NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

INDICATOR DEVELOPMENT PROGRAMME

Consultation report

Indicator area: Epilepsy

Consultation period: 22 March – 21 April 2022

Date of Indicator Advisory Committee meeting: 14 June 2022

Contents

Summary of indicators included in the consultation

ID	Indicator	Type of indicator	Evidence source
IND 2021-111	The percentage of adults receiving drug treatment for epilepsy who had a structured review in the preceding 12 months	General practice indicator suitable for use **in** the QOF	Epilepsies in children, young people and adults (2022) NICE guideline NG217 recommendations 4.5.1, 4.5.2, and 4.5.4
IND 2021-112	The percentage of adults with epilepsy and a learning disability who had a structured review in the preceding 12 months	General practice indicator suitable for use **outside** the QOF NB: People with a learning disability are defined as those included on the learning disability register (LD003)	Epilepsies in children, young people and adults (2022) NICE guideline NG217 recommendations 4.5.1, 4.5.2 and 4.5.3
IND 2021-113	The percentage of adults with epilepsy and a mental health condition who had a structured review in the preceding 12 months	General practice indicator suitable for use **outside** the QOF NB: Mental health condition is defined as schizophrenia, bipolar affective disorder and other psychoses (MH001 register)	Epilepsies in children, young people and adults (2022) NICE guideline NG217 recommendations 4.5.1, 4.5.2 and 4.5.3 Psychosis and schizophrenia in adults: prevention and management (2014) NICE guideline CG178 recommendations 1.5.3.1 and 1.5.3.2 Bipolar disorder: assessment and management (2014, updated 2020) NICE guideline CG185 recommendations 1.2.10 and 1.2.11

General comments

- Medication reviews do not have to be carried out in general practice if the person's care is managed in secondary care
- Combining health checks into the same appointment is an important resource consideration
- The needs of people with a learning disability were highlighted as was the importance of ensuring they are not excluded
- Concern that the current QOF incentivises check-ups based on an artificial calendar rather than the needs of the person. Suggested that it should be reviewed to focus on health inequalities, quality improvement and to prioritise workload
- The current QOF indicator for a register of adults receiving drug treatment for epilepsy (EP001) should be expanded to include children and young people. This would ensure that epilepsy prevalence can inform service planning including the role of primary care in prescribing for people with epilepsy of all ages

Considerations for the advisory committee

- Are there concerns about overlap between primary and secondary care?
- Do these indicators reflect current system priorities?
- Is there value in considering additional/amended epilepsy indicators to include children and young people with epilepsy?

IND 2021-111 Epilepsy: annual review for all people receiving drug treatment

The percentage of adults receiving drug treatment for epilepsy who had a structured review in the preceding 12 months

Rationale

Epilepsy is a common neurological disorder characterised by recurring seizures. Regular reviews are important to support treatment monitoring and personalised care. Treatment should be reviewed at regular intervals to ensure that adults with epilepsy are not maintained for long periods on treatment that is ineffective or poorly tolerated. Optimal management improves health and wellbeing outcomes and can also help to minimise impacts on social, educational and employment activity.

Summary of consultation comments

- Some support for the indicator to replace the epilepsy review indicator that was removed from QOF in 2013
- Concern that the indicator may not be implemented unless it is mandated and incentivised due to pressure on appointments in primary care
- If this is more than a structured medication review it may be difficult to accommodate given the current pressures in primary care
- The review should include mental health screening and referral as mental health conditions are under diagnosed in people with epilepsy and have a significant impact on health-related quality of life. Mental health conditions can impact on drug concordance, engagement with services and suicide risk
- The denominator should be extended to include children and young people or as a minimum under 18's who have transitioned to adult services (1 in 3 young people transition to adult services at age 16)
- There is potential to reduce health inequalities if the indicator can improve access for groups that are less likely to attend and are at a higher risk of mortality and morbidity from epilepsy. Invitations and appointments should be widely accessible
- A positive impact on pregnancy and maternity outcomes is likely as information and advice can be given and there can be timely referral for preconceptual counselling and active management during pregnancy

Specific question/s included at consultation

- The NICE epilepsy guideline is currently being updated and the draft recommendations indicate that annual reviews are a priority for those taking antiseizure medications associated with long-term side effects or drug interactions. This indicator has been developed as a pragmatic approach that

could use the existing register currently within QOF (EP001). Would an indicator on annual review for all adults receiving drug treatment for epilepsy be a pragmatic and acceptable approach for quality improvement purposes? Please explain your answer.

- The majority of stakeholders felt that the approach was acceptable providing the content of the review is meaningful and supports improved outcomes including mitigating epilepsy risk and reducing avoidable deaths
- However, some felt that given the pressures in primary care, the indicator is acceptable only if it refers to a medication review as these are already in place for people taking long-term medication

Considerations for the advisory committee

The committee is asked to consider:

- Mixed views among stakeholders on whether this should be a medication review or a wider structured review
- Is this feasible given pressure on workload?
- The indicator could be expanded to include children and young people receiving medication, but it is unlikely that it could identify only young people between 16 and 18 who have transferred to adult services
- Is this a pragmatic and acceptable approach given the updated guideline recommendations?

IND 2021-112 Epilepsy: annual review for people with a learning disability

The percentage of adults with epilepsy and a learning disability who had a structured review in the preceding 12 months

Rationale

Regular reviews are important to support treatment monitoring and personalised care. Adults with epilepsy and a learning disability are at higher risk of mortality and may be more vulnerable to serious consequences from loss of contact with services.

Summary of consultation comments

- Some support for this indicator providing it includes a comprehensive review and risk assessment rather than just a medication review
- Some stakeholders did not see value in this indicator given existing requirement on general practice to review all people with a learning disability and IND 2021-111
- Learning disability registers may not be comprehensive in all areas
- Estimated that 75% of people with a learning disability are not included on a GP learning disability register
- Research has suggested that 40% of children with epilepsy could have a learning disability, so it may be that more than 1 in 5 adults with epilepsy have a learning disability
- Some GP practices with a small list size may have no patients with epilepsy and a learning disability
- The denominator should be extended to include children and young people or, as a minimum, under 18's who have transitioned to adult services (1 in 3 young people transition to adult services at age 16)
- Important to ensure that people in inpatient settings are not excluded from epilepsy review

Considerations for the advisory committee

The committee is asked to consider:

- Is the indicator needed given existing requirements on general practice in relation to people with a learning disability?
- Should the indicator include children and young people?

IND 2021-113 Epilepsy: annual review for people with a mental health condition

The percentage of adults with epilepsy and a mental health condition who had a structured review in the preceding 12 months

Rationale

Regular reviews are important to support treatment monitoring and personalised care. Adults with epilepsy and a mental health condition have complex needs and may be more vulnerable to serious consequences from loss of contact with services.

Summary of consultation comments

- Some stakeholders did not see value in this indicator given existing requirement on general practice to review all people with a mental health condition and IND 2021-111
- This should be an additional follow-on review from IND 2021-111 and IND 2021-112 to support a coordinated approach for adults with a mental health condition
- Suggestions that the indicator should be extended to include children and young people or as a minimum under 18's who have transitioned to adult services (1 in 3 young people transition to adult services at age 16)
- This population is 'harder to reach' and it may be more difficult to encourage them to attend for annual review
- Some GP practices with a small list size may have no patients with epilepsy and an SMI

Specific question/s included at consultation

- Should the population for this indicator be extended to include other mental health conditions? If so, please say which populations should be included and why?

    - There was some support for extending the indicator to include anxiety, depression, dementia, personality disorders or all mental health conditions
    - However, some stakeholders did not feel the denominator should be extended to include other mental health conditions

Considerations for the advisory committee

The committee is asked to consider:

- Is the indicator needed given existing requirements on general practice in relation to people with a mental health condition?
- Should the indicator include children and young people?

- Should the population be extended to other mental health conditions? If so, which?

Appendix A: Consultation comments

General comments

ID	Indicator	Organisation name	Comments	NICE response
1	General	**British Medical Association**	We are unclear of the necessity of having separate indicators for those with learning disabilities and mental health conditions, as there are other contractual targets requiring both sets of patients to have review, so having epilepsy review in QOF would be duplication. In addition, medication reviews do not have to be done in general practice (e.g.by a GP or clinical pharmacist) if undertaken in secondary care	Thank you for your comment. The indicator advisory committee noted these concerns and agreed not to progress the separate indicators for people with learning disabilities and mental health conditions. We have also specified that those already reviewed in secondary care should count in the indicator and primary care will not have to re-review them.
2	General	**NHS England and NHS Improvement**	For people with a learning disability, the importance of understanding the context of their general health, how it is progressing, the importance of a holistic annual health check. In relation to all the indicators (and not just for people with a learning disability): important that the checks are done together rather than in multiple health appointments.	Thank you for your comment. The indicator advisory committee agreed not to progress a separate indicator for people with a learning disability and epilepsy due to overlap with the existing requirement for an annual health check for this population.
3	General	**NHS England and NHS Improvement**	It might be practically more difficult to ensure that people with a learning disability and autistic people are included and so a risk that they are left out of the denominator: which would in turn create an appearance that care of whole patient group is being given. Very important that all the denominators do not inadvertently exclude people.	Thank you for your comment. The indicator advisory committee agreed to progress the indicator for all people receiving drug treatment for epilepsy. No population groups are excluded from the denominator.
4	General	**NHS England and NHS Improvement**	Cross reference to NICE guidance on learning disability and autism to make sure the indicator is inclusive. This applies to all of the proposed indicators. There needs to be accessible appointment letters.	Thank you for your comment. The importance of accessible communication is highlighted in the equality impact assessment.
5	General	**Royal College of General Practitioners**	Background information	

ID	Indicator	Organisation name	Comments	NICE response
6	General	**Royal College of General Practitioners**	IND 2021-12 and IND 2022-13, we would question the value of having separate indicators for those with learning disabilities and mental health conditions. While we understand that they may have difference care needs outside of an epilepsy review, we do not think that better quality of care will be achieved by creating additional complex QOF indicators. Additionally, both of these groups would fall under the umbrella of IND2022-11. We would therefore strongly suggest that only IND2021-111 was included if this was taken forward.	Thank you for your comment. The indicator advisory committee noted these concerns and agreed not to progress the separate indicators for people with learning disabilities and mental health conditions.
7	General	**Royal College of General Practitioners**	In view of the safety issues surrounding Valproate, we are surprised that there is not a quality indicator being considered for review of females of child bearing age who are prescribed valproate and wonder whether this should be considered (both for people with epilepsy and those given valproate for another reason).	Thank you for your comment. The committee has previously discussed the feasibility of indicators specifically focussed on review of women of child-bearing age who are prescribed valproate. Denominator numbers on average are too small to be suitable for use in the QOF. However, the committee agreed that the NICE team are to explore the value of an indicators for use outside the QOF.
8	General	**Royal College of General Practitioners**	In view of the recent ME CFS guidance and the need for increased capacity of appointments in primary care, we are surprised that this is not considered as one of the indicators for QOF	Thank you for your comment. The suggestion to develop indicators focused on chronic fatigue syndrome has been shared with NHS England.
9	General	**Young Epilepsy**	The proposed epilepsy indicators are linked to the current QOF indicator for epilepsy (EP001), which requires the establishment and maintenance of a register of patients aged 18 years or over receiving drug treatment for epilepsy. We recommend that this QOF indicator is expanded to include people with epilepsy of all ages, including children and young people. This would ensure that epilepsy prevalence in local and national populations can be accurately tracked, to inform forward planning for service delivery. Although children's epilepsy care is led at secondary or tertiary level, primary care also plays a key role in prescribing for people with epilepsy of all ages.	Thank you for your comment. The committee discussed the potential to include people under 18 years. They acknowledged that some young people will be being supported in general practice, however the majority would be receiving most of their support from secondary or tertiary care.

IND 2021-111: The percentage of adults receiving drug treatment for epilepsy who had a structured review in the preceding 12 months

ID	Indicator	Organisation name	Comments	NICE response
10	IND 2021-111	**Association of British Neurologists**	**Do you think there are any barriers to implementing the care described by these indicators?** The barriers to implementing an annual structured review for patients with epilepsy on drug treatment in primary care are that it will not be mandated and will not remunerated under the General Medical Services agreement as it was previously when an annual structured review was a QOF. Time for these reviews will be difficult to fit in particularly given the current pressures on appointments in primary care.	Thank you for your comment. The committee agreed to progress this indicator on the basis that it is suitable for inclusion in the QOF.
11	IND 2021-111	**Association of British Neurologists**	**Do you think there are potential unintended consequences to implementing/ using any of these indicators?** No	Thank you for your comment.
12	IND 2021-111	**Association of British Neurologists**	**Do you think there is potential for differential impact (in respect of age, disability, gender and gender reassignment, pregnancy and maternity, race, religion or belief, and sexual orientation)? If so, please state whether this is adverse or positive and for which group.** Difficult to predict and will vary within individual groups. Attendance for these reviews may be variable across these minority groups and also across socially disadvantaged groups as they can be people who are traditionally less likely to access and attend healthcare appointments. The potential positive benefit for pregnancy and maternity outcomes is large with timely referral to secondary care for preconceptual counselling and active management in pregnancy.	Thank you for your comment. The committee noted the potential positive benefits from this indicator and agreed to progress it to the NICE menu.
13	IND 2021-111	**Association of British Neurologists**	**If you think any of these indicators may have an adverse impact in different groups in the community, can you suggest how the indicator**	Thank you for your comment. Your helpful suggestions have been included in the equality impact assessment for this indicator.

ID	Indicator	Organisation name	Comments	NICE response
			might be delivered differently to different groups to reduce health inequalities? I don't think an annual review if implemented well would have an adverse impact but it will only reduce health inequalities if it can reach those who traditionally do not access healthcare readily. Mortality and morbidity from epilepsy is linked to social deprivation. Those with poor concordance with appointments such as socially deprived groups may have to be accessed in alternative settings or when attending the surgery for other reasons, opportunistically. It may be that a community nurse or pharmacist could be trained in performing these reviews potentially making them more accessible to the widest population possible.	
14	IND 2021-111	**Association of British Neurologists**	**Would an indicator on annual review for all adults receiving drug treatment for epilepsy be a pragmatic and acceptable approach for quality improvement purposes?** This would be a good aim for quality improvement purposes provided that the content and outcome from the structured review was good. A review in itself may not be of benefit to patients unless the interaction and outcomes from that interaction were meaningful. We suggested that the topics that should be covered would include (additional topics may be listed in the revised NICE guidelines when published): 1. Concordance with medication (including check prescription collection frequency, consider spot blood levels) 2. Blood tests to monitor liver, renal health, full blood count and vitamin D, lipids in enzyme inducing medications 3. Bone health – see above regarding vitamin D 4. Contraception and plans for pregnancy, teratogenicity of medication including Valproate annual risk assessment form 5. Mental health: particularly anxiety, depression	Thank you for your comment. We have included a definition of what should be covered in the annual review based on SIGN guideline 143.

ID	Indicator	Organisation name	Comments	NICE response
			6. Lifestyle discussion: driving, occupational issues, safety and SUDEP risk 7. Need for referral back to secondary care particularly for medication review in the following situations: a. To review ongoing need for medication if seizure free b. Diagnostic uncertainty c. Uncontrolled epilepsy d. Side effects from medication Preconceptual counselling and teratogenicity discussion	
15	IND 2021-111	**Epilepsy Action**	**1. Do you think there are any barriers to implementing the care described by these indicators?** No there is currently a recognised field to report this within GP systems for adults. However, we would recommend that a separate reporting field be included for under 18's. There is also a need to consider under-18s who have transitioned to adult epilepsy care. It is estimated that 1 in 3 young people transitioned to adult epilepsy care at age 16.	Thank you for your comment. The committee discussed the potential to include people under 18 years. They acknowledged that some young people will be being supported in general practice, however the majority would be receiving most of their support from secondary or tertiary care.
16	IND 2021-111	**Epilepsy Action**	**2. Do you think there are potential unintended consequences to implementing/ using any of these indicators?** As always the quality of reporting may be compromise by opportunistically ticking the box rather than evidencing a structured conversation about the concerns of the patient.	Thank you for your comment. The committee were concerned to ensure the indicator is not a tick box exercise and we have therefore included a definition of what should be covered in the annual review based on SIGN guideline 143.
17	IND 2021-111	**Epilepsy Action**	**3. Do you think there is potential for differential impact (in respect of age, disability, gender and gender reassignment, pregnancy and maternity, race, religion or belief, and sexual orientation)? If so, please state whether this is adverse or positive and for which group.** There may be a differential impact in regard to pregnancy. This would be positive and an opportunity to reinforce important information relating to contraception and pregnancy and to reiterate information relating to AED safety during pregnancy.	Thank you for your comment. The committee noted the potential positive benefits from this indicator and agreed to progress it to the NICE menu.
18	IND 2021-111	**Epilepsy Action**	**4. If you think any of these indicators may have an adverse impact in different groups in the community, can you suggest how the indicator**	Thank you for your comment. Your helpful suggestion has been included

ID	Indicator	Organisation name	Comments	NICE response
			might be delivered differently to different groups to reduce health inequalities? People with epilepsy and a significant learning disability may require the involvement of their carer(s).	in the equality impact assessment for this indicator.
19	IND 2021-111	**Epilepsy Action**	**5. The NICE epilepsy guideline is currently being updated and the draft recommendations indicate that annual reviews are a priority for those taking antiseizure medications associated with long-term side effects or drug interactions. This indicator has been developed as a pragmatic approach that could use the existing register currently within QOF (EP001). Would an indicator on annual review for all adults receiving drug treatment for epilepsy be a pragmatic and acceptable approach for quality improvement purposes? Please explain your answer.** This is a starting point and will establish a level of measurable compliance. However, the detail to each annual review is the most reasonable way to determine quality improvement and improved outcomes. Young people in transition 16-18yrs may be missed, hence the need to establish the additional reporting field. The QOF indicator itself should be extended to people with epilepsy of all ages to ensure we can accurately track epilepsy prevalence in national and local populations to inform service delivery.	Thank you for your comment. We have included a definition of what should be covered in the annual review based on SIGN guideline 143. The committee discussed the potential to include people under 18 years. They acknowledged that some young people will be being supported in general practice, however the majority would be receiving most of their support from secondary or tertiary care.
20	IND 2021-111	**Pennine Care NHS Foundation Trust**	An annual review for patients newly started on anti-epileptic treatment is desirable but not sure as to how pragmatic. e.g. usually a new diagnosis of epilepsy made in neurology clinic is followed up routinely and treatment reviewed, but it sometimes happens that people experience new-onset seizures following an acquired brain injury during the acute phase of their treatment and are discharged from hospital on anti-convulsant therapy that does not always seem to be reviewed as standard. In some cases, especially polypharmacy, it's possible that this is exacerbating cognitive difficulties or fatigue.	Thank you for your comment. The committee agreed to progress this indicator for all people receiving drug treatment for epilepsy not just those with a new diagnosis. It was acknowledged that there may be potential overlap with reviews conducted in secondary care. This can be mitigated by allowing those already reviewed in secondary care to be included in the numerator and for primary care not to have to re-review them.
21	IND 2021-111	**Royal College of General Practitioners**	Can the committee clarify what a structured review is please? Do you mean a structured medication review? If so, we support this indicator and the following comments apply. If the structured review is more than a medication	Thank you for your comments. The committee wanted to ensure the indicator leads to improvements in

ID	Indicator	Organisation name	Comments	NICE response
			review then there are other considerations to take into account, such as workload in primary care and the workforce crisis that we are currently seeing with increasing difficulties accessing appointments for routine care with an aging population, the significant backlog because of the pandemic that is affecting primary care as well as secondary care and the impact on health inequalities that this is currently having. Q1. No barriers to implementation as all patients on medication are already expected to have an annual medication review and so can be covered in appointments already scheduled. It is uncertain whether it will achieve the expectation of quality improvement as this review of all medication should be in place already. Q2. No unintended consequences identified if a structured review is for medication Q3/4. No health inequality issues identified as all patients irrespective of protected characteristics are expected to have a medication review. Q5. Summary: This indicator itself would be pragmatic and acceptable within primary care because, as stated above, every patient on long term medications should receive an annual review, including those with epilepsy. This is therefore easily achievable and would not significantly add to the workload burden within primary care as this should already covered by standard care reviews a patient on long term medication already receives. However, if the structured review is more than a medication review, this will need to be reconsidered in terms of impact.	epilepsy care and outcomes. We have therefore included a definition of what should be covered in the annual review based on SIGN guideline 143.
22	IND 2021-111	**SUDEP Action**	SUDEP Action would welcome annual reviews being a priority for all people with epilepsy. Recent published research (details at end of this comment box) on epilepsy and mortality showing an increase in epilepsy related deaths, has also shown the main risk factors for epilepsy related deaths. Therefore, having a general practice indicator suitable for use in the QOF would not only be about improving wellbeing for people with epilepsy but would also be a tool for mitigating epilepsy risk and tackling avoidable deaths (at least 42% of which are known to be potentially preventable). The data from this research showed there was a 69% increase in epilepsy mortality between 2004-2014. Without this indicator being restored, and for it to have an essential risk focus (i.e. not just looking at medications but considering the whole person, their overall health, wellbeing and lifestyle alongside other	Thank you for your comment and support for this indicator. The committee agreed to progress this indicator to the NICE menu and agreed to include a definition of what should be covered in the annual review based on SIGN guideline 143.

ID	Indicator	Organisation name	Comments	NICE response
			possible risk factors), we cannot tackle avoidable mortality in epilepsy. This was originally recommended as part of the National Sentinel Audit of Epilepsy Deaths carried out in 2002 and a subsequent Government action plan in 2003. There was no consultation on the removal of the original epilepsy review QOF in 2013, and SUDEP Action have been campaigning for an annual epilepsy review to take place within the community setting since it's removal, so we would welcome this introduction as an improvement of care provided to those with epilepsy. Wojewodka G, Gulliford MC, Ashworth M, et al Epilepsy and mortality: a retrospective cohort analysis with a nested case–control study identifying causes and risk factors from primary care and linkage-derived data BMJ Open 2021;11:e052841. doi: 10.1136/bmjopen-2021-052841	
23	IND 2021-111	**Young Epilepsy**	We welcome the proposed indicator to track structured reviews for adults receiving drug treatment for epilepsy. Consideration should be given to how the indicator will function for young people under 18 whose care is overseen by adult epilepsy services. For example, a Young Epilepsy survey found that approximately 1 in 3 young people transitioned to adult epilepsy care at age 16 (i). As these young people's care is not overseen by paediatrics, an annual treatment review should be carried out in primary care (ii). i) Young Epilepsy (2021) Young people's experiences of epilepsy care: Summary of survey findings ii) NICE CKS (2021) Scenario: Routine epilepsy review	Thank you for your comment. The committee discussed the potential to include people under 18 years. They acknowledged that some young people will be being supported in general practice, however the majority would be receiving most of their support from secondary or tertiary care.

IND 2021-112: The percentage of adults with epilepsy and a learning disability who had a structured review in the preceding 12 months

ID	Indicator	Organisation name	Comments	NICE response
24	IND 2021-112	**Association of British Neurologists**	**Learning Disability and Epilepsy** No specific Questions. Answers above apply to this category too. Their vulnerability would potentially raise safeguarding issues were there to be serial non-attendance at reviews.	Thank you for your comment.
25	IND 2021-112	**British Medical Association**	These patients already have a learning disability assessment each year and if having an epilepsy review (as above) this would be a third review, which seems unnecessary.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group. This group is included in the overarching indicator being progressed.
26	IND 2021-112	**Epilepsy Action**	**1.Do you think there are any barriers to implementing the care described by these indicators?** Learning disability registers may not be comprehensive in all regional areas. There is a field within the GP system to report adults taking anti-seizure medications (ASMs). Again, we would recommend that this is extended to include under 18's. It is likely that a person with a learning disability may require a longer and adapted appointment, particularly when discussing the assessment requirements.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group. This group is included in the overarching indicator being progressed.
27	IND 2021-112	**Epilepsy Action**	**2.Do you think there are potential unintended consequences to implementing/ using any of these indicators?** Again the quality of reporting may be compromise by opportunistically ticking the box rather than evidencing a structured conversation about the concerns	Thank you for your comment.
28	IND 2021-112	**Epilepsy Action**	**3.Do you think there is potential for differential impact (in respect of age, disability, gender and gender reassignment, pregnancy and maternity, race, religion or belief, and sexual orientation)? If so, please state whether this is adverse or positive and for which group.** As above, this would be an opportunity to reinforce important information relating to contraception and pregnancy.	Thank you for your comment.

ID	Indicator	Organisation name	Comments	NICE response
29	IND 2021-112	**Epilepsy Action**	**4.If you think any of these indicators may have an adverse impact in different groups in the community, can you suggest how the indicator might be delivered differently to different groups to reduce health inequalities?** None identified	Thank you for your comment.
30	IND 2021-112	**NHS England and NHS Improvement**	Welcome that there is a specific reference to people with a learning disability. And helpful that the Indicator Type sets out the size of the issue for GP practices – how many patients are likely to be covered by the indicator. What about children and young people?	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group. This group is included in the overarching indicator being progressed.
31	IND 2021-112	**NHS England and NHS Improvement**	The difficulty with the definition and therefore the denominator is that not all patients with a learning disability will be included on the learning disability register (LD003). Estimated that approximately ¾ of people with a learning disability are not on a GP learning disability register (from QOF records + prevalence estimates: Emerson?	Thank you for your comment.
32	IND 2021-112	**NHS England and NHS Improvement**	A potential negative impact upon annual health checks (risk that GPs focus on this indicator rather than a holistic learning disability annual health check). This will apply as well to the other indicators.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
33	IND 2021-112	**NHS England and NHS Improvement**	Potential differential impact- importance of identifying/ including adults who may be in healthcare at a distance from their GP e.g. in inpatient mental health care: these people may be more likely to be on drug therapy for epilepsy but be at higher risk of being excluded from epilepsy review.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group
34	IND 2021-112	**Royal College of General Practitioners**	Q1: No significant barriers to implementation other than that experienced in standard practice when patients and carers opt not to attend as this is already expected from standard care at the current time. Q2: None identified Q3: Non identified Q4: Non identified Q5: Summary: Practices are currently already expected to deliver an annual medication review for patients with learning disabilities whether they have	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.

ID	Indicator	Organisation name	Comments	NICE response
			epilepsy or not, and therefore could this indicator is unlikely to achieve significant added benefit. Additionally, the denominator score may be very small in those practices with a smaller list size who may have no patients with both epilepsy and a learning disability.	
35	IND 2021-112	**SUDEP Action**	SUDEP Action would welcome annual reviews for people with a learning disability and epilepsy, especially considering the higher risk of mortality for people with learning disabilities and epilepsy. It would be essential to ensure that this review is not just looking at medication but considering the whole person and other possible risk factors. At present there are gaps within the care given to those with epilepsy and a learning disability as shown in the findings of the Clive Treacey national review (December 2021), which included very poor risk assessment, poor communication of epilepsy situation, lack of recognition of response to risk and failure to monitor care quality. The national review found neither Clive, his family or carers around him understood his person-centred risks of SUDEP or other fatality.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
36	IND 2021-112	**Young Epilepsy**	We welcome the proposed indicator to track structured reviews for adults with epilepsy and a learning disability. Consideration should be given to how the indicator will function for young people under 18 whose care is overseen by adult healthcare services. The consultation paper estimates that 1 in 5 people with epilepsy have a learning disability, however Young Epilepsy research found that 40% of children with epilepsy were functioning in the learning disabled range (i). i) Young Epilepsy (2014) The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) Study	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.

IND 2021-113: The percentage of adults with epilepsy and a mental health condition who had a structured review in the preceding 12 months

ID	Indicator	Organisation name	Comments	NICE response
37	IND 2021-113	**Association of British Neurologists**	***Mental Health and Epilepsy*** **Do you think there are any barriers to implementing the care described by these indicators?** The group with mental health problems and epilepsy may have additional barriers to implementing the care of an annual review as a "harder to reach" group for attendance at healthcare appointments. **See above answers regarding other questions.**	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
38	IND 2021-113	**Association of British Neurologists**	**Should the population for this indicator be extended to include other mental health conditions? If so, please say which populations should be included and why?** As the co-morbidities of anxiety and depression are particularly common in people with epilepsy, we would include this group in addition to those with schizophrenia, bipolar disorder and other psychoses. Certainly addressing these common co-morbidities of people with epilepsy should be part of an annual review for the first group (people with a diagnosis of epilepsy on medication) as likely to impact drug concordance, engagement with services and suicide risk.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
39	IND 2021-113	**British Medical Association**	As with LD patients, these patients will be having a dedicated review annually anyway, as well as a physical health check as per NICE guidance, which seems superfluous. The criteria should not be expanded to include other SMIs.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
40	IND 2021-113	**Epilepsy Action**	**1.Do you think there are any barriers to implementing the care described by these indicators?** Mental health conditions are under diagnosed in people with epilepsy and screening and referral can be poor. This focuses on people diagnosed with a mental health condition and omits to describe the requirements to measure additional requirements in the review relevant to all people with epilepsy.	Thank you for your comment. Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.

ID	Indicator	Organisation name	Comments	NICE response
41	IND 2021-113	**Epilepsy Action**	**2.Do you think there are potential unintended consequences to implementing/ using any of these indicators?** There are larger numbers of people with epilepsy, and anxiety and/or depression and this indicator does not include or reflect these conditions with no offer of additional review for them. Incidents of suicide are higher in people with epilepsy and early intervention is important. Research shows that 37% of children with epilepsy have a mental health disorder.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
42	IND 2021-113	**Epilepsy Action**	**3.Do you think there is potential for differential impact (in respect of age, disability, gender and gender reassignment, pregnancy and maternity, race, religion or belief, and sexual orientation)? If so, please state whether this is adverse or positive and for which group.** The needs of older people with epilepsy requires particular attention as there is a relationship between epilepsy and dementia.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
43	IND 2021-113	**Epilepsy Action**	**4. If you think any of these indicators may have an adverse impact in different groups in the community, can you suggest how the indicator might be delivered differently to different groups to reduce health inequalities?** In those with a significant learning disability and in older people in receipt of social care carer involvement may be needed.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
44	IND 2021-113	**Epilepsy Action**	**6. Should the population for this indicator be extended to include other mental health conditions? If so, please say which populations should be included and why?** We would recommend expanding the mental health indicator to include anxiety and depression. People with epilepsy are at increased risk of both these conditions, and are twice as likely to die by suicide than the general population https://www.epilepsy.org.uk/news/news/study-finds-increased-risk-death-suicide-and-accidents-people-epilepsy-68260	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group
45	IND 2021-112	**Pennine Care NHS Foundation Trust**	It makes sense to include chronic depression in the mental health conditions that trigger a need for annual review, has this been omitted because it is thought that most people with depression relapse / remit, rather than have a persisting condition that would impact on medication concordance over the course of a year? It may be difficult to identify that group.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.

ID	Indicator	Organisation name	Comments	NICE response
			Will consideration be given to 'personality disorder,' for whom self-harm, self-care, alcohol use (and its potential interaction with anti-convulsant meds) and impulsivity may be issues?	
46	IND 2021-113	**Royal College of General Practitioners**	Practices are currently commissioned to deliver an annual review for patients with SMI whether they have epilepsy or not, and therefore could this indicator is unlikely to achieve significant added benefit. Additionally, the denominator score may be very small in those practices with a smaller list size who may have no patients with both epilepsy and SMI and therefore not incentivise clinicians to prioritise this. Q1: No significant barriers to implementation other than that experienced in standard practice when patients and carers opt not to attend as this is already expected from standard care at the current time. Q2: None identified Q3: Non identified Q4: Non identified Q5. We do not believe that other mental health conditions outside of those already mentioned in the indicator due to the comments made above.	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.
47	IND 2021-113	**SUDEP Action**	SUDEP Action would welcome annual reviews for people with epilepsy and a mental health condition. However, within this review the overall wellbeing and other risk factors for the person with epilepsy should be considered – the mental health aspect shouldn't be looked at in isolation. If mental health issues come up as a concern in the first review for all people with epilepsy (as in IND2021-111) then we would advise they should be offered this additional review, to ensure a MDT approach and coordination between services. If this indicator goes ahead, we would like to see it as being on top of/as a follow on from IND 2021-111 and 2021-112. We also would like to see this review include people with epilepsy who may have other mental health conditions than those currently listed (for example depression or anxiety disorders) to ensure that they would also be able to access mental health treatment. At the moment this indicator is not clear that it would be completely inclusive to any/all mental health conditions. We know that people with epilepsy are predisposed to have mental health conditions causing a higher risk of mortality. If this further review could be offered on top	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.

ID	Indicator	Organisation name	Comments	NICE response
			of IND 2021-111 and 2021-112, then this may help to ensure further MDT support.	
48	IND 2021-113	**Young Epilepsy**	We welcome the proposed indicator to track structured reviews for adults with epilepsy and a mental health condition, however we recommend that all mental health disorders are included in this indicator. Consideration should also be given to how the indicator will function for young people under 18 whose care is overseen by adult healthcare services. The proposed indicator would only apply to adults with epilepsy who have schizophrenia, bipolar affective disorder or other psychoses. This is estimated as 2% of the epilepsy population. However, research shows that 37% of children and young people with epilepsy have a mental health disorder (i). A recent Young Epilepsy survey found that 77% of young people (aged 25 and under) said living with epilepsy has had a significant impact on their mental wellbeing, including their thoughts, feelings and how they are able to cope with everyday life (ii). Mental health problems can often have a greater impact than seizures on health-related quality of life for children with epilepsy (iii). As such, it is crucial that mental health needs are screened and supported as an integrated part of epilepsy care. (i) Davies et al (2003) A population survey of mental health problems in children with epilepsy (ii) Young Epilepsy (2021) Young people's experiences of epilepsy and mental wellbeing: Summary of survey findings (iii) Reilly et al (2015) Factors associated with quality of life in active childhood epilepsy: A population-based study 8. Baca et al (2011) Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy	Thank you for your comment. The committee decided not to take this indicator forward given existing review requirements in general practice for this population group.

Appendix B: Existing NICE indicators

Epilepsy

NM03: The percentage of women under the age of 55 years who are taking antiseizure medications who have a record of information and counselling about contraception, conception and pregnancy in the preceding 12 months.

NM110: The percentage of patients aged 18 or over on drug treatment for epilepsy who have been seizure free for the last 12 months recorded in the preceding 12 months

NM71: The percentage of women with epilepsy who are aged 18 or over, but under 45, who are taking antiseizure medications and have a record of being given information and advice in the previous 12 months about pregnancy or conception, or contraception tailored to their pregnancy and contraceptive intentions.

Learning disabilities

IAP00609: Excess under 75 mortality rate in adults with a learning disability

NM04: Percentage of patients on the learning disability register with Down's Syndrome aged 18 and over who have a record of blood TSH in the previous 15 months (excluding those who are on the thyroid disease register)

NM73: The contractor establishes and maintains a register of patients with learning disabilities

Mental health

IAP00133: People with serious mental illness (SMI) who have received complete list of physical checks

IAP00330: Smoking rates in people with serious mental illness (SMI)

NM108: The percentage of patients with schizophrenia, bipolar affective disorder and other psychoses who have a comprehensive care plan documented in the record, in the preceding 12 months, agreed between individuals, their family and/or carers as applicable

NM120: The percentage of patients with schizophrenia, bipolar affective disorder and other psychoses aged 25-84 (excluding those with pre-existing CHD, diabetes, stroke and/or TIA) who have had a CVD risk assessment performed in the preceding 12 months (using an assessment tool agreed with NHS England)

NM129: The percentage of patients aged 18 years and over with schizophrenia, bipolar affective disorder and other psychoses who have a record of total cholesterol: hdl ratio in the preceding 12 months

NM130: The percentage of patients aged 18 years and over with schizophrenia, bipolar affective disorder and other psychoses who have a record of blood glucose or HbA1c in the preceding 12 months

NM15: The percentage of patients with schizophrenia, bipolar affective disorder and other psychoses who have a record of alcohol consumption in the preceding 15 months

NM16: The percentage of patients with schizophrenia, bipolar affective disorder and other psychoses who have a record of BMI in the preceding 15 months

NM17: The percentage of patients with schizophrenia, bipolar affective disorder and other psychoses who have a record of blood pressure in the preceding 15 months

NM177: The percentage of patients with a new diagnosis of depression or anxiety in the preceding 12 months who have been screened for hazardous drinking using the FAST or AUDIT-C tool in the 3 months before or after their diagnosis being recorded

NM178: The percentage of patients with a new diagnosis of depression or anxiety and a FAST score of ≥3 or AUDIT-C score of ≥5 in the preceding 12 months, who have received brief intervention to help them reduce their alcohol related risk within 3 months of the score being recorded.

NM195: The percentage of women aged 25 or over and who have not attained the age of 50 with schizophrenia, bipolar affective disorder and other psychoses whose notes record that a cervical screening test has been performed in the preceding 3 years and 6 months

NM196: The percentage of women aged 50 or over and who have not attained the age of 65 with schizophrenia, bipolar affective disorder and other psychoses whose notes record that a cervical screening test has been performed in the preceding 5 years and 6 months

NM20: The percentage of women aged 25 or over and who have not attained the age of 65 with schizophrenia, bipolar affective disorder and other psychoses whose notes record that a cervical screening test has been performed in the preceding 5 years

NM21: The percentage of patients on lithium therapy with a record of serum creatinine and TSH in the preceding 9 months

NM22: The percentage of patients on lithium therapy with a record of lithium levels in the therapeutic range within the previous 4 months

NM78: The percentage of women with schizophrenia, bipolar affective disorder or other psychoses under the age of 45 years who have been given information and

advice in the previous 12 months about pregnancy, conception or contraception tailored to their pregnancy and contraceptive intentions