

NHS England – North (Yorkshire & The Humber)  
Public Health Commissioning  
Quarry House  
Quarry Hill  
LEEDS  
LS2 7UE

Date: 14 June 2023

Dear Colleague

We are writing to you to gain your support in requesting your GP Learning Disability registers are shared annually with the below NHS screening programmes providing services for Barnsley, with the aim of reducing inequalities in screening.

The screening programme already hold all the personal data for your eligible population and therefore this request is specific to be able to flag LD status. The latest LeDeR (2021) states the median age at death for people with a learning disability is 62 years. This is significantly less than the median age of death of 82.7 years for the general population. LeDeR also reports that 49% of deaths were from an avoidable cause which could have been prevented by good quality healthcare compared to 22% of deaths for the general population (as reported by ONS).

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/latest>

Sharing information to make sure patients get the best care is justified when you are satisfied that the recipient of the information is a registered and regulated care professional (which includes screening services, whether NHS or independent provider delivering NHS screening programmes) and that the information is relevant. Sharing information appropriately helps to tackle screening inequalities in line with the [2010 Equalities Act](#) requirement for public services to anticipate and prevent discrimination against people with learning disabilities and serious mental illness.

GP practices are asked to inform local screening services about eligible individuals with learning disabilities who are registered with them when it is in the interests of providing an effective service. See [NHS England's information sharing policy](#) for more detailed guidance.

The GMC states: screening is considered “direct care” it is therefore reasonable to assume consent is implicit if it's in the patient's best interest to share information. This means you can share information on individuals and the reasonable adjustments they require providing:

- Your information is up to date
- You have no reason to think that the individual would be surprised that you have shared this information
- You indicate to your patients that you will be sharing information about them for this purpose.

Currently across South Yorkshire there are differing models for GP data extraction and sharing of Learning Disability Registers with NHS screening programmes that often do not offer a complete up to date data set. We have built the below reports within your clinical IT system to help support this process. Once run they will need to be emailed securely from an nhs.net email account (all receiving accounts are secure nhs.net) and are listed below.

This letter is a request to run and email reports (instructions attached) on an annual basis. As discussed screening programmes already hold all the personal data of eligible persons, however the LD status of a person is not currently shared with all screening programmes due to IT interoperability issues and therefore your support is requested to ensure reasonable adjustments can be made for your patients.

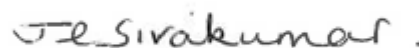
There are approximately 1.3 million people with a learning disability in England, including over 950,000 adults aged 18 or over. Please support your local screening programmes to be able to offer targeted, upscaled support for your practices learning disabled patients.

Screening programme	NHS Foundation Trust and email
Abdominal Aortic Aneurysm	Doncaster and Bassetlaw Teaching Hospitals <a href="mailto:dbh-tr.dbhaaa@nhs.net">dbh-tr.dbhaaa@nhs.net</a>
Bowel	Gateshead Health <a href="mailto:gan-tr.north-east-bowel-hub@nhs.net">gan-tr.north-east-bowel-hub@nhs.net</a>
Breast	Barnsley Hospital NHS Foundation Trust <a href="mailto:breastscreening.appointments@nhs.net">breastscreening.appointments@nhs.net</a>

Yours sincerely



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