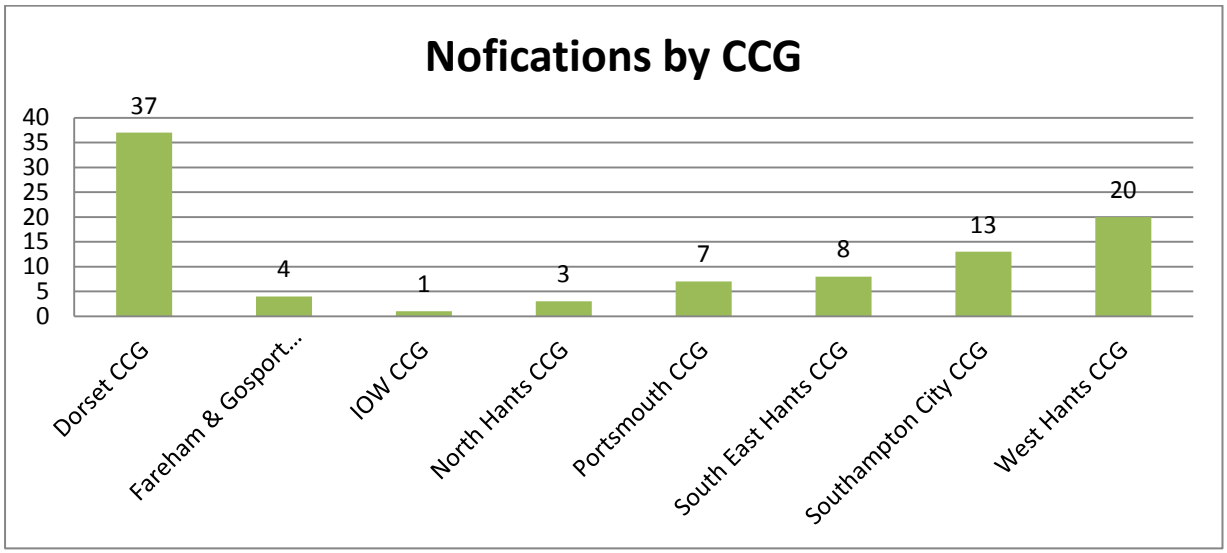
The table shows the average number of notifications of deaths to the LeDeR programme to be around 6 per month. This is below the expected average of 9 per month based on previous data (CIPOLD, 2013).

Table (3): shows the number of cases (notifications) by age



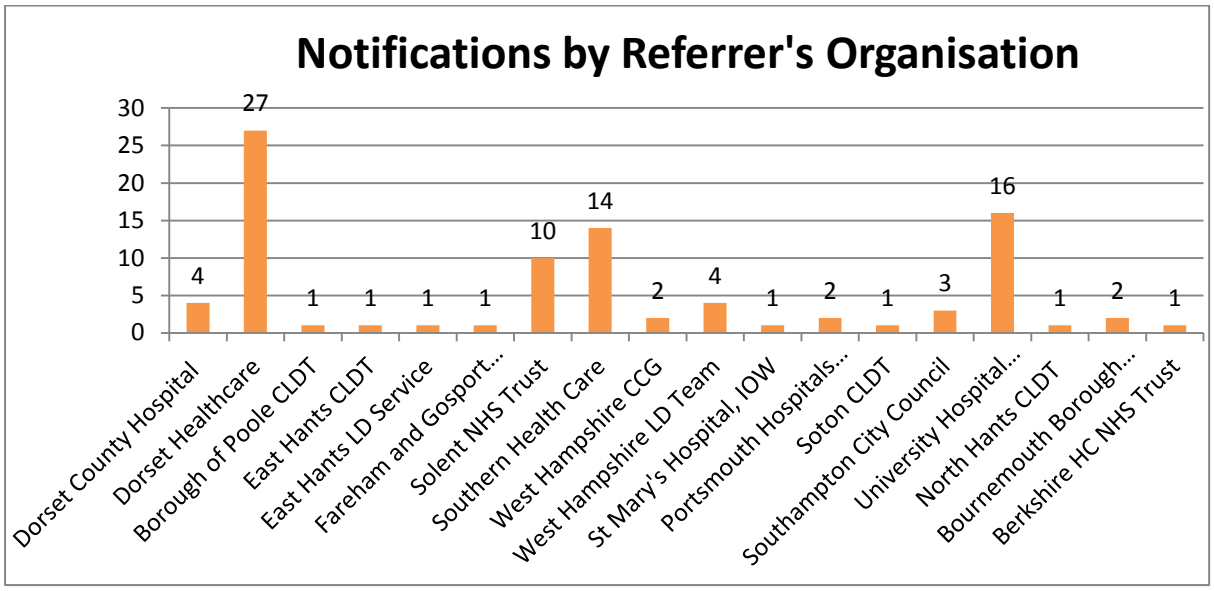
- The table shows that the majority of deaths fall within the 60-69 years.
- There have been 7 deaths reported of those aged 10-19 years. Deaths of children aged 4-17 years are required to be reported to the LeDeR programme and recorded, but they are not subject to the LeDeR review process, as they are reviewed by the CDOP (Child Death Overview Panel).
- Adults aged 18-24 years are subject to a 'priority themed' review and automatically referred for a multi-agency review.

Table (4): Shows the breakdown of notifications by individual CCG



The breakdown of notifications by TCP shows: Dorset =37 (34%) and SHIP = 56 (66%)

Table (7): shows notifications by referrer's organisation

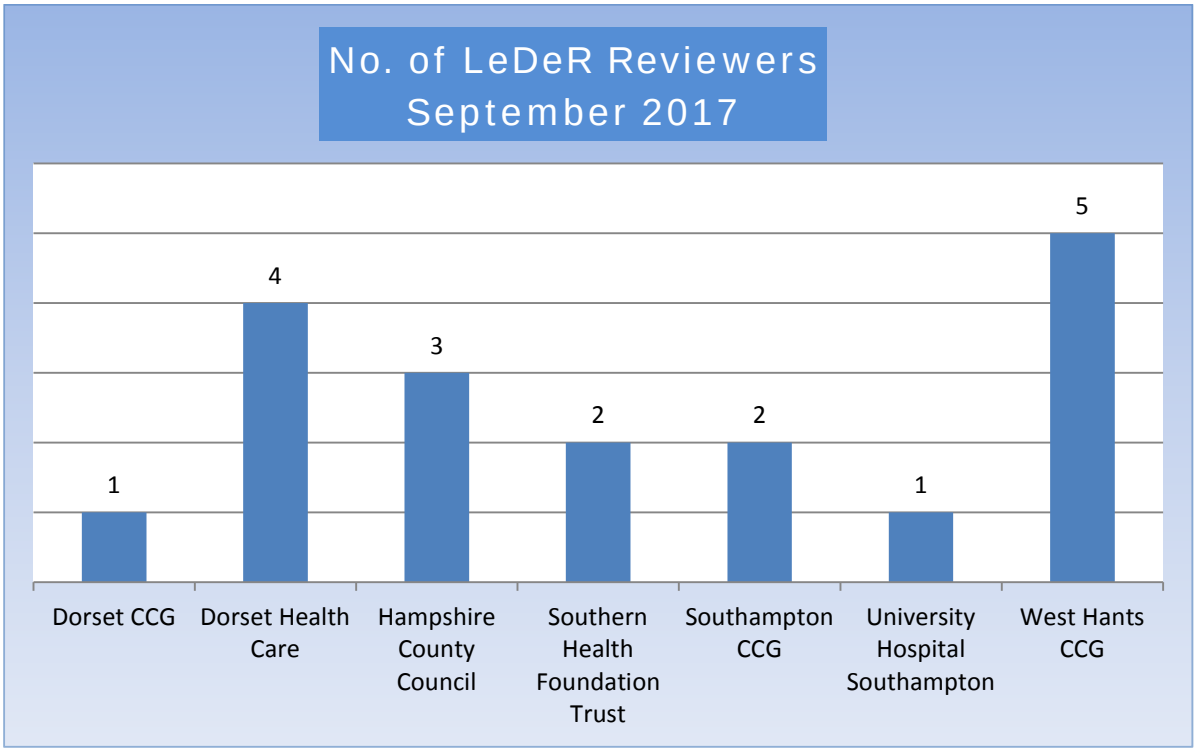


Notifications have been received by a range of organisations in Wessex. These are made directly to the LeDeR Team at the University of Bristol and then referred to the Local Area Contact. Notifications can be received from more than one source (referrer). Duplications are usually identified at the point of notification, or the Local Area Contact is made aware and asked to check.

4. Reviewers

There are 31 trained Reviewers in the Wessex Region; a mix of health and social care professionals employed within Wessex, and including one GP in Dorset. Of these there are currently 18 active reviewers:

Table (8): shows there are currently 18 Active Reviewers and their organisations:



All Reviewers have completed the LeDeR reviewer's training to be able to fulfil the role. Training sessions were provided in Wessex region in February and April 2016, with a refresher session for trained reviewers prior to pilot commencing in August 2016, and a in January 2017. Further training is planned for **12th October and 9th November 2017** and details have been circulated.

Retention and recruitment of reviewers has been an ongoing challenge to the programme. Early training sessions included a number of people who were checking out the programme requirements rather than committing to be Reviewers. The LeDeR process is not statutory and is therefore seen as an additional commitment to the Reviewers and their respective employing organisations. Drop out has generally been due to sickness or staff leaving posts but the most common theme is the lack of resource/time to be released from their existing roles with other work commitments taking priority over completing LeDeR reviews.

A key part of the role of the LAC (Local Area Contact) has been to encourage and support newly trained Reviewers. This has included buddying up with Reviewers on their first case if required and providing regular (Bi-monthly) Reviewers' meetings; to enable peer support, reflection on cases, the processes, and sharing any good practice/learning and any challenges.

Lack of Reviewers has significantly impacted on the ability to manage the number of notifications and the consequent growing backlog of cases notified for a review. The LeDeR team at the University of Bristol has recommended that a Reviewer could potentially undertake 3-4 reviews per year. This has been reflected in Wessex with two of the Reviewers, but many are on their second review and several are still on their first case.

The table (9) below shows the current list of active Reviewers, their organisations, the number of completed reviews to date:

Table 9: Current Active Reviewers

Reviewer and their Organisation	Number of Initial Reviews Allocated	Number of cases escalated to Multi-Agency Review	Reviews currently in Progress
1. IS – NHS Dorset CCG (GP)	2		0
2. SC - Dorset Healthcare University NHS Foundation Trust	1		0
3. MF -Dorset Healthcare University NHS Foundation Trust	2		1
4. AH -Dorset Healthcare University NHS Foundation Trust	4	2	1
5. JM -Dorset Healthcare University NHS Foundation Trust	1		0
6. LH – Hampshire County Council	1		1
7. SS - Hampshire County Council	1		1
8. YC - Hampshire County Council	1		0
9. AMc – University Hospital Southampton	2		1
10. DP – NHS Southampton City CCG	2		1
11. AS - NHS Southampton City CCG	3		1
12. CP - Southern Health Foundation Trust	1		1
13. NC - Southern Health Foundation Trust	2		1
14. LJo – NHS West Hampshire CCG	1		1
15. LJa – NHS West Hampshire CCG	1	1	0
16. DB – NHS West Hampshire CCG		1	1
17. CTH – NHS West Hampshire CCG (newly trained)	0		0
18. BW – NHS West Hampshire CCG (newly trained)	0		0
19. LS – NHS Somerset CCG (buddy with MF Dorset)	1		1

Somerset CCG are a new LeDeR pilot site and have a recently trained Reviewer who has kindly offered to help with Wessex reviews to gain experience of the role whilst they are waiting to 'go live'.

There is a separate list of trained reviewers who are currently inactive which can be shared. Those who have been inactive for more than 6 months to a year would need a refresher session / or buddying up with a trained reviewer.

The time taken to review a case has depended on the complexity of the case, location and access to the case records, along with making contact with family or appropriate person that knew the individual well and the Reviewer's experience. The first case usually takes longer whilst the Reviewer's become familiar with the process and using the web base platform. Time taken to complete a review can be spread over several days/weeks or months (for multi-agency review) depending on the availability of key people/records and the capacity of the Reviewer. Reviewers experience to date has varied with the average time for an initial review ranging from 12- 40 hours and a multi-agency review 3-5 days.

5. Local Area Contacts

The role of the LAC is to act as a key link between the LeDeR programme team at the University of Bristol, the Local Steering Group and the Local Reviewers, and includes:

- Receiving notification of deaths
- Alerting the local CCG where the death has occurred
- Allocation of cases to local reviewers
- Monitoring progress and completion of reviews; to ensure consistent standard, timely completion and comprehensive.
- Provide advice and support to local reviewers
- Receive and sign off completed review documents and action plans
- Anonymise and collate learning points and actions and present the information to the local steering group for action and implementation

From 1st October, coordination of the LeDeR process for all **new notifications** will formally transfer from Wessex Local Area Contact (Gina Cook) to the following LACs for the CCGs in Wessex area (Southampton, Hampshire (x5), Isle of Wight, Portsmouth and Dorset):

CCG	LAC
Southampton City CCG	• Antony Shannon
Hampshire x5 CCGs: • West Hampshire • North Hants • North East & Farnham • Fareham, Gosport & SE Hants	 • Carole Berryman • Tom Crawford • Philip Shaw • Pauline Dorn
Isle of Wight CCG	• Martin Grant
Portsmouth CCG	• Catherine Mead
Dorset CCG	• Emma Duff

All LACs have been offered training; most have attended the LeDeR LAC training and also the LeDeR Reviewers training, which enables a better understanding of the Reviewer's role. They have also been offered a one to one handover from NHSE Wessex LAC, as well as the offer of ongoing support / advice whist the new role is embedded into CCGs.

6. Backlog of Notifications

The backlog of notifications that have not been allocated for a review will remain with the NHSE Wessex. It has been agreed by the NHSE National LeDeR Ream to allocate funding to support the LeDeR programme in Wessex, and enable development of a secondment post to specifically review all cases in the backlog.

7. LeDeR Steering Group (Wessex)

The Wessex LeDeR Steering Group will continue to meet bi-monthly and membership will include all the newly appointed CCG LACs.

The role of the Steering Group includes:

- To provide oversight, support and governance o the local delivery of the programme and guide the implementation of the LeDeR programme of local reviews of deaths.
- To receive regular updates from the Local Area Contact about the local reviews of deaths of people with learning disabilities.
- To monitor action plans resulting from local reviews of deaths
- To take appropriate action as a result of information obtained from local reviews of deaths
- To ensure agreed protocols are in place for information sharing, accessing case records and keeping content confidential and secure.
- To undertake a quality assurance role

LACs will be responsible for providing the Steering Group with an update on notifications received, number of reviews and the learning/actions identified from reviews.

The role of the Wessex Steering group will be reviewed as local mortality review groups develop within each TCP. Currently the Wessex Steering Group reports to the South Regional LeDeR Steering Group, which in turn reports to the National NHSE Team.

References

CIPOLD (2013); Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with learning disabilities. Final Report. University of Bristol. Bristol

CQC (December 2016) *Learning Candour and Accountability; a review of the way NHS Trusts review and investigate deaths of patients in England*

CQC Letter (22 February 2017) to Medical Directors 'Learning from Deaths'

17022204 - Learning from deaths.pdf

LeDeR (Learning Disabilities Mortality Review Programme) - www.bristol.ac.uk/sps/leder/

Letter to all DCO Directors of Nursing

20170314 - LeDeR Programme.pdf

National Quality Board (March, 2017) *National Guidance on Deaths*