NHS

The Blueprint for improving protected characteristics data quality

Based on Sussex Partnership Foundation Trust

The Blueprint:
Introduction

- The NHS South East regional team has **investigated key opportunities and challenges** around improving protected characteristics data quality in the region.
- This work has involved **collaborating with Mental Health service providers** in the region to understand current data quality issues and efforts being undertaken to overcome these, with the ultimate goal of reducing health inequalities in the South East.
- The regional team has identified **Sussex Partnership NHS Foundation Trust** as having placed significant effort into improving data quality for mental health services, including for protected characteristics and other inclusion health groups.
- The following blueprint has been designed to **set out the methodology developed** by SPFT in order to improve data quality and tackle inequalities across mental health services.
- The purpose of this blueprint is to **share learnings with other providers** who may seek to locally adopt a similar methodology in the near future.

The Blueprint:
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The Blueprint:
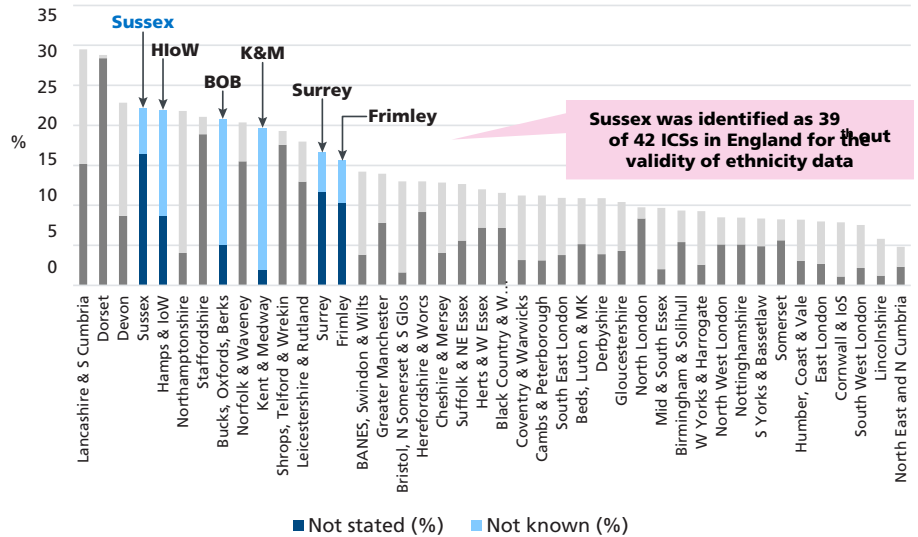## Context and case for change

Context

Why has SPFT prioritised this work?

- Data submitted via MHSDS is being used to calculate Trust performance against key national indicators (inc. Long Term Plan metrics).

- MHSDS statistics are being used by policy makers, commissioners, mental health service users, and the public.

- There are some areas where SPFT's submissions are not providing an accurate reflection of Trust activity and other areas where the Trust is not flowing activity data at all or in line with the required national specification.

- Subsequent discovery work to address data quality raised several **issues with protected characteristics data:**

  - Limited understanding of protected characteristics

  - Missing fields in data collection forms

  - Variable coding options in use for characteristics

  - Crucially, poor data quality despite good completeness levels in some areas

Historical position

Proportion of mental health patient records with an ethnicity code of 'not known' or 'not stated', June 2019 to May 2021, England

Sussex was identified as 39 of 42 ICSs in England for the validity of ethnicity data

Legend: Not stated (%) · Not known (%)

Labels on chart: Sussex, HIoW, BOB, K&M, Surrey, Frimley

What should you do? Take steps to understand and communicate the current state in your organisation

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The Blueprint:
Setting the Trust-wide agenda

Setting targets

How has SPFT set the goals needed to drive this work?

- Improving the quality of data collection and recording of protected characteristics has been set by the Executive Committee (EC) as a **Trust-wide breakthrough objective for 2022/23,** deliverable in Q4.

  - This objective has been set as part of a wider long term goal on **addressing health inequalities**, with the Chief Delivery Officer (CDO) as the SRO.

  - The action to improve the quality of data collection and recording of protected characteristics by Q4 falls under the Chief Digital Information Officer's (CDIO) remit.

  - This objective's outcome metric is an above average score in the national community mental health survey for support & wellbeing, higher than the 2021 score.

- **Executive visibility** is supported by development of an index in the Integrated Assurance Report, submitted to EC.

Strategic steps

How has SPFT driven this work across the Trust?

- The Data Quality Review Group, chaired by the CDIO (previously the Performance Team) now feeds directly into the SPFT Executive Committee.

  - This group submitted a Data Quality Overview Report to the EC, giving assurance on the unfolding programme of work, and setting out the current data quality issues, work underway and further work to resolve issues. This includes the new approach and principles needed across SPFT for this programme to be successful.

- The CDIO also submitted an informational report to the Audit Committee, to provide an overview of this work and its contribution to ensure robust improvements related to Data Quality. This report outlined the need for a Data Quality Improvement Plan, and requested the committee's advice.

What should you do? Formally raise data quality issues and codify improvement targets in your strategy

The Blueprint:
Trust agenda and governance

Key groups

Setting up new groups

3 new groups: A Health Inequalities Group and Data Quality Review Group (DQRG) were set up, while the Digital Committee and Senior Management (Mgmt) Team already existed.

A **Protected Characteristics Task & Finish Group** was also set up, directly reporting into the DQRG, Digital Committee, and Senior Mgmt Team.

The **main project headings** set for the Protected Characteristics Data Working Group, as shared with the Trust Board, include:

- Improving data capture for protected characteristics
- Digital solutions to support capture of protected characteristics
- Integrating systems within SPFT
- Integration of data across the system

Frequency & reporting

Frequency of meetings

- T&F Group meets approximately every 6 weeks
- Health Inequalities Group meets monthly
- Data Quality Review Group meets every third Monday
- Digital Committee (previously Digital Board) meets monthly
- Senior Management Team meets weekly

Reporting

- The T&F Group's Project Manager submits a monthly Highlight Report which is shared with the Digital Committee and the Senior Management Team Meeting which sits weekly.
- The Data Quality Lead presents an overview at Data Quality Review Group bi-monthly.

What should you do? Set up relevant groups within your governance structure, with a dedicated focus
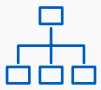
The Blueprint:
Governance and resource

Governance structure

T&F group formally reports into DQRG, and provides updates to Digital Committee & Senior Mgmt. Team

Collaborating with:
- Mental Health service teams
- SPFT Performance & Digital teams
- Other stakeholder groups, e.g. lived experience groups
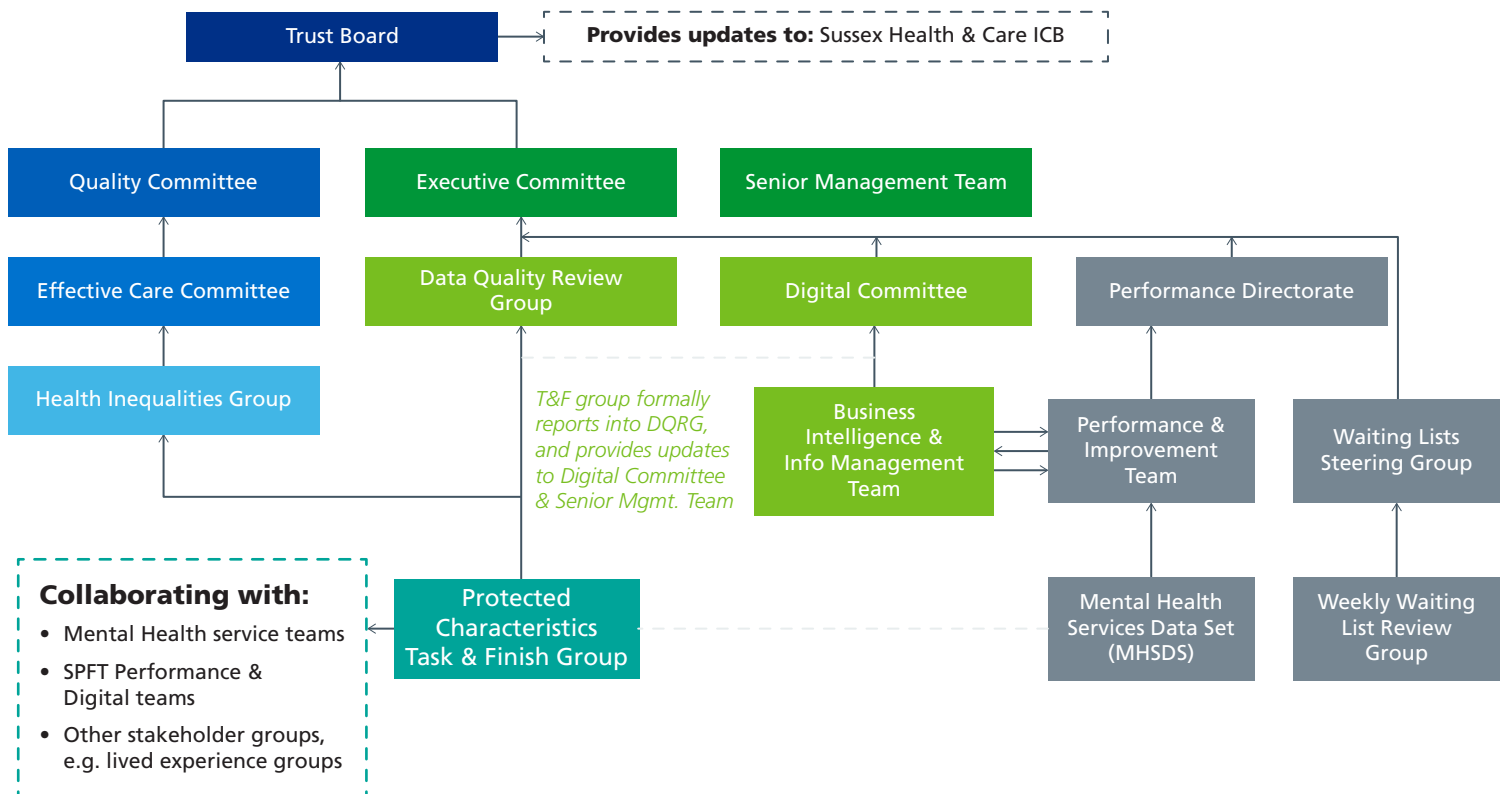
What should you do? Ensure your Task & Finish Group reports directly to other decision-making groups

The Blueprint:
Roadmap

The Task & Finish Group implemented the following Terms of Reference, to facilitate this work:

Terms of Reference: Goals

Purpose

- The Trust is committed to improving data quality, with a specific Breakthrough Objective to improve the quality of data collection and recording of protected characteristics.
- As part of a broader piece of work on health inequalities, work has been started to evaluate and improve data on protected characteristics, as defined in the Equality Act (2010).
- Initial work has identified that data is not currently captured well across all protected characteristics.
- We will work with key stakeholders to review and agree definitions for how all protected characteristics can be captured in Carenotes.
- We will use currently available data as well as the knowledge and experience of the group, to help understand barriers to staff inputting protected characteristics data - considering practicality (time, process) and knowledge (confidence to ask questions, understanding of how information is used).
- Plans are currently in place to introduce protected characteristics data to core reporting. The introduction of this data will allow the report to be seen through the lens of a protected characteristic, thus helping the understanding of any health inequalities which may be present.

Terms of Reference: Scope

Authority

- Protected Characteristics Task and Finish Group is authorised by the Data Quality Review Group (DQRG) to take any decisions which fall within its terms of reference and are in accordance with the Scheme of Delegation.

Duties

Phase 1:

- To determine the wording around the data capture in Carenotes
- To review and agree categories for all protected characteristics and Armed Forces status
- To determine priority for adding missing protected characteristics to Carenotes

Phase 2:

- To ensure effective capture of all the protected characteristics and Armed Forces status

Reporting

The group reports to the Data Quality Review Group (DQRG) and will present an update on progress at the monthly DQRG meeting.

What should you do? Ensure your Task & Finish Group has a clear remit and authority to make decisions

These Terms of Reference set out the stakeholder representation & working rhythms to deliver this work successfully:

Terms of Reference: Membership

- Equality & Diversity Lead
- Carenotes Service Improvement Manager
- CDS Business Manager - Forensics
- Clinical Team Lead - ChYPS
- Clinical Psychologist - CAMHS
- People Participation Lead
- Head of Corporate Governance
- Senior CCI Analyst
- Interim Professional Lead Nurse - Brighton & Hove CDS
- Business Manager - Neurodevelopmental Services
- Service Director - Learning Disabilities and Neurodevelopmental Services
- Expert by Experience

- Disability Staff Network Co-Chair
- Time Out Staff Committee Member
- Armed Forces Staff Network Chair
- Assoc. Dir. OD and Talent Management
- Workforce Transformation Manager
- Analytics and Business Intelligence Clinical Lead
- Digital Project Manager
- Clinical Operations Manager - Adult Mental Health Services
- Pathway Lead for Specialist Older Adult Mental Health Services

Quorum & Frequency

- The Chair or Deputy Chair, plus 11 members are required before a meeting is quorum. Meetings will take place every 6 weeks. All meetings are currently held via Zoom.

Terms of Reference: Meetings

Attendance

- Meetings will be chaired by the Analytics and Business Intelligence Clinical Lead. The Digital Project Manager will be the Deputy Chair.
- Other members may be co-opted as required, or other managers may be invited to attend for particular items.
- Deputies may attend with the prior agreement of the Chair, but will not count towards the quorum.
- Members must attend all scheduled meetings where possible or nominate a representative.

Calling Meetings

- Meetings will be called at the request of the Chair.
- Notice of each meeting, including an agenda and supporting papers will be sent to the members of the group 3 clear days before the date of the meeting.

Communication

- The notes of the meeting will be agreed by the Chair within 1 working day of the meeting. Action points will be circulated to members within 2 working days of the meeting.

What should you do? Ensure your Task & Finish Group has representation from all key stakeholders

The Blueprint:
Roadmap

Further resource was recruited in mobilising this work, and key risks were identified and mitigated early on:

Terms of Reference: Further Info

Review

These terms of reference, including membership, will be reviewed in December 2022 at the end of Phase 1.

These terms of reference can be made available in alternative formats if required.

Resource

The following **stakeholders were recruited** as part of this strategic work:

- Data Quality Lead
- Clinical Business Intelligence Lead
- Analytics Business Partner x4
- Clinical Dataset Analyst

Risk mitigation

Key risks identified in programme risk register in Phase 1	Gaps and Planned actions to mitigate the Issue
"There is a risk that we will not have **stakeholder representation from Older People's Services** resulting in lack of representation of this user group"	Further emails were sent out to other colleagues requesting representation at the Task & Finish Group, leading to sufficient attendance
"There is a risk that we will not have **stakeholder representation from Staff Networks** (Women's and Ethnic Minority) resulting in lack of representation of these user groups"	
"There is a risk that we identify the need to capture information but there is **no place in Carenotes to record this information**, resulting in continued non-capture of protected characteristics data"	The T&F group worked with the Care notes team to identify where this information could be recorded, and what changes would need to be made to facilitate this

What should you do? Ensure your Task & Finish Group has the right resource, and mitigate risks early

Key Actions

Prioritise characteristics

- **Developed a full list** of the possible protected characteristics and other inclusion health groups, e.g. Ex-British Armed Forces
- **Agreed the priority level for each characteristic**, in order to take a phased approach and focus efforts more effectively

Agree questions & coding

- **Reviewed each characteristic**, assessing possible questions to patients, and available identities for patients to choose from (drawing from NHS, ONS, etc.)
- **Agreed questions and options**, engaging with wide range of stakeholders - including people with lived experience

Establish reporting

- **Proposed new, additional performance indicator** within existing internal data reporting, to assess the completeness and accuracy of characteristics
- **Created data reporting (dashboards)** for teams to review their own performance for baselining and tracking progress

01 **02** **03** **04** **05** **06**

Map the 'As Is' state

- Understood the **current methods of collecting data, key issues being faced**, and levels of data quality
- **Set out the challenges** around forms, digital templates and the use of Carenotes (EPR system) to collect data

Identify opportunities

- **Reviewed how EPR and other forms could be changed**, to improve data collection and understand barriers to change
- **Identified how processes can be changed** around patient touchpoints, integrating datasets, Standard Operating Procedures & staff training
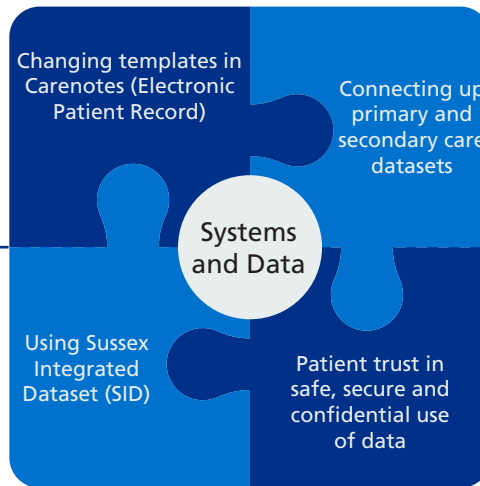
Connect datasets

- **Identified opportunities to connect datasets**, including between primary and secondary care, and with the Sussex Integrated Dataset
- **Began 'pushing' data to systems in secondary care**, in line with Information Governance, boosting coverage

What should you do? Follow the roadmap actions to identify clear priorities, challenges & opportunities

The Blueprint:
Systems and Data

- The Task & Finish Group explored the **opportunity to make modifications in Carenotes**, to improve data collection.
- The Trust is **not** able to make direct changes to the core forms
- However, the group **identified optional** fields within the Trust's control that could be changed to include questions on characteristics

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- SID is a **pseudonymised primary and secondary health and social care person-level dataset**, built as part of the 'Our Care Connected' Programme & Products in Sussex ICS.
- SID currently has data inflows from: primary, community, mental health, social care, emergency and acutes
- SPFT are exploring the opportunity to safely use this data to boost coverage

Changing templates in Carenotes (Electronic Patient Record)

Connecting up primary and secondary care datasets

Systems and Data

Using Sussex Integrated Dataset (SID)

Patient trust in safe, secure and confidential use of data

- SPFT have worked to **bring in more primary care data** into a 'data warehouse', where there are patients in secondary care who have an episode of treatment in a connected primary care system.
- Have **started to push this data** into secondary data systems on a patient basis, e.g. using Armed Forces data to complete ~30,000 records.

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- The Task and Finish Group have **emphasised the importance** of ensuring that data is safe, secure and confidentially used, in line with Trust Information Governance.
- SPFT has identified the **challenge of improving public trust in data usage**, which will require regional and national public communications, beyond the scope of their initial goals.

What should you do? Work closely with stakeholders to identify opportunities around systems & data

The Blueprint:
Monitoring Progress

Summary

- The Data Quality Review Group submitted a proposal to **add a new indicator to the Trust's 'Integrated Performance Report'** (IPR) for 2022-23.
- NHS Digital identified 5 protected characteristics and vulnerable groups with low data quality in national reporting as **priority focus areas**. The composite indicator captures these 5 characteristics.
- The completeness and accuracy of the other 6 is monitored in **supplementary reporting** and the definition of the IPR indicator can be extended to include these in future.

Construction

- This indicator assesses the **completeness and accuracy** of the 5 areas for all service users included in our MHSDS submission.
- Assessing the **accuracy** not only looks for whether a code has been recorded for a particular item, but also whether that code provides **meaningful information** i.e. it is not 'not recorded' or 'not known'.
- Gender identity is split into 2 separate codes in the MHSDS submission. *Gender ID Code* and *Gender Same as Birth* are both included in the indicator, meaning there are **6 items in scope**.

Benchmarking

- Supplementary reporting is also provided with the indicator, looking at the **accuracy of each item individually**, so improvement work can be focused, as the reasons for low accuracy vary by item.
- Baseline performance has been measured in the following format, in order to benchmark future progress:

Protected Characteristic / Other Health Inequality	Accurate Code Recorded	% Accuracy per Item
Accommodation Type	34,107	52.9%
Disability	0	0.0%
Ethnicity	39,494	61.3%
Gender ID	64,342	99.9%
Gender same as birth	0	0.0%
Sexual Orientation	0	0.0%
Total	**137,943**	
Total current patients	64,425	
Total current patients x 6	**386,550**	
Indicator %	**35.7%**	

- Improvement actions have been set for each characteristic, and reported to the Health Inequalities Steering Group.

What should you do? Monitor and review data quality over time, identifying key issues and progress

The Blueprint:
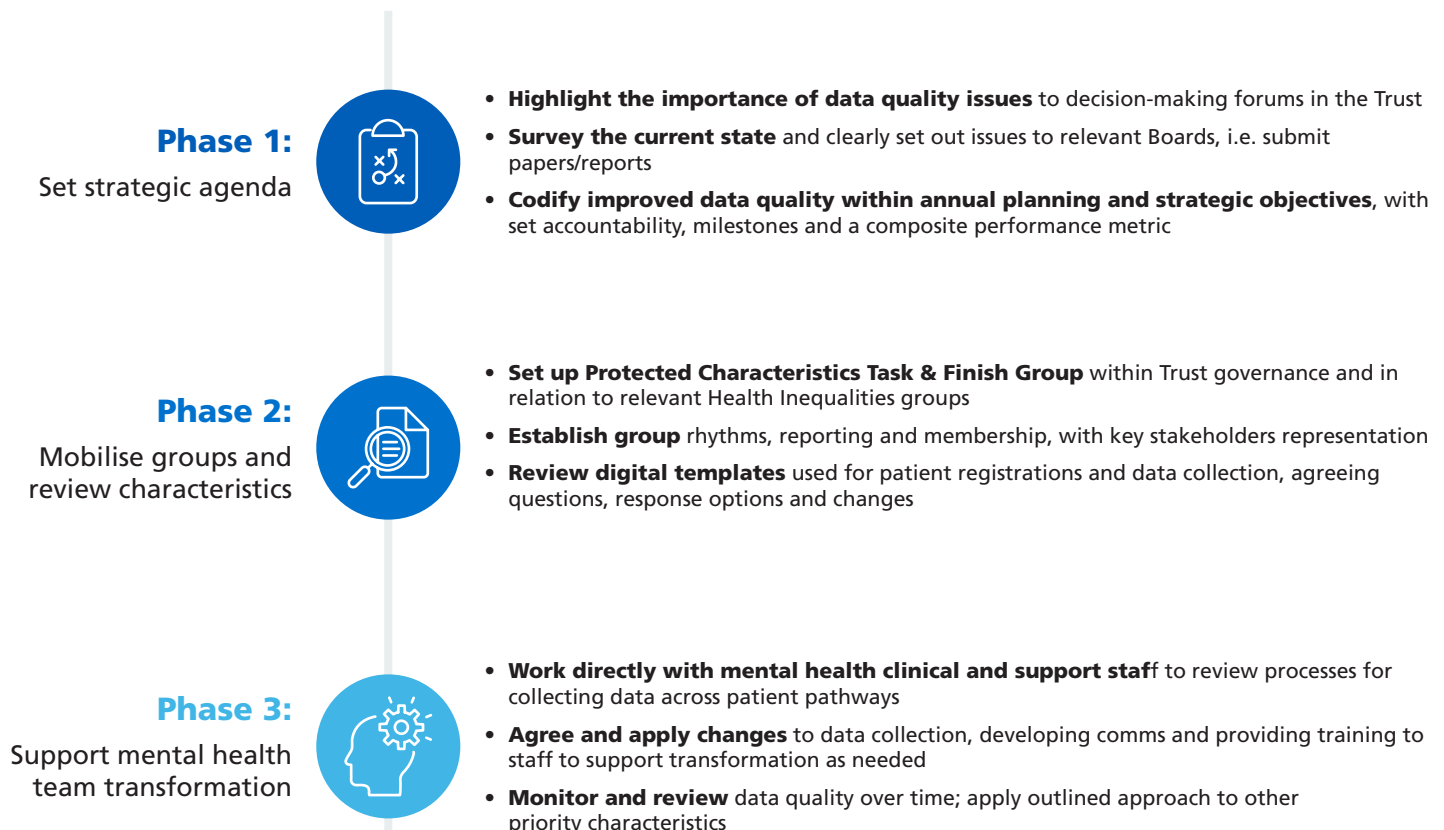## Next Steps

Planned Next Steps

1. **Develop comms materials for sharing** with mental health teams to convey the case for change and the overarching goals for this work, next steps and the requested involvement from teams, and provide further guidance on improving data quality.

2. **Use current data quality to identify and assess possible mental health teams to begin transformation support**. Apply NASSS framework*, assessing the 'adopting system' (i.e. specific mental health teams) and the opportunity to transform their processes for collecting and reporting data. This involves assessing readiness, strategic alignment, existing programmes of work, team skills, capacity, and other key dimensions.

3. **Collaborate directly with a mental health team and select a high priority characteristic** to target, e.g. ethnicity, supporting them to understand how to improve their processes and sustainably implement new structures for to collect better data. Use lessons learned from initial collaborations to inform an internal blueprint, detailing how to approach transformation with other mental health teams going forwards.

4. **Provide necessary staff training and coaching** to sustainably change behaviours and deliver longer-term improved data quality. This will need full engagement to ensure that there is consistency in behaviours within and across teams.

5. **Continue roll-out of support to other mental health teams**, refining the approach and codifying best practice for wider sharing. Liaise with the wider region on broader public comms to improve patient trust in the safe, secure and confidential collection and use of their personal data.

*   T. Greenhalgh et al., "Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies," Journal of medical Internet research, vol. 19, no. 11, p. e367, 2017. [Online]. Available: **https://www.jmir.org/2017/11/e367/**.

What should you do? Work closely with mental health clinical and support staff on changing processes

How can you apply this methodology?

Phase 1:
Set strategic agenda

- **Highlight the importance of data quality issues** to decision-making forums in the Trust
- **Survey the current state** and clearly set out issues to relevant Boards, i.e. submit papers/reports
- **Codify improved data quality within annual planning and strategic objectives**, with set accountability, milestones and a composite performance metric

Phase 2:
Mobilise groups and review characteristics

- **Set up Protected Characteristics Task & Finish Group** within Trust governance and in relation to relevant Health Inequalities groups
- **Establish group** rhythms, reporting and membership, with key stakeholders representation
- **Review digital templates** used for patient registrations and data collection, agreeing questions, response options and changes

Phase 3:
Support mental health team transformation

- **Work directly with mental health clinical and support staff** to review processes for collecting data across patient pathways
- **Agree and apply changes** to data collection, developing comms and providing training to staff to support transformation as needed
- **Monitor and review** data quality over time; apply outlined approach to other priority characteristics

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Any questions?

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