Understanding Practice in Clinical Outcome Review Programmes tool: UPCORP-tool guidance and checklist

A protocol to describe the key features of clinical outcome review programmes

FAQ

Who should complete the tool?

This tool is designed to be completed by individuals and organisations planning and implementing clinical outcome review programmes. It has been specifically designed for national clinical outcome review programmes commissioned by the Healthcare Quality Improvement Programme (HQIP) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP), but can be adapted and used by clinical outcome review programmes in other settings.

What is the tool for?

The tool provides a consistent approach, like a protocol, for describing the key features of clinical outcome review programmes. It consists of a standardised heading structure which can be completed to provide a "one-stop" summary of the key information about how clinical outcome review programmes have been designed and carried out. It is expected that this will be published openly for anyone to view, and help users and participants understand the methods, evaluate the quality and robustness of these confidential enquiries, and find information that is most relevant to them. For national clinical outcome review programmes commissioned by HQIP, the intention is that publishing this information openly will reduce the frequency of ad hoc requests for project information HQIP and other national agencies.

This tool is not intended to be used to formally "score" the quality of the responses. The design of this tool has been inspired by reporting checklists used for clinical guidelines (e.g. AGREE[1]) and in reporting research studies (e.g. STROBE[2], SQUIRE[3]).

What type of information is contained within UPCORP?

UPCORP enables structured information on the organisation, aims, governance, methods, information governance and outputs of each project. It is intended that the responses to the tool are factual and written concisely. Where possible, documents can be embedded and hyperlinks provided if information is published elsewhere. This document is intended to be a complete account of the information for the clinical outcome review programme. Please be vigilant about keeping any links included in the document up to date so readers can access full information about the clinical outcome review programme.

Who is the intended audience for the tool?

Examples of clinical outcome review programme stakeholders include:

- Patients / Carers / Public / Patient representative organisations
- Clinicians / Allied health professionals / Healthcare providers / Multi-disciplinary teams / Primary, secondary and tertiary care providers
- National agencies across the UK
- Commissioners
- Healthcare regulators

[1] AGREE stands for the Appraisal of Guidelines for Research & Evaluation. See https://www.agreetrust.org/about-the-agree-enterprise/introduction-to-agree-ii/, last accessed 24 April 2018.
[2] STROBE stands for Strengthening the Reporting of Observational Studies in Epidemiology. See https://www.strobe-statement.org/index.php?id=strobe-home, last accessed 24 April 2018.
[3] SQUIRE stands for Standards for Quality Improvement Reporting Excellence. See http://www.squire-statement.org/, last accessed 24 April 2018.

FAQ (con't)

How should the responses be written?

Responses should be clear, accessible and useful. Some tips and suggestions for writing clearly include:

- avoiding technical jargon where possible
- using short paragraphs and bullet points
- using the "active" voice rather than passive
- keeping sentences short

Where information is published openly elsewhere, links and references should be provided rather than duplicating information that is already available

When and how often should the tool be completed?

The tool is intended to provide accurate and up to date information about the clinical outcome review programme, and so can be updated whenever and however frequently it is relevant to do so. For programmes commissioned by HQIP it is intended that the tool is updated annually, although clinical outcome review programmes can update the tool more frequently if they wish to.

Each version of the tool should include a date of publication and version number.

Where should the completed UPCORP tool be published?

The completed tool should be published online e.g. on the website for the clinical outcome review programme.

How was UPCORP designed?

HQIP commission, manage and develop the NCAPOP (National Clinical Audit and Patient Outcomes Programme) under contract from NHS England and devolved nations. The work was led by HQIP who set up a Methodological Advisory Group (MAG) consisting of methodological, statistical and quality improvement experts who work with audits and registries. Meeting were held on a six monthly basis and the structure and content of the eight quality domains and their key items were agreed by the MAG. The tool was piloted by 5 audit and clinical outcome review programmes within the NCAPOP and re-edited in light of comments received. Other comments received by MAG members was also considered as part of the re-editing process. The final version of the UPCORP tool was signed off by the HQIP MAG working group and will be reviewed annually.

IPR and copyright

Contents

Domain 1: Organisational information

1.1. The name of the programme

The Mental Health Clinical Outcome Review Programme (MH-CORP).

1.2. The name of the organisation carrying out the programme

The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH).

1.3. Main website for the programme

https://www.manchester.ac.uk/ncish/

1.4. Version number and date of publication of the tool on your website

Version 1
(17/12/2020)

Domain 2: Aims and objectives

2.1. Overall aim

As the UK's leading research programme into suicide prevention in clinical services, our overall aim is to improve safety for all mental health patients. We provide crucial evidence to support service and training improvements, and ultimately, to contribute to a reduction in patient suicide rates and an overall decrease in the national suicide rate.

2.2. Objectives to achieve overall aim

Our large, internationally-unique database is a national consecutive case series of all suicides in the UK since 1996 (~6,000 deaths/year). Our specific objectives are to:

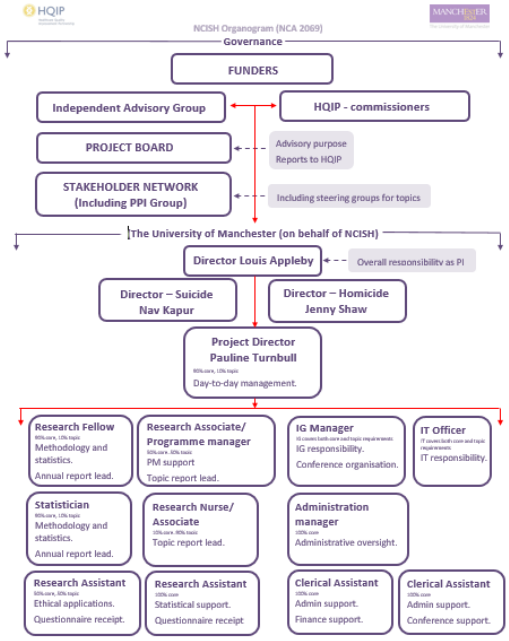
- Examine the circumstances, leading up to and surrounding the deaths by suicide of people under the recent care of, or recently discharged from, specialist mental health services;
- Identify factors in the management and care of patients which may be related to suicide;
- Recommend measures to reduce the number of suicides by people receiving specialist mental health care.

We also explore other care settings where suicide prevention is a priority, such as self-harm services and primary care, undertake studies into suicide prevention in the general population, and support NHS and partner agencies in adopting suicide and self-harm prevention measures based on our evidence.

Domain 3: Governance, programme delivery and stakeholder involvement

3.1. Organogram and governance arrangements

We have four levels of governance:
1. Independent Advisory Group (IAG)
2. Project Board
3. Stakeholder group
4. Internal governance



The IAG provide independent, external oversight of our work, and includes representatives from key stakeholder groups, and lay members. The IAG is appointed and supported by HQIP.

The independently-chaired Project Board includes people from all four UK countries to advise us through expertise and networks in clinical services, research, data, and expertise by experience. HQIP are invited to attend biannual meetings, held as extensions to internal governance meetings. Specifically, the Project Board:

- Oversees the overall direction of the programme and approve any change in direction that may emerge as a result of key findings;
- Ensures the work continues to meet the needs of wider UK suicide prevention strategies;
- Provides high-level challenge to the direction of travel, key assumptions and conclusions;
- Provides guidance on appropriate dissemination channels.

Our wider stakeholder network comprises of key contacts and partners from all UK countries, including third sector organisations, academic colleagues, and experts by experience via a dedicated Lived Experience panel. This stakeholder group has a fluid membership according to the developing needs of the project and topics selected for individual studies. We convene topic-specific reference groups from this network, including people who work with the group of interest, and experts by experience.

We have strong clinical leadership by three of the leading clinical academics in the field of suicide and homicide prevention internationally: Professors Louis Appleby, Nav Kapur and Jenny Shaw. Operational management is provided by a Project Director, supported by a Programme Manager. This team attend weekly meetings, at which key decisions are made. The regular scheduling of these meetings allow us to meet with stakeholders and potential collaborators. Every six months these meetings are expanded to host our Project Board.

3.2. Organisations involved in delivering the programme and approaches to stakeholder involvement

We engage with a wide range of stakeholders, including people who receive care (and their families and carers), deliver care (e.g. NHS providers), commission care (e.g. NHS England, devolved governments), and those who regulate care and provide national oversight (e.g. Health Select Committees, CQC, NICE). Stakeholders are involved in every stage of the design and delivery of our work via our governance groups (see above) and other channels:

- We invite feedback and suggestions for studies via our stakeholder survey;
- We prioritise disseminating our findings directly to clinicians through our annual conference, and speaking engagements with mental health services. We provide service-level data requests and an annual Safety Scorecard (in England);
- We have been working with all UK countries to ensure that we are responsive to specific concerns and supportive of their suicide prevention policies and strategies;
- We ask questions against which we can monitor adherence to clinical guidance, and many of our recommendations have been adopted into policy and guidance in all UK countries;
- Our senior clinical academic clinicians provide expertise to organisations such as CQC, NICE, Health Education England.

We also involve service users and experts by experience in our governance and study development. We consult with service users about the development of our studies examining particular aspects of mental health service practice (i.e. clinical risk assessment), priorities and invite suggestions for topic-specific reports via social media, our service user feedback form and stakeholder survey. A dedicated PPI group advises us on aspects of study design such as pro formas, and information sheets, how we present our research findings and report drafts.

3.3. Declarations of interest and Conflicts of interest

Professor Louis Appleby chairs the National Suicide Prevention Strategy Advisory Group at the Department of Health and Social Care in England. Professor Nav Kapur is a member of the Group, chairs the guideline development group for the National Institute for Health and Clinical Excellence (NICE) depression in adults' guidelines and was a topic expert member for the NICE suicide prevention guideline. He previously chaired the guideline development group for the 2012 NICE guidelines on the longer-term management of self-harm, and is a topic advisor on the new NICE guideline on self-harm, currently in development. Professor Nav Kapur is also supported by Greater Manchester Mental Health NHS Foundation Trust.

Domain 4: Methods

4.1. Data flow diagrams

Our data flow diagram shows who provides data to us, who we share that data with, and at what stage identifiable data are pseudonymised/anonymised. This diagram is updated in line with any new data sharing agreements.

4.2. The population cohort for data collection

Population Sampled	
Inclusion and Exclusion criteria	Inclusion criteria: individuals aged 10 and over who died by suicide (including probable suicide/undetermined conclusion) in any UK country. For additional inclusion criteria for patient suicides please see the below. Exclusion criteria: Failure to meet the inclusion criteria.
Define patient population	General population suicide deaths are defined as deaths by intentional self-harm (ICD-codes X60-X84) or events of undetermined intent (Y10-Y34, excluding Y33.9, Y87.0 and Y87.2) by individuals aged 10 and over. General population homicides are legally defined as convictions for murder, manslaughter (culpable homicide in Scotland), infanticide, and verdicts of not guilty by insanity and unfit to plead. Patients are those in contact with psychiatric, drug and alcohol, child and adolescent or learning disability services (if they are within mental health services) within 12 months of their death, with their care usually under a consultant

	psychiatrist. These include a range of patients, from those seen for one-off assessments to those who have been under the long term care of services. Patients who were seen for a one-off assessment in a liaison setting with no follow-up arranged would not meet our criteria for a patient suicide death.
Case selection	Individuals who die by suicide while under the recent (12 month) care of mental health services.
Cohort dates	All suicides (and probable suicides) in the general population in the UK since April 1996. Our dataset is a continuous, national consecutive case series. We also undertake time-limited studies with different methodologies in response to emerging clinical concerns and policy priorities (e.g. suicide in children and young people (aged 10-19), suicide in middle-aged men (aged 40-54).

4.3. Geographical coverage of data collection

Geographical Coverage	
England	☑
Wales	☑
Scotland	☑
Northern Ireland	☑
Crown Dependencies (please list/delete as appropriate) • Jersey • Guernsey • Isle of Man	☑ ☑ ☑ ☒
Other (please specify) _____	☒
Type Funded Care	
NHS healthcare	☑
Independent sector healthcare	☑
Social care	☒

4.4. Proforma/questionnaire for data collection

We collect detailed clinical data on individuals in contact with mental health services in the 12 months prior to their death via questionnaire from the consultant psychiatrist (or other senior professional) responsible for the care of the patient. For patients in Scotland, there is a slightly revised version of the same questionnaire.

4.5. Methods of data collection and sources of data

Our core suicide data collection follows three stages:

Stage 1

We obtain national mortality data on all general population suicides and deaths of undetermined from the Office for National Statistics (ONS) (for deaths registered in England and Wales), National Records of Scotland (NRS) (for deaths registered in Scotland) and the Northern Ireland Statistics and Research Agency (NISRA), managed by the Regulation and Quality Improvement Authority.

Stage 2

We identify contact of those individuals with mental health services in the 12 months prior to their death with the help of NHS provider organisations.

Stage 3

If contact is confirmed, we collect detailed clinical information via questionnaire from the consultant psychiatrist (or other senior professional) responsible for the care of the patient.

Data Source	
Acute care	☑
Primary care	☒
Community care	☑
Mental health	☑
Independent healthcare providers	☑
Other (please specify) Mortality data from national sources (described above)	☑

Our homicide data collection follows two stages:

Stage 1

We obtain information on all homicide convictions from the Home Office Homicide Index (England and Wales) and the Management Information Analysis Team at the Scottish Courts and Tribunals Service (Scotland).

Stage 2

We identify contact of those individuals with mental health services in the 12 months prior to the incident with the help of NHS provider organisations – allowing us to record and report on the numbers of homicides by people in contact with mental health services.

Data Source	
Acute care	☑
Primary care	☒
Community care	☑
Mental health	☑
Independent healthcare providers	☑
Other (please specify) Mortality data from national sources (described above)	☑

In addition, we have used, and continue to use, a variety of other research methodologies best suited to answering a particular research or clinical safety question.

4.6. Time period of data collection from organisations

We have been collecting data on all suicides (and probable suicides) in the general population in the UK since April 1996. Our dataset is a continuous, national consecutive case series – data collection is therefore ongoing. We receive regular data from the following organisations:

- Office for National Statistics (ONS) (England, Wales) - data received quarterly;
- National Records of Scotland (NRS) – data received quarterly; a rerun of cleaned data received annually;
- Northern Ireland Statistics and Research Agency (NISRA) (collected on our behalf by the Regulation and Quality Improvement Authority (RQIA)) – data received quarterly;
- Home Office Homicide Index (England, Wales) – data received annually;
- Management Information Analysis Team at the Scottish Courts and Tribunal Service – data received annually.

4.7. Time lag between data collection and feedback

There is a time lag of approximately 18 months between the occurrence of a death by suicide and that death being reported in aggregate analysis, e.g. a death which occurs by the end of 2018 will be reported in our 2020 annual report.

Some deaths must be referred for a coroner's inquest into the cause of death, only then may the death be recorded as suicide or undetermined intent on national registers. In England and Wales, the inquest process can take several months creating a delay in death registration and subsequently the notification of the death to us via national mortality data providers. In Scotland, delays in registration are minimal as the Procurator Fiscal system concludes more quickly. Similarly, the legal process of bringing homicide to court, the trial itself, and any subsequent appeal against conviction introduces a time lag from when the homicide was committed to the offender being convicted and this outcome being recorded on national databases and notified to us.

We aim to minimise any subsequent delay to reporting these deaths. Our dedicated administrative team focus on obtaining outstanding questionnaires prior to analysis, and our longstanding dataset allows us to estimate final year figures in our annual report.

Our topic-specific reports are published 6 months following completion of data collection.

4.8. Evidence base included in feedback, recommendations, key findings

The questions in our core questionnaire are based on factual information, developed with clinicians and people with lived experience, and revised on a regular basis to reflect changes in services and policy and guidance, as well as concerns staff and service users tell us about. Our key findings and recommendations are based on our analysis of the data collected from clinicians, in the context of our research of more than 20 years.

4.9. Data analysis

We use a variety of techniques and methods of analysis, adapted to the research or clinical question. Our comprehensive case-series allows for subgroup analysis of basic numbers, and forms the basis for in-depth questions requiring more complex analysis. We mostly utilise descriptive statistics and regression, but have also applied mapping techniques, cluster analysis, and multilevel modelling.

Data analysis is overseen by the senior management team, and led by our senior researcher and statistician, with expertise available from the wider University of Manchester as required. Basic analysis for our annual report provides an opportunity to highlight different groups of interest each year, and to look at changes over time. We also link with patient data supplied by NHS Digital to provide patient suicide rates.

Our 'spotlight' studies have often utilised mixed-method designs, and so analysis has been quantitative and qualitative, most often using thematic analysis. These focussed studies have included survey data, focus groups and interviews, as well as analysis of data from NCISH and other

sources, such as coroner's inquest files. Using different data sources expands our reach for making recommendations beyond mental health services and into the general population.

4.10. Data linkage (only if appropriate and/or applicable)

A collaboration with the Suicide Information Database Cymru (SID-Cymru) (hosted within the Secure Anonymised Information Linkage (SAIL) Database) links data (including primary care data) about all individuals in Wales who died by suicide with our clinical data.

We routinely link patient data supplied by NHS Digital with our data to provide patient suicide rates in our annual reports.

Historically, we have linked with datasets in self-harm, prisons, and primary care, and are working with the Ministry of Defence (MoD) to link data held by the MoD with our data to examine suicide by veterans.

Further information on our current collaborations in the area of suicide prevention research can be found on our website.

4.11. Validation and data quality

Every questionnaire we receive is checked by our research team for anomalies and missing data. Clinicians are contacted regarding any obvious inaccuracies or missing information that would be routinely recorded in medical records. We also run scheduled data cleaning before analysis of our databases, and there are automated validation checks in the transfer of national data and questionnaire data to our databases. All processes also include some manual quality and accuracy checks.

Anomalous missing data is followed up with the data provider, i.e. the source of national statistics, or the responding clinician. Remaining missing data varies by variable, and is acknowledged in our analysis plan.

Overall, the data completeness for patient suicide is high (~98%), but the figures for more recent years will be less complete – reflecting the time taken to process the data (time lag) and is, in part, because of delays in legal processes. We calculate how complete our data are by examining data patterns from earlier years and estimating how much more data we are likely to receive and the number of questionnaires this would generate.

Domain 5: General Data Protection Regulation (GDPR)

5.1. Information governance, information security and ethics

Our programme of work has approval from:

- The North West Greater Manchester South Research Ethics Committee (ERP/96/136);
- The Health Research Authority Confidentiality Advisory Group (HRA-CAG) under Section 251 of the NHS Health and Social Care Act 2006, enabling us to access confidential and identifiable patient information in the interest of improving care. This approval is renewed on an annual basis (PIAG 4-08(d)/2003);
- The Public Benefit and Privacy Panel for Health and Social Care (PBPP) in Scotland (eDRIS ref: 1718-0171);

Local research and development approval and data sharing agreements are in place with each mental health trust or health board in the four UK countries. Separate arrangements are in place for care providers in Jersey. Data sharing agreements are also in place with national data providers, and we establish new agreements as required.

We hold data in accordance with the requirements of the Data Protection Act 2018 and the General Data Protection Regulation (GDPR); in addition we have developed and implement an Information Security and Management Policy (ISMP) that sets out clear operational requirements for the processing, storage and ongoing management of confidential information. The ISMP is reviewed annually against policy developments. Our Data Protection Impact Assessment (DPIA) addresses our data protection obligations and how we meet individuals' expectations of privacy. Our privacy policy explains how we use the information that we collect, and the rights we have to hold this information. The ISMP, DPIA and privacy notice are published on our website. We do not transfer data outside the European Union.

Our System Level Security Policy (SLSP), developed in consultation with University of Manchester colleagues with expertise in IT systems security, sets out:

- The names of the senior management team and NCISH technical personnel responsible for the ongoing development, review and monitoring of day to day compliance with the SLSP;
- Describes the physical location and security of NCISH offices;
- Describes the configuration of the NCISH isolated network and measures in place to ensure the security of electronic data.

In relation to effective information governance, protocols for the processing and management of data are routinely updated. In addition, staff undertake annual information governance training.

We submit an annual review of our information governance and IT security arrangements to the NHS Data Security and Protection Toolkit and have been reviewed as 'Standards Met' (8D594/ECC0020).

Domain 6: Outputs

6.1. The intended users or audience for the outputs (including modalities of feedback and outputs)

All our work is intended to improve patient care, through the provision of crucial evidence to support service and training improvements. Our primary outputs are our annual reports and topic-specific reports published every 18 months. Our target audiences are (i) people who deliver care (NHS provider organisations and other agencies that work with people with mental ill health); (ii) people who commission care (NHS England, devolved governments); (iii) people who regulate and provide national over sight (Care Quality Commission, NICE, Health Education England and equivalent bodies in all UK countries), and (iv) people who receive care (patients and service users, their families and carers). Each report has a communications strategy, engaging stakeholders' help with dissemination, and planning social media content.

Our reports are published on our website and presented with infographics of the key messages, and videos discussing the findings and clinical recommendations. These are designed to be shared with clinical colleagues and used in staff training. Our infographics for service users summarise what our findings mean for care. Other outputs include journal articles, speaking engagements, national and international conferences, and other resources we have published on our website (e.g. Toolkits). We also work directly with services to support local quality improvement plans.

The recommendations cited in our outputs support all six domains of healthcare quality:
SAFE: Our overall aim is to improve safety for all mental health patients;
EFFECTIVE: Our cross sectional before-and-after studies of implementation of recommendations and service structure identified which specific recommendations and service variables are most strongly associated with a reduction in suicide rates;
PATIENT-CENTRED: We are committed to listening to patient views. Our studies, for example ('Safer care for patients with personality disorder' and 'The assessment of clinical risk in mental health services'), highlight when patients have, or have not felt that services were respectful of and responsive to individual patient needs;
TIMELY: Our recommendation that post-discharge follow-up should occur within 2-3 days has been adopted into the NHS Standard Contract;
EFFICIENT: We estimate that our work has contributed to an overall decrease in suicide nationally (estimated 250-300 fewer deaths per year). The economic cost of each suicide death is around £1.67 million. Based on these figures, 300 fewer suicide deaths in England and Wales represent a potential cost saving of £500 million annually;
EQUITABLE: Our findings have highlighted differences in care needs of groups of people according to gender, ethnicity, and physical health.

6.2. Editorial independence

All reports are sent for review and comment to our Independent Advisory Group including funders. We respond to clarification queries, though retain editorial independence.

All key findings and recommendations in our publications are based on the analysis of the data, and reasonable application to clinical and other settings. All reports are written by a team comprising:

- Skilled statistician and senior researcher;
- Management staff;
- Clinical Academics;

We also seek independent feedback on our key findings from our Project Board, including academics, clinicians, coroner, quality improvement expert, and people with lived experience.

6.3. Recommendations and/or key findings

Our recommendations have improved patient safety in mental health settings and reduced patient suicide rates, contributing to an overall reduction in suicide in the UK. Our evidence is cited in national policies and clinical guidance and regulation in all UK countries. Several recommendations have led directly to policy change, and our research has shown a reduction in suicide rates in mental health services that implemented our recommendations, and these formed our "10 ways to improve safety" (a list of 10 key elements for safer care for patients based on our evidence, available as a toolkit against which services can assess their own suicide prevention plans). We are working directly with local areas to improve their suicide prevention quality improvement plans and self-harm care in the community based on our recommendations.

We report the key findings and recommendations from our data in annual, national and themed reports. These provide health professionals, policy makers, and service managers with the evidence and practical suggestions they need to effectively manage change and reduce risk of suicide and homicide by service users. Every report is published on our website with accompanying infographics and videos of the key findings and recommendations.

Our latest annual report provides findings relating to people who died by suicide in 2007-2017 across all UK countries. Additional findings are presented on the number of people convicted of homicide, and those under mental health care. The key messages are summarised on the reports pages of our website, including on in-patient and post-discharge care, alcohol and drug use, methods of suicide, internet risks and in groups of patients according to age, gender, and diagnosis.

We also publish 'topic-specific' reports. Our most recent themed report aimed to establish preliminary data about women who died by suicide while employed as nurses. The key messages from this report are summarised on the reports pages of our website. Our next themed report to be published will be examining suicide by middle-aged men.

6.4. Comparators and benchmarking (only if applicable)

System level outputs	
Consultant or team level data (COP)	☒
CQC (NCAB)	☑
Outlier Analysis	☑
BPT	☒
CQUIN	☒
GIRFT	☒
Peer review	☑
Other (please specify) • Bespoke benchmarked data at trust level in England via our 'Safety Scorecard'; • Bespoke NCISH data benchmarked against the national average for quality improvement work.	☑

6.5. Planning and stimulating quality improvement

We are working with experts in Quality Improvement at the National Collaborating Centre for Mental Health (NCCMH) to support local areas (STPs – Sustainability and Transformation Partnerships) to strengthen their suicide prevention quality improvement plans. Together with the Manchester Self-Harm Project and NIHR Greater Manchester Patient Safety Translational Research Centre (PSTRC) we are also supporting 12 local areas to improve self-harm care in the community.

Quality Improvement	
Real time data	☑
Quarterly reporting	☒
QI guides	☒
Toolkits or Action Plans	☑
QI workshops	☒
Collaborative involvement	☑
AHSN collaboration	☒
Other (please specify) _____	☒