Indicator Advisory Committee Meeting

Draft minutes of the meeting held on Wednesday 7th June 2017

NICE Office, Manchester

Due to the nature of the day's business and the current period of purdah, this meeting was held as a part 2 meeting and therefore closed to the public

Attendees	**Committee Members:** Daniel Keenan (DK) [Chair], Andrew Anderson (AA), Nigel Beasley (NB), Andrew Black (AB) [Vice Chair], Rachel Brown (RB), Kate Francis (KF), Chris Gale (CG), Richard Garlick (RG), Elena Garralda (EG), Simon Hairsnape (SH), Dominic Horne (DH), Tony Kendrick (TK), Tessa Lewis (TL), Jan Norman (JN), Linn Phipps (LP), Allison Streetly (AS), Mary Weatherstone (MW) and Paula Whitty (PW). **NICE Attendees:** Gavin Flatt (GF), Craig Grime (CG), Mark Minchin (MM) and Shaun Rowark (SR) , Ania Wasielewska (AW) & Sabina Keane (SK) **NHS Digital:** Chris Dew (CD) **Invited observers:** Linda Issot – NHS England, Raechel Newell – NHS Employers & Andrea Brown - North East Quality Observatory Service
Apologies	Ronny Cheung, Emily White, Robert Walton & Jo Jerrome

Agenda item	Discussions
16. Outline of meeting	DK welcomed all attendees to the meeting. DK advised the committee that the first part of the day will be carrying on looking at the outcomes from testing, piloting and consultation for a number of indicators previously discussed at the committee. The rest of the day will be looking at some new areas for indicator development. Apologies were noted.
17. NICE advisory body declarations of interest	The following committee members repeated declarations of interest raised during day 1's meeting. NB – advised that he has recently started a new role at Sheffield Children's NHS Foundation Trust. TK – advised that he is involved in current research looking at the impact of the QOF EG – advised that she has a non-specific financial interest as she has shares in a pharmaceutical company AB – advised that his practice has been involved in the piloting of the diabetes prevention programme work
18. Update on indicator development process and decision options for the committee	MM gave the committee an overview of the indicator development process, reminding them the first part of today's business will be focused on reviewing the outcomes from piloting / feasibility testing and consultation. The committee were advised that for each indicator under discussion there would be 3 main decision options: 1. Recommend for the indicator menu 2. Further work is required 3. Cease development work Following that the committee will be looking at some new areas and will be asked to recommend what aspects of those topics should be progressed for potential indicator development.
19. End of life care	Tested indicator: **CCG17: Reported experience of care across services in the last 3 months of life** GF went through consultation comments. Stakeholders asked how the data collection process would work, as it would need to occur every 3 months for all people deemed to be at the end of life as death is not predictable. The use of retrospective feedback from relatives was questioned as this can result in a poor return rate if undertaken too soon after death. If carried out a long time after death the reliability of someone's recall may be questioned. One stakeholder also flagged an issue with this indicator focusing purely on care at the end of life as there may be situations, particularly for younger people, where people can be in receipt of palliative care for a number of years.

Agenda item	Discussions
	The committee heard that the main data source for this indicator, the VOICES survey may not be repeated on a regular basis. The coverage was relatively limited and the survey is based on feedback from carers. The committee also questioned the focus on the final 3 months of life and the fact that there would be a large number of variables that could impact on personal experiences, or the perceived experience as reported by carers / relatives. The committee suggested that the NICE team should look for other potential data sources that focus more on patient experiences in this population. DK advised the committee that NHS England have commissioned an end of life care national audit. NICE team to monitor progress on this. **Recommendation** The committee agreed to recommend that work on this indicator is ceased and that further work should be done when the national audit is in place. <u>Tested indicator</u> **Proportion of the practice population on the practice palliative care register** GF advised the committee that at the last meeting NICE were asked to work with NHS Digital to assess the potential for an indicator in this area. The rationale was that it could be used as a benchmarking indicator, between areas to assess the extent to which local practices were identifying and including people on their palliative care registers. Being on the palliative care register would mean that the patient would be then included in associated indicators. GF presented some initial findings from NHS Digital's review of this. They noted that there was a relatively wide level of variation in the proportion of the registered population on local palliative care registers – though this was a crude rate not standardised for demographics. The committee discussed the factors behind the apparent variation between areas. The committee agreed that this was something worth considering further, and could form part of an academic paper. The committee also considered further indicators in this area and suggested looking at an indicator focused on the proportion of people with a long term condition who died that were on the palliative care register. **Recommendation** The committee asked NICE and colleagues to do some further work following the NHS Digital high level feasibility analysis on the proportion of people in general practice on the palliative care registers. This might be in the form of an academic paper or there might be merit in comparing register size to prescribing units.

Agenda item	Discussions
	Also, the team to explore a new indictor of the proportion of people with a long term condition who died who were on a palliative care register at the time of death.
20. Mental health of children and young people	Tested indicator **CCG18 – The proportion of children and young people with severe mental illness (SMI) recorded as being overweight or obese** SR went through the consultation comments for this indicator. Stakeholders suggested that there would need to be related indicators about what interventions should be in place for people in this population identified as being overweight or obese. It is unlikely that specialist weight management services would be available for children and young people. Some stakeholders identified the sensitivity of addressing weight gain in what is quite a vulnerable population and that talking about BMI rates may not be the appropriate language as it is not necessarily the best way to record obesity in children and young people. SR presented the outcome of the feasibility assessment carried out by NHS Digital. The assessment found that information on BMI is not currently contained in the MHSDS. The National Child Measurement Programme does provide high level details of weight, but would not be able to identify if a child has a SMI. It may be possible to link the 2 datasets, but this would need further investigation and resources. The recommendation from NHS Digital was that this is not currently feasible, but that a request should be made to have height and weight recorded in the MHSDS. The committee discussed these findings. They suggested it would be surprising if CAMHS were not recording the height and weight of the children and young people in their service. The fact that there weren’t specific weight management services for this population was not deemed to be a reason for not progressing an indicator in this area. Committee members questioned whether the issue concerning weight gain associated with antipsychotics was specific to children and young people, and that there is already increasing awareness of this as an issue across mental health services. It was questioned whether an indicator focused on children and young people would add anything. It was also asked whether the numbers would be too low for indicator development to support measurement and comparison at CCG level. Recommendation The committee agreed to recommend that this area should focus on all ages and that a request should be made to the MHSDS to include height and weight in the dataset for all people with SMI. If this is not possible, then the committee recommend to cease further work on this indicator.

Agenda item	Discussions
	Tested indicator **CCG19 – The proportion of children and young people who are referred to a specialist mental health service with a first episode of psychosis who start assessment within 2 weeks** SR advised the committee that we had not received many consultation comments on the remaining indicators for SMI in children and young people. The team did target specific stakeholders for comments post consultation, but still did not receive anything further. However, the limited feedback received was positive, suggesting that this was an important area to focus on. SR presented the outcome of the feasibility assessment carried out by NHS Digital. The review included looking at the number for this indicator for under 35s, under 25s and under 18 to see at what age level there would be sufficient numbers to support a feasible indicator at CCG level. The MHSDS does collect data concerning early intervention in psychosis, and that whilst there are some current issues with data quality it is anticipated that this will improve as coverage improves. The recommendation from NHS Digital is that the indicator should focus on under 35s to ensure sufficient numbers and that this should be reviewed in 2018 to see if data quality has improved. The committee noted that this indicator already exists within the CCG indicator assurance framework for all ages and questioned how useful it would be to add another indicator focused on under 35s who make up 3 quarters of all those included in this indicator. The committee also noted the poor response to consultation, and how it is a missed opportunity for stakeholders to influence programme. **Recommendation** DK agreed to write to key stakeholders encouraging them to engage with the consultation process. The NICE team to contact colleagues leading on the CCG IAF to see whether they would be willing to explore a sub-population indicator focused on those 25 years and under. If this is not possible, the committee recommend that this indicator ceases development. Tested indicator **CCG20 – The duration of untreated psychosis in children and young people.**

Agenda item	Discussions
	SR advised the committee that one comment was received about this indicator, which suggested that it would be difficult to measure as coding may be open to subjective estimates. SR presented the outcome of the feasibility assessment. NHS digital found that there were low numbers and substantial variation in the data which would suggest there are data quality issues. They did not think that this was likely to improve. A suggestion was made that if the data for CCG 19 was available then it could be feasible to develop a proxy measure which would look at the median length of time of that indicator as a measure of duration of untreated psychosis. The committee noted that in its current format it doesn't work and that it isn't necessarily a good reflection of practice. The committee also didn't feel that the proposed proxy measure would be a good measure of quality. It was also felt that this indicator simply highlighted a problem, without information on what was causing it or how to address the issue. **Recommendation** The committee agreed to cease further development of this indicator Tested indicator: **CCG21 – The proportion of children and young people with SMI who have arrangements for accessing education or employment‑related training included in their care plan** SR went through the stakeholder comments received. Suggestions were made that this should be reported at local authority level rather than CCG and that it could be difficult to measure. SR presented the outcome of the feasibility assessment. Data is held in the National Pupil Database (NPD) and it could be possible to link between the NPD and the MHSDS to get attainment levels for young people with an SMI rather than measure engagement with services which would not provide any outcome measures such as attainment. The committee noted that an indicator focused on attainment would have a wide remit with a number of services being responsible for the outcome. It may be of interest at a locality level. The committee questioned whether it would be possible to get permission to link the two datasets. **Recommendation**

Agenda item	Discussions
	The committee recommended that indicator CCG21 ceases development. NICE to work with NHS Digital to look at the viability of linking the datasets to report educational attainment in children and young people with SMI. If this is possible, this could be progressed. If not – recommendation is to cease development. Tested indicator: **CCG22 – The proportion of children and young people with psychosis and schizophrenia referred for family interventions** SR advised the committee than one comment had been received suggesting that a definition is required for family intervention. SR presented the outcome of the feasibility assessment. This intervention is not currently recorded on the MHSDS, however it should start being recorded as part of the early intervention in psychosis work in the future. NHS Digital recommend that this is looked at again in 2018 to see whether the implementation of SNOMED which includes codes for family therapy will allow this analysis to be done. The committee agreed that this would be a useful indicator to review in the future **Recommendation** The committee agreed to support further work on this indicator, for NHS Digital to review the available data in 2018 to see whether a full feasibility report could be carried out. Tested indicator **Children and young people inpatient stays on general paediatric wards or on adult wards.** SR advised the committee that NHS Digital have done some initial exploratory work to look at the feasibility of some indicators looking at inappropriate wards stays for children and young people with SMI, either admissions to general paediatric units or young people admitted onto adult mental health wards. Looking at the data for 2016, it would appear to be incomplete and NHS Digital think they may rise, but even so the figures are low and they wouldn't be high enough for a feasible measure at CCG level.

Agenda item	Discussions
	The committee noted that this is an important issue and may be worth further investigation as data improves. It could be looked into as part of an academic paper. **Recommendation** Monitor the data available for this indicator and look at the potential to write up initial findings into an academic paper Tested indicator **Out of area treatment and distance to treatment** SR advised the committee that NHS Digital have done some initial exploratory work to look at the feasibility of some indicators looking at out of area treatment for children and young people with SMI. The main issue identified was that there is no recognised definition of out of area treatment. The committee agreed that this is worth reviewing. **Recommendation** NICE to request a definition of 'out of area' from NHS England and to do produce feasibility testing with NHS Digital when this is available.
21. Serious mental illness in adults	GF introduced the topic of SMI in adults, highlighting that it links to a number of the areas just discussed in relation to children. Following a review of the NICE guidelines, 5 areas have been identified to potential indicator development. 1. Clozapine GF advised that clozapine is the only drug with established efficacy in reducing symptoms and the risk of relapse for adults with treatment resistant schizophrenia. The National Audit of Schizophrenia found that of those identified as having treatment resistant schizophrenia, 43% had not been offered clozapine and no documented reason was given. The committee noted that this medication would normally be prescribed by a specialist and not a GP so would be a CCG focused indicator. The committee discussed the need for clear guidelines about adequate doses and length of prescriptions, but it was noted that the Royal College of Psychiatrists have guidelines in this area. The committee asked whether any indicator in this area should focus on the receipt of the medication rather than them being offered. **Recommendation**

Agenda item	Discussions
	The committee agreed to recommend that this area is progressed for indicator development. Consideration should be given as to whether the focus should be on receipt of the medication or the offer of the medication being recorded. 2. Side effects of antipsychotic medication GF described the issue of side effects for people on antipsychotic medication and how lack of awareness of the side effects amongst patients can lead to poor medication adherence. Two potential areas for indicator development were presented, one concerning information provision about possible side effects when people receive a prescription and the other about a documented review of side effects. The committee discussed these 2 proposals. They suggested that neither of the indicators would contribute to quality improvement initiatives **Recommendation** The committee agreed to recommend that this area was not progressed for indicator development. 3. Psychological interventions GF advised the committee that access to psychological interventions for people with bipolar disorder was identified in the NICE quality standard (QS95) as an area for quality improvement and that CBT for psychosis (CBTp) in conjunction with or without antipsychotic medication can improve outcomes for people with psychosis and schizophrenia. The National Audit of Schizophrenia (2014) found only 45% of mental health service users, who were not in remission, had been offered CBTp. The committee were asked to consider potential indicators focused on access to CBT for people with psychosis and those with bipolar disorder who receive psychological interventions. A number of potential outcome measure were also proposed. The committee agreed that these areas were important. The coding of the diagnoses and the interventions would need to be clear to allow accurate measurement. Therefore the availability of relevant SNOMED codes would need to be investigated. **Recommendation**

Agenda item	Discussions
	The committee agreed to recommend this area for further indicator development. 4. Supported employment programmes GF highlighted the low employment rate in this population and that there is evidence to show that supported employment programmes can be effective in increasing employment in this population. The committee discussed this area. It was agreed that this is an important issue but questioned whether this is something that health services have control over and whether it should be the responsibility of the Department of Work and Pensions. The employment related training gap was highlighted as the key issue for this. It should be a multi-agency measure at a locality rather than a CCG measure. The committee suggested that any indicator in this area should focus on specialist mental health services. **Recommendation** The committee agreed to recommend this area for further development 5. Carer education programmes GF highlighted that the provision of carer-focused education and support programmes was identified as an area for improvement in QS80. In the National Audit of Schizophrenia (2014) only 9% of Trusts met 90% threshold for carers feeling either ‘very’ or ‘somewhat’ satisfied with the information and support they were receiving. The committee agreed that this is an important area to focus on. The committee highlighted that there is a lot of variation in the provision of carer focused education and support programmes between CCGs and an indicator around this may help to drive up service provision. There was a discussion about clarifying who should be included in the denominator for any indicator. **Recommendation** The committee agreed to recommend this area for further indicator development.

Agenda item	Discussions
22. Multimorbidity and frailty	SR introduced the topics of multimorbidity and frailty to the committee. Following review of the NICE guideline, draft NICE quality standard and some informal discussions with colleagues at NHS England, 4 areas were identified for discussion with the committee. Identification SR presented to the committee some investigatory work carried out by the NCCID that looked at using current QOF registers as a starting point to identify a population for indicators focused on people with multimorbidity. A data extraction was carried out from 14 practices identifying those patients on 2 or more, 3 or more and 4 or more QOF registers. The data showed 13% of patients (all ages) were on 2 or more, 6% on 3 or more and 3% on 4 or more registers. SR provided some background about some national work focusing on identified a 'frail' population within general practice. In the 2017/18 GP contract, practices will be required (using an appropriate tool) to identify patients aged 65 and over who are living with moderate to severe frailty. Using the electronic frailty index (eFI), it can be estimated that a register based on this tool would include approximately 15% of people over 65 with 3% classed as severe and 12% moderate. The committee were asked whether they think a register focused on multimorbidity and/or frailty should be progressed. The committee recognised that there is overlap between the 2 areas, but they are quite distinct, for example the eFI is only validated for people over 65. It was also noted that just focusing on QOF registers will mean that a number of long term conditions would be missed. However, it was also noted that using 2 or more QOF registers includes 13% of the registered population, which is a large proportion of patients. **Recommendation** The committee asked the NICE team to explore the overlap between the two approaches – the number of people on multiple QOF registers and the number of people aged 65 years and over identifies by the eFI. This piece of exploratory analysis will inform the intervention indictors. Medication review SR went through the rationale for focusing on medication review in this population. Many people will have a number of conditions and will be receiving a number of different treatments. A medication review should be carried out to help optimize treatment, this may involve reducing the number of prescribed medications and establishing goals.

Agenda item	Discussions
	The committee were advised that there is a metric included in the new GP contract focused on: the number of patients over 65 with severe frailty who had a medication review in the past 12 month. The committee were asked whether it would be worthwhile progressing an indicator in line with the one in the GP contract focused on people with severe frailty and also whether a separate indicator should be progressed focused on medication reviews in people with multimorbidity. The committee noted that the questions about whether to develop an indicator focused on multimorbidity would be determined by the outcome from the previous discussion. The committee discussed how to make a meaningful indicator rather than a tick box indicator around medication review. They committee also felt that a review should be more holistic and should also include an assessment of the person values, priorities and goals. **Recommendation** The committee agreed to recommend that this area was investigated further, with a specific focus on start / stop reviews for medication review as well a focus on values, priorities and goals Falls prevention SR went through the rationale for an indicator focused on fall prevention, suggesting that asking about falls during routine assessments and reviews can identify people who may be at risk who can then be referred to relevant support and preventative services. SR identified several statements from the NICE quality standard on falls in older people (QS86). The committee were advised that there is a metric in the new GP contract looking at the number of people over 65 with severe frailty who had a fall in the past 12 months. The committee were asked whether it would be worthwhile progressing an indicator linked to the metric in the GP contract and also whether it would be worthwhile investigating a similar indicator for people with multimorbidity. The committee did not feel that someone with multimorbidity who didn't appear on the frailty register would be particularly at risk of a fall, and therefore didn't feel that 2 separate indicators would be required. It would also be interesting to see what proportion of those with moderate frailty might be at risk of a fall as this could prevent people from becoming severely frail. **Recommendation**

Agenda item	Discussions
	The committee agreed to recommend that NICE further investigate an indicator focused on falls identification in people with severe and moderate frailty. The committee also recommended that the NICE team investigate a potential indicator about referring people identified as being at risk to relevant falls prevention services Outcome indicators SR presented 3 potential overarching outcome measures for the committee to consider. These focused on: Unplanned hospital admission; length or ward stay and care home utilisation for people with frailty or multimorbidity. The committee agreed that it would be useful to develop some outcome indicators in this area. **Recommendation** The committee agreed to recommend the development of the following outcome indicators: - Unplanned admissions - Length of stay following an unplanned admission - Delayed transfers of care - Re-admissions - Return to usual place of residence following hospital admission
23. HIV testing: Uptake	AW introduced this topic to the committee. AW went through the rationale for indicators on encouraging uptake of testing for HIV. Hospital services, GP surgeries and prisons are key settings to focus on in high and extremely high prevalence areas. Early identification of HIV is linked to improved treatment outcomes and reduces the risk of transmission. The committee noted that indicators aimed at specific localities such as high or extremely high prevalence areas would be a new type of output for the programme, these indicators would not be suitable for a national framework but could be used to support local measurement schemes in these area with high and extremely high prevalence of HIV. HIV testing in hospitals The committee discussed HIV testing on admission to hospital and attendance at emergency departments. There were some concerns raised around creating inequality of access to HIV testing, sensitivities in conversations with patients and out of area attendances. However it was acknowledged that the proposals were in line with the guidance. **Recommendation**

Agenda item	Discussions
	The committee agreed to recommend two indicators are progressed for further development: - Testing on admission to hospitals or attendance at emergency departments in areas of extremely high prevalence. - Testing during routine blood tests on admission to hospitals or attendance at emergency departments in areas of high prevalence The committee requested further work is undertaken to understand the resource impact and current uptake rates. HIV testing in GP surgeries The committee discussed HIV testing on registration with GP practices and when receiving routine blood tests. There were some concerns raised around the resource impact of testing during routine blood tests and creating a requirement for annual testing based on geographical location and not risk factors. However it was acknowledged that the proposals were in line with the guidance. **Recommendation** The committee agreed to recommend two indicators are progress for further development: - Testing at GP registration in areas of high and extremely high prevalence. - Testing during routine blood tests in GP practices in areas of high and extremely high prevalence HIV testing in prisons The committee discussed HIV testing on entry into prison. It was felt that any potential indicator should be expanded to testing for other blood borne viruses (BBV) as outlined in the NICE guideline (NG57). The committee also discussed current practice and queried current uptake levels in prison. **Recommendation** The committee agreed to recommend one indicator progresses for further development on BBV testing when entering prison. The committee also requested further work is undertaken to understand current performance.
24. Familial hypercholesterolaemia (FH)	SK introduced this topic to the committee, highlighting the significant increase in risk of coronary heart disease in people with FH. The condition can often go undiagnosed, with estimates suggesting approximately 120,000 people are affected by FH but 80% of those are currently undiagnosed. Following a review of the NICE guidance and quality standards, 3 areas were identified for potential indicator development.

Agenda item	Discussions
	Diagnosis The committee noted the upcoming update to the underpinning NICE guidance, particularly the baseline cholesterol level thresholds. It was agreed that any progressed indicator should be aligned following publication of the guideline update. **Recommendation** The committee agreed to recommend one indicator progresses for further development on assessment for a clinical diagnosis of FH. Specialist referral The committee noted that clinical diagnosis of FH was unlikely to be made in GP practice. In practice, referral to a specialist service would be based on the baseline total cholesterol. **Recommendation** The committee agreed to recommend one indicator progresses for further development on the referral of people with the threshold baseline total cholesterol for specialist assessment. DNA testing The committee noted that DNA testing is currently only provided at specialist services and there is variation in provision. The committee noted that an additional indicator should be progressed on cascade testing in addition to DNA testing to enable effective identification of relatives. **Recommendation** The committee agreed to recommend two indicators progress for further development: - DNA testing - Cascade testing.
Close of committee Meeting	DK thanked all those in attendance and closed the meeting.