

University of Bristol Learning Disability Mortality Review Programme (LeDeR)



Team members:

- Professor Pauline Heslop – Programme Lead
- Richard Jeffery – Programme Manager
- Jess Winkler – Training and Quality Assessment Coordinator
- Lindsey Allen - Training and Quality Assessment Coordinator
- Ade Murphy - Training and Quality Assessment Coordinator
- Lucy Brockbank – Programme Officer (Priority Themed Reviews)
- Dave Hanford – Information Officer
- Irena Holdsworth – Senior Administrator
- Mel Avis – Programme Administrator
- Anni Sutt – Programme Administrator
- Owen Cranshaw – Research Data Officer
- Rachel Calkin – Data Analyst
- Fred Dunwoodie Stirton – Coordinator for Additional Projects

The NCAPOP project journey so far

- The disparity in average age of death between a person with learning disabilities and the normative baseline is approximately 13-20 years (F/M)
- The programme aims to reduce avoidable deaths through improving care – currently people with learning disability are three times more likely to die from causes related to poor quality care
- The LeDeR programme is rolling out a governance structure, processes, methodology and training to enable a review of every death of a person with learning disabilities aged 4 years and above within NHS England
- Through reviewing deaths of people with learning disabilities, subsequent learning, actions and recommendations lead to service improvements and help to reduce premature deaths
- Involving those who knew the person and their situation best is central to the programme. This could be a family member, carer or friend.
- The reviews are holistic – they look at the overall picture and how services interrelate

The NCAPOP project journey so far

- To date we have received 1,400 notifications of deaths and completed close to 100 reviews.
- We have set up 39 local steering groups covering the whole of NHS England, with an ideal membership, Terms of Reference and brief. Members are comprised of professionals from primary, secondary and social care.
- The programme has trained 1,300 (active) Reviewers
- We have also trained 180 Local Area Contacts who supervise Reviewers. Both are aligned to a specific steering group.
- The programme has developed its own national IT system and database which manages and produces all data for the programme.
- The programme has developed its own Quality Assurance process to ensure consistent quality reviews, no matter where a review is completed.
- Learnings and service developments are shared nationally, regionally and locally to improve quality of Learning Disability services.

All Teach, All Learn

- To date local areas have completed close to 100 reviews and generated many actions and recommendations.
- The collated findings, learning points and actions with regard quality improvements & impactful recommendations is shared at a national, regional and local level
- The LeDeR programme can have immediate impact from one review and doesn't require typical facets of a national audit, such as benchmarking or data audit to prove its success. Although these are used.
- Actions and recommendations cover all sectors of care for a person with learning disabilities.
- Our work is summarised annually in a national report.
- The next aim is to ensure data is used in various organisations to drive change.

Insights from work

1. The programme is about changing hearts and minds, just as much as it is about methodologies, processes and delivery. We are utterly dependent on the good will of all staff who participate.
2. Completing a review in itself is irrelevant if the insights they generate don't subsequently improve or change services for those with learning disabilities.
3. Sharing benefits, and more importantly outcomes of the programme, accelerates engagement, as well as improving services.
4. Learn & share good practice.

Advice to peers

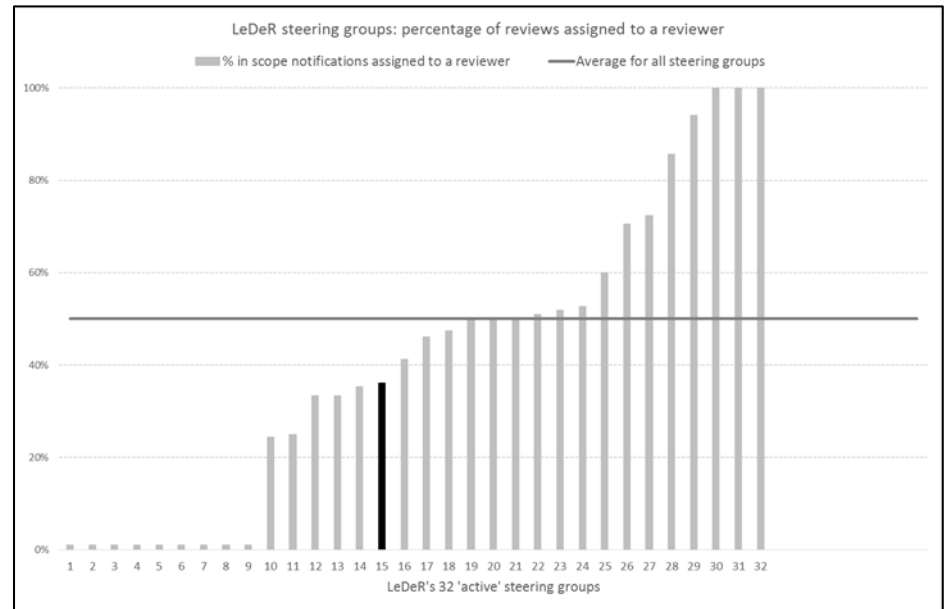
- Keep it clear and simple. Communication and sharing is best when the message can be received easily. It then makes it easier to action.
- Identify key stakeholders and map out how you will communicate with them through a communications delivery plan.
- Use all forms of communication, such as social media and where possible get buy-in from key stakeholders before committing to certain channels or methods. Check it will work for them.
- You cant do enough communication. Whilst “communication fatigue” is a valid response to too much communication, the project will fail if there isn’t enough.

We are keen to learn:

- How to turn data into meaningful impactful changes on the ground
- How to maintain momentum and progress at all times within an audit / programme
- How to get people to do what they don't want to do!

Sharing effective and impactful ways of presenting data/recommendations

- Easy-read material
- Pre-defined key performance metrics
- Benchmarking e.g. steering group reports
- User defined views of data at all relevant levels
- Annual report



Next Steps

- Hard-code the governance structure by which outcomes will be measured throughout the programme and ensure that data is used appropriately where relevant to drive service improvement.
- We need to consider if our data could have even bigger impact, if shared more widely and who this might be with.
- We want to employ a Health Economist to prove that our programme works and generates not only better services for people with learning disabilities but also saves money in the long run.

How can HQIP help?

- Focus on outcomes
- Help the programme to avoid scope creep
- Keep networks of audits open and share important relevant information that's common to all audits e.g. confidentiality, anonymisation etc
- Help unblock blockages in the system when necessary